



**Exploring Patient-centred Preparatory
Information Provision in the Digital Era:
An Investigation among MRI and CT Medical
Imaging Outpatients**

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BPsych (Hons) (University of Newcastle)

A thesis submitted in fulfilment of the requirements for the degree of
Master of Philosophy (Public Health and Behavioural Science)

School of Medicine and Public Health

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Submitted June 2020

This research was supported by an Australian Government Research Training
Program (RTP) Scholarship

Declarations

Statement of originality

I hereby certify that the work embodied in the thesis is my own work, conducted under normal supervision. The thesis contains no material which has been accepted, or is being examined, for the award of any other degree or diploma in any university or other tertiary institution and, to the best of my knowledge and belief, contains no material previously published or written by another person, except where due reference has been made. I give consent to the final version of my thesis being made available worldwide when deposited in the University's Digital Repository, subject to the provisions of the Copyright Act 1968 and any approved embargo.

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Thesis by publication

I hereby certify that this thesis is in the form of a series of papers. I have included as part of the thesis a written declaration from each co-author, endorsed in writing by the Faculty Assistant Dean (Research Training), attesting to my contribution to any jointly authored papers.

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Acknowledgements

Higher degree candidature has been exciting, challenging and incredibly rewarding. A network of remarkably talented and supportive people have helped me along the way, and to them I am deeply thankful.

To my supervisors, Allison, Lisa and Kristy, your unwavering support despite the many twists and turns that I have taken along this path has meant so much. Allison, I am in awe at your ability to critically analyse and articulate complex concepts. Your eye for detail and focus on robust research are exceptional and have certainly made me a better researcher. The forward-thinking approach that you take to all facets of supervision has also benefitted me greatly. Lisa, you are such a caring person, which is reflected in the way you complete high-quality, patient-focused research and in the way you supervise. Thanks for always being so approachable, kind and supportive. Kristy, I have appreciated the many insights that you have shared about the study setting, subject area, thesis development and student life. You were always willing to go the extra mile to help, which really meant a lot.

A special thanks must also go to Rob Sanson-Fisher and the broader Health Behaviour Research Collaborative. Rob, thank you for setting me up along the higher degree path and always being on hand to give oversight and mentorship. Your inquisitive mind and big-picture thinking are truly admirable. I feel very fortunate to have had your guidance along the way. To the broader team within the Health Behaviour Research Collaborative, your drive and commitment is inspiring. The advice, resources and opportunities within the group have made my experience much richer.

I would also like to extend a heartfelt thank you to the staff and patients at the Hunter New England Medical Imaging Department. In particular, Sandy, Simon and Michael, thank you for always going above and beyond. Your focus on improving the patient experience within the Department is very special and gave me extra motivation to conduct this research in the most meaningful way possible. To the patients, thank you for taking the time and effort to participate. Speaking with you gave me a new perspective and reinforced the importance of this research.

To my candidature buddies, Jan, Anne and Bree, there is so much that I could say. Jan and Anne, I hold our friendship very close. In the good times and the bad, you have both been there to provide support, honesty and a lot of laughs. I know we will be close friends for a very long time! Bree, I definitely wouldn't be at this point without you. We've been by one another's side since early undergraduate days. Thanks for always being there for me as both a friend and colleague.

I have undertaken this degree with many "balls in the air", one of which was working with Deloitte. I must say thanks to the team, especially Vanessa, Helen, Jenna, Renee and Kamini, who not only accommodated my idea of pursuing employment whilst undertaking this research program, but also gave an invaluable outside perspective. Experiences with Deloitte have given me important skills that I could apply to my higher degree studies.

To my husband, Dean, your stability and endless support over the last few years is a reflection of the amazing person that you are. You always tell me that you'll support me no matter what, and you have truly lived and breathed that throughout this candidature. Thanks for listening when I needed it, keeping life admin going when I couldn't, sacrificing time together, and also recognising when I needed to take a break.

Finally and importantly, thanks to my beautiful family, Mum, Dad, Chris, Rob, Jess and Sy. During my studies, you have each helped me reflect on what's important whilst also teaching me to be ambitious and to challenge myself. Your guidance motivates me to be the best version of myself. Thanks for always being there. A special thanks goes to my dad, who left us midway through this journey. Dad, you were always so proud, and I know that if you were here, this submission would be no exception. I am forever grateful to have had your love and guidance for the time that I did.

Thank you.

Acknowledgement of editor's contribution

I would also like to thank and acknowledge the contribution of Dr. Gloria Webb from Wordfix for completing professional editing of this thesis. This editing was completed in accordance with the guidelines for editing research theses as provided by the Institute of Professional Editors and the Australian Council of Graduate Research. Dr. Webb has a PhD in Behavioural Science in Relation to Medicine from the University of Newcastle and has extensive editorial experience in this and other areas of research.

List of publications included in the thesis

Paper One

Hyde LL, Mackenzie LJ, Boyes AW, Symonds M, Brown S, Sanson-Fisher R. Medical imaging outpatients' experiences with receiving information required for informed consent and preparation: a cross-sectional study. *Journal of Patient Experience* 2018; **5**(4): 296-302.

Paper Two

Hyde LL, Mackenzie LJ, Boyes AW, Evans TJ, Symonds M, Sanson-Fisher R. Prevalence and correlates of patient-centred preparatory information provision to computed tomography and magnetic resonance imaging outpatients: a cross-sectional study. *Patient Education and Counseling* 2018; **101**(10): 1814-22.

Paper Three

Hyde LL, Boyes AW, Evans TJ, Mackenzie LJ, Sanson-Fisher R. Three-factor structure of the eHealth Literacy Scale among magnetic resonance imaging and computed tomography outpatients: a confirmatory factor analysis. *JMIR Human Factors* 2018; **5**(1): e6.

Paper Four

Hyde LL, Boyes AW, Mackenzie LJ, Leigh L, Oldmeadow C, Riveros C, Sanson-Fisher, R. Electronic health literacy among magnetic resonance imaging and computed tomography medical imaging outpatients: cluster analysis. *Journal of Medical Internet Research* 2019; **21**(8): e13423.

List of publications relevant to, but not included in, the thesis

Original research article

Watson R, Bryant J, Sanson-Fisher R, Turon H, Hyde L, Herrmann A. Do haematological cancer patients get the information they need about their cancer and its treatment? Results of a cross-sectional survey. *Supportive Care in Cancer* 2019; **27**(4): 1509-17.

(See Thesis Appendix 7)

Acronyms

BIC	Bayesian Information Criterion
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
CHERRIES	Checklist for Reporting Results of Internet E-Surveys
CI	Confidence Intervals
CONSORT	Consolidated Standards of Reporting Trials
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
CR	Composite Reliability
CT	Computed Tomography
CTT	Classical Test Theory
EFA	Exploratory Factor Analysis
eHealth	Electronic Health
eHEALS	eHealth Literacy Scale
IQR	Interquartile Range
IR	Indicator Reliability
IRR	Incidence Rate Ratio
IRT	Item Response Theory
LCA	Latent Class Analysis
LM	Lagrange Multiplier
MRI	Magnetic Resonance Imaging
OR	Odds Ratio
PROMIS	Patient-Reported Outcomes Measurement Information System

RANZCR	Royal Australian and New Zealand College of Radiologists
RMSEA	Root Mean Square Error of Approximation
SD	Standard Deviation
SRMR	Standardised Root Mean Residual
STAI	State-Trait Anxiety Inventory
STROBE	Strengthening the Reporting of Observational studies in Epidemiology
TNSE	t-Distribution Stochastic Network Embedding
VEE	Variance Extracted Estimates

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Abstract

Many patients undergoing magnetic resonance imaging (MRI) and computed tomography (CT) scans experience elevated anxiety. Patients should be informed about the procedural, behavioural, psychosocial and sensory aspects of preparation before these procedures. Providing preparatory information the way patients prefer is central to high-quality, patient-centred care and may improve patient outcomes. eHealth shows promise for delivering patient-centred preparatory information, as patient education websites can be tailored to individuals' preferences. However, little research has assessed whether patients' preferences for receiving a range of preparatory information items are met before MRI and CT procedures. Furthermore, no studies have examined MRI and CT patients' ability to locate and apply online health information, a concept termed eHealth literacy, necessary for patients to engage with and benefit from eHealth.

This thesis addresses these knowledge gaps by evaluating MRI and CT outpatients' experiences of, and preferences for receiving, preparatory information. It also examines issues related to measuring and describing eHealth literacy. Four published papers based on one cross-sectional study are included. Paper One assesses patient-perceived information receipt, concluding that provision of preparatory information linked to guideline recommendations needs improvement. Paper Two evaluates patient preferences for receiving this information, with findings highlighting a need for improved elicitation of, and responsiveness to, patients' preferences. Paper Three evaluates the factorial validity of the eHealth Literacy Scale (eHEALS). Findings support a three-factor eHEALS structure and raise questions about existing interpretations of eHEALS data. Paper Four is the first to apply exploratory analyses to identify four subgroups of patients, characterised as having low to very high eHEALS

factor scores. Collectively, this body of work indicates that patient-centred preparatory information provision before MRI and CT procedures should be enhanced. However, not all patients perceive that they can engage meaningfully with eHealth. eHealth should be offered alongside other information modes to improve patient-centred preparation before MRI and CT procedures.

Synopsis

Magnetic resonance imaging (MRI) and computed tomography (CT) scans are increasingly common diagnostic and surveillance processes within Australian healthcare settings. Patients who are scheduled to undergo these imaging procedures may experience elevated anxiety and distress, reinforcing a need for adequate preparation. It is recommended that preparatory information for such potentially threatening medical procedures address the procedural, sensory, psychosocial and behavioural aspects of care. Furthermore, the content and amount of preparatory information provided should be adapted to suit patients' preferences. Responding to patients' preferences in this way is important for high-quality, patient-centred care, and may result in improved psychosocial and clinical outcomes. Providing too little preparatory information can heighten patient anxiety and distress, prevent informed medical decision-making and limit compliance with clinical requirements, whereas providing too much preparatory information can overwhelm patients and increase anxiety levels. Delivering the right amount of patients' preferred preparatory information is therefore paramount.

The internet holds promise as a standardised and sustainable mode for providing patients' preferred information about how to prepare for MRI and CT procedures. This is because the internet is highly accessible and provides advanced capabilities (e.g. tailoring, multimedia, interactive functionality). eHealth refers to the organisation and delivery of health services and information using the internet and related technologies, and is a focus of national and international healthcare agendas. Optimal use of patient education websites is, however, contingent on patients having the ability to seek, find, understand, appraise and apply electronic health information, otherwise termed eHealth literacy. eHealth literacy research is challenged by the rapid speed of eHealth

development, limited application of emerging analytical techniques for psychometric assessment, and paucity of measurement research in clinical settings. This limits the credibility of eHealth literacy findings and makes it unclear whether medical imaging patients have the capabilities to meaningfully engage with and benefit from eHealth.

This thesis-by-publication reports research examining MRI and CT medical imaging outpatients' experiences of and preferences for receiving preparatory information, and their eHealth literacy. It consists of an Introduction, an overview of the Thesis Structure and Study Scope, four peer-reviewed publications and a Discussion. The four publications are based on a cross-sectional survey of MRI and CT outpatients recruited from a major public tertiary referral hospital in metropolitan Australia.

The **Introduction** contextualises the importance of patient-centred preparatory information and the relevance of eHealth. The prevalence and burden of MRI and CT procedures are discussed, and the procedural, behavioural, psychosocial and sensory domains of preparatory information are introduced. The importance of preparatory information is outlined in relation to policy and ability to influence patient outcomes. The chapter defines patient-centred care and discusses the need for information to be delivered in accordance with patient preferences. Shortcomings of existing medical imaging research are highlighted, including the limited assessment of patient-centred information provision across all four domains of preparation, and the lack of studies using dual assessment of patient receipt of both too much and too little preparatory information. As eHealth presents an opportunity to deliver information that is tailored to patient preferences, rates of internet access and functionality are discussed. Strategic initiatives to promote the implementation of eHealth are also described. eHealth literacy components (i.e. awareness, skills and evaluation) are introduced as necessary for

facilitating engagement and maximising potential benefits from eHealth. The chapter concludes by identifying the need for more research assessing the measurement properties of the commonly used eHealth Literacy Scale (eHEALS), and describing eHealth literacy in patient populations.

Paper One reports the findings from 234 MRI and CT outpatients who completed at least one of 33 survey items assessing receipt of preparatory information. Information items most commonly endorsed as having been received related to the reason for referral (85%) and how to find the imaging department (74%). The median number of preparatory information items that were not received was 18 (interquartile range: 8–25; possible maximum: 33). The prevalence of information non-receipt was highest for items addressing management of anxiety after (74%) and during (69%) the scan. These findings indicate that not all recommended preparatory information items assessed as part of this study were recalled as received by patients before MRI and CT procedures. The implications for informed consent and preparation are discussed. Paper One has been published in *Journal of Patient Experience*.

Paper Two examines the prevalence and correlates of receiving preparatory information that is aligned with the preferences of 234 MRI and CT outpatients. Building on Paper One findings, Paper Two reports that unmet information preferences are commonly related to receiving too little information, as opposed to receiving too much. The 10 highest ranked unmet information preferences were endorsed by at least 25% of participants; these mostly related to information about the scan (e.g. how to alert the radiographer if you have questions or concerns during the scan) and post-scan periods (e.g. how and when you will receive the scan results). Contrary to expectations, none of the scan or sociodemographic characteristics assessed were significantly

associated with reporting an increased number of unmet information preferences. These findings indicate there is room to improve responsiveness to patients' information preferences in this medical imaging setting. It is suggested that interventions should elicit and respond to preferences at an individual patient level, rather than being targeted to groups defined by scan or sociodemographic characteristics. Findings from Papers One and Two support the potential utility of eHealth as a way of delivering patient-centred information that is tailored to the individual, whilst also being accessible, scalable and easily integrated into existing service models. Paper Two has been published in *Patient Education and Counseling*.

To enable the evaluation of eHealth as an approach to address patient information preferences in medical imaging settings, there is a need to firstly measure eHealth literacy in this population. **Paper Three** contributes to our understanding of eHealth literacy measurement by validating the three-factor structure of the commonly used 8-item eHEALS with 256 MRI and CT outpatients. Confirmatory factor analysis resulted in all reliability measures being acceptable and two out of three goodness-of-fit indices being adequate (SRMR = 0.38; CFI = 0.944; RMSEA = 0.156). These findings challenge accumulated evidence supporting a unidimensional eHEALS structure. Furthermore, they allow for greater insights to be derived from eHEALS data, as specific aspects (i.e. awareness, skills, evaluation) of eHealth literacy can be discerned. This may lead to more targeted eHealth literacy improvement interventions and more effective eHealth implementation approaches. Paper Three has been published in *JMIR Human Factors*.

Paper Four extends the findings of Paper Three by assessing the number and correlates of eHealth literacy subgroups among 256 MRI and CT outpatients. This included an

evaluation of how eHEALS factors (i.e. awareness, skills, evaluation) co-exist within subgroups of patients who have similar eHealth literacy. Four latent classes were identified, distinguishing participants with low (21.1% of participants), moderate (26.2% of participants), high (32.8% of participants) and very high (19.9% of participants) eHealth literacy. Across each class, participants were most competent in relation to eHealth skills, followed by either awareness or evaluation. Those who preferred not to receive a lot of information about their health were significantly more likely to be assigned to the low eHealth literacy class, compared with the moderate eHealth literacy class. Similarly, those who used the internet less than daily were significantly more likely to be assigned to the low eHealth literacy class, compared with the high eHealth literacy class. These findings make an important contribution to the interpretation of eHEALS scores. Whilst dichotomising high versus low eHealth literacy subgroups is common practice in the literature, Paper Four findings suggest this method may not provide the most reliable and meaningful understanding of how eHealth literacy varies within a population. This study's identification of multiple subgroups suggests that patients undergoing MRI and CT procedures may require differentially targeted support, addressing specific components of eHealth literacy (i.e. awareness, skills, evaluation), to better engage with eHealth. Paper Four has been published in *Journal of Medical Internet Research*.

In conclusion, this thesis-by-publication makes a unique and methodologically robust contribution to our understanding of MRI and CT outpatients' experiences of, and preferences for receiving, preparatory information that is linked to guideline recommendations. Furthermore, it builds knowledge about the psychometric quality and interpretation of eHealth literacy data. Together, findings indicate there is capacity to improve the patient-centred provision of preparatory information in advance of MRI

and CT procedures. Approaches that better elicit and respond to patients' preparatory information preferences are needed in this setting. Whilst patient education websites have the capability to provide widely accessible preparatory information in line with patient preferences, the study findings indicate that not all patients are able to engage at the same level with these programs. eHealth literacy improvement interventions, targeting specific eHealth literacy components (i.e. awareness, skills, evaluation) and patient subgroups (e.g. those with low and moderate eHealth literacy) therefore warrant investigation. Such intervention research may maximise the potential benefits of providing online preparatory information to patients undergoing MRI and CT procedures. Until such time, eHealth should be part of a suite of modes of information offered to patients, so they can access the information they prefer in advance of MRI and CT procedures.

INTRODUCTION

The burden of high-technology potentially threatening medical imaging procedures

Computed tomography and magnetic resonance imaging scans are increasingly used, potentially threatening medical procedures

High-technology medical imaging, such as computed tomography (CT) and magnetic resonance imaging (MRI) scans are examples of potentially threatening medical procedures used to diagnose, treat and monitor a range of health conditions, including musculoskeletal conditions and cancer^{1,2}. These procedures are performed by public and private radiology providers, on both an inpatient and an outpatient basis³. Over 100 million CT scans and 80 million MRI scans are performed worldwide each year^{4,5}. Australia is the 8th and 15th highest provider of CT and MRI scans, respectively, compared with other member countries of the Organisation for Economic Co-operation and Development^{6,7}. Between 2008 and 2018, the number of scans performed per 1000 inhabitants in Australia increased from 88 to 134 for CT scans⁶ and from 20 to 48 for MRI scans⁷, with a commensurate rise in medical imaging expenditure³. In 2012–2013, Medicare expenditure for CT and MRI scans was \$790 million⁸ and \$250 million⁹ respectively, and since this time, financial outlays have continued to grow³. An MRI scan is approximately 20% more expensive than a CT scan and seven times more expensive than an x-ray⁹. The increase in CT and MRI service usage across Australia has been attributed to a number of factors: advances in medical imaging technology leading to improved image quality and patient safety¹⁰; wider availability of scanning machines delivering imaging services that are eligible for Medicare Benefits Schedule rebates⁹; a growing and ageing population causing an increase in the prevalence of health conditions for which these procedures are performed⁹; and national reform extending MRI requesting rights to general practitioners⁹.

Patients may feel threatened about undergoing MRI and CT scans for a number of reasons, including unfamiliarity with the imaging process, fear of the results and their implications, and the potential risks associated with the procedure^{11,12}. MRI scans use strong magnets, radiofrequency pulses and a computer to create detailed images of the inside of the body². There are many different MRI techniques (e.g. functional MRI of metabolic function versus cardiac MRI of heart and blood vessel structures), with each providing specific information about the patient². An MRI scan requires the patient to lie on a bed, which moves into a tunnel within the scanner² (Figure 1.1). The patient must remain still in this enclosed space for a length of time, ranging from 10 minutes to over an hour, depending on the body part being scanned and the MRI technique being used². Similarly, a patient having a CT scan must lie on a bed which moves in and out of a large circular gantry¹ (Figure 1.2). A CT scanner uses x-rays and computer technology to take images or “photo slices” of the body, and these images are combined to produce three-dimensional images¹. In some cases, patients undergoing MRI and CT scans are injected or asked to ingest (CT patients only) a contrast medium to highlight body structures (e.g. blood vessels and the bowel)^{13,14}.



Figure 1.1: Magnetic resonance imaging scanner

Source: Unpublished video.
Missing Piece Media.



Figure 1.2: Computed tomography scanner

Source: Unpublished video.

Missing Piece Media

There are a number of precautions and risks that patients must be aware of prior to undergoing MRI or CT. For example, if metal objects are taken into an MRI scanner, they can move, heat up and make electrical currents, potentially causing serious harm to patients². A CT scan exposes patients to a level of radiation that may slightly increase their cancer risk, with the increased risk dependent on their age and the number of CT scans received¹. Contrast medium can induce minor allergic reactions, such as nausea or itchy skin, in about 1 to 3 out of every 100 patients. It can also cause more severe allergic reactions, such as difficulty breathing, in less than 1 in 25,000 patients^{13,14}. Despite these risks, MRI and CT scans provide much higher diagnostic precision, image clarity and detail (e.g. ability to show soft tissue structures) than other types of scans, such as x-rays, and as a result, referring doctors commonly consider the benefits of these procedures to outweigh the risks¹⁵.

There can be a substantial psychosocial burden associated with undergoing magnetic resonance imaging and computed tomography scans

Patients have widely varying perceptions of threat from, and experiences of, MRI and CT procedures. A systematic review of 15 qualitative studies examining patients' experiences with having high-technology medical imaging identified 127 findings related to pre- and post- procedure time points. These findings were synthesised into 11 key themes¹⁶. Feelings of lack of control, anxiety and claustrophobia were commonly reported by patients, and these feelings were often intensified by the high importance that patients placed on having a scan¹⁶. Similarly, Forshaw et al (2018) conducted a cross-sectional study of outpatients preparing for a medical imaging procedure in an Australian tertiary referral hospital¹¹. Even after controlling for other variables, MRI and CT imaging modalities were associated with significantly higher odds of patients' reports of raised state anxiety before undergoing the procedure, compared with other types of imaging modalities, such as ultrasounds¹¹. State anxiety refers to anxiety in relation to the procedure itself, rather than proneness to anxiety or general feelings of anxiety (i.e. trait anxiety)¹¹. In Forshaw et al's (2018) study, 56% (95/169) and 59% (46/78) of patients undergoing MRI and CT respectively, reported raised state anxiety prior to the scan¹¹. Other studies have also reported elevated pre-procedure anxiety among MRI¹⁷⁻¹⁹ and CT patients^{20,21}.

Objective measures of heart rate, respiratory rate and hormone levels suggest that psychological distress often persists throughout the procedure^{17,22,23}. For example, van Minde et al (2014) monitored the heart rates of 67 MRI patients and concluded that high rates of stress and anxiety were commonly experienced across the entirety of the procedure¹⁷. Participants' heart rates peaked as they were being moved into the scanner, indicating that anxiety and stress levels were highest at the beginning of the

procedure¹⁷. Medical imaging patients more likely to report significantly high levels of anxiety include females^{11,20}, those having a scan for the first time^{11,20}, patients having a head scan¹⁷ and those requiring an injection of contrast medium²⁰. Whilst psychological wellbeing typically improves once the scan is completed¹⁷, some patients experience anxiety after the procedure. The expectation of test results is consistently reported as a major cause of anxiety among MRI and CT patients^{11,16,21,24}. Thompson et al's (2010) qualitative study of long-term lymphoma survivors undergoing surveillance CT scans reported that the time between the scan and the receipt of results is particularly distressing²¹. Quantitative studies indicate that approximately half of patients report feeling most anxious or worried about results^{11,24}. These findings emphasise the need for adequate preparation to address the psychosocial burden commonly experienced among patients undergoing MRI and CT procedures.

Providing patients with preparatory information may improve patient outcomes

Adequate patient preparation is a clinical and ethical necessity

Preparatory requirements for medical imaging vary depending on the patient's medical history, scan type and part of the body being scanned^{1,2}. For example, an abdominal MRI may require the patient to fast in advance of the appointment, whereas MRI of the leg may not require restricted food or drink intake. Other preparations required may involve changing drug prescriptions in advance of the procedure, arriving early to the appointment, preparing for an injection or ingestion of contrast medium and/or arranging alternative transport home^{1,2}. The implications of poor preparation are significant, with some risks, such as interactions with metal objects and allergic reactions to contrast medium, having the potential to cause serious harm to patients (e.g.

burns, skin irritation or difficulty breathing)^{1,2}. Accordingly, guidelines specify that healthcare providers must communicate preparatory information to patients prior to the procedure and seek informed patient consent²⁵. The *Medical Imaging Informed Consent Guidelines* of the Royal Australian and New Zealand College of Radiologists (RANZCR, 2019) recommend that information is provided to patients about scan risks and benefits, and whom to contact with questions²⁵. Information addressing other aspects of the procedure (e.g. any significant short- and/or long-term physical, emotional, mental, social, sexual or other outcomes from the scan) may also be provided, but the amount of information delivered is at the discretion of the healthcare provider and dependent on factors such as examination complexity and patient characteristics (e.g. age, education and cultural background)²⁵. These recommendations are consistent with international medical imaging policies^{26,27}.

Guidelines and systematic reviews also recommend that patients undergoing potentially threatening medical procedures be provided with specific information about the procedural, sensory, psychosocial and behavioural elements of preparation²⁸⁻³¹.

Procedural, sensory, psychosocial and behavioural information respectively refers to: the risks, sequence of events and equipment to be used; sensations that will be felt, seen or heard; management of emotions; and the patient's role in facilitating the procedure²⁸⁻³¹. Preparatory information provided to patients aims to build a realistic schema of the procedure to be experienced^{32,33}. This allows the patient to anticipate what is coming and reassures them of the normality of their medical encounter^{32,33}, i.e. the patient's expectation is congruent with the experience of having the procedure. In this way, preparatory information has the potential to mediate patients' reactions to potentially threatening medical procedures³⁴. This notion is consistent with the Transactional Model of Stress and Coping, which posits that when coping with stressful events (e.g. a

medical imaging procedure), an individual assesses the information they have, including what they think they know about the environment (e.g. scan process, benefits and risks) and evaluates the perceived implications of that information for their wellbeing, in order to formulate a coping response³⁵. This is pertinent to high-technology medical imaging, as psychological discomfort has been associated with degraded imaging quality³⁶, as well as increased delays in or terminations of the procedure³⁷. The Royal Australian College of General Practitioners reports that between 2% and 5% of patients cannot tolerate the tight space of an MRI scanner³⁸. International research suggests that up to 10% of MRI patients abort a scan due to anxiety or claustrophobia^{22,39}. This may result in delayed diagnoses and subsequent adverse impacts on the long-term health of patients, highlighting the importance of adequate patient preparation.

Providing information is effective for improving some patient and service outcomes

Improved outcomes have been reported for some patient populations undergoing potentially threatening medical procedures when they have been provided with preparatory information^{29,40-42}. A meta-analysis of 191 studies conducted with patients undergoing a range of major and minor surgical procedures found that providing pre-operative information resulted in small-to-moderate beneficial effects on post-operative physical outcomes (e.g. recovery, post-operative pain) and psychological distress⁴². More recently, Powell et al (2016) conducted a meta-analysis of 105 studies which examined the effects of psychological preparation on general surgical patients' post-operative outcomes²⁹. It was reported that additional information improved some service outcomes (e.g. length of stay) and patient outcomes (e.g. negative affect), but not other outcomes (e.g. post-operative pain)²⁹. Furthermore, systematic reviews of descriptive and intervention studies with cancer patients undergoing chemotherapy,

radiotherapy and surgery found that preparatory information often improved patients' quality of life, satisfaction, information needs, knowledge, physical symptoms and healthcare costs^{40,41}. However, findings were mixed for the impact of such information on patients' psychological outcomes, including anxiety, depression and psychological distress^{40,41}. These meta-analyses and systematic reviews consistently recommend that more evidence from high-quality experimental studies is needed to confirm the beneficial effects of information provision^{29,40-42}.

Inconsistencies in findings may be attributed to variation between studies in methodological quality and intervention characteristics (e.g. content and amount of information provided). For example, Waller et al (2015) reported that providing a smaller amount of patient-specific information may be more effective than providing a larger quantity of generic information when preparing patients for chemotherapy and radiotherapy⁴¹. Similarly, a recent meta-analysis of 71 trials found that no single element of procedural, sensory or behavioural preparatory information was effective in improving post-surgical psychological outcomes. It was concluded that multiple elements of preparatory information should be delivered, as each plays a role in holistically preparing patients⁴³.

In contrast to surgery^{29,40,42}, the body of research assessing the impact of information provision on patient and service outcomes in medical imaging is small, with only two reviews having been conducted^{44,45}. Munn and Jordan's (2012) systematic review assessed the effectiveness of preparatory interventions in improving anxiety and scan completion for outpatients undergoing high-technology medical imaging procedures, including MRI, CT and positron emission tomography⁴⁴. Six intervention studies were identified with MRI and CT outpatients in Europe and Egypt, and these studies

suggested that information provision was likely to be effective in improving patient anxiety and worries when coupled with a psychological intervention⁴⁴. Similarly, Munn and Jordan (2014) systematically reviewed intervention studies assessing the effects of non-pharmacological interventions on nuclear medical imaging patients' outcomes. Of the four studies that examined the impact of providing additional information, two studies found it had positive effects on patient anxiety and satisfaction, one study found it increased anxiety, and one study found it had no effects on anxiety⁴⁵. More recent studies have examined the effects of videos containing procedural and sensory information on MRI outpatients' motion artefacts, with conflicting results reported^{46,47}. These mixed findings are consistent with those from studies of surgical^{29,40,42}, chemotherapy and radiotherapy⁴¹ populations, and suggest that there is a need to determine optimal approaches to providing preparatory information, including specific preparatory information items (i.e. procedural, behavioural, sensory, psychosocial) that should be addressed.

Meeting patient information preferences is a component of high-quality patient-centred care

Patient-centred information provision is recommended

Providing care that is aligned with patients' wants and needs has been prioritised by international governments, organisations and lobby groups as a key principle of high-quality, patient-centred care⁴⁸⁻⁵⁰. Patient-centred care refers to providing care that is "respectful of and responsive to individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions"⁴⁹. This model of care is based on open and genuine communication that recognises the rights and responsibilities of the patient⁴⁸. In particular, a patient-centred approach ensures that patient autonomy is

maintained to the level patients desire, whilst also enabling shared decision-making⁵¹. The Institute of Medicine and the Picker Institute recognise information provision as central to patient-centred care^{49,50}. Patients should be provided with information that is attentive, responsive and tailored to their needs and preferences⁴⁹.

An information need refers to knowledge that patients perceive they need to satisfy a goal that is relevant to a medical context or situation, at a specific point in time⁵². For example, in the case of MRI and CT procedures, an information need may refer to knowledge that patients think they need to allow them to prepare adequately in advance of the scan. Patient information preferences refer to the relative desirability of different types of information^{53,54}. These include the content, amount, source, format and timing of information that patients want to receive^{41,54}. To provide information in a preference-sensitive manner, healthcare professionals must give patients options and choices for the way in which they receive information⁵³. This process may be complex, since patients' information preferences often change as they proceed through different stages of care^{54,55}. Moreover, factors such as age, gender, prior utilisation of medical services, literacy levels and coping styles have been found to mediate patient preferences for health information^{54,56-58}. For example, a study of medical imaging patients found that participants who had undergone fewer scans previously (i.e. <6 scans) were significantly more likely to consider it important to receive preparatory information, compared with those who had undergone a greater number of prior scans (i.e. 6 or more scans)⁵⁸.

Continued research is needed to evaluate whether medical imaging patients receive the content and amount of preparatory information they prefer

Patient-centred care is a key focus area for quality improvement in Australian⁵⁹ and international⁶⁰ medical imaging bodies. In addition to the need to ensure that information required for informed patient consent is provided²⁵, medical imaging patients' preferences for information should be used to guide the delivery of preparatory information. However, a recent scoping review of six international radiology reporting guidelines, including that of the RANZCR, found that recommendations to consider patient preferences when reporting results (e.g. desires for lay language summaries) were not included in any guidelines⁶¹. Additionally, few studies examine medical imaging patients' preferences for preparatory information. Whilst many aspects (i.e. content, amount, source, format and timing) should be addressed to deliver information in a patient-centred manner, a plausible first step to achieving patient-centred care is understanding what (i.e. content) and how much (i.e. amount) preparatory information patients prefer to receive. This is important, as providing too little information (resulting in unmet information needs) can heighten patients' anxiety and distress⁶², limit their ability to make informed medical decisions⁴⁹, and prevent compliance with clinical requirements (e.g. preparation for a procedure)⁴⁹. Conversely, providing too much information can overwhelm patients and increase anxiety levels^{63,64}.

Of the studies that evaluate medical imaging patients' preferences for content of preparatory information, few examine information related to all four domains of preparation (i.e. procedural, behavioural, sensory and psychosocial). Studies conducted with patients undergoing a range of medical imaging procedures, including MRI and CT scans, indicate that between 53% and 82% of participants would like to receive procedural information from a healthcare professional before the procedure^{24,65}.

Similarly, 68% of medical imaging patients report needing reassurance before a procedure²⁴, suggesting a desire for psychosocial information. Pahade et al (2018) conducted a multi-institutional cross-sectional survey with 1542 carers and patients undergoing MRI, CT and other medical imaging procedures, and asked participants how important it was for them to have the answers about areas of information before the scan⁵⁸. Thus, this measure provided a proxy for patient preferences to receive information content. Information about how to prepare was perceived as being most important (74%), followed by what the imaging test would be like (68%), and whether the test used radiation (64%)⁵⁸. However, the broad nature of information assessed in this study (e.g. how to prepare) prevented the identification of clearly defined content areas (e.g. specific aspects of preparation) to be delivered in accordance with patient preferences.

To enhance patient-centred information provision, it is also important to determine whether these preferences for information are being met by clinical practice; this aspect was not assessed by Pahade et al⁵⁸. Ollivier et al's (2009) cross-sectional study with 190 outpatients attending a cancer imaging department found that 66% of participants felt poorly informed and wanted more information about the personnel who would be treating them (i.e. procedural information)²⁴. Rosenkrantz et al (2015) reported that, among 176 patients awaiting MRI, CT, ultrasound and nuclear medicine examinations, 19% of participants had unanswered questions. These questions often related to imaging logistics (e.g. the sequence of events when having the scan), the use of contrast medium and when results would be available, suggesting that not enough information was received by patients in a way that they could understand⁶⁵. Moreover, Thornton et al (2015) conducted six qualitative focus groups with patients who were undergoing or had received cancer treatment or screening, and identified a substantial gap between

patients' expectations and experiences with receiving procedural and behavioural medical imaging information⁶⁶. Patients regularly needed to initiate discussions with healthcare providers to meet their preferences for more information about the reason for the examination, testing alternatives and intervals between follow-up⁶⁶. Whilst these findings indicate that too little information had been received, it was also reported that patients' preferences for amount of information varied substantially. Most patients felt that risk information should be available, but some considered open discussions of medical imaging risks to be useless or frightening⁶⁶. A conflict between wanting but being afraid to receive information has also been reported among patients with chronic obstructive pulmonary disease and cancer^{67,68}, and highlights sensitivities in delivering the right amount of information and the right content to facilitate patient coping. Despite this, there is a lack of studies that rigorously conduct a dual assessment of patient receipt of both too much and too little preparatory information in advance of medical imaging. Identifying discrete information content items, which address each domain of preparation, that are not provided in the amount that medical imaging patients prefer, is necessary to inform targeted areas for service improvement.

The internet is a potential mechanism for delivering patient-centred information

Internet access and use has proliferated

Access to information customisable to patient preferences is increasingly possible since the emergence of the internet. Globally, the number of internet users has increased four-fold, from 1.1 billion people (8% of world's population) in 2005 to 4.1 billion people (53.6% of the world's population) in 2019⁶⁹. Whilst the number of internet users is greatest in the developed world (86.6% of individuals), usage is steadily increasing

across the least developed countries of the world (19.1% of individuals)⁶⁹. In Australia, access to the internet has increased from 56% of households in 2004–2005 to 86% of households in 2016–2017⁷⁰. Population-based data from 2019 indicate that digital inclusion gaps for age and geographical location are wide but narrowing⁷¹. Younger Australians have higher rates of internet use, with 97.7% of those aged 18–24 years accessing the internet in the previous three months, compared with 55.2% of those aged 65 years and over⁷⁰. Rates of internet access are highest in major Australian cities (87.9% of individuals) and lowest in remote areas (80.6% of individuals)⁷⁰. Due to the widespread adoption of the internet, online information and services are increasingly relevant to Australians' everyday lives. In 2013, as part of the World Internet Project, the Swinburne Institute for Social Research administered telephone-based surveys to 1000 nationally representative Australian adults⁷². This study found that, of those who used the internet in the past three months, 84% classified the internet as important to their current way of life, 92% felt that the internet was a fast and efficient means to gain information and 85% felt that the internet made life easier⁷².

The internet can be leveraged for the patient-centred delivery of health-related information

eHealth refers to the organisation and delivery of health services and information using the internet and related technologies⁷³, and has been lauded as a key component of future healthcare delivery⁷⁴. In May 2005, the World Health Organization's eHealth Resolution, which promotes international, multisector collaboration to facilitate the integration of eHealth into healthcare systems, was adopted⁷⁵. Additionally, the Global Observatory for eHealth was developed to mark the start of a centrally coordinated, international focus in the area⁷⁶. Since this time, significant investments in developing Australia's eHealth capability have been made, as demonstrated by the \$51 billion

investment in the National Broadband Network⁷⁷. The National eHealth Transition Authority and, more recently, the Australian Digital Health Agency have been developed to lead the uptake and adoption of digital health solutions across the country⁷⁸. Australia's National Digital Health Strategy for 2018–2022 identifies priority areas for the safe, seamless and secure integration of eHealth into modern healthcare systems⁷⁹. These priority areas include, for example, ensuring health information is available for consumers whenever and wherever it is needed⁷⁹.

Given the increased attention to eHealth over the last decade, it is not surprising that the internet is one of the most common sources that people turn to for health-related information⁸⁰. In 2015, 78% of Australian adults with internet access reported using the internet for health purposes in the previous 12 months⁸⁰. This finding is reflected in other developed countries, including the United Kingdom where 69% of a nationally representative sample of current internet users sought health information on the internet in 2013, compared with only 37% in 2005⁸¹. Studies of the general public and patients consistently report that specific diseases, conditions or symptoms are the most searched health topics on the internet, followed by information about treatments or procedures, and doctors or other health professionals^{82–86}. Those more likely to search for health information online are younger, are women, and have greater internet use and higher education^{87–91}. For example, Powell et al (2011) undertook a cross-sectional survey of 792 people accessing the United Kingdom's National Health Service website, and reported that participants who were 35 years or younger were significantly more likely than those over 35 years of age to search for health information online prior to consulting a healthcare professional⁹². Such online health information searching is important as it has been found to have significant effects on subsequent medical decision-making, such as whether to attend ambulatory care or undergo treatment⁹³.

Online health information-seeking has increased despite decreased public trust in online health resources^{94,95}. Diminishing trust can be attributed to the varying quality, accuracy and reliability of the large volume of online health information available^{96,97}; despite this, people turn to the internet for its convenience, coverage and anonymity^{92,97}.

Qualitative studies indicate that people seek health information online to obtain reassurance, to challenge and supplement information received from health services, and to overcome external barriers (e.g. difficulty getting an appointment, travelling to see a healthcare professional) to accessing information from traditional services^{92,97}.

Additionally, the health information that is available online is increasingly sophisticated, with interactive features such as modules, quizzes, tailored content and multimedia⁹⁸. van Gemert-Pijnen et al (2013) highlight the potential of the internet for personalising health information, therefore providing a mechanism for patient-centred care⁹⁹. In particular, web-based algorithms that tailor features, interfaces, interaction design and messaging to individual needs, preferences and context, can be used to increase the usefulness and persuasiveness of health information⁹⁹.

Internet-based health information may be effective in improving patient outcomes

Patient education websites and internet interventions are commonly studied in the field of eHealth¹⁰⁰. Patient education websites are relatively low intensity interventions that provide consumers with self-guided access to online information about health-related issues¹⁰⁰. In contrast, internet interventions are typically high-intensity, structured behavioural or cognitive treatments converted for online delivery. They are based on effective face-to-face interventions; personalised to the user; interactive; enhanced by graphics, animations, audio, and possibly video; and tailored to provide follow-up and feedback¹⁰⁰. Thus, patient education websites hold relevance for patient-centred

information provision and should be differentiated from internet interventions when reviewing research that reports on effectiveness and usage.

Studies examining patient education websites are largely descriptive, with a focus on website quality^{101,102}, development¹⁰³⁻¹⁰⁵ and engagement¹⁰⁶. Experimental studies conducted with surgical^{107,108}, cardiac¹⁰⁹, cancer¹¹⁰ and general practitioner¹¹¹ populations suggest that patient education websites may be effective in improving a range of physical, psychosocial and service outcomes. van der Meij et al (2016) systematically reviewed trials evaluating the effectiveness of perioperative educational or supportive websites or devices, which provide information about the surgery and recovery processes¹⁰⁸. Of the 12 studies identified, eight reported significant positive impacts on patient outcomes, including physical functioning, self-efficacy and anxiety¹⁰⁸. Elkjaer et al (2010) evaluated a website providing specific education and self-treatment information for patients with ulcerative colitis¹¹². Compared with usual care, the website resulted in greater treatment adherence, knowledge and quality of life, as well as reduced numbers of acute and routine outpatient clinic visits¹¹². Spoelman et al (2016) conducted an interrupted time series analysis of 912,000 patients visiting their general practitioners from 2009 to 2014, and found that two years after the release of an evidence-based patient education website, the consultation rate had reduced by 12%¹¹¹, suggesting that eHealth may be effective in minimising healthcare usage within this population.

There is an absence of research assessing the effectiveness of patient education websites in improving patient and service outcomes in the medical imaging context^{44,45}.

Nevertheless, descriptive studies suggest an appetite for web-based information provision in this setting^{66,113}. Horton et al's (2000) study of 205 adult CT outpatients

reported that 83% of participants with internet access indicated that web-based information about radiological examinations would be useful¹¹³. A qualitative study of six focus groups with cancer patients undergoing medical imaging reported that self-directed internet searches were most commonly used to retrieve benefit and risk information, and that patients wanted to receive hospital-endorsed online preparatory information, along with face-to-face information⁶⁶. The American College of Radiology and Radiological Society of North America's publicly accessible website, radiologyinfo.org, receives over one million visitors per month¹¹⁴. However, a recent cross-sectional study of 1542 radiology patients and caregivers across the United States (US) found that materials by national radiology organisations account for only 5% of sources from which people seek information about a procedure⁵⁸. Collectively, these findings point to the challenge of a disconnect between patients' intention to use, and their behaviours engaging with, patient education websites. Although the internet holds promise as a future mode of information provision for medical imaging, credible online information sources are not being used to their potential.

eHealth literacy is important in maximising the potential benefits of internet-based health information

There is considerable variation between patients in eHealth literacy

Before assessing the potential effectiveness of the internet in delivering patient-centred information to medical imaging patients, it is important firstly to ensure that patients have adequate eHealth literacy. eHealth literacy refers to an individuals' ability to seek, find, understand and appraise health information from electronic sources, and apply the knowledge gained to addressing or solving a health problem¹¹⁵. A series of analytic and context-specific literacy types comprise the concept of eHealth literacy: traditional;

computer; media; health; information; and science¹¹⁵. An eHealth-literate individual must be able to: read and understand website content; navigate through the various website pages, links and downloadable content; identify credible sources; manage vast amounts of information; understand which health-related material will meet their needs; and interpret the information to achieve associated benefits¹¹⁵.

However, consumers have been found to have limited search and evaluation skills required for using online health information effectively⁸³. Peak Australian healthcare bodies, including the Consumers Health Forum of Australia and the Australian College of Rural and Remote Medicine, have identified eHealth literacy as a significant barrier to patients achieving optimal and equal benefits from eHealth⁷⁹. Cross-sectional studies of the general public and older adults indicate that male gender, increased age and lower education are associated with reduced eHealth literacy^{116,117}. A review by Watkins and Xie (2014) reported that older adults are particularly susceptible to poor eHealth literacy, despite the potential effectiveness of high-quality interventions that target eHealth literacy¹¹⁸. Whilst older people may have one of the greatest needs for eHealth support, studies with younger people¹¹⁹, adult patients¹²⁰ and minority groups¹²¹ suggest that eHealth literacy could also be improved among these populations. However, no descriptive research has examined levels of eHealth literacy among patients undergoing MRI and CT procedures. It is therefore unclear whether patients in this setting have the capabilities to engage meaningfully with patient education websites, and whether eHealth could be an appropriate channel for the patient-centred delivery of preparatory information prior to MRI and CT procedures.

The need to address this gap in the literature is accentuated, as greater eHealth literacy has been found to be associated with improved instrumental outcomes (e.g. self-

management of healthcare needs, physical exercise, eating a balanced diet) and interpersonal outcomes (e.g. asking physicians questions, consulting with physicians on information retrieved) among the general population^{117,122}. Additionally, Stellefson et al's (2019) recent study of 174 patients with chronic obstructive pulmonary disease reported that greater eHealth literacy was associated with increased lung-specific health-related quality of life¹²³. However, Neter and Brainin's (2019) recent systematic review highlights a paucity of research examining the association between eHealth literacy and health outcomes among patient populations¹²⁴. Only two of eight studies surveyed patients with diagnosed medical conditions (e.g. HIV and cancer survivors), with the remaining assessing college students and community adults¹²⁴. No studies evaluated the association between eHealth literacy and health outcomes among patients undergoing potentially threatening medical procedures. This highlights the under-representation of and need for eHealth literacy research with patients undergoing MRI and CT procedures, who could benefit greatly from online health information. Furthermore, the quality of evidence within the eight studies was classified as low to moderate, suggesting that whilst eHealth literacy may be beneficial, ongoing research of higher methodological rigour should be conducted to strengthen the reliability of conclusions¹²⁴.

Limited quality of and engagement with online health information reinforces the need for eHealth literacy

An abundance of readily accessible health-related information on the internet¹²⁵ further highlights the importance of eHealth literacy among MRI and CT patients. Several studies have examined the quality of information contained on websites designed specifically for patients undergoing medical imaging procedures^{114,126,127}. For example, Bowden et al (2017) applied the DISCERN, a validated instrument for the assessment

of healthcare information quality, to 108 websites providing information about common radiological procedures, including MRI and CT, and concluded that the overall quality of websites examined was poor¹²⁷. Hansberry et al (2017) found that only 2 of 100 radiology website articles assessed were written at the 3rd to 7th grade reading level recommended by the National Institutes of Health and American Medical Association¹¹⁴. Furthermore, few imaging websites address the range of preparatory information that patients require for a procedure^{126,128}. Smart and Burling (2001) systematically searched the internet for patient radiology resources, and reported that of 21 websites identified, 79% did not address procedural risks and 46% did not address result availability¹²⁶. Moreover, Johnson et al's (2017) recent assessment of US private practice radiology websites found that information addressing examination quality, safety and experience was missing in up to 60% of websites¹²⁸. Collectively, these findings indicate the need for patients to be able to critically evaluate online health information, thus reinforcing the necessity of eHealth literacy.

eHealth literacy is also required to maximise engagement with eHealth resources^{129,130}. Limited eHealth literacy has been identified as a key self-reported barrier to the use of the internet for health purposes by people with chronic health conditions¹²⁹. Holt et al (2019) conducted a cross-sectional study with 246 outpatients diagnosed with gastrointestinal diseases, diabetes and other endocrine conditions, and found that those with lower eHealth literacy were less likely to be users of digital health services¹³⁰. eHealth research is impacted by high rates of non-usage attrition, whereby consumers either do not use or prematurely stop using web-based eHealth interventions¹³¹. Non-usage attrition rates between 40% and 50% are commonly reported, but attrition may be even higher^{132,133}. It is possible that non-usage of patient education websites exceeds that of internet interventions, as characteristics specific to internet interventions (e.g.

counsellor support and a modular set-up) have been associated with increased eHealth exposure¹³³. In line with this, Kakkar and Jacobson (2013) examined the effects of a preparatory website on colonoscopy patients' bowel preparation, and found that only 6% of participants randomised to the intervention watched the online video¹³⁴. More aggressive efforts to enhance engagement were recommended, including the use of nursing staff to support patients in using the website, therefore suggesting that some participants did not have the skills or desire to engage with web-based materials. Such lack of engagement, which may be partly a consequence of limited eHealth literacy, restricts the potential benefits of online health information and also presents methodological issues for this field of research¹³¹. eHealth literacy should therefore be assessed to inform the development of targeted eHealth support strategies that maximise the use of patient education websites and the potential benefits to be achieved from this use.

Accurate assessment of eHealth literacy is an essential first step towards effective delivery of internet-based health information

Valid and reliable measurement is essential

Valid, reliable and responsive scales are required to minimise measurement error in descriptive and intervention research¹³⁵. Table 1.1 shows the psychometric properties that are used to evaluate the rigour of measurement instruments. In combination, these properties provide unique information about the accuracy, precision and sensitivity of each measure¹³⁶. Evidence for these properties should guide the selection and application of measurement instruments for research, as well as the assessment and interpretation of results obtained using these instruments¹³⁶.

Table 1.1: Description of psychometric properties

Measurement property	Description
Reliability: Refers to error in measurement ¹³⁵	
Internal consistency	The extent to which items in a scale are homogeneous ¹³⁷
Test-retest reliability	Reproducibility or stability over time ¹³⁸
Measurement invariance	Equivalence of measurement among different groups ¹³⁹
Validity: Refers to the extent to which a scale measures the construct of interest ¹³⁵	
Content validity	Extent to which items represent the issue being measured ¹³⁵
Face validity	Assessment of whether the scale appears to measure what it intends to measure ¹⁴⁰
Construct validity	Extent to which scores on a scale are consistent with hypotheses, based on an assumption that the scale validly measures the construct of interest ¹³⁶
Factorial (or structural) validity	Degree to which scores on an instrument are an adequate reflection of the dimensionality of the construct to be measured ¹³⁶
Convergent validity	Positive correlation with another scale measuring the same construct ¹³⁵
Divergent validity	No correlation with another scale measuring a different construct ¹³⁵
Known groups	Ability of a scale to differentiate between two or more known groups ¹³⁷
Criterion validity	How well the scale agrees with a criterion ¹³⁵
Concurrent validity	Ability to render equivalent scores to an alternative “gold standard” measure ¹³⁵
Predictive validity	Ability to predict scores for a future outcome ¹³⁵
Cross-cultural validity	Degree to which an adapted version displays similar scores to the original instrument ¹³⁶
Responsiveness: Capacity of a scale to detect changes over time ¹³⁸	
Acceptability: Extent to which an instrument is acceptable to complete ¹⁴¹	
Feasibility: Level of burden for those administering the instrument ¹³⁸	

The importance of rigorous assessment of a measure's psychometric properties is highlighted by the development of the Consensus-based Standards for the Selection of Health Measurement Instruments (COSMIN)¹³⁶ and the Patient-Reported Outcomes Measurement Information System (PROMIS)¹⁴². COSMIN is an international initiative aiming to improve the selection of outcome measurement instruments in research and clinical practice, whilst PROMIS is an initiative of the National Institutes of Health to accelerate and bolster medical research processes¹⁴². These initiatives provide standardised, best-practice direction for the scientific development, evaluation and implementation of patient-reported measurement instruments, from conceptualisation through to widespread psychometric testing among diverse populations^{136,142}. It is recommended that establishing reliable, valid and responsive scales involves multiple studies across multiple settings, conducted over time¹⁴². Following initial development, measurement instruments should continue to be refined as new data about scale adequacy accumulate. This includes retesting a scale when it is used in new populations and as new analytical techniques become available. These recommendations support the need for ongoing evaluation of eHealth literacy measurement, particularly as technological advancements change the way that eHealth programs are intended to be used¹⁴³.

Psychometric evaluation of eHealth literacy measures is warranted

One of the first and most commonly used measures of eHealth literacy is the self-reported eHealth Literacy Scale (eHEALS)¹⁴⁴. This eight-item tool measures consumers' combined knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems¹⁴⁴. Strengths of the eHEALS include its brevity and ease of administration among populations with diverse

sociodemographic^{116,145-147}, ethnic^{145,148,149} and disease^{120,150,151} profiles. The scale has been translated from English into at least six other languages^{145,146,148,152-154} and has demonstrated measurement invariance across English-speaking countries¹⁵⁵. Acceptable test-retest reliability^{148,156} and internal consistency among populations of varying age and ethnicity^{145,146,148,149,156,157} have been reported. Whilst mixed findings exist, some studies report that the eHEALS demonstrates convergent validity by significantly correlating with measures of computer knowledge and computer skills^{146,156}. Additionally, the eHEALS has recently been adapted so that it can be administered to carers of people with chronic disease¹⁵⁸.

Despite its wide use, there are limitations associated with the eHEALS that need to be addressed, including the factorial validity of the scale. As shown in Table 1.1, factorial validity refers to the degree to which scores on an instrument (e.g. the eHEALS) are an adequate reflection of the dimensionality of the construct to be measured (e.g. eHealth literacy)¹³⁶. A majority of studies have used data-driven analytical techniques, such as exploratory factor analysis, to conclude that the eHEALS measures a single dimension^{144-148,156,157,159}. This type of analysis is most appropriate in the early phases of measure development, when latent variable structures are unknown¹⁶⁰. However, more recently, theoretically driven analytical approaches, such as confirmatory factor analysis, have been applied to verify hypothesised eHEALS factor structures. This has resulted in findings of scale multidimensionality^{155,161,162}. For example, Sudbury-Riley et al (2018) used the self-efficacy and social-cognitive theories underpinning eHealth literacy to propose and validate a three-factor eHEALS structure, comprising awareness, skills and evaluation domains, among a multi-national sample of adult internet users¹⁵⁵. These factors are empirically supported as there are conceivably many aspects involved in seeking, finding, applying and evaluating online health information.

Uncertainties about the factorial validity of the eHEALS contributes to inconsistencies in the interpretation of eHEALS data, and makes it difficult to compare and contrast findings of various studies. In accordance with literature suggesting that the eHEALS is unidimensional^{144-148,156,157,159}, many studies have evaluated eHEALS scores on a global level, reporting total score mean or median values^{116,117,149,163}. Meanwhile, other studies report item response frequencies^{116,164,165}, thereby disregarding scale constructs, and others arbitrarily assign total score cut-points to differentiate high versus low overall eHealth literacy^{166,167}. For example, Richtering et al (2017) examined eHealth literacy among people with moderate-to-high cardiovascular disease risk, and predetermined that a score of 26 or more would indicate high eHealth literacy¹⁶⁶. Without an understanding of clinically important thresholds, which consistently define eHEALS scores that indicate that a person can meaningfully engage with eHealth to obtain health-related benefits (e.g. greater self-management of illness), the implications of existing eHEALS findings are unclear. If multiple eHEALS dimensions do exist, the global assessment of eHEALS scores limits the depth of insights that can be drawn about specific components of eHealth literacy that potentially require improvement. Together, limitations regarding factorial validity and the interpretation of eHEALS scores emphasise a need for continuing psychometric analyses across populations and settings¹⁴², particularly in populations where the eHEALS has not been applied previously, such as medical imaging patients.

eHealth literacy should inform eHealth design and implementation approaches

Ongoing psychometric analyses may better inform eHealth design and implementation approaches. Despite emerging evidence for eHEALS multidimensionality^{155,161,162}, existing literature does not identify specific components of eHealth literacy that should

be targeted for improvement (e.g. awareness, skills and evaluation), and the use of global cut-points sets a precondition for two types of eHealth literacy (i.e. high versus low). Thus, the identification of meaningful subgroups of patients who have differing eHealth literacy and associated support needs is limited. This is important to address as the Australian Office of the eSafety Commissioner states the need to match digital training options to the levels of need and confidence of consumers¹⁶⁸. Furthermore, Norman and Skinner (2006) propose that core eHealth literacy skills are not fixed and can therefore be improved with appropriate training and support¹¹⁵. The identification and evaluation of novel eHealth literacy subgroups may therefore be an appropriate next step towards building knowledge about the nature of eHealth literacy and its implications for research and clinical practice. This is pertinent to MRI and CT outpatients, where studies of eHealth literacy are yet to be conducted, despite the high potential utility of patient education websites for preparatory information provision. Such knowledge could inform more targeted eHealth literacy improvement strategies, by identifying unique support needs within different sections of the population. This research may also result in more targeted time and resource investments in eHealth, by identifying groups of people who have the required competency and are therefore more likely to benefit from eHealth implementation.

Thesis aims

This literature review has identified several research gaps in preparing patients for potentially threatening MRI and CT procedures. For example, despite the increasing global focus on patient-centred care, there is scant literature assessing Australian MRI and CT medical imaging outpatients' experiences with receiving discrete items of procedural, sensory, psychosocial and behavioural preparatory information in line with

their preferences. The internet holds promise as a wide-reaching and sustainable vehicle to deliver patient-centred preparatory information, but patients need adequate eHealth literacy to effectively engage with and benefit from these programs. Valid and reliable measurement of eHealth literacy is important for identifying patients who need support to benefit from eHealth. Uncertainties regarding the factorial validity of the eHEALS, the most commonly used measure of eHealth literacy, cast doubt on findings related to this measure. These uncertainties limit the assessment and understanding of eHealth literacy among populations, and must be addressed to determine whether eHealth is a suitable channel for the delivery of preparatory information before MRI and CT procedures.

This thesis therefore aims to:

1. examine MRI and CT medical imaging outpatients' experiences of and preferences for receiving procedural, sensory, psychosocial and behavioural preparatory information in advance of a scan (Papers One and Two);
2. evaluate the factorial validity of the eHealth Literacy Scale among MRI and CT outpatients (Paper Three); and
3. identify the number and correlates of subgroups of MRI and CT outpatients reporting similar eHealth literacy (Paper Four).

References

1. The Royal Australian and New Zealand College of Radiologists. Computed Tomography: Consumer Information. 2015.
<http://www.ranzcr.edu.au/resources/consumers> (accessed 26 June 2016).
2. The Royal Australian and New Zealand College of Radiologists. Magnetic Resonance Imaging (MRI): Consumer Information. 2015.
<http://www.ranzcr.edu.au/resources/consumers> (accessed 26 June 2016).
3. Australian Diagnostic Imaging Association. ADIA Budget Submission 2017-18: A Fairer and Smarter Medicare for Radiology Patients. Melbourne: ADIA, 2017.
4. Enders J, Zimmermann E, Rief M, et al. Reduction of claustrophobia during magnetic resonance imaging: methods and design of the "CLAUSTRO" randomized controlled trial. *BMC Medical Imaging* 2011; **11**(1): 4.
5. World Health Organization. Communicating Radiation Risks in Paediatric Imaging: Information to Support Healthcare Discussions about Benefit and Risk. Switzerland WHO, 2016.
6. Organisation for Economic Co-operation and Development. Computed Tomography (CT) Exams (Indicator). 2020. <https://www.oecd-ilibrary.org/content/data/3c994537-en> (accessed 5 February 2020).
7. Organisation for Economic Co-operation and Development. Magnetic Resonance Imaging (MRI) Exams (Indicator). 2020. https://www.oecd-ilibrary.org/social-issues-migration-health/magnetic-resonance-imaging-mri-exams/indicator/english_1d89353f-en (accessed 5 February 2020).
8. Wright CM, Bulsara MK, Norman R, Moorin RE. Increase in computed tomography in Australia driven mainly by practice change: A decomposition analysis. *Health Policy* 2017; **121**(7): 823-9.

9. Australian National Audit Office. The Auditor-General, ANAO Report No.12 2014–15, Performance Audit: Diagnostic Imaging Reforms. Canberra: ANAO, 2014.
10. Smith-Bindman R, Miglioretti DL, Larson EB. Rising use of diagnostic medical imaging in a large integrated health system: the use of imaging has skyrocketed in the past decade, but no one patient population or medical condition is responsible. *Health Affairs* 2008; **27**(6): 1491-502.
11. Forshaw K, Boyes A, Carey M, et al. Raised anxiety levels among outpatients preparing to undergo a medical imaging procedure: prevalence and correlates. *Journal of the American College of Radiology* 2018; **15**(4): 630-8.
12. Tornqvist E, Mansson A, Larsson EM, Hallstrom I. It's like being in another world - patients' lived experience of magnetic resonance imaging. *Journal of Clinical Nursing* 2006; **15**(8): 954-61.
13. The Royal Australian and New Zealand College of Radiologists. Iodine-Containing Contrast Medium. 2020. <https://www.insideradiology.com.au/iodine-containing-contrast-medium/> (accessed 27 May 2020).
14. The Royal Australian and New Zealand College of Radiologists. Gadolinium Contrast Medium (MRI Contrast Agents). 2020. <https://www.insideradiology.com.au/gadolinium-contrast-medium/> (accessed 27 May 2020).
15. Hendee WR, Becker GJ, Borgstede JP, et al. Addressing overutilization in medical imaging. *Radiology* 2010; **257**(1): 240-5.
16. Munn Z, Jordan Z. The patient experience of high technology medical imaging: a systematic review of the qualitative evidence. *Radiography* 2011; **17**(4): 323-31.

17. van Minde D, Klaming L, Weda H. Pinpointing moments of high anxiety during an MRI examination. *International Journal of Behavioral Medicine* 2014; **21**(3): 487-95.
18. Grey SJ, Price G, Mathews A. Reduction of anxiety during MR imaging: a controlled trial. *Magnetic Resonance Imaging* 2000; **18**(3): 351-5.
19. Klaming L, van Minde D, Weda H, Nielsen T, Duijm LE. The relation between anticipatory anxiety and movement during an MR examination. *Academic Radiology* 2015; **22**(12): 1571-8.
20. Heyer CM, Thuring J, Lemburg SP, et al. Anxiety of patients undergoing CT imaging-an underestimated problem? *Academic Radiology* 2015; **22**(1): 105-12.
21. Thompson CA, Charlson ME, Schenkein E, et al. Surveillance CT scans are a source of anxiety and fear of recurrence in long-term lymphoma survivors. *Annals of Oncology* 2010; **21**(11): 2262-6.
22. Dziuda Ł, Zieliński P, Baran P, Krej M, Kopka L. A study of the relationship between the level of anxiety declared by MRI patients in the STAI questionnaire and their respiratory rate acquired by a fibre-optic sensor system. *Scientific Reports* 2019; **9**(1): 4341.
23. Tazegul G, Etcioğlu E, Yildiz F, Yildiz R, Tuney D. Can MRI related patient anxiety be prevented? *Magnetic Resonance Imaging* 2015; **33**(1): 180-3.
24. Ollivier L, Apiou F, Leclerc J, et al. Patient experiences and preferences: development of practice guidelines in a cancer imaging department. *Cancer Imaging* 2009; **9**: S92-7.
25. The Royal Australian and New Zealand College of Radiologists. Medical Imaging Informed Consent Guidelines, Version 3. Sydney, Australia: RANZCR, 2019.

26. The Royal College of Radiologists. Standards for Patient Consent Particular to Radiology, Second Edition. London: The Royal College of Radiologists, 2012.
27. American College of Radiologists. ACR–SIR–SPR Practice Parameter on Informed Consent for Image-Guided Procedure. Res. 17: American College of Radiologists, 2016.
28. National Breast Cancer Centre and National Cancer Control Initiative. Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer. Camperdown, NSW: National Breast Cancer Centre, 2003.
29. Powell R, Scott NW, Manyande A, et al. Psychological preparation and postoperative outcomes for adults undergoing surgery under general anaesthesia. *Cochrane Database of Systematic Reviews* 2016; (5): CD008646.
30. Schofield MJ, Sanson-Fisher R. How to prepare cancer patients for potentially threatening medical procedures: consensus guidelines. NSW Cancer Council Cancer Education Research Program. *Journal of Cancer Education* 1996; **11**(3): 153-8.
31. Cockburn J., NSW Cancer Council. How to Prepare Patients for Potentially Threatening Clinical Procedures: An Interactional Skills Training Manual for General Practitioners, Junior Medical Officers, Nurses, Surgeons. Kings Cross, NSW: NSW Cancer Council, 1997.
32. Porocho D. The effect of preparatory patient education on the anxiety and satisfaction of cancer patients receiving radiation therapy. *Cancer Nursing* 1995; **18**(3): 206-14.
33. Hjelm-Karlsson K. Comparison of oral, written and audio-visually based information as preparation for intravenous pyelography. *International Journal of Nursing Studies* 1989; **26**(1): 53-68.

34. Johnson JE, Leventhal H. Effects of accurate expectations and behavioral instructions on reactions during a noxious medical examination. *Journal of Personality and Social Psychology* 1974; **29**(5): 710-8.
35. Folkman S, Lazarus RS. Stress, Appraisal, and Coping: New York: Springer Publishing Company; 1984.
36. Evans REC, Taylor SA, Kalasthry J, et al. Patient deprivation and perceived scan burden negatively impact the quality of whole-body MRI. *Clinical Radiology* 2020; **75**(4): 308-15.
37. Munn Z, Jordan Z. Interventions to reduce anxiety, distress and the need for sedation in adult patients undergoing magnetic resonance imaging: a systematic review. *International Journal of Evidence-Based Healthcare* 2013; **11**(4): 265-74.
38. Royal Australian College of General Practitioners. Clinical Guidance for MRI Referral. East Melbourne: RACGP, 2013.
39. Sadigh G, Applegate KE, Saindane AM. Prevalence of unanticipated events associated with MRI examinations: a benchmark for MRI quality, safety, and patient experience. *Journal of the American College of Radiology* 2017; **14**(6): 765-72.
40. Waller A, Forshaw K, Bryant J, Carey M, Boyes A, Sanson-Fisher R. Preparatory education for cancer patients undergoing surgery: a systematic review of volume and quality of research output over time. *Patient Education and Counseling* 2015; **98**(12): 1540-9.
41. Waller A, Forshaw K, Bryant J, Mair S. Interventions for preparing patients for chemotherapy and radiotherapy: a systematic review. *Supportive Care in Cancer* 2014; **22**(8): 2297-308.
42. Devine EC. Effects of psychoeducational care for adult surgical patients: a meta-analysis of 191 studies. *Patient Education and Counseling* 1992; **19**(2): 129-42.

43. Freeman SC, Scott NW, Powell R, Johnston M, Sutton AJ, Cooper NJ. Component network meta-analysis identifies the most effective components of psychological preparation for adults undergoing surgery under general anesthesia. *Journal of Clinical Epidemiology* 2018; **98**: 105-16.
44. Munn Z, Jordan Z. The effectiveness of interventions to reduce anxiety, claustrophobia, sedation and non-completion rates of patients undergoing high technology medical imaging. *JBIC Library of Systematic Reviews* 2012; **10**(19): 1122-85.
45. Munn Z, Jordan Z. The Effectiveness of Nonpharmacologic Interventions to Reduce Anxiety and Increase Patient Satisfaction and Comfort during Nuclear Medicine Imaging. *Journal of Medical Imaging and Radiation Sciences* 2014; **45**(1): 47-54.
46. Powell R, Ahmad M, Gilbert FJ, Brian D, Johnston M. Improving magnetic resonance imaging (MRI) examinations: development and evaluation of an intervention to reduce movement in scanners and facilitate scan completion. *British Journal of Health Psychology* 2015; **20**(3): 449-65.
47. Tugwell JR, Goulden N, Mullins P. Alleviating anxiety in patients prior to MRI: A pilot single-centre single-blinded randomised controlled trial to compare video demonstration or telephone conversation with a radiographer versus routine intervention. *Radiography (Lond)* 2018; **24**(2): 122-9.
48. Kitson A, Marshall A, Bassett K, Zeitz K. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing* 2013; **69**(1): 4-15.
49. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington D.C., 2001.
50. Picker Institute. Influence, Inspire, Empower: Impact Report 2018-2019. Oxford, 2018.

51. Abujudeh HH, Danielson A, Bruno MA. A patient-centered radiology quality process map: opportunities and solutions. *American Journal of Roentgenology* 2016; **207**(5): 940-6.
52. Ormandy P. Defining information need in health - assimilating complex theories derived from information science. *Health Expectations* 2011; **14**(1): 92-104.
53. Brennan PF, Strombom I. Improving health care by understanding patient preferences: the role of computer technology. *Journal of the American Medical Informatics Association* 1998; **5**(3): 257-62.
54. Ramsay I, Peters M, Corsini N, Eckert M. Consumer Health Information Needs and Preferences: A Rapid Evidence Review. Sydney: ACSQHC, 2017.
55. Halkett GKB, Kristjanson LJ, Lobb E, et al. Information needs and preferences of women as they proceed through radiotherapy for breast cancer. *Patient Education and Counseling* 2012; **86**(3): 396-404.
56. Vosbergen S, Peek N, Mulder-Wiggers JM, et al. An online survey to study the relationship between patients' health literacy and coping style and their preferences for self-management-related information. *Patient Preference and Adherence* 2014; **8**: 631.
57. Ende J, Kazis L, Ash A, Moskowitz MA. Measuring patients' desire for autonomy: decision making and information-seeking preferences among medical patients. *Journal of General Internal Medicine* 1989; **4**(1): 23-30.
58. Pahade JK, Trout AT, Zhang B, et al. What patients want to know about imaging examinations: a multiinstitutional us survey in adult and pediatric teaching hospitals on patient preferences for receiving information before radiologic examinations. *Radiology* 2018; **287**(2): 554-62.

59. The Royal Australian and New Zealand College of Radiologists Quality and Safety Committee. Strategic Planning Discussion Paper – Radiology Quality and Safety. Sydney, Australia: RANZCR, 2014.
60. European Society of Radiology. Patient Information. The Most Important Stakeholder in Radiology: The Patient. 2017. <https://www.myesr.org/quality-safety/patient-information> (accessed 7 July 2017).
61. Farmer CI, Bourne AM, O'Connor D, Jarvik JG, Buchbinder R. Enhancing clinician and patient understanding of radiology reports: a scoping review of international guidelines. *Insights into Imaging* 2020; **11**(1): 62.
62. Suls J, Wan CK. Effects of sensory and procedural information on coping with stressful medical procedures and pain: a meta-analysis. *Journal of Consulting and Clinical Psychology* 1989; **57**(3): 372-9.
63. Miller S. Individual Differences in the Coping Process: What to Know and When to Know It. In: Carpenter B, ed. *Personal Coping: Theory, Research and Application*. Westport, CT, US: Praeger Publishers/Greenwood Publishing Group; 1992: 77-91.
64. Case DO, Andrews JE, Johnson JD, Allard SL. Avoiding versus seeking: the relationship of information seeking to avoidance, blunting, coping, dissonance, and related concepts. *Journal of the Medical Library Association* 2005; **93**(3): 353-62.
65. Rosenkrantz AB, Flagg ER. Survey-based assessment of patients' understanding of their own imaging examinations. *Journal of the American College of Radiology* 2015; **12**(6): 549-55.
66. Thornton RH, Dauer LT, Shuk E, et al. Patient perspectives and preferences for communication of medical imaging risks in a cancer care setting. *Radiology* 2015; **275**(2): 545-52.

67. Leydon GM, Boulton M, Moynihan C, et al. Cancer patients' information needs and information seeking behaviour: in depth interview study. *British Medical Journal* 2000; **320**(7239): 909.
68. Disler RT, Green A, Luckett T, et al. Experience of advanced chronic obstructive pulmonary disease: metasynthesis of qualitative research. *Journal of Pain and Symptom Management* 2014; **48**(6): 1182-99.
69. International Telecommunication Union. Measuring Digital Development: Facts and Figures 2019. 2020. <https://www.itu.int/en/ITU-D/Statistics/Pages/facts/default.aspx> (accessed 20 February 2020).
70. Australian Bureau of Statistics. 8146.0 - Household Use of Information Technology, Australia, 2016-17. 2018. <http://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0> (accessed 24 June 2018).
71. Thomas J, Barraket J, Wilson C, Rennie E, Ewing S, MacDonald T. Measuring Australia's Digital Divide: The Australian Digital Inclusion Index 2019. Melbourne: RMIT University and Swinburne University of Technology, 2019.
72. Ewing S, van der Nagel E, Thomas J. CCI Digital Futures 2014: The Internet in Australia Melbourne: ARC Centre of Excellence for Creative Industries and Innovation, Swinburne University of Technology, 2014.
73. Pagliari C, Sloan D, Gregor P, et al. What is eHealth (4): a scoping exercise to map the field. *Journal of Medical Internet Research* 2005; **7**(1): e9.
74. Silber D. The case for eHealth. *Studies in Health Technology and Informatics* 2004; **100**: 3-27.
75. World Health Organization. WHO eHealth Resolution. 2020. <https://www.who.int/healthacademy/news/en/> (accessed 10 April 2020).

76. World Health Organization. Global Observatory for eHealth. 2017.
<http://www.who.int/goe/en/> (accessed 21 August 2017).
77. Telstra Corporation Limited. ACCC Inquiry into NBN Access Pricing - Discussion Paper. Canberra, 2019.
78. Australian Digital Health Agency. About the Agency. 2020.
<https://www.digitalhealth.gov.au/about-the-agency> (accessed 10 April 2020).
79. Australian Digital Health Agency. Australia's National Digital Health Strategy. Safe, Seamless and Secure: Evolving Health and Care to Meet the Needs of Modern Australia. Sydney: ADIA, 2018.
80. Australian Institute of Health and Welfare. Australia's Health 2018: in brief. Cat. no. AUS 222. Canberra: AIHW, 2018.
81. Dutton W, Blank G, Groselj D. Cultures of the Internet: The Internet in Britain. United Kingdom: OxIS, 2013.
82. Cline RJW, Haynes KM. Consumer health information seeking on the Internet: the state of the art. *Health Education Research* 2001; **16**(6): 671-92.
83. Morahan-Martin JM. How internet users find, evaluate, and use online health information: a cross-cultural review. *Cyberpsychology & Behaviour* 2004; **7**(5): 497-510.
84. Wong DK-K, Cheung M-K. Online health information seeking and eHealth literacy among patients attending a primary care clinic in Hong Kong: a cross-sectional survey. *Journal of Medical Internet Research* 2019; **21**(3): e10831.
85. Cocco AM, Zordan R, Taylor DM, et al. Dr Google in the ED: searching for online health information by adult emergency department patients. *Medical Journal of Australia* 2018; **209**(8): 342-7.

86. Xiao N, Sharman R, Rao HR, Upadhyaya S. Factors influencing online health information search: an empirical analysis of a national cancer-related survey. *Decision Support Systems* 2014; **57**: 417-27.
87. Reinfeld-Kirkman N, Kalucy E, Roeger L. The relationship between self-reported health status and the increasing likelihood of South Australians seeking Internet health information. *Australian and New Zealand Journal of Public Health* 2010; **34**(4): 422-6.
88. Atkinson NL, Saperstein SL, Pleis J. Using the internet for health-related activities: findings from a national probability sample. *Journal of Medical Internet Research* 2009; **11**(1): e4.
89. Pollard CM, Pulker CE, Meng X, Kerr DA, Scott JA. Who uses the Internet as a source of nutrition and dietary information? An Australian population perspective. *Journal of Medical Internet Research* 2015; **17**(8): e209.
90. Reiners F, Sturm J, Bouw L, Wouters E. Sociodemographic factors influencing the use of eHealth in people with chronic diseases. *International Journal of Environmental Research and Public Health* 2019; **16**(4): 645.
91. Kasparian N, Lieu N, Winlaw D, Cole A, Kirk E, Sholler G. eHealth literacy and preferences for eHealth resources in parents of children with complex CHD. *Cardiology in the Young* 2017; **27**(4): 722-30.
92. Powell J, Inglis N, Ronnie J, Large S. The characteristics and motivations of online health information seekers: cross-sectional survey and qualitative interview study. *Journal of Medical Internet Research* 2011; **13**(1): e20-e.
93. Chen Y-Y, Li C-M, Liang J-C, Tsai C-C. Health information obtained from the internet and changes in medical decision making: questionnaire development and cross-sectional survey. *Journal of Medical Internet Research* 2018; **20**(2): e47.

94. Jacobs W, Amuta AO, Jeon KC. Health information seeking in the digital age: an analysis of health information seeking behavior among US adults. *Cogent Social Sciences* 2017; **3**(1): 1302785.
95. Hesse BW, Moser RP, Rutten LJ. Surveys of physicians and electronic health information. *New England Journal of Medicine* 2010; **362**(9): 859-60.
96. Sbaffi L, Rowley J. Trust and credibility in web-based health information: a review and agenda for future research. *Journal of Medical Internet Research* 2017; **19**(6): e218.
97. Chu JT, Wang MP, Shen C, Viswanath K, Lam TH, Chan SSC. How, when and why people seek health information online: qualitative study in Hong Kong. *Interactive Journal of Medical Research* 2017; **6**(2): e24-e.
98. Ahern DK. Challenges and opportunities of eHealth research. *American Journal of Preventive Medicine* 2007; **32**(5): S75-S82.
99. van Gemert-Pijnen JE, Peters O, Ossebaard HC. Improving eHealth. The Netherlands: Eleven International Publishing; 2013.
100. Ritterband LM, Thorndike F. Internet interventions or patient education web sites? *Journal of Medical Internet Research* 2006; **8**(3): e18.
101. Sun Y, Zhang Y, Gwizdka J, Trace CB. Consumer evaluation of the quality of online health information: systematic literature review of relevant criteria and indicators. *Journal of Medical Internet Research* 2019; **21**(5): e12522.
102. Reen GK, Muirhead L, Langdon DW. Usability of health information websites designed for adolescents: systematic review, neurodevelopmental model, and design brief. *Journal of Medical Internet Research* 2019; **21**(4): e11584.
103. van Veen MR, Beijer S, Adriaans AMA, Vogel-Boezeman J, Kampman E. Development of a website providing evidence-based information about nutrition and

- cancer: fighting fiction and supporting facts online. *JMIR Research Protocols* 2015; **4**(3): e110.
104. Hightow-Weidman LB, Fowler B, Kibe J, et al. HealthMpowerment.org: development of a theory-based HIV/STI website for young black MSM. *AIDS Education and Prevention* 2011; **23**(1): 1-12.
105. Mayer DK, Ratichek S, Berhe H, et al. Development of a health-related website for parents of children receiving hematopoietic stem cell transplant: HSCT-CHESS. *Journal of Cancer Survivorship* 2010; **4**(1): 67-73.
106. Sillence E, Briggs P, Harris PR, Fishwick L. How do patients evaluate and make use of online health information? *Social Science & Medicine* 2007; **64**(9): 1853-62.
107. Fraval A, Chandrananth J, Chong YM, Coventry LS, Tran P. Internet based patient education improves informed consent for elective orthopaedic surgery: a randomized controlled trial. *BMC Musculoskeletal Disorders* 2015; **16**: 14.
108. van der Meij E, Anema JR, Otten RH, Huirne JA, Schaafsma FG. The effect of perioperative e-health interventions on the postoperative course: a systematic review of randomised and non-randomised controlled trials. *PLoS One* 2016; **11**(7).
109. Wagenaar KP, Broekhuizen BD, Jaarsma T, et al. Effectiveness of the European Society of Cardiology/Heart Failure Association website ‘heartfailurematters.org’ and an e-health adjusted care pathway in patients with stable heart failure: results of the ‘e-Vita HF’ randomized controlled trial. *European Journal of Heart Failure* 2019; **21**(2): 238-46.
110. Idriss NZ, Alikhan A, Baba K, Armstrong AW. Online, video-based patient education improves melanoma awareness: a randomized controlled trial. *Telemedicine Journal and e-Health* 2009; **15**(10): 992-7.

111. Spoelman WA, Bonten TN, de Waal MWM, et al. Effect of an evidence-based website on healthcare usage: an interrupted time-series study. *British Medical Journal* 2016; **6**(11): e013166.
112. Elkjaer M, Shuhaibar M, Burisch J, et al. E-health empowers patients with ulcerative colitis: a randomised controlled trial of the web-guided 'constant-care' approach. *Gut* 2010; **59**: 1652-61.
113. Horton KM, Garland MR, Fishman EK. The Internet as a potential source of information about radiological procedures for patients. *Journal of Digital Imaging* 2000; **13**(1): 46-7.
114. Hansberry DR, Ayyaswami V, Sood A, Prabhu AV, Agarwal N, Deshmukh SP. Abdominal imaging and patient education resources: enhancing the radiologist–patient relationship through improved communication. *Abdominal Radiology* 2017; **42**(4): 1276-80.
115. Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. *Journal of Medical Internet Research* 2006; **8**(2): e9.
116. Tennant B, Stellefson M, Dodd V, et al. eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults. *Journal of Medical Internet Research* 2015; **17**(3): e70.
117. Neter E, Brainin E. eHealth literacy: extending the digital divide to the realm of health information. *Journal of Medical Internet Research* 2012; **14**(1): e19.
118. Watkins I, Xie B. eHealth literacy interventions for older adults: a systematic review of the literature. *Journal of Medical Internet Research* 2014; **16**(11): e225.
119. Stellefson M, Hanik B, Chaney B, Chaney D, Tennant B, Chavarria EA. eHealth literacy among college students: a systematic review with implications for eHealth education. *Journal of Medical Internet Research* 2011; **13**(4): e102.

120. Stellefson ML, Shuster JJ, Chaney BH, et al. Web-based health information seeking and eHealth literacy among patients living with chronic obstructive pulmonary disease (COPD). *Health Communication* 2017: 1-15.
121. Chesser A, Burke A, Reyes J, Rohrberg T. Navigating the digital divide: a systematic review of eHealth literacy in underserved populations in the United States. *Informatics for Health and Social Care* 2016; **41**(1): 1-19.
122. Mitsutake S, Shibata A, Ishii K, Oka K. Associations of eHealth literacy with health behavior among adult internet users. *Journal of Medical Internet Research* 2016; **18**(7): e192.
123. Stellefson M, Paige SR, Alber JM, et al. Association between health literacy, electronic health literacy, disease-specific knowledge, and health-related quality of life among adults with chronic obstructive pulmonary disease: cross-sectional study. *Journal of Medical Internet Research* 2019; **21**(6): e12165.
124. Neter E, Brainin E. Association between health literacy, eHealth literacy, and health outcomes among patients with long-term conditions. *European Psychologist* 2019; **24**(1): 68-81.
125. Swar B, Hameed T, Reyhav I. Information overload, psychological ill-being, and behavioral intention to continue online healthcare information search. *Computers in Human Behavior* 2017; **70**: 416-25.
126. Smart JM, Burling D. Radiology and the internet: a systematic review of patient information resources. *Clinical Radiology* 2001; **56**(11): 867-70.
127. Bowden DJ, Yap L-C, Sheppard DG. Is the Internet a suitable patient resource for information on common radiological investigations? Radiology-related information on the internet. *Academic Radiology* 2017; **24**(7): 826-30.

128. Johnson EJ, Doshi AM, Rosenkrantz AB. Strengths and deficiencies in the content of US radiology private practices' websites. *Journal of the American College of Radiology* 2017; **14**(3): 431-5.
129. Lee K, Hoti K, Hughes JD, Emmerton L. Dr Google and the consumer: a qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. *Journal of Medical Internet Research* 2014; **16**(12): e262.
130. Holt KA, Karnoe A, Overgaard D, et al. Differences in the level of electronic health literacy between users and nonusers of digital health services: an exploratory survey of a group of medical outpatients. *Interactive Journal of Medical Research* 2019; **8**(2): e8423.
131. Eysenbach G. The law of attrition. *Journal of Medical Internet Research* 2005; **7**(1): e11.
132. Bennett GG, Glasgow RE. The delivery of public health interventions via the Internet: actualizing their potential. *Annual Review of Public Health* 2009; **30**: 273-92.
133. Kelders SM, Kok RN, Ossebaard HC, Van Gemert-Pijnen JE. Persuasive system design does matter: a systematic review of adherence to web-based interventions. *Journal of Medical Internet Research* 2012; **14**(6): e152.
134. Kakkar A, Jacobson BC. Failure of an Internet-based health care intervention for colonoscopy preparation: a caveat for investigators. *JAMA Internal Medicine* 2013; **173**(14): 1374-6.
135. McDowell I. The Theoretical and Technical Foundations of Health Measurement. *Measuring Health: A Guide to Rating Scales and Questionnaires*. 3rd ed. New York: Oxford University Press; 2006: 10 - 54.

136. Mokkink LB, Terwee CB, Patrick DL, et al. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. *Journal of Clinical Epidemiology* 2010; **63**(7): 737-45.
137. DeVellis RF. Scale Development: Theory and Applications: Sage Publications; 2016.
138. Lohr KN, Aaronson NK, Alonso J, et al. Evaluating quality-of-life and health status instruments: development of scientific review criteria. *Clinical Therapeutics* 1996; **18**(5): 979-92.
139. Coulacoglou C, Saklofske DH. Chapter 1 - Recent Advances in Psychological Assessment and Test Construction. In: Coulacoglou C, Saklofske DH, eds. Psychometrics and Psychological Assessment. San Diego: Academic Press; 2017: 3-25.
140. Anastasi A, Urbina S. Psychological Testing: Prentice Hall/Pearson Education; 1997.
141. Forshaw KL, Carey ML, Hall AE, Boyes AW, Sanson-Fisher R. Preparing patients for medical interventions: a systematic review of the psychometric qualities of published instruments. *Patient Education and Counseling* 2016; **99**(6): 960-73.
142. Cella D, Yount S, Rothrock N, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH Roadmap cooperative group during its first two years. *Medical Care* 2007; **45**(5 Suppl 1): S3-S11.
143. Griebel L, Enwald H, Gilstad H, Pohl A-L, Moreland J, Sedlmayr M. eHealth literacy research - quo vadis? *Informatics for Health and Social Care* 2018; **43**(4): 427-42.
144. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. *Journal of Medical Internet Research* 2006; **8**(4): e27.

145. van der Vaart R, van Deursen AJ, Drossaert CH, Taal E, van Dijk JA, van de Laar MA. Does the eHealth Literacy Scale (eHEALS) measure what it intends to measure? Validation of a Dutch version of the eHEALS in two adult populations. *Journal of Medical Internet Research* 2011; **13**(4): e86.
146. Koo M, Norman CD, Hsiao-Mei C. Psychometric evaluation of a Chinese version of the eHealth Literacy Scale (eHEALS) in school age children. *Global Journal of Health Education and Promotion* 2012; **15**(1): 29-36.
147. Nguyen J, Moorhouse M, Curbow B, Christie J, Walsh-Childers K, Islam S. Construct validity of the eHealth Literacy Scale (eHEALS) among two adult populations: a rasch analysis. *JMIR Public Health and Surveillance* 2016; **2**(1): e24.
148. Bazm S, Mirzaei M, Fallahzadeh H, Bazm R. Validity and reliability of the Iranian version of eHealth Literacy Scale. *Journal of Community Health Research* 2016; **5**(2): 121-30.
149. Mitsutake S, Shibata A, Ishii K, Oka K. Association of eHealth literacy with colorectal cancer knowledge and screening practice among internet users in Japan. *Journal of Medical Internet Research* 2012; **14**(6): e153.
150. Paige SR, Krieger JL, Stellefson M, Alber JM. eHealth literacy in chronic disease patients: an item response theory analysis of the eHealth Literacy Scale (eHEALS). *Patient Education and Counseling* 2017; **100**(2): 320-6.
151. Lee K, Hoti K, Hughes JD, Emmerton LM. Consumer use of “Dr Google”: a survey on health information-seeking behaviors and navigational needs. *Journal of Medical Internet Research* 2015; **17**(12): e288.
152. Chung S, Park BK, Nahm ES. The Korean eHealth Literacy Scale (K-eHEALS): reliability and validity testing in younger adults recruited online. *Journal of Medical Internet Research* 2018; **20**(4): e138.

153. Diviani N, Dima AL, Schulz PJ. A psychometric analysis of the Italian version of the eHealth Literacy Scale using Item Response and Classical Test Theory methods. *Journal of Medical Internet Research* 2017; **19**(4): e114.
154. Cardoso Tomás C, Pina Queirós PJ, Rodrigues Ferreira TdJ. Analysis of the psychometric properties of the Portuguese version of an eHealth literacy assessment tool. *Revista de Enfermagem Referência* 2014: 19-28.
155. Sudbury-Riley L, FitzPatrick M, Schulz PJ. Exploring the measurement properties of the eHealth Literacy Scale (eHEALS) among baby boomers: a multinational test of measurement invariance. *Journal of Medical Internet Research* 2017; **19**(2): e53.
156. Chung SY, Nahm ES. Testing reliability and validity of the eHealth Literacy Scale (eHEALS) for older adults recruited online. *CIN: Computers, Informatics, Nursing* 2015; **33**(4): 150-6.
157. Sheng X, Simpson PM. Seniors, health information, and the Internet: motivation, ability, and Internet knowledge. *Cyberpsychology, Behavior, and Social Networking* 2013; **16**(10): 740-6.
158. Efthymiou A, Middleton N, Charalambous A, Papastavrou E. Adapting the eHealth Literacy Scale for carers of people with chronic diseases (eHeals-Carer) in a sample of Greek and Cypriot carers of people with dementia: reliability and validation study. *Journal of Medical Internet Research* 2019; **21**(11): e12504.
159. Nahm E-S, Resnick B, Orwig D, et al. A theory-based online hip fracture resource center for caregivers: effects on dyads. *Nursing Research* 2012; **61**(6): 413-22.
160. O'Rourke N, Hatcher L. A Step-by-Step Approach to using SAS® for Factor Analysis and Structural Equation Modeling. Second ed. Cary, NC: SAS Institute Inc.; 2013.

161. Soellner R, Huber S, Reder M. The concept of eHealth literacy and its measurement. *Journal of Media Psychology* 2014; **26**(1): 29-38.
162. Neter E, Brainin E, Baron-Epel O. The dimensionality of health literacy and eHealth literacy. *The European Health Psychologist* 2015; **17**(6): 275-80.
163. Choi NG, Dinitto DM. The digital divide among low-income homebound older adults: Internet use patterns, eHealth literacy, and attitudes toward computer/Internet use. *Journal of Medical Internet Research* 2013; **15**(5): e93.
164. Knapp C, Madden V, Wang H, Sloyer P, Shenkman E. Internet use and eHealth literacy of low-income parents whose children have special health care needs. *Journal of Medical Internet Research* 2011; **13**(3): e75.
165. Manafò E, Wong S. Assessing the eHealth literacy skills of older adults: a preliminary study. *Journal of Consumer Health on the Internet* 2012; **16**(4): 369-81.
166. Richtering SS, Hyun K, Neubeck L, et al. eHealth literacy: predictors in a population with moderate-to-high cardiovascular risk. *JMIR Human Factors* 2017; **4**(1): e4.
167. Milne RA, Puts MT, Papadakos J, et al. Predictors of high eHealth literacy in primary lung cancer survivors. *Journal of Cancer Education* 2015; **30**(4): 685-92.
168. Office of the eSafety Commissioner. Understanding the Digital Behaviours of Older Australians: Summary of National Survey and Qualitative Research. Sydney: Australian Government, 2018.

THESIS STRUCTURE AND STUDY SCOPE

Thesis structure

This thesis-by-publication comprises four published papers which are based on one cross-sectional study. Papers One and Two provide descriptive data evaluating preparatory information receipt and preferences, whilst Papers Three and Four contribute to measurement literature by exploring the interpretation and understanding of eHealth literacy. To supplement the published methodology (for Papers One to Four), a summary of the study design characteristics is described below.

Study scope

Design

A cross-sectional survey was conducted. This design was selected due to the paucity of published research examining the provision of preparatory information (i.e. procedural, sensory, psychosocial and behavioural information) to patients undergoing medical imaging procedures. Specifically, a cross-sectional design was chosen to: (i) quantify the need to improve patient-centred preparatory information provision; (ii) identify subgroups that may be targeted for improved patient-centred information provision and eHealth literacy support; and (iii) explore relationships among eHEALS constructs. In accordance with best practice for research design and methodology¹, this descriptive research is necessary to identify the need for, and inform the objectives of, future intervention research in this field.

Sample

The study was conducted from November 2016 to January 2017 with 280 magnetic resonance imaging (MRI) and computed tomography (CT) medical imaging outpatients recruited from the Hunter New England Medical Imaging Department, located in the

John Hunter Hospital, New South Wales, Australia. This hospital is a major service provider to the broad geographic Hunter New England region. The Hunter New England Local Health District spans 131,785 square kilometres, encompassing a major metropolitan centre, as well as regional and remote communities².

Procedure

Medical imaging receptionists identified potentially eligible participants attending for outpatient CT or MRI appointments, and asked whether they would be interested in talking to a researcher about a study that they might be eligible to participate in.

Interested patients were introduced to the student researcher who provided an overview of the study, assessed patient eligibility to participate and sought verbal patient consent to complete one online questionnaire. Consenting patients were provided with a tablet computer and asked to complete the questionnaire prior to their scans. If the patient was called for the scan prior to finishing the survey, only those questions which had been completed were used for data analysis. For examination of consent bias, the receptionist and researcher sought verbal permission from non-consenting patients to record their age, gender and scan type.

Measures

The cross-sectional survey was comprised of three components:

1) Information about preparing for the scan: A 33-item scale (developed by the student researcher, supervisory team and clinical collaborators) examining preparatory information receipt and preferences. These items were systematically designed to measure recommended preparatory content areas (i.e. procedural, sensory, psychosocial and behavioural information)^{3,4}, align with governing imaging policy by the Royal

Australian and New Zealand College of Radiologists^{5,6} and be relevant to the Hunter New England Medical Imaging context (refer to Paper Two Methods for a full description of measure development). Self-report was selected as a means of data collection as patient-reported outcome measures are critical for reliable evaluation of the extent to which communication and care are patient-centred⁷. Three additional items that were not the focus of this thesis, but provided preliminary insights into patients' preferences for information source, as well as format and timing of information, were included in the questionnaire.

2) Your internet use: The 8-item eHealth Literacy Scale (eHEALS) was selected as it has demonstrated reliability and validity, and was the most commonly used self-report measure of eHealth literacy available when the study was conceptualised⁸ (refer to Thesis Introduction and Discussion for details of psychometric properties of eHealth literacy measures). Two additional items, adapted from existing informatics research^{9,10}, assessed participants' internet access and frequency of use. One author-developed item assessed participants' use of the internet for scan preparation.

3) About you and your scan: 12 items examining participants' sociodemographic, disease and scan characteristics. Some sociodemographic items were adapted from the Australian Bureau of Statistics National Health Survey 2014-15¹¹, whilst the item assessing participants' overall health has demonstrated reproducibility, reliability, and concurrent scale performance with the established health status measure, SF-12V¹².

References

1. World Health Organization. Health Research Methodology: A Guide for Training in Research Methods. Manila: WHO Regional Office for the Western Pacific, 1992.
2. NSW Government. Local Health Districts: Hunter New England. 2016.
<https://www.health.nsw.gov.au/lhd/pages/hnelhd.aspx> (accessed 11 April 2020).
3. Schofield MJ, Sanson-Fisher R. How to prepare cancer patients for potentially threatening medical procedures: consensus guidelines. NSW Cancer Council Cancer Education Research Program. *Journal of Cancer Education* 1996; **11**(3): 153-8.
4. Cockburn J., NSW Cancer Council. How to Prepare Patients for Potentially Threatening Clinical Procedures: An Interactional Skills Training Manual for General Practitioners, Junior Medical Officers, Nurses, Surgeons. Kings Cross, NSW: NSW Cancer Council, 1997.
5. The Royal Australian and New Zealand College of Radiologists. Standards of Practice for Diagnostic and Interventional Radiology, Version 10.1: RANZCR, 2016.
6. The Royal Australian and New Zealand College of Radiologists. Medical Imaging Consent Guidelines, Version 2. Sydney, Australia: RANZCR, 2013.
7. Tzelepis F, Sanson-Fisher RW, Zucca AC, Fradgley EA. Measuring the quality of patient-centered care: why patient-reported measures are critical to reliable assessment. *Patient Preference and Adherence* 2015; **9**: 831-5.
8. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. *Journal of Medical Internet Research* 2006; **8**(4): e27.

9. Anandarajan M, Simmers C, Igarria M. An exploratory investigation of the antecedents and impact of internet usage: an individual perspective. *Behaviour & Information Technology* 2000; **19**(1): 69-85.
10. Igarria M, Pavri FN, Huff SL. Microcomputer applications: an empirical look at usage. *Information & Management* 1989; **16**(4): 187-96.
11. Australian Bureau of Statistics. 4364.0.55.001 - National Health Survey: First Results, 2014-15. 2016.
<http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4364.0.55.0012014-15?OpenDocument> (accessed 27 April 2016).
12. DeSalvo KB, Fisher WP, Tran K, Bloser N, Merrill W, Peabody J. Assessing measurement properties of two single-item general health measures. *Quality of Life Research* 2006; **15**(2): 191-201.

PAPER ONE

Medical Imaging Outpatients' Experiences with Receiving Information Required for Informed Consent and Preparation: A Cross-sectional Study

PAPER ONE

There is a clinical and ethical requirement to appropriately prepare patients for potentially threatening medical procedures, including high-technology medical imaging. However, limited research has examined patients' experiences of receiving such preparatory information before undergoing MRI and CT procedures in Australia. In the absence of existing measures, a study-specific self-report scale was developed and administered to evaluate the extent to which medical imaging patients received 33 items of preparatory information linked to guideline recommendations. Paper One describes the pre-procedure preparatory information experiences of MRI and CT outpatients attending a major tertiary referral centre in metropolitan NSW. This paper was published in *Journal of Patient Experience* (Thesis Appendix 3.2).

Hyde LL, Mackenzie LJ, Boyes AW, Symonds M, Brown S, Sanson-Fisher R. Medical imaging outpatients' experiences with receiving information required for informed consent and preparation: A cross-sectional study. *Journal of Patient Experience* 2018; **5**(4): 296-302.

**Medical Imaging Outpatients' Experiences with Receiving Information
Required for Informed Consent and Preparation:
A Cross-sectional Study**

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Abstract

Background: Medical imaging outpatients often experience inadequate information provision and report high levels of anxiety. However, no studies have assessed patients' receipt of preparatory information in this setting.

Objective: To examine medical imaging outpatients' perceived receipt or non-receipt of preparatory information from health professionals and imaging department staff prior to their procedure.

Method: Computed Tomography and Magnetic Resonance Imaging outpatients at one Australian hospital self-completed a touchscreen computer survey assessing their perceived receipt of 33 guideline-recommended preparatory information items.

Results: Of 317 eligible patients, 280 (88%) consented to participate. Eight percent (95% CI 5%-12%) of participants reported receiving all information items. The median number of information items not received was 18 (IQR 8-25). Items most frequently endorsed as "not received" were: *how to manage anxiety after* (74%) and *during the scan* (69%). Items most commonly endorsed as "received" were: *reason for referral* (85%) and *how to find the imaging department* (74%).

Conclusion: Few medical imaging outpatients recalled receiving recommended preparatory information. Preparatory communication needs to be improved to better meet patient-centred service imperatives.

Key words: Communication; patient education; imaging; survey data

Introduction

International medical imaging bodies endorse the importance of appropriately communicating procedural risks and benefits to patients before the point of care¹⁻⁵.

Providing comprehensive preparatory information is a legal and ethical imperative, as it supports patient autonomy, quality of care and informed patient consent¹⁻⁷. The provision of this information may also improve patient outcomes, such as reducing anxiety and distress⁸. General recommendations regarding preparation for potentially threatening medical procedures highlight the need to communicate procedural, behavioural, sensory and psychosocial information^{9,10}. This information refers, respectively, to the sequence of events and equipment to be used, the patient's role in facilitating the procedure, the sensations that will be felt, and the management of emotions, and should relate to the time before, during and after the procedure⁹⁻¹².

Magnetic Resonance Imaging (MRI) and Computed Tomography (CT) medical imaging outpatients are an increasing population undergoing a potentially threatening, high technology medical procedure, who require such preparatory information. For example, in Australia, the four year service growth rate since 2010 for MRI and CT scans was 47.4% and 29.4% respectively¹³. Similar growth has been seen internationally, including in the USA, Canada and Turkey^{14,15}. Although these procedures occur frequently, they are considered potentially threatening because of their association with high levels of anxiety¹⁶⁻¹⁹. Consistent with broader international literature, a recent Australian study found that 56% of MRI and 59% of CT outpatients reported raised state anxiety (using the short-form state scale of the State-Trait Anxiety Inventory) prior to undergoing their procedure²⁰. Such anxiety contributes to patients feeling a loss of control during the procedure^{17,19}. Research findings in France, the USA and Scotland

suggest that communication could be improved for these patients^{16,21,22}. Inadequate communication prior to diagnostic medical procedures contributes to negative patient experiences²³, and efforts are being made to enhance patient-provider communication within medical imaging settings²⁴⁻²⁶. However, very limited research has assessed MRI and CT medical imaging outpatients' experiences with receiving preparatory information, and no Australian-based studies have been completed. Therefore, this study examined MRI and CT medical imaging outpatients' perceived receipt and non-receipt of preparatory information from health professionals and imaging department staff prior to their imaging procedure.

Methods

Design and setting

A cross-sectional survey of medical imaging outpatients scheduled for MRI or CT examinations was conducted in one medical imaging clinic within the John Hunter Hospital located in Newcastle, New South Wales, Australia. In this setting, MRI and CT medical imaging outpatients are typically provided with mailed written preparatory information and verbal information when scheduling and attending their appointment.

Sample

Eligible patients were: (i) attending for an outpatient MRI or CT appointment at the Hunter New England Medical Imaging Department at John Hunter Hospital; and (ii) 18 years or older. Patients were excluded if they had (i) insufficient English language proficiency; or (ii) a cognitive or physical impairment which precluded informed consent and/or survey completion.

Procedure

Medical imaging receptionists identified potentially eligible patients when they presented for their appointment, informed them about the research and invited them to speak with a trained researcher. The researcher provided interested patients with written and verbal information about the study, and gained verbal informed consent to participate. The age, gender and scan type of non-consenting patients was recorded with their permission.

Patients who consented to participate were provided with a tablet computer and asked to self-complete an online questionnaire prior to their scan. The researcher was available to help participants who had difficulties using the tablet computer, and paper and pen versions of the questionnaire were available for those who requested it. If the patient was called for their procedure prior to finishing the questionnaire, only those questions that had been completed were used for data analysis. Ethics approval was obtained from the Human Research Ethics Committees of the Hunter New England Local Health District (16/10/19/5.11) and University of Newcastle (H-2016-0386).

Measure

Patient perceived receipt of information: was measured using a series of investigator-developed items. General standards addressing patient preparation for potentially threatening medical procedures were initially used to identify the preparatory domains (i.e. procedural, behavioural, sensory and psychosocial) that items should address^{9,10,27}. Domain-related items were developed using these general standards^{9,10,27}. As this study was based in Australia, items were also informed by the Royal Australian and New Zealand College of Radiologists (RANZCR) Standards of Practice², consumer materials^{28,29} and informed consent guidelines¹. Behavioural scientists, radiographers

and imaging department management staff initially reviewed and agreed upon the face validity of the questionnaire. This version was then reviewed by members of the general public and health professionals in the ageing, disability and nursing sector, for ease of comprehension and completion time. Minor amendments to survey item wording and screen presentation were made. The revised questionnaire was pilot-tested with patients across a two week period in the medical imaging department, which resulted in further changes to item structure and presentation. The final questionnaire included 33 items which asked participants whether they had received information from imaging department staff or health care professionals prior to arriving for the scan procedure, with response options: *'no, but I wanted this information'*, *'no, but I didn't want this information'*, *'yes, but I didn't want this information'*, and *'yes, and I wanted this information'*. This analysis was centred on patient experiences with receiving information, given the legal and ethical implications, as well as the requirement for information delivery to facilitate patient preparation. As such, 'no' responses and 'yes' responses were combined to indicate the non-receipt and receipt of preparatory information respectively. The internal consistency (Kuder-Richardson coefficient) of these dichotomised preparatory information items was 0.96³⁰.

Study factors

Sociodemographic and scan characteristics: Standard items assessed age, gender, marital status, highest level of education completed, postcode, scan type and prior scans. Postcode was mapped to the Accessibility/Remoteness Index of Australia Plus (ARIA + 2011) classification to examine remoteness³¹.

Data analysis

The gender, age group (<65 years versus ≥ 65 years) and scan type of consenters and non-consenters were compared using chi-squared tests. The median number of received and non-received items (and interquartile range [IQR]) were reported due to non-normally distributed data. The proportion of participants reporting a) non-receipt of each information item; and b) 0-33 non-received information items was calculated with 95% confidence intervals (CI's). Due to an absence of theoretically or empirically sound hypotheses, this study was not powered to explore patient characteristics associated with perceived receipt or non-receipt of information.

Results

Sample

Of the 394 patients considered for the study during the 6 week recruitment period, 317 were eligible and invited to speak with the researchers. Of eligible patients, 280 (88%) consented to take part in the study. There was no significant difference between consenters and non-consenters based on gender ($\chi^2=2.200$; $p=0.138$) and age group ($\chi^2=0.003$; $p=0.956$). Significantly more CT patients than MRI patients declined the study participation invitation ($\chi^2=6.565$; $p=0.010$). Of consenting participants, 273 (98%) started the survey, 234 (84%) started "information received" items, 218 (78%) completed these items and 208 (74%) completed all survey items. There were no significant differences in participant characteristics between those who did and did not complete all survey items (gender: $\chi^2=0.614$, $p=0.433$; age: $\chi^2=0.537$ $p=0.464$; scan: $\chi^2=0.095$, $p=0.758$).

Table 2.1 provides a summary of the sociodemographic and scan characteristics of participants who started the survey.

Table 2.1: Participant sociodemographic, scan and information preference profile (N = 273^a)

Characteristic		n (%)
Mean years of age, (SD)		57 (14)
Gender	Male	130 (48%)
	Female	142 (52%)
Marital status	Married or living with partner	133 (63%)
	Single or never married	28 (13%)
	Divorced or separated	34 (16%)
	Widowed	17 (8%)
Education completed	High school or less	195 (71%)
	More than high school	78 (29%)
Geographic location	Metropolitan	209 (78%)
	Non-metropolitan	59 (22%)
Scan type	CT	108 (40%)
	MRI	157 (59%)
	Don't know	3 (1%)
Prior scans	Not had scan before	66 (25%)
	Had scan <1 year ago	93 (35%)
	Had scan ≥1 year ago	97 (37%)
	Don't know	8 (3%)

^a Completed at least one item. Item sample sizes vary due to missing data.

Self-reported non-receipt of preparatory information items

The median number of preparatory information items received was 15 (IQR 8-25) and non-received information items was 18 (IQR 8-25). Eight percent (95% CI 5%-12%) of participants reported receiving all preparatory information items, whereas 69% (95% CI 63%-75%) reported not having received at least 10 information items, and 45% (95%

CI 39%-52%) reported not having received at least 20 information items. As shown in Table 2.2, the proportion of respondents who reported not having received each preparatory information item from health professionals prior to their scan ranged between 15%-74%.

Table 2.2: Prevalence of patient perceived non-receipt of preparatory information items (N = 234^a)

Rank	Item	Information not received n (%)
1	How to manage scan-related fear or anxiety after the scan?	150 (74%)
2	How to manage scan-related fear or anxiety during the scan?	151 (69%)
3	Who will be with you during the scan?	149 (66%)
4	How to manage scan-related fear or anxiety before the scan?	151 (65%)
	What you will see during the scan?	147 (65%)
6	Any after-effects in the day/s following the scan?	129 (63%)
	Whether someone should come with you to the scan?	144 (63%)
8	Where to find information about any aspects related to the scan?	144 (62%)
9	How to alert the radiographer if you have questions or concerns during the scan?	135 (61%)
10	How the scanner takes images of the body?	132 (59%)
12	Any physical sensations you may feel during the scan?	130 (58%)
	Whether you can drive home from the scan?	127 (58%)
14	What to do if you suffer from claustrophobia?	125 (56%)
	How long you will have to stay at the department after the scan?	123 (56%)
15	What the scanner looks like?	124 (55%)
18	What you will hear during the scan?	122 (54%)
	Where to park in the hospital?	124 (54%)
	Whether you can move during the scan?	122 (54%)
20	When to expect the results of the scan?	105 (51%)
	What you will be asked to wear during the scan?	117 (51%)

Rank	Item	Information not received n (%)
21	Any risks associated with the scan?	113 (50%)
23	Whether you will need an injection at the scan?	102 (45%)
	Who to speak to if you had any questions about the scan in the week/s before your appointment?	104 (45%)
24	Being required to lie on a table that moves in and out of the scanner?	99 (43%)
26	How you will receive the results of the scan?	84 (41%)
	How long the scan will take?	92 (41%)
28	The benefits of having a CT or MRI scan?	86 (37%)
	How long you will have to wait in the department before having the scan?	84 (37%)
29	Steps you needed to take to prepare for your scan in the day/s before your appointment?	80 (34%)
30	What to eat or drink on the day of the scan?	78 (33%)
31	What to bring to the scan (e.g. prior scan results)?	70 (31%)
32	How to find the imaging department in the hospital?	60 (26%)
33	Why your doctor referred you for a CT or MRI scan?	35 (15%)

^a Completed at least one item. Item sample sizes vary due to missing data

Discussion

This study explored patient experiences in relation to preparatory information communication in an Australian medical imaging setting. MRI and CT medical imaging outpatients perceived that they received approximately half of the assessed preparatory information items from health professionals and imaging department staff prior to their scan. These findings suggest that future improvements are needed to better meet patient-centred, legal and ethical imperatives associated with preparatory information delivery.

Most patients received information about scan type, reason for referral and appointment practicalities

Consistent with Chesson et al.'s (2002) Scottish cross-sectional study of 372 medical imaging outpatients, which reported that 82% of respondents were aware of why their examination was required, 85% of participants in this study *had received* information about the reason for referral²². Similarly, when arriving for their procedure, 99% of participants in this study were able to self-report the type of scan they were attending for. Information addressing the type and requirement for the scan was therefore received by patients, indicating appropriate service delivery in this element of preparatory communication.

At least two-thirds of patients reported they had received information that could facilitate timely appointment attendance and enhanced imaging quality: how to find the imaging department (74%), what to bring to the scan (69%), what to eat or drink (67%) and steps to prepare beforehand (66%). These findings align with a small US-based study conducted with patients undergoing diagnostic medical interventions, where a majority of participants, or their families, recalled receiving procedural (97.9%) or behavioural (100%) information about the intervention²³. Our study findings may reflect that the appointment letter received by patients specifies how to find the imaging department and what to bring to the scan. Alternatively, these findings may indicate that patients place a higher level of importance on practical aspects of preparation, which is reflected in higher rates of recall of this information. Future research is needed to assess the concordance between information delivery and patient-reported information needs, as well as the impact of patient-centred information provision on patient outcomes.

Some imaging-specific and general preparatory information items were commonly not received

Up to 74% of respondents perceived that they *had not received* preparatory information items from medical imaging department staff or other health professionals prior to their scan. This included between 37%-50% reporting not having received items required for informed consent (i.e. procedural risks, benefits and who to speak to with questions), despite being recommended by RANZCR Medical Imaging Consent Guidelines¹ and literature suggesting that receipt of the right amount of such information can reduce pre-procedural anxiety³². However, these findings mirror those of otorhinolaryngology head and neck surgery patients preparing for invasive diagnostic or therapeutic medical procedures, in which patient recall of risk-related information ranged between 35%-54%³³. Whilst factors including patient age, education, time since information provision and perceived relevance of information may influence recall rates³³, these findings indicate that there is room to improve information provision prior to medical imaging procedures, and current practices may not be meeting medical imaging-specific standards.

Some general standards for preparation for potentially threatening medical procedures were also commonly not met in this medical imaging setting. Despite MRI and CT medical imaging outpatients experiencing high levels of anxiety¹⁶⁻¹⁸, which is associated with procedure terminations, motion artifacts and reduced diagnostic utility of images^{18,34}, information on how to manage anxiety before, during and after the scan were among the most commonly non-received items (i.e. by 65-74% of respondents). This gap in patient-reported receipt of information may be a result of misalignment between medical imaging guidelines (which do not explicitly mandate the provision of such information)^{2,4,5} and broader preparatory guidelines (which do recommend the

delivery of anxiety-related information)^{9,10}. Although Australian and international medical imaging bodies advocate the importance of emotional support and alleviation of patient anxiety^{3,29,35}, these findings suggest a need for standards that more clearly guide communication of psychosocial information to patients.

The pre-procedural timing of survey completion is another important consideration for information provision findings. It is likely that the information required for informed consent is provided when patients attend for their scan. Additionally, anxiety management strategies, such as telling the patient that they can press the alert buzzer if they become uncomfortable, may be provided at the point of care when presenting the scan room and equipment. However, providing information in advance of potentially threatening medical procedures has been suggested to increase patient preparation and participation in health care³⁶. Further research is needed to assess medical imaging outpatients' post-procedural perceptions of information provision, and whether the timing of information delivery meets patients' needs. There is also a lack of clarity about what low intensity, evidence-based approaches may assist patients to self-manage imaging-related anxiety^{8,37}. Consequently, we are undertaking a randomised controlled trial to test the impact of an information intervention on reducing anxiety among medical imaging outpatients.

Most imaging patients are left to self-source information about their scan

Over half (62%) of the respondents reported not being informed of where to find further information about the scan. Medical imaging outpatients who self-source information most commonly do so from family and friends, drawing the accuracy of sourced information into question²². To ensure information seekers' needs are met by credible

sources, there is a need to enhance patient awareness of reliable information materials that are developed by peak medical imaging bodies.

Limitations

This research was designed to establish current patterns of preparatory information receipt, in order to inform service-wide improvements that may benefit all MRI and CT outpatients. This study was not intended to assess preparatory information receipt among medical imaging inpatients, nor was it designed to test for differences in information receipt by specific CT or MRI scan type. Although the sample size was small relative to the volume of outpatients attending the department annually, it was sufficient for detecting prevalence estimates with 95% CIs with 7% margin of error. Findings may not generalize beyond the single, large metropolitan medical imaging department study setting. However, the age and gender profile of the sample was similar to that of participants in other large Australian^{38,39} and international studies^{40,41} with medical imaging outpatients.

Significantly more CT patients than MRI patients refused study participation, suggesting that the sample is less representative of CT patients. This may be due to some CT patients being asked to arrive at least 15 minutes in advance of their scheduled appointment (versus 30 minutes for MRI patients), thus perceiving they have insufficient time to participate in the research prior to their scan. The exclusion of those with insufficient English to allow survey completion may have led to an underestimation of the proportion of medical imaging patients who didn't receive information items⁴². Patient self-report may have been influenced by recall bias, however patient perceptions of past communication have been suggested to influence present health behaviours⁴³. Whilst further evaluation of the psychometric properties of

the information receipt measure is required, item development was informed by relevant guidelines, standards, and expert views, and demonstrated excellent internal consistency.

Conclusion

This study contributes important knowledge regarding key preparatory information items that are commonly received and not received by MRI and CT medical imaging outpatients, and may inform enhanced medical imaging preparation guidelines and improved forms of information delivery. Although information relating to scan type, reason for referral and practicalities are commonly received, these findings suggest that not all recommended preparatory information is provided to patients. Further research is needed to assess whether current information provision is aligned with patient preferences for this information, and determine the impact that preparatory information has on patient outcomes.

Acknowledgements

The authors thank the patients for their involvement in this study, as well as the practice and managerial staff at Hunter New England Imaging for assistance with recruitment and data collection.

Funding

Mrs Lisa Hyde is supported by an Australian Government Research Training Program Scholarship. Dr Lisa Mackenzie is supported by a Postdoctoral Fellowship grant [PF-16-011] from the Australian National Breast Cancer Foundation. Dr Allison Boyes is supported by a National Health and Medical Research Council Early Career Fellowship

[APP1073317] and Cancer Institute New South Wales Early Career Fellowship
[13/ECF/1-37].

Declaration of conflicting interests

The authors declare that there is no conflict of interest.

References

1. The Royal Australian and New Zealand College of Radiologists. Medical Imaging Consent Guidelines, Version 2. Sydney, Australia: RANZCR, 2013.
2. The Royal Australian and New Zealand College of Radiologists. Standards of Practice for Diagnostic and Interventional Radiology, Version 10.1: RANZCR, 2016.
3. European Society of Radiology. Patient Information. The Most Important Stakeholder in Radiology: The Patient. 2017. <https://www.myesr.org/quality-safety/patient-information> (accessed 7 July 2017).
4. The Royal College of Radiologists. Standards for Patient Consent Particular to Radiology, Second Edition. London: The Royal College of Radiologists, 2012.
5. American College of Radiologists. ACR–SIR–SPR Practice Parameter on Informed Consent for Image-Guided Procedure. Res. 17: American College of Radiologists, 2016.
6. Nievelstein RA, Frush DP. Should we obtain informed consent for examinations that expose patients to radiation? *American Journal of Roentgenology* 2012; **199**(3): 664-9.
7. Törnqvist E, Månsson Å, Larsson EM, Hallström I. Impact of extended written information on patient anxiety and image motion artifacts during magnetic resonance imaging. *Acta Radiologica* 2006; **47**(5): 474-80.
8. Munn Z, Jordan Z. Interventions to reduce anxiety, distress and the need for sedation in adult patients undergoing magnetic resonance imaging: a systematic review. *International Journal of Evidence-Based Healthcare* 2013; **11**(4): 265-74.
9. Cockburn J., NSW Cancer Council. How to Prepare Patients for Potentially Threatening Clinical Procedures: An Interactional Skills Training Manual for General

Practitioners, Junior Medical Officers, Nurses, Surgeons. Kings Cross, NSW: NSW Cancer Council, 1997.

10. Schofield MJ, Sanson-Fisher R. How to prepare cancer patients for potentially threatening medical procedures: consensus guidelines. NSW Cancer Council Cancer Education Research Program. *Journal of Cancer Education* 1996; **11**(3): 153-8.
11. Powell R, Scott NW, Manyande A, et al. Psychological preparation and postoperative outcomes for adults undergoing surgery under general anaesthesia. *Cochrane Database of Systematic Reviews* 2016; (5): CD008646.
12. Henwood SM, Munro L. Principles of Communication. In: Ramlaul A, Vosper M, eds. Patient Centred Care in Medical Imaging and Radiotherapy. London: Churchill Livingstone; 2013: 3-6.
13. Medical Benefits Reviews Task Group, Diagnostic Imaging Review Team. Review of Funding for Diagnostic Imaging Services: Final Report. Australia: Department of Health and Ageing, 2012.
14. Organisation for Economic Co-operation and Development. Health at a Glance 2015: OECD indicators. Paris: OECD 2015.
15. Organisation for Economic Co-operation and Development. Geographic Variations in Health Care: What Do We Know and What Can Be Done to Improve Health System Performance? Paris: OECD Health Policy Studies, 2014.
16. Ollivier L, Apiou F, Leclerc J, et al. Patient experiences and preferences: development of practice guidelines in a cancer imaging department. *Cancer Imaging* 2009; **9**: S92-7.
17. Heyer CM, Thuring J, Lemburg SP, et al. Anxiety of patients undergoing CT imaging-an underestimated problem? *Academic Radiology* 2015; **22**(1): 105-12.

18. Dewey M, Schink T, Dewey CF. Claustrophobia during magnetic resonance imaging: cohort study in over 55,000 patients. *Journal of Magnetic Resonance Imaging* 2007; **26**(5): 1322-7.
19. Tornqvist E, Mansson A, Larsson EM, Hallstrom I. It's like being in another world - patients' lived experience of magnetic resonance imaging. *Journal of Clinical Nursing* 2006; **15**(8): 954-61.
20. Forshaw K, Boyes A, Carey M, et al. Raised anxiety levels among outpatients preparing to undergo a medical imaging procedure: prevalence and correlates. *Journal of the American College of Radiology* 2018; **15**(4): 630-8.
21. Thornton RH, Dauer LT, Shuk E, et al. Patient perspectives and preferences for communication of medical imaging risks in a cancer care setting. *Radiology* 2015; **275**(2): 545-52.
22. Chesson RA, McKenzie GA, Mathers SA. What do patients know about ultrasound, CT and MRI? *Clinical Radiology* 2002; **57**(6): 477-82.
23. Jacob DA, Franklin L, Bernstein B, Pall H. Results from a patient experience study in pediatric gastrointestinal endoscopy. *Journal of Patient Experience* 2015; **2**(2): 23-8.
24. Creagh C, Flamm SD, Madonia H, O'Keefe P, Ricaurte F, Triner J. Cleveland Clinic Imaging Institute's "Commitment to Respect" and impact on quality of care and patient satisfaction. *Journal of Patient Experience* 2017; **4**(3): 88-94.
25. Williams G, Greene S. From analogue to apps - developing an app to prepare children for medical imaging procedures. *Journal of Visual Communication in Medicine* 2015; **38**(3-4): 168-76.

26. Bolejko A, Sarvik C, Hagell P, Brinck A. Meeting patient information needs before magnetic resonance imaging: development and evaluation of an information booklet. *Journal of Radiology Nursing* 2008; **27**(3): 96-102.
27. Forshaw KL, Carey ML, Hall AE, Boyes AW, Sanson-Fisher R. Preparing patients for medical interventions: a systematic review of the psychometric qualities of published instruments. *Patient Education and Counseling* 2016; **99**(6): 960-73.
28. The Royal Australian and New Zealand College of Radiologists. Computed Tomography: Consumer Information. 2015.
<http://www.ranzcr.edu.au/resources/consumers> (accessed 26 June 2016).
29. The Royal Australian and New Zealand College of Radiologists. Magnetic Resonance Imaging (MRI): Consumer Information. 2015.
<http://www.ranzcr.edu.au/resources/consumers> (accessed 26 June 2016).
30. Kuder GF, Richardson MW. The theory of the estimation of test reliability. *Psychometrika* 1937; **2**(3): 151-60.
31. Hugo Centre for Migration and Population Research. ARIA (Accessibility/Remoteness Index of Australia): The University of Adelaide, 2005.
32. Yucel A, Gecici O, Emul M, et al. Effect of informed consent for intravascular contrast material on the level of anxiety: how much information should be given? *Acta Radiologica* 2005; **46**(7): 701-7.
33. Laccourreye O, Garabedian EN, Samad MA, Dubreuil C. Medical information prior to invasive medical procedures in otorhinolaryngology-head and neck surgery in France. *European Annals of Otorhinolaryngology, Head and Neck Diseases* 2012; **129**(1): 38-43.

34. Thompson MB, Coppens NM. The effects of guided imagery on anxiety levels and movement of clients undergoing magnetic resonance imaging. *Holistic Nursing Practice* 1994; **8**(2): 59-69.
35. Itri JN. Patient-centered radiology. *RadioGraphics* 2015; **35**(6): 1835-46.
36. Waller A, Forshaw K, Bryant J, Carey M, Boyes A, Sanson-Fisher R. Preparatory education for cancer patients undergoing surgery: a systematic review of volume and quality of research output over time. *Patient Education and Counseling* 2015; **98**(12): 1540-9.
37. Munn Z, Jordan Z. The effectiveness of interventions to reduce anxiety, claustrophobia, sedation and non-completion rates of patients undergoing high technology medical imaging. *JBIC Library of Systematic Reviews* 2012; **10**(19): 1122-85.
38. Gibson DA, Moorin RE, Holman CDAJ. Cohort study of Western Australia computed tomography utilisation patterns and their policy implications. *BMC Health Services Research* 2014; **14**(1): 526.
39. Gibson DA, Moorin RE, Semmens J, Holman DJ. The disproportionate risk burden of CT scanning on females and younger adults in Australia: a retrospective cohort study. *Australian and New Zealand Journal of Public Health* 2014; **38**(5): 441-8.
40. Boone JM, Brunberg JA. Computed tomography utilization in a tertiary care university hospital. *Journal of the American College of Radiology* 2008; **5**(2): 132-8.
41. Dovalés AC, da Rosa LA, Kesminiene A, Pearce MS, Veiga LH. Patterns and trends of computed tomography usage in outpatients of the Brazilian public healthcare system, 2001–2011. *Journal of Radiological Protection* 2016; **36**(3): 547.
42. Schenker Y, Wang F, Selig SJ, Ng R, Fernandez A. The impact of language barriers on documentation of informed consent at a hospital with on-site interpreter services. *Journal of General Internal Medicine* 2007; **22**(Suppl 2): 294-9.

43. Sutherland J. Patient information in radiation therapy: strategies to meet patient needs. *Journal of Radiation Oncology* 2014; **3**(2): 223-8.

PAPER TWO

Prevalence and Correlates of Patient-centred Preparatory Information Provision to Computed Tomography and Magnetic Resonance Imaging Outpatients: A Cross-sectional Study

PAPER TWO

Understanding whether health information is delivered in accordance with patient preferences is a key component of high-quality patient-centred care.

This is emphasised by national and international medical imaging bodies (e.g. Royal Australian and New Zealand College of Radiologists and Royal College of Radiologists). Paper One found that, prior to undergoing their MRI or CT procedures, many patients did not receive the items of preparatory information assessed in the study. Paper Two builds on these findings by assessing whether patients received preparatory information in accordance with their preferences. It also evaluates the factors associated with patients reporting a high number of unmet information preferences. This paper was published in *Patient Education and Counseling* (Thesis Appendix 4.2).

Hyde LL, Mackenzie LJ, Boyes AW, Evans TJ, Symonds M, Sanson-Fisher R. Prevalence and correlates of patient-centred preparatory information provision to Computed Tomography and Magnetic Resonance Imaging outpatients: A cross-sectional study. *Patient Education and Counseling* 2018; **101**(10): 1814-22.

**Prevalence and Correlates of Patient-centred Preparatory Information
Provision to Computed Tomography and Magnetic Resonance
Imaging Outpatients: A Cross-sectional Study**

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Abstract

Objective: Responsiveness to information preferences is key to high-quality, patient-centred care. This study examined the top ten preparatory information items not delivered in accordance with medical imaging outpatients' preferences, and patient characteristics associated with reporting a greater number of unmet information preferences.

Methods: Magnetic resonance imaging and computed tomography outpatients were recruited consecutively in one major public hospital waiting room. Participants self-administered a touchscreen computer questionnaire assessing their sociodemographic and scan characteristics, and unmet preferences for 33 guideline-endorsed preparatory information items.

Results: Of 317 eligible patients, 280 (88%) consented to participate. Given equal rankings, the top ten unmet information preferences included 13 items which were endorsed by at least 25% of participants, and commonly related to receiving 'too little' information. One item related to the pre-scan period, seven items to the scan period and five items to the post-scan period. None of the patient characteristics examined were significantly associated with reporting a greater number of unmet information preferences.

Conclusion: There is room to improve responsiveness to medical imaging outpatients' preparatory information preferences. Improvements should be targeted at individuals, rather than groups defined by sociodemographic or scan characteristics.

Practice implications: A standardised approach to addressing individual patient's information preferences is needed.

Key words: computed tomography; cross-sectional study; information preferences; magnetic resonance imaging; patient-centred care

Introduction

How can we assess whether health information provision is patient-centred?

A key pillar of high-quality patient-centred care is responsiveness to patient needs, values and preferences¹⁻³. This includes delivery of patients' preferred format, amount and timing of health-related information¹⁻³. Patient-centred communication styles are typically associated with higher rates of patient satisfaction than more paternalistic, provider-centred approaches^{4,5}, and may lead to improved health outcomes, including enhanced medical decision-making, and improved physical and emotional health^{6,7}. Whilst it is increasingly acknowledged that information should be made available to patients in a variety of formats, less is known about how to improve responsiveness to patient's preferences for *amount* of information, including how much information patients want at key points in the trajectory of care^{3,8}. Patients who receive less information than they want can be characterised as having an unmet information need, whilst patients who receive either too much or too little information can be characterised as having an unmet information preference. Too little information can result in heightened anxiety and distress^{9,10}, and too much information can overwhelm patients and increase anxiety levels^{11,12}. As such, assessment of patient's unmet information preferences can help to identify areas where patient-centred communication could be improved. Despite this, research has tended to focus on patients' unmet information needs¹³⁻¹⁶.

Does patient-centred information provision vary by patient subgroup?

Studies in oncology and rheumatology settings have indicated that patients' unmet needs for more information vary according to patient characteristics such as age¹⁴⁻¹⁷, stage of illness¹⁷⁻¹⁹ and physical functioning^{14,16,17}. The assessment of factors associated

with a greater number of unmet information preferences is important for informing the development of targeted strategies to improve care, yet remains under-studied.

Furthermore, despite findings which suggest that the most frequent information needs are treatment-related¹⁹, little research has been conducted with general populations undergoing anxiety-provoking medical procedures. The research that has been conducted commonly focuses on preparatory information provision prior to surgery²⁰⁻²⁴. There is a need for research assessing patient-centred information delivery relating to other potentially threatening medical procedures.

Is preparatory information provision prior to medical imaging procedures patient-centred?

Adequate communication of preparatory information prior to potentially threatening medical procedures is important, as it allows the patient to anticipate what is coming and reassures them of the normality of their experience⁹. Preparatory information should address procedural, sensory, psychosocial and behavioural aspects of care, which refers, respectively, to the sequence of events and equipment to be used, sensations that will be felt, management of emotions and patient's role in facilitating the procedure²⁵⁻²⁷. The number of patients undergoing potentially threatening medical imaging procedures, such as magnetic resonance imaging (MRI) and computed tomography (CT) scans, has increased over time²⁸. These procedures are associated with high anxiety levels^{29,30} which has been suggested to increase procedure delays or terminations, and resultantly impacts on patient wellbeing, and service timeliness, coordination and quality^{31,32}.

However, little research assesses whether information provision aligns with patient preferences in this setting. Thornton and colleagues' USA-based qualitative study of cancer patients found that participants often wanted a wide range of medical imaging information yet were regularly left to initiate these discussions themselves³³. Similarly,

Ollivier and colleagues reported that French cancer patients undergoing MRI and CT scans needed greater reassurance and procedural explanations³⁰. These findings highlight that most of the research in this area has focused on cancer and emphasise the need for studies assessing unmet information preferences across general CT and MRI outpatient settings. This research should identify specific information items commonly reported as unmet preferences, so that findings translate to clearly defined areas for future practice improvement.

This study aims to identify, among MRI and CT medical imaging outpatients:

1. the ten most prevalent preparatory information content items reported as unmet information preferences (i.e. participants perceived they were given too little or too much information); and
2. sociodemographic, scan and information preference characteristics associated with reporting a greater number of unmet information preferences.

Methods

Design and setting

A cross-sectional survey of CT and MRI medical imaging outpatients was conducted over six weeks in one medical imaging clinic in the John Hunter Hospital located in Newcastle, NSW, Australia. This study is reported in accordance with the STROBE checklist of observational studies in epidemiology³⁴.

Participants

Eligible participants were: (i) attending for an outpatient CT or MRI appointment at the Hunter New England Medical Imaging Department at John Hunter Hospital; and (ii) 18 years or older. Inclusion was not restricted to specific medical conditions being

investigated by these diagnostic scans. Participants were excluded if they (i) had poor English proficiency as determined by medical imaging reception staff; or (ii) had a cognitive or physical impairment precluding informed consent and/or survey completion.

Procedure

Medical imaging receptionists identified potentially eligible patients presenting for their appointment, informed them about the research and invited them to speak with a trained researcher. The researcher provided interested patients with written and verbal study information, and gained verbal consent to participate. The age, gender and scan type of non-consenting patients was recorded with their permission.

Patients who consented to participate were provided with a tablet computer and asked to self-complete an online questionnaire prior to their scan. The researcher was available to help participants who had difficulties using the tablet computer, and paper-and-pen versions of the questionnaire were available upon request. If the patient was called for their procedure prior to finishing the questionnaire, only those questions that had been completed were analysed. Ethics approval was obtained from the Human Research Ethics Committees of the Hunter New England Local Health District (16/10/19/5.11) and University of Newcastle (H-2016-0386).

Unmet information preferences measure

Development: Unmet information preferences were measured using a series of investigator-developed items. General standards addressing patient preparation for potentially threatening medical procedures were initially used to identify preparatory domains (i.e. procedural; behavioural; sensory; psychosocial) that items should

address²⁵⁻²⁷. Domain-related items were developed using these general standards²⁵⁻²⁷, as well as Royal Australian and New Zealand College of Radiologists (RANZCR) Standards of Practice³⁵, consumer materials^{36,37} and informed consent guidelines³⁸. The items were applicable to patients having MRI or CT scans. Behavioural scientists, radiographers and health administrators initially reviewed and agreed upon the face validity of the questionnaire.

Pilot testing: Members of the general public and health professionals in the ageing, disability and nursing sector reviewed the questionnaire for item comprehension and completion time. Minor amendments to item wording and screen presentation were made based on the feedback. Prior to data collection, the revised questionnaire and recruitment protocol were tested with 134 MRI and CT outpatients [mean years of age (SD) = 53.6 (15.8); 61% female; 51.6% MRI] in the medical imaging department over a two week period. This timeframe ensured that the recruitment protocol was appropriately tested given high rotation of medical imaging receptionists in the study setting. Further changes to item structure and presentation were made.

Final version: The final questionnaire included an explanation indicating that the items related to information that participants were given by a health professional or other imaging department staff before arriving for their scan. The item stem “*Before arriving for your scan today, were you given any information about...*”, was followed by a list of 33 items of information (refer Appendix A (provided at Thesis Appendix 4.3)).

Participants were asked to respond either: ‘*no, but I wanted this information*’, ‘*no, but I didn’t want this information*’, ‘*yes, but I didn’t want this information*’, and ‘*yes, and I wanted this information*’. Item presentation was randomised using computer algorithms to reduce systematic bias in missing data and account for potential order effects³⁹. An

unmet information preference was defined as items where there was discordance between patient preferences and experiences⁴⁰. Responses indicating the receipt of too little (*no, but I wanted this information*) and too much (*yes, but I didn't want this information*) information were therefore combined to indicate an unmet information preference. The internal consistency (Kuder-Richardson coefficient) of these dichotomised information items was 0.94⁴¹.

Study factors

Sociodemographic, scan and information preference characteristics: included age, gender, residential postcode, scan type, prior scans, marital status, highest level of education completed, perceived overall health, and preference for amount of health information. Postcode was mapped to the Accessibility/Remoteness Index of Australia Plus (ARIA + 2011) classification to examine remoteness⁴², and categorised as metropolitan (major cities of Australia) or non-metropolitan (inner regional, outer regional, remote or very remote Australia).

Data analysis

To investigate consent bias, the gender, age group (< 65 years; ≥ 65 years) and scan type of consenters and non-consenters were compared using chi-squared tests. To investigate sampling bias, t-tests and chi-squared tests were used to compare the gender, age, scan type and geographic location profile of participants, versus all patients seen in the department during the study period. The proportion of participants reporting an unmet information preference for each item was calculated with 95% confidence intervals (CIs). The distribution of total number of unmet information preferences for all participants who had completed all 33 items (i.e. all items with non-missing values) were summarised as percentages. Data for patients having MRI and CT scans were

analysed together, however scan type was included as a study factor in regression analyses. Zero-inflated negative binomial regression was used to model the counts of unmet preferences across 33 items. This model was used due to the possibility that zeros occur by two different methods and due to over dispersion of the count outcome variable. Model fit was assessed using the Vuong test and the likelihood ratio test for the over dispersion coefficient $\alpha = 0$. A zero-inflated model assumes that the zero outcome may be due to two different processes. The same predictors were used to model the counts and the excess zeros: gender, age (< 65 years; ≥ 65 years), marital status (married or living with partner; not married or living with partner), geographic location (metropolitan; non-metropolitan), education (high school or less; more than high school), information amount preference (not a lot of information; a lot of information), overall health (poor or fair; good or better than good), scan type (MRI; CT), and prior scans (had scan before; don't know or not had scan before). Available case analysis was conducted. All analyses used a significance level of 5%. Analysis was conducted using STATA Version 13.1.

Sample size

Sample size was calculated based on an intent to dichotomise the outcome variable, for which a sample size of 200 would be sufficient to detect differences of approximately 20% in characteristics between those who were classified as having at least one unmet preparatory information preference (versus no unmet preparatory information preferences) with 80% power and a 5% significance level. However, after data collection, the analysis was refined to investigate the more meaningful and quantitative outcome of number of unmet information preferences. Modelling of a count outcome is

generally more powerful than a binary outcome and this change is expected to have increased the statistical power of the study.

Results

Sample

Of the 394 patients considered for the study during the six week recruitment period, 317 were eligible and invited to speak with the researcher (Figure 3.1). Of eligible patients, 280 (88%) consented to participate, 273 (86%) started the full survey, and 234 (74%) started information preference items. There was no significant difference between consenters and non-consenters based on gender and age group. Significantly more CT patients than MRI patients did not consent to participate ($\chi^2 = 6.565$; $p = 0.010$). The gender, age, scan type and geographic location of participants who commenced the survey was not significantly different from that of all potentially eligible patients seen in the department during the study period (Table 3.1). Two hundred and eighteen (78%) participants completed all of the unmet information preference items and 208 (74%) completed the full questionnaire. There were no significant differences in gender, age and scan type between those who did and did not complete the full questionnaire. Table 3.1 provides a summary of the sociodemographic and scan characteristics of the included sample.

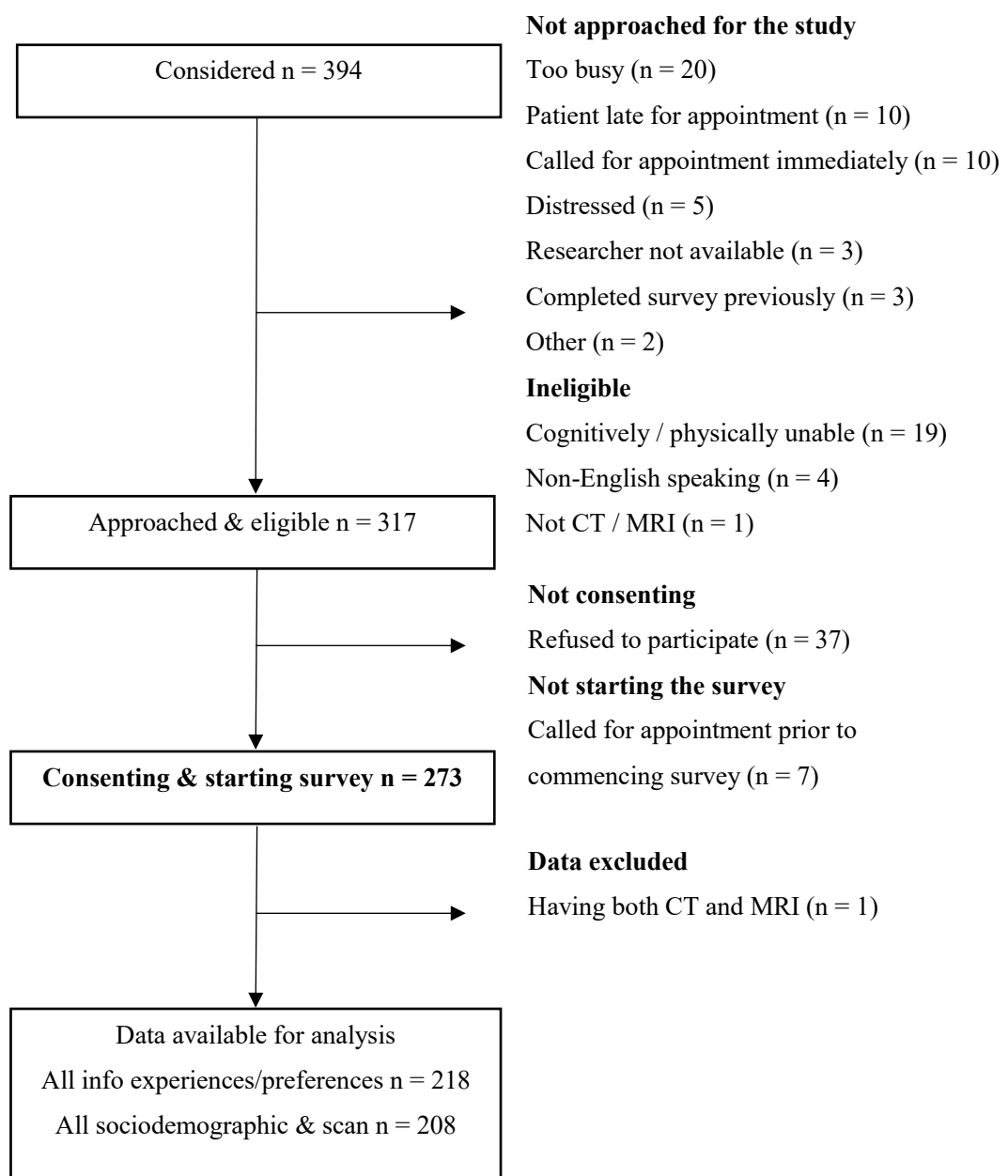


Figure 3.1: Flow diagram of recruitment

Table 3.1: Participant sociodemographic, scan and information preference profile

Characteristic		Participants who commenced the survey (N = 273 ^a)	Potentially eligible patients seen in the department during the study period (N = 754)	
		n (%)		Test statistic, <i>p</i>
Mean years of age, (SD)		57 (14)	55 (17)	$t = 1.72$ $p = 0.08$
Gender	Male	130 (48%)	352 (47%)	$\chi^2 = 0.75$
	Female	142 (52%)	402 (53%)	$p = 0.10$
Marital status	Married or living with partner	133 (63%)	-	-
	Single or never married	28 (13%)	-	-
	Divorced or separated	34 (16%)	-	-
	Widowed	17 (8%)	-	-
Education completed	High school or less	195 (71%)	-	-
	More than high school	78 (29%)	-	-
Geographic location	Metropolitan	209 (78%)	557 (74%)	$\chi^2 = 1.55$
	Non-metropolitan	59 (22%)	197 (26%)	$p = 0.21$
Overall health	Fair or worse	151 (55%)	-	
	Good or better than good	122 (45%)	-	
Scan type	CT	108 (40%)	329 (44%)	$\chi^2 = 0.66$
	MRI	157 (59%)	425 (56%)	$p = 0.41$
	Don't know	3 (1%)	-	
Scan experience	Not had scan before	66 (25%)	-	
	Had scan <1 year ago	93 (35%)	-	
	Had scan ≥ 1 year ago	97 (37%)	-	
	Don't know	8 (3%)	-	
Information amount preferences	Not a lot of information	121 (44%)	-	
	A lot of information	152 (56%)	-	

^a Not all items add to 273 due to missing data from incomplete surveys

Top 10 ranked preparatory information items reported as unmet information preferences

Each of the top ten ranked information items delivered in discordance with patient preferences were endorsed by at least one quarter of participants (Table 3.2). Five of these commonly unmet information preference items were procedural, four behavioural, two psychosocial and two sensory. Of the thirteen items reported as the most common unmet information preferences, one related to the pre-scan period, seven to the scan period and five to the post-scan period. Across the 33 information items, the proportion of respondents reporting unmet information preferences ranged from 12% - 33%.

Among those reporting unmet information preferences, the proportion receiving too little information ranged from 38% - 90%, while the proportion receiving too much information ranged from 10% - 62%.

Table 3.2: Top ten ranked items for which CT and MRI medical imaging outpatients reported not receiving their preferred amount of information (N = 234^a).

			<i>Unmet preference option endorsed</i>		Sum of unmet preference percentages ^b
			<i>No, but I wanted this information “Too little information”</i>	<i>Yes, but I didn’t want this information “Too much information”</i>	Preferences unmet “Too much or too little information”
Rank	Item	Domain	n (%)		
1	When to expect the results of the scan?	Procedural	61 (28%)	10 (5%)	71 (33%)
2	How to alert the radiographer if you have questions or concerns during the scan?	Behavioural	59 (27%)	10 (5%)	69 (32%)

			<i>Unmet preference option endorsed</i>		Sum of unmet preference percentages ^b
			<i>No, but I wanted this information “Too little information”</i>	<i>Yes, but I didn’t want this information “Too much information”</i>	Preferences unmet “Too much or too little information”
Rank	Item	Domain	n (%)		
3	How you will receive the results of the scan?	Procedural	51 (23%)	15 (7%)	66 (30%)
4	Whether you can drive home from the scan?	Behavioural	50 (23%)	13 (6%)	63 (29%)
5	How to manage scan-related fear or anxiety during the scan?	Psychosocial	49 (22%)	12 (6%)	61 (28%)
	Any after-effects in the day/s following the scan?	Sensory	54 (25%)	6 (3%)	60 (28%)
7	How long you will have to stay at the department after the scan?	Behavioural	48 (22%)	12 (5%)	60 (27%)
8	Where to find information about any aspects related to the scan?	Behavioural	43 (18%)	15 (6%)	58 (25%)
	Any risks associated with the scan?	Procedural	44 (20%)	13 (5%)	57 (25%)
	What you will see during the scan?	Sensory	39 (17%)	17 (8%)	56 (25%)

			<i>Unmet preference option endorsed</i>		Sum of unmet preference percentages^b
			<i>No, but I wanted this information “Too little information”</i>	<i>Yes, but I didn’t want this information “Too much information”</i>	Preferences unmet “Too much or too little information”
Rank	Item	Domain	n (%)		
	What to do if you suffer from claustrophobia?	Psychosocial	36 (16%)	20 (9%)	56 (25%)
	How long the scan will take?	Procedural	38 (17%)	18 (8%)	56 (25%)
	What you will be asked to wear during the scan?	Procedural	40 (18%)	16 (7%)	56 (25%)

^a Not all items were completed by 234 participants due to missing data

^b Percentages don’t add to 100% due to met preference responses being omitted

Characteristics associated with reporting a greater number of unmet information preferences

Figure 3.2 shows the distribution of number of unmet information preferences as a percentage of the 218 participants who completed all 33 items. Twenty five percent of participants reported no unmet information preferences (n = 54; 95% CI 19% - 31%).

The

Table 3.3 zero inflated negative binomial model (count equation) shows that there was no significant association between participants’ sociodemographic and scan characteristics, and reporting a greater number of unmet information preferences. The inflation model shows that there was no significant association between participants’ sociodemographic and scan characteristics, and reporting zero unmet information preferences. Despite this, the Vuong test indicated that the zero inflated model was an improvement over the standard negative binomial model (p = 0.004). The test for alpha

= 0 was highly significant ($p < 0.001$) indicating that the model was more appropriate than Poisson.

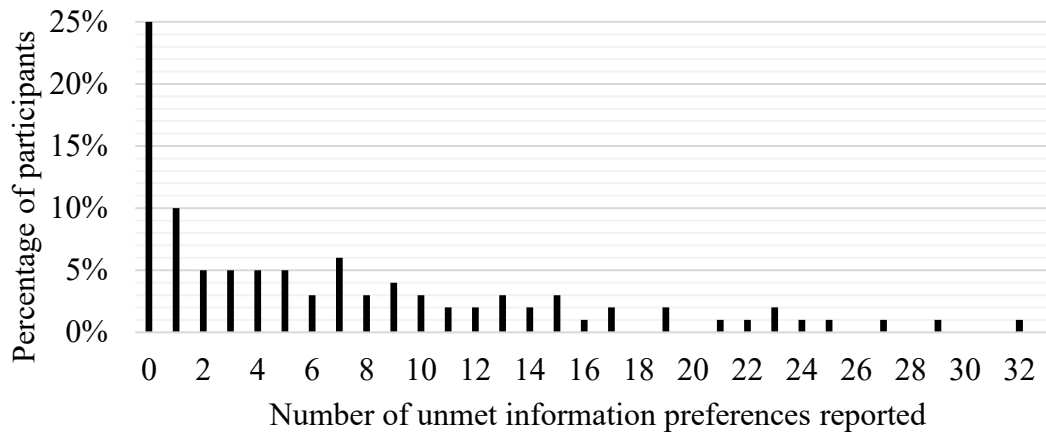


Figure 3.2: Proportion of participants reporting 0-33 unmet preferences for preparatory information content items (N = 218).

Table 3.3: Zero-inflated negative binomial regression of sociodemographic and scan characteristics associated with reporting a greater number of unmet information preferences (N = 208).

Variable	Count equation (IRR for number of unmet needs)		Inflation (binary) equation (Odds of zero count)	
	IRR ^a (95% CI)	<i>p</i>	OR ^b (95% CI)	<i>p</i>
Gender				
Male	1.00		1.00	
Female	1.15 (0.84 – 1.60)	0.38	0.64 (0.24 – 1.70)	0.37
Age				
Less than 65 years	1.00		1.00	
65 years or older	0.80 (0.54 – 1.17)	0.25	2.20 (0.72 – 6.68)	0.16
Marital status				
Married / living with partner	1.00		1.00	
Not married / living with partner	1.27 (0.91 – 1.76)	0.16	0.84 (0.31 – 2.24)	0.73
Geographic location				
Metropolitan	1.00		1.00	

Variable	Count equation (IRR for number of unmet needs)		Inflation (binary) equation (Odds of zero count)	
	IRR ^a (95% CI)	<i>p</i>	OR ^b (95% CI)	<i>p</i>
Non-metropolitan	1.26 (0.86 – 1.84)	0.24	2.36 (0.90 – 6.17)	0.08
Education				
High school or less	1.00		1.00	
More than high school	0.99 (0.72 – 1.37)	0.96	0.97 (0.36 – 2.60)	0.96
Information amount preference				
Not a lot of information	1.00		1.00	
A lot of information	0.78 (0.55 – 1.12)	0.18	0.58 (0.22 – 1.54)	0.28
Overall health				
Fair or worse	1.00		1.00	
Good or better than good	0.91 (0.66 – 1.26)	0.57	1.82 (0.65 – 5.08)	0.25
Scan				
CT	1.00		1.00	
MRI	0.78 (0.55 – 1.10)	0.16	3.86 (0.82 – 18.06)	0.09
Scan experience				
Not had scan before / don't know	1.00		1.00	
Had scan before	0.74 (0.51 – 1.08)	0.12	1.02 (0.33 – 3.18)	0.97

^a Incidence rate ratio

^b Odds ratio

Discussion and conclusion

Patient-centred care is a strategic priority across peak Australian and international medical imaging bodies^{43,44}. This study is the first to assess the extent to which preparatory information delivery meets the preferences of patients attending a large, Australian metropolitan medical imaging department. Whilst patient-centred care is important for quality improvement within diagnostic services^{43,44}, this study found that

there is room to improve responsiveness to individual patient's preferences for information across all assessed sociodemographic and scan characteristics.

Which information items are most commonly not delivered in accordance with patient preferences?

Patients more commonly receive too little information, as opposed to too much information

MRI and CT medical imaging outpatients more commonly reported receiving too little information relating to the “top ten” unmet information preferences, as opposed to too much information. This aligns with earlier findings indicating that many benefit and risk-related information items are reported as not received across medical imaging patients³³. Collectively these findings suggest that efforts are needed to ensure that those who want information are receiving it. Provider responsiveness to those who don't want information comes with greater complexity, as legal and ethical imperatives mandate the provision of certain information items for informed consent³⁸. Obligations at the patient- and service- level are therefore not always aligned, and it is not always possible to provide all information in a patient-centred manner. Further efforts are needed to ensure improved responsiveness to patient preferences for information, where legally and ethically appropriate.

The most frequently endorsed unmet information preferences related to all types of preparatory information

All preparatory domains (i.e. procedural, behavioural, sensory, psychosocial) were represented in the “top ten” unmet information preference items, suggesting that limited responsiveness to patient preferences is not isolated to one information type. Unmet preferences across multiple preparatory domains has also been reported in other research, particularly amongst those undergoing potentially threatening medical

procedures⁴⁵⁻⁴⁷. Mackenzie and colleagues' study of radiation oncology outpatients, found that better care could be provided with respect to information about patients' cancer (procedural and behavioural information), emotional and spiritual support (psychosocial information) and management of physical symptoms (behavioural information)⁴⁵. A holistic approach to providing preparatory information is important, as such information has been found to work synergistically⁹, and therefore unmet preferences in one preparatory domain may reduce the effectiveness of information provision within another domain. Hence, strategies are needed to concurrently respond to individual patient preferences for information across the behavioural, procedural, sensory and psychosocial aspects of care. This is increasingly difficult given time and resource constraints impacting healthcare delivery⁴⁸ and indicates a requirement for standardised approaches that ensure holistic patient-centred information provision.

Information about the time during and after the scan was most commonly not delivered in accordance with patient preferences

Our findings indicate that unmet information preferences often relate to the procedural and post-procedural period. It is possible that information relating to the time during and after the scan is provided at the point of care, however this does not reflect best-practice recommendations^{35,49}, and is not meeting patients' expressed need for information prior to their examination. Early information provision, addressing all phases of the procedure, is important as many patients experience high anxiety levels before their procedure³⁰, and information at this time can empower the patient, facilitate active care management²⁴ and allow them to anticipate what is coming⁵⁰. Greater efforts are therefore needed to ensure prompt responsiveness to patient preferences for information relating to the whole trajectory of care, from referral to receipt of results.

Which patient characteristics are associated with having a greater number of unmet information preferences?

Surprisingly, none of the sociodemographic or scan characteristics examined in this study were associated with the number of unmet information preferences reported.

Whilst mixed findings exist regarding factors associated with unmet information needs in other fields of research¹⁴⁻¹⁹, findings relating to the health status measure used in this study did not support the link between physical and psychological health status and unmet need that has been reported across other settings and patient groups^{14,16,17,51}.

Adult, adolescent and young adult patients across oncology and rheumatology settings have been reported to experience a higher number of unmet information and service needs when experiencing poorer physical health or requiring psychological support^{14,16,51}. The discrepancy between existing supportive care literature and our findings may be attributable to measurement differences, with the majority of studies focusing on unmet information needs^{14,16,17,51}, as opposed to unmet information preferences.

Of the small number of studies assessing patient-perceived receipt of too much information⁵²⁻⁵⁵, few examine patient characteristics associated with unmet information preferences (i.e. by examining the receipt of too much and too little information in combination). Zucca and colleagues examined the correlates of oncology patients' perceived receipt of too much or too little life expectancy information⁵². Particular patient characteristics were related to perceived receipt of too much information (e.g. stage of illness, being younger) and too little information (e.g. stage of illness, being anxious or depressed). Although, as is commonly the case across the field, too much and too little information were examined separately rather than in combination⁵², hence limiting capacity for comparisons with this study. Zucca and colleagues' findings⁵² do,

however, indicate that other factors which we did not examine, such as psychological distress and illness progression (where applicable), may be related to unmet information preferences. These factors, as well as those relevant to the delivery and receipt of information but not examined in our study (e.g. quality of referrer, health condition under examination), may warrant further investigation.

Multiple approaches can, and have been, used to assess patient-centred communication, including observation, physician and student experiences, and patient perception questionnaires⁴⁰. Whilst patient self-report has potential limitations, such as possible recall bias or patient misunderstanding, it is recommended as the gold standard measure in this field, as the patient is conceivably the best person to assess whether their preferences have been met^{40,56}. The current study, and others⁵², attempt to capture the mismatch between preferred and actual information delivery concurrently in a single self-report scale (as opposed to comparing agreement between two measures), hence reducing participant burden. This approach builds on unmet needs and preference literature and has promise, given the high survey completion rate, participant ease in responding to the items and endorsement by behavioural scientists. As such, the reliability and validity of data captured by this type of hybrid assessment is also worth exploring in future research.

Practice implications

As no sociodemographic characteristics were associated with reporting a greater number of unmet information preferences, patient-centred information provision may vary at an individual rather than a group level. This highlights the need for health professionals and other imaging department staff to elicit and respond to individual patient's information preferences at each touch point in the care trajectory. Given that the

majority of commonly unmet preferences related to receiving ‘too little’ information, strategies are needed to support healthcare professionals to identify and respond to patients who want more information. This may include communication training and question aids to prompt clinicians in eliciting unique information preferences⁵⁷, followed by the use of widely used information provision approaches, such as information sheets targeted to specific aspects of preparation (i.e. procedural, behavioural, sensory, psychosocial), for those seeking more information⁵⁸. It is recognised that these approaches may be challenging to implement given time and resource constraints impacting healthcare^{59,60}.

An alternative and potentially feasible strategy may be supplementing existing information provision practices with online information delivery. The internet provides tailoring functionality so that individuals can indicate their preferences for format, timing and amount of information, and materials can be adapted accordingly⁶¹. Additional benefits include wide accessibility and high interactivity of online information⁶¹. However, this approach assumes that patients have an ability to seek, find, understand and evaluate online health resources (otherwise termed eHealth literacy)⁶² as well as decide how much and what information they would like to receive. Research may be needed to assess patient eHealth literacy, and identify strategies or aids which may assist patients in expressing personal information preferences. High-quality research is also needed to assess the impact of the internet in facilitating patient-centred communication on outcomes for imaging services (e.g. appointment terminations) and imaging patients (e.g. anxiety and distress).

Limitations

Findings may not generalise beyond the single, metropolitan medical imaging department study setting, and may not apply to groups that were excluded (i.e. non-English speaking patients, cognitively and physically impaired patients) or underrepresented (CT patients). The sociodemographic and scan profile of study participants did, however, reflect that of all patients seen through the department in the study period (Table 3.1). In the absence of a standardised measure of patient-centred preparatory information provision in medical imaging settings, this study used an investigator-developed patient self-report measure to determine alignment between patients' preferred and actual receipt of preparatory information⁵⁶. Whilst the instrument has demonstrated internal consistency⁴¹, further evaluation of its psychometric properties is needed. The reason for reporting an unmet information preference was not explored. It is therefore unclear whether health professionals or other imaging department staff failed to elicit and respond to patient information preferences, or whether alternative factors, such as changing preferences over time, contributed to study findings.

Conclusion

There is room to improve responsiveness to patients' preferences for preparatory information within the medical imaging setting. The number of unmet information preferences did not vary significantly based on participants' sociodemographic and scan characteristics, suggesting that health care professionals and imaging department staff should be supported and encouraged to elicit and respond to information preferences at an individual patient level. A standardised approach to patient-centred information exchange that elicits patient preferences, and tailors information delivery accordingly,

may be an important first step to improving the quality of preparatory communication prior to medical imaging procedures.

Acknowledgements

The authors thank the patients for their involvement in this study, as well as the practice and managerial staff at Hunter New England Imaging for assistance with recruitment and data collection.

Funding

Mrs Lisa Hyde is supported by an Australian Government Research Training Program Scholarship. Dr Lisa Mackenzie is supported by a Postdoctoral Fellowship grant [PF-16-011] from the Australian National Breast Cancer Foundation. Dr Allison Boyes is supported by a National Health and Medical Research Council Early Career Fellowship (APP1073317) and Cancer Institute New South Wales Early Career Fellowships 13/ECF/1-37).

Informed consent and patient details

All patient/personal identifiers have been removed so the patient/person(s) described are not identifiable and cannot be identified through the details of the manuscript.

Conflicts of interest

None.

Appendix A: Unmet information preference measure

(Refer Thesis Appendix 4.3)

References

1. Kitson A, Marshall A, Bassett K, Zeitz K. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing* 2013; **69**(1): 4-15.
2. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington D.C., 2001.
3. Gerteis M, Edgman-Levitan S, Daley J, Delbanco T, editors. Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care. First ed. San Francisco: Jossey-Bass; 1993.
4. Kinnersley P, Stott N, Peters TJ, Harvey I. The patient-centredness of consultations and outcome in primary care. *British Journal of General Practice* 1999; **49**(446): 711-6.
5. Mead N, Bower P, Hann M. The impact of general practitioners' patient-centredness on patients' post-consultation satisfaction and enablement. *Social Science & Medicine* 2002; **55**(2): 283-99.
6. Epstein RM, Street RL. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. Bethesda, MD: National Cancer Institute, NIH, 2007.
7. Stewart M, Brown JB, Donner A, et al. The impact of patient-centered care on outcomes. *Journal of Family Practice* 2000; **49**(9): 796-804.
8. Ramsay I, Peters M, Corsini N, Eckert M. Consumer Health Information Needs and Preferences: A Rapid Evidence Review. Sydney: ACSQHC, 2017.

9. Suls J, Wan CK. Effects of sensory and procedural information on coping with stressful medical procedures and pain: a meta-analysis. *Journal of Consulting and Clinical Psychology* 1989; **57**(3): 372-9.
10. Jefford M, Tattersall MHN. Informing and involving cancer patients in their own care. *The Lancet Oncology* 2002; **3**(10): 629-37.
11. Miller SM, Mangan CE. Interacting effects of information and coping style in adapting to gynecologic stress: should the doctor tell all? *Journal of Personality and Social Psychology* 1983; **45**(1): 223-36.
12. Miller S. Individual Differences in the Coping Process: What to Know and When to Know It. In: Carpenter B, ed. *Personal Coping: Theory, Research and Application*. Westport, CT, US: Praeger Publishers/Greenwood Publishing Group; 1992: 77-91.
13. Husson O, Mols F, Oranje WA, et al. Unmet information needs and impact of cancer in (long-term) thyroid cancer survivors: results of the PROFILES registry. *Psychooncology* 2014; **23**(8): 946-52.
14. Keegan TH, Lichtensztajn DY, Kato I, et al. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *Journal of Cancer Survivorship* 2012; **6**(3): 239-50.
15. Kowalski C, Lee S-YD, Ansmann L, Wesselmann S, Pfaff H. Meeting patients' health information needs in breast cancer center hospitals - a multilevel analysis. *BMC Health Services Research* 2014; **14**(1): 601.
16. Meesters J, de Boer I, van den Berg M, Fiocco M, Vliet Vlieland T. Unmet information needs about the delivery of rheumatology health care services: a survey among patients with rheumatoid arthritis. *Patient Education and Counseling* 2011; **85**(2): 299-303.

17. Pieper D, Jülich F, Antoine S-L, et al. Studies analysing the need for health-related information in Germany - a systematic review. *BMC Health Services Research* 2015; **15**(1): 407.
18. Chen SC, Lai YH, Liao CT, Chang JT, Lin CC. Unmet information needs and preferences in newly diagnosed and surgically treated oral cavity cancer patients. *Oral Oncology* 2009; **45**(11): 946-52.
19. Rutten LJ, Arora NK, Bakos AD, Aziz N, Rowland J. Information needs and sources of information among cancer patients: a systematic review of research (1980-2003). *Patient Education and Counseling* 2005; **57**(3): 250-61.
20. Sjöstedt L, Hellström R, Stomberg MW. Patients' need for information prior to colonic surgery. *Gastroenterology Nursing* 2011; **34**(5): 390-7.
21. Steptoe A, O'Sullivan J. Monitoring and blunting coping styles in women prior to surgery. *British Journal of Clinical Psychology* 1986; **25**(2): 143-4.
22. King NK, Cheeseman GA, Siriwardena AK. Development of procedure-specific patient information sheets for acute abdominal surgery and validation in patients undergoing urgent cholecystectomy or appendicectomy. *International Journal of Clinical Practice* 2004; **58**(6): 559-63.
23. Garretson S. Benefits of pre-operative information programmes. *Nursing Standard* 2004; **18**(47): 33-7.
24. Waller A, Forshaw K, Bryant J, Carey M, Boyes A, Sanson-Fisher R. Preparatory education for cancer patients undergoing surgery: a systematic review of volume and quality of research output over time. *Patient Education and Counseling* 2015; **98**(12): 1540-9.

25. Schofield MJ, Sanson-Fisher R. How to prepare cancer patients for potentially threatening medical procedures: consensus guidelines. NSW Cancer Council Cancer Education Research Program. *Journal of Cancer Education* 1996; **11**(3): 153-8.
26. Cockburn J., NSW Cancer Council. How to Prepare Patients for Potentially Threatening Clinical Procedures: An Interactional Skills Training Manual for General Practitioners, Junior Medical Officers, Nurses, Surgeons. Kings Cross, NSW: NSW Cancer Council, 1997.
27. Forshaw KL, Carey ML, Hall AE, Boyes AW, Sanson-Fisher R. Preparing patients for medical interventions: a systematic review of the psychometric qualities of published instruments. *Patient Education and Counseling* 2016; **99**(6): 960-73.
28. Organisation for Economic Co-operation and Development. Health at a Glance 2015: OECD indicators. Paris: OECD 2015.
29. Heyer CM, Thuring J, Lemburg SP, et al. Anxiety of patients undergoing CT imaging-an underestimated problem? *Academic Radiology* 2015; **22**(1): 105-12.
30. Ollivier L, Apiou F, Leclerc J, et al. Patient experiences and preferences: development of practice guidelines in a cancer imaging department. *Cancer Imaging* 2009; **9**: S92-7.
31. Munn Z, Jordan Z. Interventions to reduce anxiety, distress and the need for sedation in adult patients undergoing magnetic resonance imaging: a systematic review. *International Journal of Evidence-Based Healthcare* 2013; **11**(4): 265-74.
32. Dewey M, Schink T, Dewey CF. Claustrophobia during magnetic resonance imaging: cohort study in over 55,000 patients. *Journal of Magnetic Resonance Imaging* 2007; **26**(5): 1322-7.

33. Thornton RH, Dauer LT, Shuk E, et al. Patient perspectives and preferences for communication of medical imaging risks in a cancer care setting. *Radiology* 2015; **275**(2): 545-52.
34. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *British Medical Journal* 2007; **335**(7624): 806-8.
35. The Royal Australian and New Zealand College of Radiologists. Standards of Practice for Diagnostic and Interventional Radiology, Version 10.1: RANZCR, 2016.
36. The Royal Australian and New Zealand College of Radiologists. Computed Tomography: Consumer Information. 2015.
<http://www.ranzcr.edu.au/resources/consumers> (accessed 26 June 2016).
37. The Royal Australian and New Zealand College of Radiologists. Magnetic Resonance Imaging (MRI): Consumer Information. 2015.
<http://www.ranzcr.edu.au/resources/consumers> (accessed 26 June 2016).
38. The Royal Australian and New Zealand College of Radiologists. Medical Imaging Consent Guidelines, Version 2. Sydney, Australia: RANZCR, 2013.
39. Strack F. "Order Effects" in Survey Research: Activation and Information Functions of Preceding Questions. In: Schwarz N, Sudman S, eds. *Context Effects in Social and Psychological Research*. New York, NY: Springer New York; 1992: 23-34.
40. Stewart M. Towards a global definition of patient centred care. *British Medical Journal* 2001; **322**(7284): 444.
41. Kuder GF, Richardson MW. The theory of the estimation of test reliability. *Psychometrika* 1937; **2**(3): 151-60.

42. Hugo Centre for Migration and Population Research. ARIA (Accessibility/Remoteness Index of Australia): The University of Adelaide, 2005.
43. The Royal Australian and New Zealand College of Radiologists Quality and Safety Committee. Strategic Planning Discussion Paper – Radiology Quality and Safety. Sydney, Australia: RANZCR, 2014.
44. European Society of Radiology. Patient Information. The Most Important Stakeholder in Radiology: The Patient. 2017. <https://www.myesr.org/quality-safety/patient-information> (accessed 7 July 2017).
45. Mackenzie LJ, Sanson-Fisher RW, Carey ML, Este CA. Radiation oncology outpatient perceptions of patient-centred care: a cross-sectional survey. *British Medical Journal* 2013; **3**(2).
46. Tsianakas V, Robert G, Maben J, Richardson A, Dale C, Wiseman T. Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services. *Supportive Care in Cancer* 2012; **20**(11): 2639-47.
47. Sinfield P, Baker R, Agarwal S, Tarrant C. Patient-centred care: what are the experiences of prostate cancer patients and their partners? *Patient Education and Counseling*; **73**(1): 91-6.
48. Verheijde J. Health Care Costs and Scarcity of Health Care Resources. Managing Care: A Shared Responsibility. Netherlands: Springer; 2006: 1-30.
49. Henwood SM, Munro L. Principles of Communication. In: Ramlal A, Vosper M, eds. Patient Centred Care in Medical Imaging and Radiotherapy. London: Churchill Livingstone; 2013: 3-6.

50. Porocho D. The effect of preparatory patient education on the anxiety and satisfaction of cancer patients receiving radiation therapy. *Cancer Nursing* 1995; **18**(3): 206-14.
51. Zebrack B. Information and service needs for young adult cancer survivors. *Supportive Care in Cancer* 2009; **17**(4): 349-57.
52. Zucca AC, Sanson-Fisher RW, Waller A, Carey M, Grady A, Mackenzie L. Life expectancy discussions in a multisite sample of Australian medical oncology outpatients. *The Medical Journal of Australia* 2015; **203**(10): 405.
53. Oldman M, Moore D, Collins S. Drug patient information leaflets in anaesthesia: effect on anxiety and patient satisfaction. *British Journal of Anaesthesia* 2004; **92**(6): 854-8.
54. Katz SJ, Wallner LP, Abrahamse PH, et al. Treatment experiences of Latinas after diagnosis of breast cancer. *Cancer* 2017; **123**(16): 3022-30.
55. Gaucher N, Nadeau S, Barbier A, Janvier A, Payot A. Personalized antenatal consultations for preterm labor: responding to mothers' expectations. *The Journal of Pediatrics* 2016; **178**: 130-4. e7.
56. Tzelepis F, Sanson-Fisher RW, Zucca AC, Fradgley EA. Measuring the quality of patient-centered care: why patient-reported measures are critical to reliable assessment. *Patient Preference and Adherence* 2015; **9**: 831-5.
57. Dwamena F, Holmes-Rovner M, Gaulden CM, et al. Interventions for providers to promote a patient-centred approach in clinical consultations. *Cochrane Database of Systematic Reviews* 2001; **4**.
58. Bolejko A, Sarvik C, Hagell P, Brinck A. Meeting patient information needs before magnetic resonance imaging: development and evaluation of an information booklet. *Journal of Radiology Nursing* 2008; **27**(3): 96-102.

59. Kirch DG, Henderson MK, Dill MJ. Physician workforce projections in an era of health care reform. *Annual Review of Medicine* 2012; **63**(1): 435-45.
60. Department of Health. Review of Australian Government Health Workforce Programs. Canberra, Australia: Department of Health, 2013.
61. Cline RJW, Haynes KM. Consumer health information seeking on the Internet: the state of the art. *Health Education Research* 2001; **16**(6): 671-92.
62. Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. *Journal of Medical Internet Research* 2006; **8**(2): e9.

PAPER THREE

Three-factor Structure of the eHealth Literacy Scale among Magnetic Resonance Imaging and Computed Tomography Outpatients: A Confirmatory Factor Analysis

PAPER THREE

To understand the potential utility of eHealth in eliciting and responding to medical imaging patients' information preferences, we must be able to accurately measure their eHealth literacy, i.e. their ability to locate and use online health materials. The eHealth Literacy Scale (eHEALS) is a brief measure of eHealth literacy, which has been widely used since its development in 2006. However, there are mixed findings regarding the factorial validity of the eHEALS. It was recently proposed that the eHEALS has a multidimensional structure rather than a unidimensional structure. Paper Three seeks to validate the recently proposed three-factor eHEALS structure using confirmatory factor analysis. This paper was published in *JMIR Human Factors* (Thesis Appendix 5.2).

Hyde LL, Boyes AW, Evans TJ, Mackenzie LJ, Sanson-Fisher R. Three-factor structure of the eHealth Literacy Scale among magnetic resonance imaging and computed tomography outpatients: A confirmatory factor analysis. *JMIR Human Factors* 2018; **5**(1): e6.

Three-factor Structure of the eHealth Literacy Scale among Magnetic Resonance Imaging and Computed Tomography Outpatients: A Confirmatory Factor Analysis

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Abstract

Background: eHealth literacy is needed to effectively engage with web-based health resources. The 8-item eHealth literacy scale (eHEALS) is a commonly used self-report measure of eHealth literacy. Accumulated evidence has suggested that the eHEALS is unidimensional. However, a recent study by Sudbury-Riley and colleagues suggested that a theoretically-informed three-factor model fitted better than a one-factor model. The 3 factors identified were: awareness (2 items), skills (3 items), and evaluate (3 items). It is important to determine whether these findings can be replicated in other populations.

Objective: The aim of this cross-sectional study was to verify the three-factor eHEALS structure among magnetic resonance imaging (MRI) and computed tomography (CT) medical imaging outpatients.

Methods: MRI and CT outpatients were recruited consecutively in the waiting room of one major public hospital. Participants self-completed a touchscreen computer survey, assessing their sociodemographic, scan, and internet use characteristics. The eHEALS was administered to internet users, and the three-factor structure was tested using structural equation modelling.

Results: Of 405 invited patients, 87.4% (354/405) were interested in participating in the study, and of these, 75.7% (268/354) were eligible. Of the eligible participants, 95.5% (256/268) completed all eHEALS items. Factor loadings were 0.80 to 0.94, and statistically significant ($P < .001$). All reliability measures were acceptable (indicator reliability: awareness=.71–.89, skills=.78–.80, evaluate=.64–.79; composite reliability: awareness=.89, skills=.92, evaluate=.89; variance extracted estimates: awareness=.80,

skills=.79, evaluate=.72). Two out of three goodness-of-fit indices were adequate (standardised root mean square residual [SRMR]=.038; comparative fit index [CFI]=.944; root mean square error of approximation [RMSEA]=.156). Item 3 was removed because of its significant correlation with item 2 (Lagrange multiplier [LM] estimate=104.02; $P<.001$), and high loading on 2 factors (LM estimate=91.11; $P<.001$). All three indices of the resulting 7-item model indicated goodness of fit ($\chi^2(11)=11.3$; SRMR=.013; CFI=.999; RMSEA=.011).

Conclusions: The three-factor eHEALS structure was supported in this sample of MRI and CT medical imaging outpatients. Although further factorial validation studies are needed, these 3 scale factors may be used to identify individuals who could benefit from interventions to improve eHealth literacy awareness, skill, and evaluation competencies.

Key words: eHealth; literacy; factor analysis; measures; psychometrics

Introduction

Consumer eHealth literacy is critical to maximising the benefits of eHealth

Technologically-enabled healthcare is important at both the patient and service level, given the increasing resource and timing pressures on the health care system¹, the digital transformation of health-related industries², and changing consumer expectations about their role in care³. eHealth refers to the organization and delivery of health services and information using the internet and related technologies⁴. eHealth holds potential as a scalable form of service delivery that is accessible, low-cost, promotes patient empowerment and enhances patient-provider information exchange⁵. However, to reap the possible benefits, patients must be eHealth literate⁶. eHealth literacy refers to an individual's ability to seek, find, understand and appraise health information from electronic sources, and apply the knowledge gained to addressing or solving a health problem⁶. Limited ability to seek, find, understand, and appraise electronic health information has been recognised as a key self-reported barrier to the utilisation of the internet for health purposes⁷. The first step in identifying individuals who may benefit from improved eHealth literacy is the development of valid and reliable tools assessing this construct.

The eHealth literacy scale is a standardised and widely used measure

The eHealth literacy scale (eHEALS) was among the first, and continues to be one of the most commonly used, self-reported measures of eHealth literacy^{8,9}. The scale comprises 8 items, which assess consumers' combined knowledge, comfort, and perceived skills at finding, evaluating and applying electronic health information to health problems⁸. Consistent with the current definition of eHealth⁴, all eHEALS items are specific to health information access via the internet, as opposed to other electronic

forms of information provision (e.g. Compact Disc Read-Only Memory [CD-ROM], computer games). The scale was developed to address the need for an easily self-administrable eHealth literacy measure that could be applied across a wide range of populations and contexts⁸. Widespread adoption of the scale has been demonstrated, with the measure translated into multiple languages¹⁰⁻¹⁷, and used across participants with diverse sociodemographic^{10,15,16,18}, ethnic^{11,14,19} and disease profiles^{13,20,21}. Items were originally developed and validated among Canadian youths more than a decade ago⁸, and subsequent studies have demonstrated test-retest reliability across younger¹⁴ and older age cohorts¹⁰, internal consistency across populations of varying age and ethnicity^{10,11,14,15,19,22}, and measurement invariance across English speaking countries²³. However, inconsistent findings exist regarding the convergent and predictive validity of the scale^{10,11,24}, and debate continues about its factor structure^{10-17,22,23,25-28}. We sought to contribute to this knowledge by assessing the factorial validity and internal consistency of a three-factor structure of the eHEALS.

The factor structure of the eHealth literacy scale is uncertain

Norman and Skinner's original factorial validation of the eHEALS found that the scale assesses a single dimension⁸. Numerous studies with the general public have supported this finding^{10,11,14-16,22,25,26}, including those specific to children¹⁵, university students^{14,16} and older adults^{10,22}. However, the strength of these conclusions is limited by the common use of exploratory factor analysis (EFA)^{8,10,11,14,15,22,25,26}. EFA originates from classical test theory and holds value in the early stages of scale development when factor structure is unknown and latent variable structures need to be identified²⁹. EFA does, however, have some limitations. For example, it often involves subjective

decision-making processes, and does not account for the theory which may inform latent variable structures³⁰.

Confirmatory factor analysis (CFA) is an alternative analysis technique, also derived from classical test theory, that allows models to be tested via theoretically or empirically driven hypotheses³¹. However, studies assessing a unidimensional eHEALS structure using CFA commonly report poor fit indices^{13,23,27,28}. This may be because a single factor structure does not account for the multifaceted nature of the concept of eHealth literacy, such as its inherent literacy types (i.e. traditional, health, information, scientific, media, and computer) or the multiple components of information retrieval and use (i.e. finding, applying and evaluating electronic health information)⁶. Paige and colleagues¹³ completed one of the only studies of the construct validity of the eHEALS using CFA with chronically ill patients, and found evidence for a three-factor structure. Despite this, multidimensionality of the eHEALS was refuted on the basis that a large proportion of variance loaded on one factor only. The authors applied the partial credit model, which is a unidimensional item response theory technique, to conclude that a single structure exists, despite CFA values indicating a poor unidimensional fit¹³. A two-factor model based on the concepts of information-seeking and appraisal has also been tested^{12,27,28}. Although this model has a strong theoretical basis, 2 of the 3 studies testing this structure reported inadequate fit indices^{12,27}. Furthermore, all were based on translated versions of the scale, which can result in varied item meaning and interpretation³².

Recent literature proposes that the eHealth literacy scale has a three-factor structure

Sudbury-Riley and colleagues²³ used CFA to test a three-factor structure of the English-language version of the eHEALS with a multinational sample of adult internet users from the United Kingdom (n=407), New Zealand (n=276), and the United States (n=313). A hypothesis-driven approach was adopted, whereby 2 eHEALS items were mapped to an “awareness” factor, 3 items to a “skills” factor and 3 items to an “evaluate” factor. These factors were derived from the self-efficacy and social-cognitive theoretical constructs underpinning eHealth literacy^{8,23}. Self-efficacy theory is based on the premise that goal achievement is mediated by self-belief and confidence, and social cognitive theory states that social context influences goal achievement³³. Sudbury-Riley and colleagues²³ therefore proposed that an individual’s awareness is shaped by their environment (e.g. exposure to web-based health information), their skills are influenced by social factors (e.g. modelling, instruction and social persuasion), and their ability to evaluate eHealth resources is mediated by their confidence and persistence. CFA fit indices supported the hypothesized three-factor eHEALS structure across all 3 countries²³.

Further research is needed to verify the three-factor structure of the standardised eHealth literacy scale with patient populations

The study by Sudbury-Riley and colleagues²³ contributes to our understanding of the underlying structures of the eHEALS, however it has some limitations. In particular, a modified version of the scale was used, based on feedback from the authors’ family, friends and colleagues, in which “and information” was added to items to address the increasing interactivity of eHealth materials. It is therefore unclear whether the three-factor structure also applies to the original version of the scale. The study was also

conducted with middle aged members of the general population, restricting the generalisability of findings across medical populations and age cohorts. This adds to the common under-representation of chronically ill patients in the eHEALS measurement literature, despite the potential benefits of eHealth to this population¹³.

Given that evidence about the properties of a measure is accumulated over a number of studies, the appropriate next step it is to determine whether Sudbury-Riley and colleagues' findings can be replicated in a different population. To address this need, and also overcome some of the limitations of Sudbury-Riley and colleagues' work²³, this factorial validation study was conducted with patients, using the standardised eHEALS. Magnetic resonance imaging (MRI) and computed tomography (CT) medical imaging outpatients represent a high volume of patients with diverse demographic characteristics and medical diagnoses^{34,35}, and as such, research completed with these patients may have high generalisability. Furthermore, MRI and CT medical imaging outpatients require substantial preparatory information that could potentially be delivered on the internet³⁶. Hence, this study aimed to test the factorial validity and internal consistency of the three-factor structure of the eHEALS, identified by Sudbury-Riley and colleagues²³, among MRI and CT medical imaging outpatients.

Methods

Design and setting

A cross-sectional survey of CT and MRI medical imaging outpatients was conducted in a medical imaging clinic at a tertiary referral hospital located in regional New South Wales, Australia.

Participants

Eligible participants were attending for an outpatient CT or MRI appointment at the tertiary referral hospital, were 18 years or older, and had access to the internet for personal use. Participants were excluded from the study if they had a cognitive or physical impairment which precluded them from providing informed consent or participating in the study; or if they were unable to complete the questionnaire because of poor English proficiency. These criteria mean that a diversity of participants in terms of frequency, confidence and reasons for personal use of the internet were eligible to participate. Consistent with the original eHEALS validation study⁸, use of the internet for health was not an eligibility requirement.

Procedure

Patients who were potentially eligible for the study were identified by medical imaging reception staff when they presented for their outpatient appointment. These patients were informed about the research and invited to speak with a trained research assistant. Interested patients were provided with a written information sheet and introduced to the research assistant, who gave an overview of the study and obtained patients' verbal consent to participate. The age, gender and scan type of non-interested and non-consenting patients were recorded. Consenting participants were provided with a tablet computer and asked to complete a web-based questionnaire before their scan. A paper version of the questionnaire was provided to participants who requested it. Ethics approval was obtained from the Hunter New England Human Research Ethics Committee (16/10/19/5.11) and University of Newcastle (H-2016-0386).

Measures

Participants' eHealth literacy was assessed using the 8-item English-language version of the eHEALS⁸. Respondents indicated their level of agreement with each statement on a 5-point Likert scale, which was scored from 1 "strongly disagree" to 5 "strongly agree".

Sociodemographic, scan, and information preference characteristics were examined using standard items. These items assessed participant age, gender, marital status, highest level of education completed, postcode, and scan type. Postcodes were mapped to the Accessibility/Remoteness Index of Australia Plus 2011 classification to examine remoteness³⁷ and categorised as metropolitan (major cities of Australia) or non-metropolitan (inner regional, outer regional, remote or very remote Australia). One item, adapted from an existing health information wants questionnaire³⁸, assessed how much information participants liked to have about their health. Response options were "no information", "some information", and "a lot of information".

Internet characteristics were assessed by 2 items. Use of the internet for scan preparation was assessed by an author-developed item: *Have you searched the internet for information to help you prepare for your scan?* with response options "no", "yes", and "don't know". Frequency of internet use was measured with a single item used in existing informatics literature³⁹, in which participants respond on a 6-point scale ranging from "less than once a month" to "several times a day".

Sample size

Rules of thumb for CFA recommend a sample size of at least 200 participants^{40 41}, or 10 participants per parameter estimated⁴². Wolf and colleagues⁴³ found that a sample size of at least 150 is required for three-factor models with fewer than 4 indicator variables

per factor and assuming strong factor loadings of .8. To accommodate deviation from these assumptions, and given that 19 parameters were estimated for the eHEALS CFA, the more conservative estimate of at least 200 participants was applied to this study.

Statistical analyses

Participant characteristics and eHEALS responses were summarised as frequencies and percentages, or means and standard deviations. Consent bias was assessed for gender, scan type and age group using chi-square tests. CFA was undertaken using the CALIS procedure of SAS software v9.4 (SAS Institute, Cary, NC, USA). We chose CFA as it is the same theoretically-sound technique used by Sudbury-Riley and colleagues²³, and therefore allowed for a direct comparison of results. Given the high completion rate (98.1% [256/261] of participants who started the eHEALS completed all items), this analysis was restricted to participants with complete eHEALS data. The relationship between latent variables (i.e. awareness, skills, evaluate) and manifest variables (eHEALS items 1-8), as proposed by Sudbury-Riley and colleagues²³, was tested using structural equation modelling (Figure 4.1). All loadings were standardised, with variances fixed at 1. The model was estimated using the full information maximum likelihood method. Standardised factor loadings and co-variances were calculated with 95% CIs.

Reliability measures included: indicator reliability to determine the percentage of variation in the item explained by each factor; composite reliability (CR) to assess internal consistency (>.70 ideal)²⁹; and variance extracted estimates (VEEs) to determine the amount of variance captured by factors with regard to variance attributable to measurement error (>.50 ideal)⁴⁴. Discriminant validity was assessed following the method proposed by Anderson and Gerbing⁴⁵.

Model goodness of fit was assessed using a range of metrics. Absolute indices included the chi-square statistic, the chi-square to degrees of freedom ratio (<2 ideal)⁴⁶ and the standardised root mean square residual (SRMR; $<.055$ ideal)²⁹. The incremental index was reported as the comparative fit index (CFI; $>.95$ good fit)⁴⁷. The parsimony index used was the root mean square error of approximation (RMSEA; $<.05$ close approximate fit, $.05-.08$ acceptable fit, $>.10$ poor fit)^{29,47}. Lagrange multiplier (LM) estimates of items on different factors were assessed to identify complex items and possible ways to improve the model.

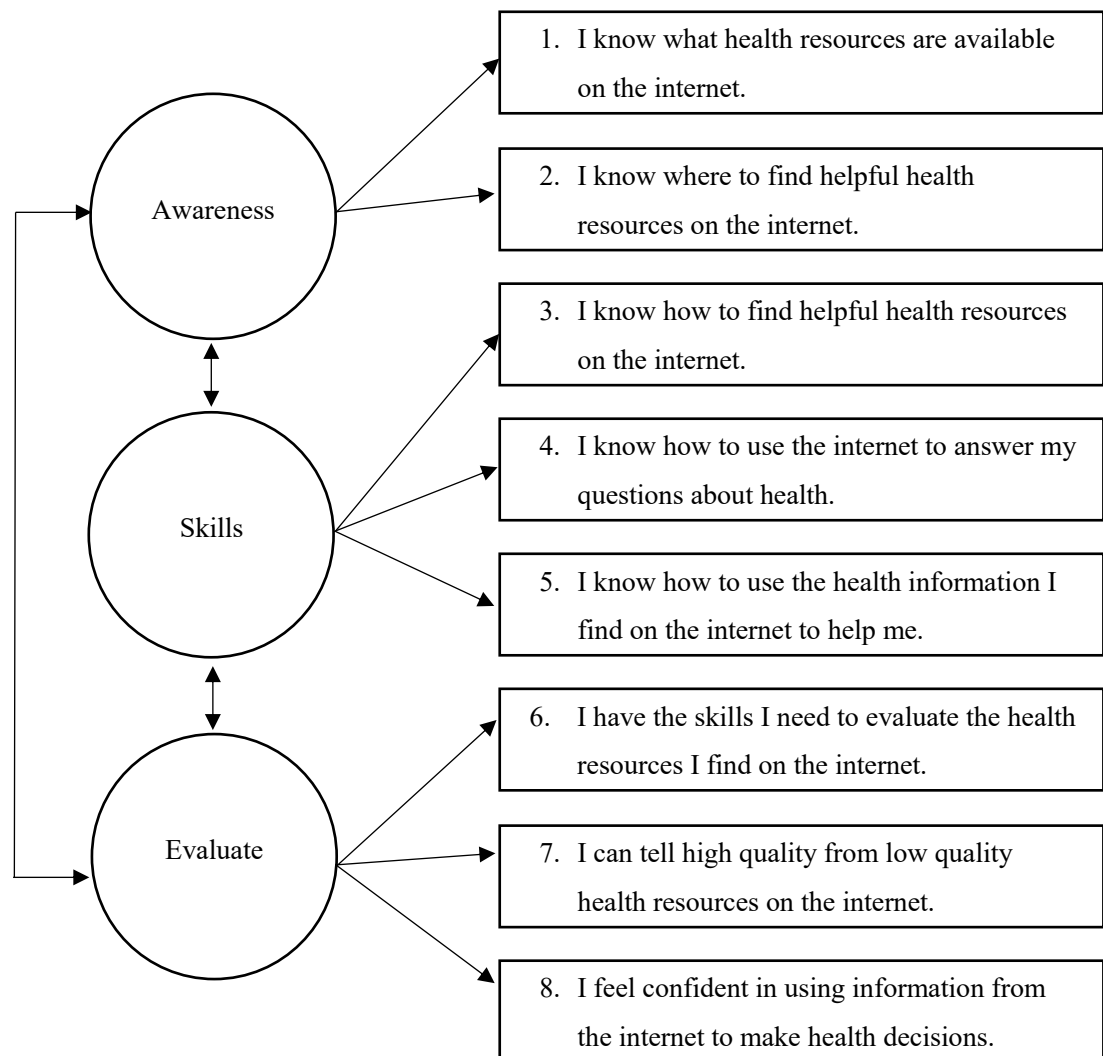


Figure 4.1: eHealth Literacy Scale three-factor model proposed by Sudbury-Riley and colleagues²³

Results

Sample

A total of 405 potentially eligible patients were invited to discuss the study with a research assistant during the 7-week recruitment period. Of the invited patients, 87.4% (354/405) were interested in participating in the study, and of these, 75.7% (268/354) were eligible. Of these eligible participants, 97.4% (261/268) started the eHEALS, and 95.5% (256/268) completed all eHEALS items. There were no significant differences between patients who were and were not interested in participating in the study based on gender, scan type or age group. Figure 4.1 provides a summary of the sociodemographic, scan and internet characteristics of eligible participants. Multimedia Appendix 1 (provided at Thesis Appendix 5.3.1) provides a summary of participant responses to eHEALS items.

Table 4.1: Participant sociodemographic, scan and internet characteristics (N = 268)

Characteristic		n (%) ^a
Mean age years (SD ^b)		53 (15)
Gender		
	Male	120 (44.8)
	Female	148 (55.2)
Marital status		
	Married or partner	148 (64.9)
	Not married/living with partner	80 (35.1)
Education completed		
	High school or less	169 (63.1)
	More than high school	99 (36.9)
Geographic location		
	Metropolitan	212 (79.1)

Characteristic		n (%) ^a
	Nonmetropolitan	56 (20.9)
Scan type		
	CT	104 (38.8)
	MRI	160 (59.7)
	Don't know	4 (1.5)
Used Internet for scan		
	Yes	29 (10.9)
	No	237 (88.8)
	Don't know	1 (0.3)
Frequency of Internet use		
	Less than once a month	11 (4.1)
	Once a month	5 (1.8)
	A few times a month	14 (5.2)
	A few times a week	36 (13.5)
	About once a day	51 (19.1)
	Several times a day	150 (56.2)
Information amount preference		
	No information	2 (0.8)
	Some information	59 (26.0)
	A lot of information	166 (73.1)

^a Number of observations for each characteristic may not total 268 because of missing data

^bSD: standard deviation.

Confirmatory factor analysis

Convergence between the implied and observed variance co-variance matrices was achieved within 10 iterations. As shown in Table 4.2, all factor loadings were at or above .80 and were statistically significant ($P < .001$). All CRs exceeded .70, indicating good reliability, and all VEEs exceeded the cutoff of .50 indicating convergent validity. Discriminant validity of the model was demonstrated, with statistically significant chi-

square difference-tests ($P<.001$) for each pair of factors. The absolute index SRMR was .038, indicating adequate fit to the hypothesized model. The incremental index CFI was .944, and therefore close to the .95 threshold of acceptability (Table 4.3). However, the chi-square statistic ($\chi^2_{17}=124.2$) was highly significant and suggestive of poor fit, and the chi-square statistic to degrees of freedom ratio of 7.3 exceeded the acceptability cut-off of 2⁴⁶. The parsimony index RMSEA was .16, indicating poor fit.

When investigating the possible reasons for less than ideal fit, LM estimates provided strong evidence for a path between item 3 “*I know how to find helpful health resources on the internet*” and the awareness factor (LM estimate=107.66; $P<.001$). There was also strong evidence for a path between item 2 “*I know where to find helpful health resources on the internet*” and item 3 “*I know how to find helpful health resources on the internet*” (LM estimate = 91.11; $P<.001$). Given apparent overlap between items 2 and 3, a 7-item model which excluded item 3 was tested, which indicated good model fit (Table 4.3). See Multimedia Appendix 2 (provided at Thesis Appendix 5.3.2) for factor loading and residual error estimates for this altered model.

Table 4.2: Factor loading and residual error estimates for confirmatory factor analysis of hypothesized model

Factor-variable		Factor loadings (95% CI)	Error estimates (95% CI)	IR ^a	CR ^b	VEE ^c
Awareness						
	I know what health resources are available on the Internet	0.85 (0.80-0.89) ^e	0.29 (0.21-0.36) ^e	.71	.89	.80
	I know where to find helpful health resources on the Internet	0.94 (0.91-0.97) ^e	0.11 (0.05-0.17) ^e	.89		
Skills						

Factor-variable		Factor loadings (95% CI)	Error estimates (95% CI)	IR ^a	CR ^b	VEE ^c
	I know how to find helpful health resources on the Internet ^d	0.90 (0.86-0.93) ^e	0.20 (0.14-0.26) ^e	.80	.92	.79
	I know how to use the Internet to answer my questions about health	0.88 (0.85-0.92) ^e	0.22 (0.16-0.28) ^e	.78		
	I know how to use the information I find on the Internet to help me	0.88 (0.85-0.92) ^e	0.22 (0.16-0.28) ^e	.78		
Evaluate						
	I have the skill I need to evaluate the health resources I find on the Internet	0.89 (0.85-0.92) ^e	0.21 (0.15-0.28) ^e	.79	.89	.72
	I can tell high quality from low quality health resources on the Internet	0.86 (0.82-0.90) ^e	0.26 (0.19-0.33) ^e	.74		
	I feel confident in using information from the Internet to make health decisions	0.80 (0.75-0.85) ^e	0.36 (0.28-0.44) ^e	.64		

^a IR: indicator reliability.

^b CR: composite reliability.

^c VEE: variance extracted estimate.

^d This item was dropped in the alternative 7-item model (see Multimedia Appendix 2 (provided at Thesis Appendix 5.3.2)).

^e P < .001.

Table 4.3: Goodness-of-fit indices for tested models

Index type and fit index		Statistics for hypothesized 8-item model	Statistics for tested 7-item model
Absolute index			
	chi-square	124.2	11.3
	chi-square degrees of freedom	17	11
	<i>P</i> -value for the chi-square	<.001	.417
	SRMR ^a	.038	.012
Incremental index			
	Bentler CFI	.944	.999
Parsimony index			
	RMSEA ^c estimate	.156	.011
	RMSEA lower 90% CI	.131	.000
	RMSEA upper 90% CI	.182	.066

^aSRMR: standardized root mean square residual.

^bCFI: comparative fit index.

^cRMSEA: root mean square error of approximation.

Discussion

Principal findings

This study was the first to examine the theoretically-derived three-factor structure of the eHEALS, as proposed by Sudbury-Riley and colleagues²³, among a sample of MRI and CT medical imaging outpatients. This three-factor structure was supported, with 2 out of 3 goodness-of-fit indices indicating adequate fit to the hypothesized model. Although these findings oppose accumulated evidence for a unidimensional structure of the eHEALS^{8,10,11,14-16,22,25,26}, they are consistent with the social cognitive and self-efficacy theory underpinning eHealth literacy^{8,23,33}. As a result, it may be timely for researchers to examine patients' eHealth literacy across eHEALS factors, to inform targeted eHealth literacy improvement interventions. This study contributes important knowledge about

the structure of the eHEALS, yet further factorial analyses, including multidimensional item response theory analyses are required across populations to increase the reliability of these findings.

Findings broadly support the proposed three-factor structure of the eHEALS

The proposed model demonstrated strong internal consistency and discriminant validity, suggesting that items within each factor measured the same general construct, and these constructs were sufficiently different from one another. Similarly, 2 out of 3 fit indices demonstrated good fit to the proposed three-factor model. Factor loadings were high and statistically significant, similar to that reported by Sudbury-Riley and colleagues²³. This finding contrasts to the majority of existing literature, where it is argued that a single factor structure exists^{8,10-16,19,22,25,26}. Most such prior research is based on data-driven EFA techniques^{8,10,11,14,15,22,25,26}, which may indicate that limited reference to the theoretical underpinnings of eHealth literacy has resulted in inaccurate interpretations of eHEALS data in the past.

Not all goodness-of-fit indices were ideal

Poor fit of the parsimony index suggests that complexity exists within the three-factor model. RMSEA estimates have also been identified as a poor performing goodness of fit metric in other CFA eHEALS literature^{12,13,27} and are rarely reported as being a close approximate fit, indicating that relationships among items need to be interrogated.

When we investigated further, it was found that item 3 “*I know how to find helpful health resources on the internet*” loaded on both “skills” and “awareness” domains, and correlated significantly with item 2 “*I know where to find helpful health resources on the internet*”. This finding supports that of Sudbury-Riley and colleagues²³, who identified substantial overlap between items 2 and 3. Potential item homogeneity is also evident in prior literature, as measures of internal consistency have commonly been

reported to be approaching the .95 threshold of acceptability for Cronbach alpha^{10,11,15,19}, with some reported to have reached .97²². The redundancy of items 2 and 3 is unsurprising given their similar structure and meaning (i.e. about how and where to find helpful health resources on the internet). It is also possible that the low education level of the sample⁴⁸, and the distressing setting of a hospital waiting room⁴⁹, contributed to participants' difficulties in differentiating between item meanings. However, patient understanding of eHEALS items has been questioned previously, and the need for further research investigating item interpretation across populations has been indicated¹¹.

For this study, we did not restrict our sample to health-related internet users. This aligns with the majority of studies assessing the factorial validity of the eHEALS, including Norman and Skinner's original validation study^{8,10-17,19,22,26-28}. Furthermore, Norman and Skinner⁸ highlight the potential application of the scale to those with varying levels of technology use. eHEALS response options of *disagree* and *strongly disagree* provide for those who do not use the internet for health. Despite this, some participants within this study voluntarily reported being unsure of how to respond to each item as they did not use the internet for health. This anecdotal feedback suggests that items within the scale may not be interpretable to the wide population for which it was originally intended⁸, and further research is needed to investigate the face and content validity of the scale among those who do and do not use the internet for health purposes.

As model fit improved when item 3 "*I know how to find helpful health resources on the internet*" was excluded, an adapted 7-item eHEALS may be appropriate to consider. Reducing the number of items would result in two factors containing 2 items, which could create difficulties with model identification and convergence²⁹. Likewise, it is

unknown whether a reduced 2-item “skill” factor would adequately measure the construct and appropriately detect changes over time. As such, further research is needed to test the psychometric properties (specifically content validity, test-retest reliability, predictive validity, and responsiveness) of a 7-item eHEALS. Until this point, it is recommended that the standardised 8-item scale is used, with consideration of preliminary evidence supporting a three-factor structure.

The three-factor structure of the eHEALS may reflect an eHealth literacy pathway among internet users

Despite some fit indices being less than ideal, considering eHealth literacy by factor may help to guide web-based health information provision in research and clinical practice. Furthermore, in accordance with the eHealth literacy continuum proposed by Diviana and colleagues¹², the eHEALS may measure an eHealth literacy pathway. In this instance, eHEALS factors are structured sequentially, and a user gradually demonstrates proficiency in more complex tasks. That is, a user must first be aware of eHealth resources, before they can use their skills to navigate and interact with electronic content, and finally evaluate content quality and applicability to their health situation. Only once a user has undertaken all 3 of these steps, will they be able to effectively engage with eHealth resources and reap related benefits. This proposed pathway structure is supported by findings of Neter and colleagues²⁴, who reported that success rates gradually declined for older adults performing health-related computerised simulation tasks, as they stepped through the process of accessing, understanding, appraising, applying and generating new health information. These findings may, however, be influenced by order effects of the simulated tasks⁵⁰, and further research is needed to validate such a causal pathway.

Important implications for the future development and evaluation of eHealth literacy improvement strategies

On the basis of these findings, researchers and health care professionals have the opportunity to identify areas (i.e. awareness, skills or evaluate) where competency is low, and target eHealth literacy improvement interventions accordingly. These interventions may, for example, include clinician recommendations to web-based materials to increase awareness and reduce the need to evaluate content⁵¹, training sessions to enhance eHealth literacy skills⁵², or the promotion of checklists to aid in the evaluation of web-based resources⁵³. Additionally, user characteristics, such as sociodemographic, health and internet use attributes, that are associated with lower competency across eHEALS factors could be identified, so that assistance is directed towards those most in need. No studies have been conducted to determine the competency of individuals across eHEALS awareness, skill and evaluate domains, and further research is needed.

Limitations

CFA was selected as it represents an understudied yet rigorous aspect of classical test theory, and logically extends on the existing body of EFA and CFA measurement literature. The recent emergence of item response theory analyses of the eHEALS^{12,13,16} has advantages over classical test theory approaches, including the capacity to establish increased item level psychometric information (e.g. item difficulty). The application of multidimensional item response theory techniques to validate the three-factor eHEALS structure should be explored further. Furthermore, this study assessed one psychometric property (i.e. factorial validity), and more research is needed to investigate other understudied measurement properties of the eHEALS, such as its predictive validity.

It is possible that findings may not be generalisable beyond the medical imaging context. Similarly, as most participants reported using the internet at least daily (75.3%, 201/267), study findings may not be generalisable to those who use the internet less frequently. As we did not ask participants about the activities they undertook on the internet, it is unclear whether the results are applicable to those who do or do not use the internet for health. Future research is consequently needed to validate study findings across patients with diverse demographics, medical diagnoses and internet use patterns. Additionally, our study was based on the standardised version of the eHEALS. As recognised in prior research^{12,23}, this version may not sufficiently capture competency in using Web 2.0 (e.g. social networking) for health. Further research is needed to determine whether scale modifications are needed to reflect the evolving nature of eHealth interventions.

Conclusions

Although potential item redundancy impacted fit indices, the three-factor structure of the eHEALS was broadly supported. On the basis of these findings, the eHEALS could be used to inform the development of tailored eHealth literacy enhancement strategies, which may in turn increase engagement with web-based health resources. Further research is needed to confirm the three-factor structure across other medical settings and populations to support the generalisability of these findings.

Acknowledgements

The authors thank the patients for their involvement in this study, as well as the administrative and clinical staff at Hunter New England Imaging for assistance with recruitment and data collection. This research was supported by a Hunter Cancer Research Alliance statistical support grant (HCRA_157) and has received funding

support from the Hunter Cancer Research Alliance Implementation Science Flagship Program as part of the 2018 HDR Student Award initiative. LH is supported by an Australian Government Research Training Program Scholarship. AB is supported by a National Health and Medical Research Council Early Career Fellowship (APP1073317) and Cancer Institute New South Wales Early Career Fellowship (13/ECF/1-37). LM is supported by a Postdoctoral Fellowship (PF-16-011) from the Australian National Breast Cancer Foundation.

Conflicts of interest

None declared.

Multimedia Appendix 1: Participant responses to eHEALS items (N = 261)

(Refer Thesis Appendix 5.3.1)

Multimedia Appendix 2: Factor loading and residual error estimates for the confirmatory factor analysis of the 7-item model

(Refer Thesis Appendix 5.3.2)

References

1. Zurn P, Dal Poz MR, Stilwell B, Adams O. Imbalance in the health workforce. *Human Resources for Health* 2004; **2**: 13.
2. Agarwal R, Gao G, DesRoches C, Jha AK. The digital transformation of healthcare: current status and the road ahead. *Information Systems Research* 2010; **21**(4): 796-809.
3. Ball MJ, Lillis J. E-health: transforming the physician/patient relationship. *International Journal of Medical Informatics* 2001; **61**(1): 1-10.
4. Pagliari C, Sloan D, Gregor P, et al. What is eHealth (4): a scoping exercise to map the field. *Journal of Medical Internet Research* 2005; **7**(1): e9.
5. Eysenbach G. What is e-health? *Journal of Medical Internet Research* 2001; **3**(2): e20.
6. Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. *Journal of Medical Internet Research* 2006; **8**(2): e9.
7. Lee K, Hoti K, Hughes JD, Emmerton L. Dr Google and the consumer: a qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. *Journal of Medical Internet Research* 2014; **16**(12): e262.
8. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. *Journal of Medical Internet Research* 2006; **8**(4): e27.
9. Karnoe A, Kayser L. How is eHealth literacy measured and what do the measurements tell us? A systematic review. *Knowledge Management & E-Learning* 2015; **7**(4): 576-600.

10. Chung SY, Nahm ES. Testing reliability and validity of the eHealth Literacy Scale (eHEALS) for older adults recruited online. *CIN: Computers, Informatics, Nursing* 2015; **33**(4): 150-6.
11. van der Vaart R, van Deursen AJ, Drossaert CH, Taal E, van Dijk JA, van de Laar MA. Does the eHealth Literacy Scale (eHEALS) measure what it intends to measure? Validation of a Dutch version of the eHEALS in two adult populations. *Journal of Medical Internet Research* 2011; **13**(4): e86.
12. Diviani N, Dima AL, Schulz PJ. A psychometric analysis of the Italian version of the eHealth Literacy Scale using Item Response and Classical Test Theory methods. *Journal of Medical Internet Research* 2017; **19**(4): e114.
13. Paige SR, Krieger JL, Stellefson M, Alber JM. eHealth literacy in chronic disease patients: an item response theory analysis of the eHealth Literacy Scale (eHEALS). *Patient Education and Counseling* 2017; **100**(2): 320-6.
14. Bazm S, Mirzaei M, Fallahzadeh H, Bazm R. Validity and reliability of the Iranian version of eHealth Literacy Scale. *Journal of Community Health Research* 2016; **5**(2): 121-30.
15. Koo M, Norman CD, Hsiao-Mei C. Psychometric evaluation of a Chinese version of the eHealth Literacy Scale (eHEALS) in school age children. *Global Journal of Health Education and Promotion* 2012; **15**(1): 29-36.
16. Nguyen J, Moorhouse M, Curbow B, Christie J, Walsh-Childers K, Islam S. Construct validity of the eHealth Literacy Scale (eHEALS) among two adult populations: a rasch analysis. *JMIR Public Health and Surveillance* 2016; **2**(1): e24.
17. Cardoso Tomás C, Pina Queirós PJ, Rodrigues Ferreira TdJ. Analysis of the psychometric properties of the Portuguese version of an eHealth literacy assessment tool. *Revista de Enfermagem Referência* 2014: 19-28.

18. Tennant B, Stellefson M, Dodd V, et al. eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults. *Journal of Medical Internet Research* 2015; **17**(3): e70.
19. Mitsutake S, Shibata A, Ishii K, Oka K. Association of eHealth literacy with colorectal cancer knowledge and screening practice among internet users in Japan. *Journal of Medical Internet Research* 2012; **14**(6): e153.
20. Stellefson ML, Shuster JJ, Chaney BH, et al. Web-based health information seeking and eHealth literacy among patients living with chronic obstructive pulmonary disease (COPD). *Health Communication* 2017: 1-15.
21. Lee K, Hoti K, Hughes JD, Emmerton LM. Consumer use of “Dr Google”: a survey on health information-seeking behaviors and navigational needs. *Journal of Medical Internet Research* 2015; **17**(12): e288.
22. Sheng X, Simpson PM. Seniors, health information, and the Internet: motivation, ability, and Internet knowledge. *Cyberpsychology, Behavior, and Social Networking* 2013; **16**(10): 740-6.
23. Sudbury-Riley L, FitzPatrick M, Schulz PJ. Exploring the measurement properties of the eHealth Literacy Scale (eHEALS) among baby boomers: a multinational test of measurement invariance. *Journal of Medical Internet Research* 2017; **19**(2): e53.
24. Neter E, Brainin E. Perceived and performed eHealth literacy: survey and simulated performance test. *JMIR Human Factors* 2017; **4**(1): e2.
25. Nahm E-S, Resnick B, Orwig D, et al. A theory-based online hip fracture resource center for caregivers: effects on dyads. *Nursing Research* 2012; **61**(6): 413-22.
26. Neter E, Brainin E. eHealth literacy: extending the digital divide to the realm of health information. *Journal of Medical Internet Research* 2012; **14**(1): e19.

27. Soellner R, Huber S, Reder M. The concept of eHealth literacy and its measurement. *Journal of Media Psychology* 2014; **26**(1): 29-38.
28. Neter E, Brainin E, Baron-Epel O. The dimensionality of health literacy and eHealth literacy. *The European Health Psychologist* 2015; **17**(6): 275-80.
29. O'Rourke N, Hatcher L. A Step-by-Step Approach to using SAS® for Factor Analysis and Structural Equation Modeling. Second ed. Cary, NC: SAS Institute Inc.; 2013.
30. Henson RK, Roberts JK. Use of exploratory factor analysis in published research. *Educational and Psychological Measurement* 2006; **66**(3): 393-416.
31. Costello A, Osborne J. Best practices in exploratory factor analysis: four recommendations for getting the most from your analysis. *Practical Assessment Research and Evaluation* 2005; **10**(7): 1-9.
32. Harkness JA, Van de Vijver FJ, Mohler PP. Cross-Cultural Survey Methods: Wiley-Interscience Hoboken, NJ; 2003.
33. Bandura A. Social Cognitive Theory. In: Vasta R, ed. Annals of child development. Greenwich, CT: JAI Press; 1989.
34. Smith-Bindman R, Miglioretti DL, Larson EB. Rising use of diagnostic medical imaging in a large integrated health system: the use of imaging has skyrocketed in the past decade, but no one patient population or medical condition is responsible. *Health Affairs* 2008; **27**(6): 1491-502.
35. Medical Benefits Reviews Task Group, Diagnostic Imaging Review Team. Review of Funding for Diagnostic Imaging Services: Final Report. Australia: Department of Health and Ageing, 2012.

36. Horton KM, Garland MR, Fishman EK. The Internet as a potential source of information about radiological procedures for patients. *Journal of Digital Imaging* 2000; **13**(1): 46-7.
37. Hugo Centre for Migration and Population Research. ARIA (Accessibility/Remoteness Index of Australia): The University of Adelaide, 2005.
38. Xie B, Wang M, Feldman R, Zhou L. Internet use frequency and patient-centered care: measuring patient preferences for participation using the Health Information Wants Questionnaire. *Journal of Medical Internet Research* 2013; **15**(7): e132.
39. Anandarajan M, Simmers C, Igbaria M. An exploratory investigation of the antecedents and impact of internet usage: an individual perspective. *Behaviour & Information Technology* 2000; **19**(1): 69-85.
40. Kline R. Principles and Practice of Structural Equation Modeling. 2nd ed. New York: The Guilford Press; 2005.
41. Boomsma A. Robustness of Lisrel against Small Sample Sizes in Factor Analysis Models. In: Jöreskog K, Wold H, eds. Systems under Indirection Observation: Causality, Structure, Prediction (Part I). Amsterdam, Netherlands: North Holland; 1982: 149-73.
42. Floyd F, Widaman K. Factor analysis in the development and refinement of clinical assessment instruments. *Psychological Assessment* 1995; **7**(3): 286-99.
43. Wolf EJ, Harrington KM, Clark SL, Miller MW. Sample size requirements for structural equation models: an evaluation of power, bias, and solution propriety. *Educational and Psychological Measurement* 2013; **76**(6): 913-34.
44. Fornell C, Larcker DF. Evaluating structural equation models with unobservable variables and measurement error. *Journal of Marketing Research* 1981; **18**(1): 39-50.

45. Anderson JC, Gerbing DW. Structural equation modeling in practice: a review and recommended two-step approach. *Psychological Bulletin* 1988; **103**(3): 411.
46. Carmines E, McIver J. Unobserved Variables. In: Bohrnstedt G, Borgatta E, eds. *Social Measurement: Current Issues*. Beverly Hills, CA: Sage; 1981: 65-115.
47. Hu Lt, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Structural Equation Modeling: A Multidisciplinary Journal* 1999; **6**(1): 1-55.
48. Sheehan-Holt JK, Smith MC. Does basic skills education affect adults' literacy proficiencies and reading practices? *Reading Research Quarterly* 2000; **35**(2): 226-43.
49. Podsakoff PM, MacKenzie SB, Lee J-Y, Podsakoff NP. Common method biases in behavioral research: a critical review of the literature and recommended remedies. *Journal of Applied Psychology* 2003; **88**(5): 879.
50. Strack F. "Order Effects" in Survey Research: Activation and Information Functions of Preceding Questions. In: Schwarz N, Sudman S, eds. *Context Effects in Social and Psychological Research*. New York, NY: Springer New York; 1992: 23-34.
51. Usher WT. Australian health professionals' health website recommendation trends. *Health Promotion Journal of Australia* 2011; **22**(2): 134-41.
52. Watkins I, Xie B. eHealth literacy interventions for older adults: a systematic review of the literature. *Journal of Medical Internet Research* 2014; **16**(11): e225.
53. Bernstam EV, Shelton DM, Walji M, Meric-Bernstam F. Instruments to assess the quality of health information on the World Wide Web: what can our patients actually use? *International Journal of Medical Informatics* 2005; **74**(1): 13-9.

PAPER FOUR

Electronic Health Literacy among Magnetic Resonance Imaging and Computed Tomography Medical Imaging Outpatients: Cluster Analysis

PAPER FOUR

Paper Three confirmed the multidimensional three factor structure of the eHEALS. The three factors identified were awareness, skills and evaluation. Paper Four builds on these findings by using cluster analyses to identify and characterise subgroups of patients reporting similar eHealth literacy based on eHEALS scores. This analysis provides the first assessment of variability in eHEALS factors (i.e. awareness, skills, evaluation) across subgroups of patients, and allows specific areas of low competency that require targeted improvement or support to be identified. This paper was published in *Journal of Medical Internet Research* (Thesis Appendix 6.2).

Hyde LL, Boyes AW, Mackenzie LJ, Leigh L, Oldmeadow C, Riveros C, Sanson-Fisher, R. Electronic health literacy among magnetic resonance imaging and computed tomography medical imaging outpatients: Cluster analysis. *Journal of Medical Internet Research* 2019; **21**(8): e13423.

Electronic Health Literacy among Magnetic Resonance Imaging and Computed Tomography Medical Imaging Outpatients: Cluster Analysis

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Abstract

Background: Variations in individual's electronic health (eHealth) literacy may influence the degree to which health consumers can benefit from eHealth. The eHealth Literacy Scale (eHEALS) is a common measure of eHealth literacy. However, the lack of guidelines for the standardised interpretation of eHEALS scores limits its research and clinical utility. Cut points are often arbitrarily applied at the eHEALS item or global level which assumes a dichotomy of high and low eHealth literacy. This approach disregards scale constructs and results in inaccurate and inconsistent conclusions. Cluster analysis is an exploratory technique which can be used to overcome these issues, by identifying classes of patients reporting similar eHealth literacy without imposing data cut-points.

Objective: The aim of this cross-sectional study was to identify classes of patients reporting similar eHealth literacy and assess characteristics associated with class membership.

Methods: Medical imaging outpatients were recruited consecutively in the waiting room of one major public hospital in New South Wales, Australia. Participants completed a self-report questionnaire assessing their sociodemographic characteristics and eHealth literacy, using the eHEALS. Latent class analysis was used to explore eHealth literacy clusters identified by a distance-based cluster analysis, and to identify characteristics associated with class membership.

Results: Of 268 eligible and consenting participants, 256 (95.5%) completed the eHEALS. Consistent with distance-based findings, 4 latent classes were identified, which were labelled as low (21%; n = 54), moderate (26%; n = 67), high (33%; n = 84)

and very high (20%; $n = 51$) eHealth literacy. Compared with the low class, participants who preferred to receive a lot of health information reported significantly higher odds of moderate eHealth literacy (odds ratio 16.67; 95% CI 1.67-100.00; $P=.02$), and those who used the internet at least daily reported significantly higher odds of high eHealth literacy (odds ratio 4.76; 95% CI 1.59-14.29; $P=.007$).

Conclusions: The identification of multiple classes of eHealth literacy, using both distance-based and latent class analyses, highlights the limitations of using the eHEALS global score as a dichotomous measurement tool. The findings suggest that eHealth literacy support needs vary in this population. The identification of low and moderate eHealth literacy classes indicate that the design of eHealth resources should be tailored to patients' varying levels of eHealth literacy. eHealth literacy improvement interventions are needed, and these should be targeted based on individuals' internet use frequency and health information amount preferences.

Key words: internet; health; literacy; cluster analysis; medical imaging

Introduction

Electronic health literacy is important for the use and receipt of benefits from electronic health programs

Web-based interventions have been reported to be consistently more effective than non-Web-based modalities in changing patient health behaviours and health-related knowledge¹. Information and communication technology is also recognised as a promising enabler of safe, integrated, and high-quality health care, yet more scientifically rigorous research is needed^{2,3}. Accordingly, internet-enabled healthcare is a strategic priority globally⁴⁻⁷. Electronic health (eHealth) literacy is one important factor influencing the use and receipt of benefits from Web-based health resources⁸⁻¹⁰. eHealth literacy refers to an individual's ability to seek, find, understand and appraise health information from electronic sources, and apply the knowledge gained to addressing or solving a health problem¹¹. The concept is derived from 6 literacy types (i.e. health, computer, media, science, information, traditional literacy, and numeracy), which play an important role in facilitating engagement with Web-based health resources¹¹. Inadequate eHealth literacy has been self-reported as a barrier to use of the internet for health information seeking purposes amongst the chronically ill¹². Furthermore, descriptive research indicates that eHealth literacy is associated with positive cognitive (e.g. understanding of health status)⁸, instrumental (e.g. self-management, physical exercise and dieting)⁸⁻¹⁰ and interpersonal (e.g. physician interaction)⁸ outcomes from Web-based health information searches. Individuals with lower eHealth literacy have been suggested to be older^{8,13,14}, less educated^{8,14,15}, have lower access to, or use of, the internet¹⁵⁻¹⁷, and have poorer health⁸.

Interpretations of electronic health literacy data are inconsistent

Approaches used to assess eHealth literacy have included objective performance testing^{18,19} and self-reported measurement²⁰⁻²³. The most commonly used self-reported measure is the 8-item, eHealth Literacy Scale (eHEALS)²⁰. Compared with other self-report measures of eHealth literacy, strengths of the eHEALS include its psychometric rigour, brevity, ease of administration, and availability in a number of languages^{17,19,20,24-26}. One of the key issues limiting the utility of the eHEALS is the lack of information about interpretation of these data. Although there is a convention that higher scores represent a higher level of eHealth literacy²⁰, there is an absence of guidance for the standardised interpretation of these scores. This guidance is needed to inform decision-making and follow-up actions²⁷. eHEALS mean and median scores^{8,13,14,28}, as well as item response frequencies^{14,29,30}, are typically reported. Cut-points have been arbitrarily applied at the item level¹⁵, which disregards scale constructs. Furthermore, the common use of a single cut-point to the global scale^{8,16,28} implies a dichotomy of high versus low eHealth literacy, and does not account for respondent self-perceived competency across the multiple eHEALS factors (i.e. awareness, skills and evaluation)^{24,31}. These factors have only recently been identified^{24,31}, demonstrating that our understanding of the eHEALS and its psychometric properties is continuing to evolve more than a decade after the scale was published.

A robust approach to analysing electronic health literacy data is required

Shortcomings in the interpretation of eHEALS scores highlights the need for a robust approach to analysing and interpreting eHealth literacy data. In line with the principles of scale development^{27,32}, measures should be refined as new data about a scale's

properties accumulates. This includes retesting a scale when it is used in new populations and as new analytical techniques become available^{27,32}. Cluster analysis is a sophisticated analytical approach, which has not previously been applied to eHealth literacy research. This powerful technique is used to identify natural groupings or structures within data, and can therefore classify individuals who score similarly on an outcome measure, such as the eHEALS³³. It has several strengths including: First, it is a data-driven, exploratory technique, and therefore not dependent on scoring thresholds which are arbitrarily imposed by the author(s). Second, being able to observe and characterise natural structures or groupings means that researchers have a better understanding of subgroups of eHealth literacy in the sample population. If classes (or clusters) exist, ignoring their presence by analysing the data as a single group could lead to an averaging out of any effects of interest³⁴. Third, this approach allows for the multiple eHEALS domains (i.e. skill, awareness and evaluate) to be considered simultaneously across subgroups. For example, it can be known if one subgroup self-rates their *awareness* as highest, whereas another subgroup self-rates their *skills* as highest. Finally, regression analyses can be completed to examine patient characteristics associated with assignment to each eHealth literacy class.

By understanding the number and characteristics of groupings, it can be known whether a one size fits all approach to eHealth literacy improvement is appropriate, or whether more tailored interventions are required. If tailoring is needed, understanding how different classes scored across the eHEALS factors allows researchers and clinicians to ensure interventions are designed to specifically address the needs of that subgroup. Furthermore, understanding patient characteristics associated with class membership allows the identification of individuals who should be targeted for interventions, or who will require more intensive support throughout periods of eHealth delivery. A cluster

analysis of eHEALS data is therefore an important next step to better understand the multi-component nature of eHealth literacy and how these eHEALS factors co-exist in subgroups of patients.

This study aimed to determine (1) whether there are identifiable eHealth literacy classes among magnetic resonance imaging (MRI) and computed tomography (CT) medical imaging outpatients; and (2) sociodemographic and internet use characteristics associated with each eHealth literacy class.

Methods

Design and setting

This cross-sectional study was completed with MRI and CT medical imaging outpatients attending the imaging department of a large, tertiary hospital, located within New South Wales, Australia. The results of this study have been reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology checklist of observational studies in epidemiology³⁵ and the Checklist for Reporting Results of Internet E-Surveys³⁶.

Participants

Eligible participants were: (1) attending for an outpatient MRI or CT scan; (2) 18 years or older; and (3) reported having access to the internet for personal use. Participants were excluded if they were: (1) non-English speaking; (2) deemed by reception staff to be cognitively or physically unable to consent or complete the survey; or (3) identified as having completed the survey previously. MRI and CT medical imaging outpatients were the focus of this research because they have high unmet information preferences which could potentially be met by eHealth capabilities³⁷.

Procedure

Medical imaging department receptionists identified potentially eligible participants when they presented for their outpatient appointment. Potentially eligible participants were informed about the research and invited to speak with a trained research assistant. Interested patients were provided with a written information sheet and introduced to the research assistant, who gave an overview of the study and obtained the patient's verbal consent to participate. During this overview, interested patients were told that the Web-based questionnaire would take approximately 10-15 minutes to complete, participation was voluntary and responses would remain confidential. The age, gender and scan type of non-interested and non-consenting patients were recorded. Consenting patients were provided with a tablet computer and asked to complete a Web-based questionnaire before their scan. Participants' study identification number, assigned by the receptionist and entered by the research assistant, provided access to the questionnaire. Each participant could move freely through each screen using next and back buttons. The questionnaire was pilot tested with MRI and CT medical imaging outpatients 2 weeks before study commencement, which confirmed the acceptability and feasibility of electronic survey administration in this study setting. A paper-and-pen version of the questionnaire was available to participants who requested it. If the patient was called for their procedure before finishing the questionnaire, only those questions that had been completed were used for data analysis. Electronic responses were de-identified, collected using the QuON platform³⁸, and stored securely on an access-restricted part of the University of Newcastle server. Ethics approval was obtained from the Human Research Ethics Committees of the Hunter New England Local Health District (16/10/19/5.11) and University of Newcastle (H-2016-0386).

Measure

eHealth literacy was assessed using the 8-item eHEALS. All 8 eHEALS items were administered on 1 screen within the Web-based questionnaire, and the presentation of these items was not random. Respondents indicated their level of agreement with each statement on a 5-point Likert scale from 1 *strongly disagree* to 5 *strongly agree*. Responses were summed to give a final score ranging from 8 to 40, with higher scores indicating higher eHealth literacy. The tool has demonstrated test-retest reliability¹⁷, internal consistency^{17,19,28}, and measurement invariance across English speaking countries²⁴. Previous studies, largely employing exploratory factor analysis, have suggested that the scale measures a single factor^{8,17,19,20}. Emerging research using confirmatory factor analysis and based on the theoretical underpinnings of eHealth literacy, suggests that the scale measures 3 factors: awareness, skills, and evaluate^{24,31}. This 3-factor eHEALS structure has been identified in the medical imaging study setting (standardised root mean residual=0.038; confirmatory fit index=0.944; and root mean square error of approximation=0.156)³¹. As such, self-rated awareness, skills, and evaluate competencies of patients within each subgroup were explored within this study.

Study factors

On the basis of previous research indicating an association with eHealth literacy, standard self-report items assessed participant gender, age, marital status, education, internet use frequency, and overall health status^{8,13-17}. Remoteness of residence, health information amount preference (no information; some information; and a lot of information), and internet use for scan preparation (yes; no; and don't know) were hypothesised to influence eHealth literacy and were therefore included as covariates.

Participant postcodes were mapped to the Accessibility/Remoteness Index of Australia Plus (ARIA + 2011) to categorise participant remoteness as metropolitan (major cities of Australia) or non-metropolitan (inner regional, outer regional, remote or very remote Australia)³⁹.

Data analysis

Participant characteristics were summarised as frequencies and percentages or means and standard deviations. Consent bias was assessed for gender, scan type and age group using Chi-square tests. Given the high completion rate (98.1% [256/261] for individuals starting eHEALS items), only complete eHEALS data were included in the analyses. Items relating to each eHEALS factor were summed to generate separate awareness, skill and evaluate factor scores.

Identification of electronic health literacy classes

Cluster analysis was completed using a 2-phased approach. Distance-based unsupervised clustering was undertaken as an initial exploratory knowledge discovery technique, to identify natural clusters of patients according to their responses (refer Multimedia Appendix 1 (provided at Thesis Appendix 6.3.1) for methods and results). Secondary clustering of patients, using latent class analysis (LCA) as a statistical modelling approach, was to be completed as a follow-up if distance-based cluster structures were observed. LCA was subsequently performed to verify the 4-cluster structure identified. LCA is less sensitive to choice of parameters (e.g. distance metric), allows for uncertainty in class membership, and has greater power and lower type 1 error rates when compared with other clustering techniques³⁴, and was, therefore, selected as the primary analysis technique. Latent class membership probabilities were calculated to determine the proportion of the sample that belonged to each of the

classes. Item response probabilities were calculated to determine the probability of endorsing each response option, conditional on class membership. The Bayesian Information Criterion (BIC) and G^2 -statistic were computed to aid in determining the optimal number of classes (with plateauing indicating no improvements to model fit)⁴⁰, as were overall class interpretability and model parsimony. Model entropy was computed, with values closer to 1 representing clear class delineation⁴¹. The maximum posterior probability of class membership was also calculated for each participant, based on the optimal number of classes, with values greater than .5 indicating adequate probability for class assignment⁴².

Characteristics associated with class membership

An LCA regression analysis was performed to identify participant sociodemographic and internet use characteristics associated with class membership. Given the exploratory nature of data analysis, all covariates were initially cross-tabulated with class membership (assigned according to maximum posterior probability) to identify model sparseness, and then analysed using univariate LCA regression: gender; age (<65 years vs 65+ years); geographic location of residence (major city vs regional or rural); marital status (married or living with spouse vs not married), education (high school or less vs more than high school); overall health (fair or worse; good or better than good); information amount preference (a lot of information vs not a lot of information); internet use for scan preparation and internet use frequency (daily vs less than daily). Likelihood ratio tests (based on the univariate results) were performed to determine whether each predictor significantly improved the fit of the model. Covariates with a statistically significant likelihood ratio test ($P < .05$) were included in the final multivariable LCA regression. Distance-based and latent class analyses were performed in R 3.4⁴³. Descriptive statistics were computed in STATA v13.

Sample size

Sample sizes of at least 200 have been suggested as adequate for LCA, dependent on subsequent model fit and number of classes^{40,44}. As such, a sample of at least 200 was deemed appropriate for this study.

Results

Sample

A total of 405 potentially eligible patients were invited to discuss the study with a research assistant during the 7-week recruitment period, of which 354 (87.4%) were interested in participating. Of 268 eligible participants, 261 (97.4%) started the eHEALS, 256 (95.5%) completed all eHEALS items, and 222 (85.1%) completed all eHEALS and study factor items. There were no significant differences between patients who were and were not interested in participating in the study based on gender, scan type or age group. Table 5.1 provides a summary of the sociodemographic, scan and internet characteristics of the study sample.

Table 5.1: Participant sociodemographic, scan and internet characteristics (N = 256). Number of observations for each characteristic may not total 256 because of missing data.

Characteristic		Value
Age (years), mean (SD)		53 (15.0)
Electronic Health Literacy Scale (eHEALS) domain score, mean (SD)		
	Awareness (possible total=10)	6.9 (2.0)
	Skills (possible total=15)	10.9 (2.9)
	Evaluate (possible total=15)	10.0 (3.1)
Gender, n (%)		
	Male	112 (43.8)
	Female	144 (56.3)

Characteristic		Value
Marital status, n (%)		
	Married or partner	146 (64.6)
	Not married/living with partner	80 (35.4)
Education completed, n (%)		
	High school or less	128 (56.6)
	More than high school	98 (43.4)
Geographic location, n (%)		
	Metropolitan	200 (78.1)
	Nonmetropolitan	56 (21.9)
Overall health, n (%)		
	Poor	17 (7.7)
	Fair	75 (34.1)
	Good	94 (42.7)
	Very good	34 (15.5)
Scan type, n (%)		
	Computed tomography	101 (39.4)
	Magnetic resonance imaging	152 (59.4)
	Don't know	3 (1.2)
Used internet for scan, n (%)		
	Yes	27 (10.5)
	No	228 (89.1)
	Don't know	1 (0.4)
Frequency of internet use, n (%)		
	Less than once a month	11 (4.3)
	Once a month	5 (1.9)
	A few times a month	14 (5.5)
	A few times a week	33 (12.9)
	About once a day	47 (18.4)
	Several times a day	146 (57.0)
Information amount preference, n (%)		
	No information	2 (0.8)

Characteristic		Value
	Some information	58 (25.9)
	A lot of information	165 (73.3)

Identification of electronic health literacy classes

The BIC and G^2 -statistic continued to decrease as the number of classes (K) increased, but the improvement was progressively smaller after 3 classes (see Table 5.2). On the basis of the interpretability of the latent classes, the reduction in class size beyond K = 4, and parsimony, the 4 class model was selected as the optimal class structure. The lowest maximum posterior probability under this 4 class model was .516. As such, all participants exceeded the threshold of .5 for maximum posterior probability and were assigned to a class. Hence, LCA findings on number of classes were consistent with that of distance-based clustering (see Multimedia Appendix 1 (provided at Thesis Appendix 6.3.1)).

Table 5.2: Goodness of fit indices for 1 to 5 class structures

	BIC ^a	G ² -statistic	Entropy
1 class structure	5893.74	3402.83	1.00
2 class structure	5148.66	2474.76	0.97
3 class structure	4651.68	1794.79	0.98
4 class structure	4556.81	1516.93	0.92
5 class structure	4545.21	1322.34	0.90

^a BIC: Bayesian Information Criterion.

Multimedia Appendix 2 (provided at Thesis Appendix 6.3.2) shows the unconditional item response probabilities of each eHEALS response option based on class assignment. Classes were named according to likely level of eHealth literacy, with respect to that of other classes identified in the analysis:

Class 1–*low eHealth literacy* (21.1% of respondents, 54/256): when compared with other classes, class 1 had the highest probability of responding *disagree* and *strongly disagree* across all eHEALS items. The probability of this group responding either *disagree* or *strongly disagree* was highest for awareness items (0.88 and 0.89), followed by evaluate items (0.79, 0.81, and 0.88) and skills items (0.66, 0.75, and 0.84).

Class 2–*moderate eHealth literacy* (26.2% of respondents, 67/256): when compared with other classes, class 2 had the highest probability of responding *undecided* across all eHEALS items, and the second highest probability of responding *agree* across awareness and skills items. This group was most likely to respond *undecided* to awareness items (0.56 and 0.59), either *agree* (0.54 and 0.58) or *undecided* (0.48) to skills items, and *undecided* to evaluate items (0.55, 0.61, and 0.63).

Class 3–*high eHealth literacy* (32.8% of respondents, 84/256): when compared with other classes, class 3 had the highest probability of responding *agree* across all eHEALS items. The probability of this class responding *agree* was greatest for skills items (0.97, 0.97, and 1.00), followed by awareness (0.80 and 0.91), and evaluate items (0.68, 0.71, and 0.81).

Class 4–*very high eHealth literacy* (19.9% of respondents, 51/256): when compared with other classes, class 4 had the highest probability of responding *strongly agree* across all eHEALS items. The probability of this class responding *strongly agree* was greatest for skills items (0.71, 0.79, and 0.90), followed by evaluate (0.57, 0.74, and 0.86) and awareness items (0.53 and 0.61).

Characteristics associated with class membership

Internet use for scan preparation was not included in regression analyses due to sparseness (i.e. 10.5%, 27/256 of participants responded *yes* to internet use for scan preparation). Following univariate analyses, likelihood ratio difference tests indicated that age, education, marital status, overall health status, information amount preference, and internet use frequency all significantly improved the fit of the model ($P < .05$; see Multimedia Appendix 3 (provided at Thesis Appendix 6.3.3)), and were included in the multivariable regression analysis (see Table 5.3).

Class 1 (low eHealth literacy) was selected as a reference class for multivariable regression. This was because these participants likely need additional support to engage with eHealth, making identification of the characteristics of participants in this subgroup a priority. As shown in Table 5.3, participants who indicated that they preferred not to receive a lot of information about their health had 0.06 times the odds of belonging to class 2 (moderate eHealth literacy), compared to class 1 (low eHealth literacy), and this difference was statistically significant. Furthermore, participants who reported using the internet less than daily had 0.21 times the odds of belonging to class 3 (high eHealth literacy), compared to class 1 (low eHealth literacy), and this difference was statistically significant. There were no other significant differences in sociodemographic or internet use attributes between participants in class 1 (low eHealth literacy) and classes 2, 3, and 4 (moderate, high and very high eHealth literacy, respectively).

Table 5.3: Adjusted odds ratios associated with membership of class 2, 3 and 4, compared with class 1.

Variable		Class 1 versus class 2 (low vs moderate)		Class 1 versus class 3 (low vs high)		Class 1 versus class 4 (low vs very High)	
		Odds ratio (95% CI)	P value	Odds ratio (95% CI)	P value	Odds ratio (95% CI)	P value
Age							
	<65 years	Ref ^a	Ref	Ref	Ref	Ref	Ref
	65 years or older	0.37 (0.06-2.11)	.26	0.32 (0.10-1.03)	.06	0.37 (0.07-2.00)	.25
Education							
	High school or less	Ref	Ref	Ref	Ref	Ref	Ref
	More than high school	1.09 (0.15-7.65)	.93	2.21 (0.52-9.47)	.29	3.89 (0.67-22.76)	.14
Marital status							
	Married or living with spouse	Ref	Ref	Ref	Ref	Ref	Ref
	Not married	1.63 (0.26-10.23)	.60	0.96 (0.27-3.41)	.96	0.91 (0.14-6.01)	.92
Information amount preference							
	A lot of information	Ref	Ref	Ref	Ref	Ref	Ref
	Not a lot of information	0.06 (0.01-0.60)	.02 ^b	0.61 (0.18-2.04)	.43	0.23 (0.04-1.29)	.10
Overall health							
	Fair or worse	Ref	Ref	Ref	Ref	Ref	Ref

Variable		Class 1 versus class 2 (low vs moderate)		Class 1 versus class 3 (low vs high)		Class 1 versus class 4 (low vs very High)	
		Odds ratio (95% CI)	<i>P</i> value	Odds ratio (95% CI)	<i>P</i> value	Odds ratio (95% CI)	<i>P</i> value
	Good or better than good	1.10 (0.24-5.02)	.91	1.16 (0.35-3.87)	.81	1.48 (0.33-6.68)	.61
Internet use frequency							
	Daily	Ref	Ref	Ref	Ref	Ref	Ref
	Less than once a day	0.62 (0.14-2.67)	.52	0.21 (0.07-0.63)	.007 ^b	0.17 (0.02-1.76)	.14

^aRef: reference category.

^bStatistically significant.

Discussion

Principal findings

This study was the first to identify classes of patients based on eHealth literacy, and to assess characteristics associated with class membership. The identification of multiple classes, using both distance-based and latent class analyses, highlights issues with using the eHEALS global score as a dichotomous measurement tool. In particular, these findings suggest that it may be important to account for multiple eHealth literacy subgroups when developing standardised guidance for the interpretation of eHEALS scores. Furthermore, the identification of multiple classes suggests that the design and delivery of eHealth resources may need to be tailored based on eHealth literacy. Patient characteristics, such as internet use frequency and health-related information amount preferences, may provide an indication of eHealth literacy, and related support needs.

Multiple electronic health literacy subgroups were identified

In total, 4 eHealth literacy classes were identified, and the probabilities of belonging to each of the 4 classes were similar (i.e. range from 19.9% to 32.8%). The finding that eHealth literacy varied substantially in this population suggests that MRI and CT medical imaging outpatients may have differing support needs relating to the use of eHealth technology. Subgroups of patients were characterised by having either very high, high, moderate or low eHealth literacy. Within the very high eHealth literacy subgroup, awareness was the lowest scoring competency. This may be because consumers who are familiar with eHealth also understand the masses of Web-based information that is available and the common difficulty of locating valid and reliable information sources¹². Across all classes, participants reported being most competent in their skills using eHealth resources. Such skills may be perceived highly because they align to the computer and media literacy types, which comprise eHealth literacy¹¹. These literacy types are increasingly used in the digital era, with 87% of Australians being identified as internet users in 2016-2017⁴⁵.

In total, 2 out of 4 classes, comprising 52.7% of respondents, had the highest probability of responding either *agree* or *strongly agree* to eHEALS items, reflecting high and very high eHealth literacy. Despite this, there was room for improvement in awareness, skills and evaluation competencies for the remaining 2 classes, comprising 47.3% of respondents and reflecting low and moderate eHealth literacy. This approximately even split in eHealth literacy capabilities is also apparent in other studies completed with cardiovascular disease patients¹⁶ and chronic disease patients⁴⁶, which used arbitrary cut-points to dichotomise high versus low eHealth literacy. It is possible that the application of dichotomous cut points prevented the identification of such diverse eHealth literacy subgroups. Further research using cluster analysis should be conducted

to determine whether multiple eHealth literacy subgroups exist across other health consumer populations. This information may inform the development of more targeted eHealth literacy improvement interventions.

Internet use frequency and health information amount preferences predicted class membership

Those who had used the internet less than daily had approximately 5 times the odds of belonging to the low eHealth literacy class compared with the high eHealth literacy class. Although mixed findings exist¹⁹, an association between internet use and eHealth literacy has been reported in studies with chronically ill patients and the general public¹⁵⁻¹⁷. Our findings may suggest that frequent internet users do use the internet for health, and this may result in greater self-reported eHealth literacy. Alternatively, they may indicate that frequent internet users self-perceive that their ability to engage with and evaluate general internet resources is transferable to health-related content.

Those with a preference not to receive a lot of information about their health had over 16 times the odds of belonging to the low eHealth literacy class, compared with the moderate eHealth literacy class. To the authors' knowledge, this study is the first to explore the association between preferred amount of information and eHealth literacy. It is possible that the inclusion of an *undecided* response option, resulted in imposter syndrome for those in the moderate class⁴⁷. In this case, participants underestimate their competency, opting for a neutral response option, to prevent being perceived as overconfident. Therefore, those in the moderate class may be more eHealth literate than findings suggest, which could contribute to a significant finding when comparing low and moderate classes. It may also be possible that those who prefer to receive a lot of information about their health are Web-based health-related information seekers, hence

requiring eHealth literacy. An evidence review completed by the Australian Commission on Quality and Safety in Health Care found that patients typically use the internet as a supplement to advice from a health professional⁴⁸. It is therefore likely that those who have greater preferences for health-related information, require and develop the awareness, skills and evaluation abilities needed to use this Web-based supplementary information. An analysis of the potentially moderating effects of Web-based health-related information seeking on the association between information amount preference and eHealth literacy should be explored in the future. This analysis should include an examination of the types of eHealth resources being accessed and used.

The technology acceptance model provides a theoretical justification for the characteristics related to a subgroup assignment⁴⁹. Under this model, technology acceptance is influenced by perceived ease of use, and usefulness of the internet⁴⁹. Accordingly, those who use the internet more frequently may be more likely to perceive ease of use of Web-based health resources. Similarly, those who prefer to receive a lot of health-related information may be more likely to deem eHealth as useful. Such perceived acceptability may result in greater self-rated eHealth literacy. Continued studies are needed to investigate this association and determine whether other factors not explored in this study, which promote perceived ease of use and usefulness of eHealth (e.g. speed and availability of the internet, and self-management of chronic conditions, respectively), are associated with eHealth literacy. Contrary to expectations and inconsistent with previous studies^{8,13-15}, no other examined sociodemographic characteristics significantly influenced class membership. Inconsistencies with existing literature may indicate that the predictors of eHealth literacy differ across populations, settings, or cut points applied.

Practice implications

The identification of low and moderate eHealth literacy classes suggests that eHealth literacy improvement interventions may be warranted within this population. However, there is minimal high-quality research investigating the effectiveness of such interventions, highlighting a need for continued research in this area⁵⁰. Given their association with low class membership, those who use the internet less than daily and prefer not to receive a lot of health information should be the focus of such eHealth literacy improvement interventions. In the interim, researchers and clinicians should tailor the design and delivery of eHealth resources to patients' eHealth literacy, in order to maximise engagement and potential receipt of benefits. As skills were the highest rated competency across all classes within this study population, future eHealth interventions should be designed with a focus on promoting awareness and reducing the need to evaluate eHealth resources within the imaging setting. A written provider recommendation which directs consumers towards credible eHealth resources may be one scalable strategy to do this^{31,51}. In cases where skills are low, alternative strategies may be needed, such as clear instructions on how to appropriately navigate Web-based content, reduced click-through requirements to retrieve Web-based materials, and the use of persuasive system design elements to enhance usability and maintain engagement⁵².

Limitations and future research

To aid in the interpretation of findings, labels (i.e. very high, high, moderate and low) were arbitrarily assigned to eHealth literacy classes. It is therefore unclear whether, for example, those classified as very high eHealth literacy were indeed very high. As this study applied a novel approach to data analysis and interpretation, the generalisability of

findings across medical imaging settings and to other patient groups is unknown. This class structure and the predictors of class membership should be studied and replicated in other populations. Furthermore, it is possible that the setting influenced responses as participants may have assumed that eHEALS questions related to scan-specific information on the internet rather than general eHealth resources.

The eHEALS was selected due to its established psychometric properties, emerging research proposing a 3-factor structure, and wide application^{17,19,20,24,28,31}. However, it has been criticised for not measuring health 2.0. (i.e. user-generated content and interactivity) and therefore lacking relevance to modern technology^{21,24,53}. Some studies have adapted the scale to address this limitation, yet the body of research is small and as a result, the impacts on scale psychometric properties remain unclear^{21,24}. The generation of new Web-based content is, however, not highly relevant within the context of preparatory information provision for medical imaging procedures and this limitation is therefore not expected to influence our study.

Conclusions

This study used sophisticated analytical techniques to add to evidence about the nature of eHEALS scores within a clinical population. Cluster analyses were used to identify 4 classes of patients with differing eHealth literacy within this sample of MRI and CT medical imaging outpatients. The proportion of participants assigned to each latent class was similar, suggesting that eHealth literacy varies within this study setting. Across all classes, skills were perceived as the highest rated competency followed by either awareness or evaluation. The frequency of participants' personal internet use and their health-related information preferences predicted class membership. Tools such as the eHEALS may need to be administered to identify class assignment, and inform eHealth

literacy improvement interventions, as well as the design and delivery of eHealth resources. Findings from this study should also contribute to the development of guidance for eHEALS scoring interpretation, which is a necessary next step to improve scale utility²⁷. Study findings should be replicated in other populations and settings to increase the generalisability of results.

Acknowledgements

The authors thank the patients for their involvement in this study, as well as the administrative and clinical staff at Hunter New England Imaging for assistance with recruitment and data collection. This research was supported by a Priority Research Centre for Health Behaviour Small Grant, and Hunter Cancer Research Alliance Implementation Science Flagship 2018 Student Award. Mrs Lisa Hyde is supported by an Australian Government Research Training Program Scholarship. Dr Allison Boyes is supported by a National Health and Medical Research Council Early Career Fellowship (APP1073317) and Cancer Institute New South Wales Early Career Fellowship (13/ECF/1-37). Dr Lisa Mackenzie is supported by a Postdoctoral Fellowship [PF-16-011] from the Australian National Breast Cancer Foundation.

Conflicts of interest

None declared.

Multimedia Appendix 1: Distance-based cluster analysis

(Refer Thesis Appendix 6.3.1)

Multimedia Appendix 2: Unconditional item response probabilities for a 4-class model of electronic health literacy

(Refer Thesis Appendix 6.3.2)

Multimedia Appendix 3: Log likelihood difference tests

(Refer Thesis Appendix 6.3.3)

References

1. Wantland DJ, Portillo CJ, Holzemer WL, Slaughter R, McGhee EM. The effectiveness of Web-based vs. non-Web-based interventions: a meta-analysis of behavioral change outcomes. *Journal of Medical Internet Research* 2004; **6**(4): e40.
2. Car J, Black A, Anandan C, et al. The Impact of eHealth on the Quality & Safety of Healthcare: A Systematic Overview & Synthesis of the Literature. Report for the NHS Connecting for Health Evaluation Programme. United Kingdom: The University of Edinburgh, Imperial College London, 2008.
3. Black AD, Car J, Pagliari C, et al. The impact of eHealth on the quality and safety of health care: a systematic overview. *PLoS Medicine* 2011; **8**(1): e1000387.
4. Queensland Health. eHealth Investment Strategy. 2015.
<https://www.health.qld.gov.au/system-governance/strategic-direction/plans/ehealth-investment-strategy> (accessed 27 April 2018).
5. Health and Social Care Board. eHealth and Care Strategy for Northern Ireland. Northern Ireland: Department of Health, 2016.
6. NHS Scotland. eHealth Strategy 2014-2017. Scotland: Scottish Government, 2015.
7. United States Department of Health and Human Services. Federal Health IT Strategic Plan: 2015 - 2020. 2015. https://www.healthit.gov/sites/default/files/9-5-federalhealthitstratplanfinal_0.pdf (accessed 8 August 2019).
8. Neter E, Brainin E. eHealth literacy: extending the digital divide to the realm of health information. *Journal of Medical Internet Research* 2012; **14**(1): e19.
9. Kim S-H, Son Y-J. Relationships between eHealth literacy and health behaviors in Korean adults. *CIN: Computers, Informatics, Nursing* 2017; **35**(2): 84-90.

10. Mitsutake S, Shibata A, Ishii K, Oka K. Associations of eHealth literacy with health behavior among adult internet users. *Journal of Medical Internet Research* 2016; **18**(7): e192.
11. Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. *Journal of Medical Internet Research* 2006; **8**(2): e9.
12. Lee K, Hoti K, Hughes JD, Emmerton L. Dr Google and the consumer: a qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. *Journal of Medical Internet Research* 2014; **16**(12): e262.
13. Choi NG, Dinitto DM. The digital divide among low-income homebound older adults: Internet use patterns, eHealth literacy, and attitudes toward computer/Internet use. *Journal of Medical Internet Research* 2013; **15**(5): e93.
14. Tennant B, Stellefson M, Dodd V, et al. eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults. *Journal of Medical Internet Research* 2015; **17**(3): e70.
15. Milne RA, Puts MT, Papadakos J, et al. Predictors of high eHealth literacy in primary lung cancer survivors. *Journal of Cancer Education* 2015; **30**(4): 685-92.
16. Richtering SS, Hyun K, Neubeck L, et al. eHealth literacy: predictors in a population with moderate-to-high cardiovascular risk. *JMIR Human Factors* 2017; **4**(1): e4.
17. Chung SY, Nahm ES. Testing reliability and validity of the eHealth Literacy Scale (eHEALS) for older adults recruited online. *CIN: Computers, Informatics, Nursing* 2015; **33**(4): 150-6.
18. Neter E, Brainin E. Perceived and performed eHealth literacy: survey and simulated performance test. *JMIR Human Factors* 2017; **4**(1): e2.

19. van der Vaart R, van Deursen AJ, Drossaert CH, Taal E, van Dijk JA, van de Laar MA. Does the eHealth Literacy Scale (eHEALS) measure what it intends to measure? Validation of a Dutch version of the eHEALS in two adult populations. *Journal of Medical Internet Research* 2011; **13**(4): e86.
20. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. *Journal of Medical Internet Research* 2006; **8**(4): e27.
21. van der Vaart R, Drossaert C. Development of the Digital Health Literacy Instrument: measuring a broad spectrum of Health 1.0 and Health 2.0 skills. *Journal of Medical Internet Research* 2017; **19**(1): e27.
22. Hsu W, Chiang C, Yang S. The effect of individual factors on health behaviors among college students: the mediating effects of eHealth literacy. *Journal of Medical Internet Research* 2014; **16**(12): e287.
23. Koopman RJ, Petroski GF, Canfield SM, Stuppy JA, Mehr DR. Development of the PRE-HIT instrument: patient readiness to engage in health information technology. *BMC Family Practice* 2014; **15**: 18.
24. Sudbury-Riley L, FitzPatrick M, Schulz PJ. Exploring the measurement properties of the eHealth Literacy Scale (eHEALS) among baby boomers: a multinational test of measurement invariance. *Journal of Medical Internet Research* 2017; **19**(2): e53.
25. Diviani N, Dima AL, Schulz PJ. A psychometric analysis of the Italian version of the eHealth Literacy Scale using Item Response and Classical Test Theory methods. *Journal of Medical Internet Research* 2017; **19**(4): e114.
26. Chung S, Park BK, Nahm ES. The Korean eHealth Literacy Scale (K-eHEALS): reliability and validity testing in younger adults recruited online. *Journal of Medical Internet Research* 2018; **20**(4): e138.

27. HealthMeasures. PROMIS® Instrument Maturity Model. 2013.
http://www.healthmeasures.net/images/PROMIS/PROMISStandards_Vers_2_0_MaturityModelOnly_508.pdf (accessed 5 May 2019).
28. Mitsutake S, Shibata A, Ishii K, Oka K. Association of eHealth literacy with colorectal cancer knowledge and screening practice among internet users in Japan. *Journal of Medical Internet Research* 2012; **14**(6): e153.
29. Knapp C, Madden V, Wang H, Sloyer P, Shenkman E. Internet use and eHealth literacy of low-income parents whose children have special health care needs. *Journal of Medical Internet Research* 2011; **13**(3): e75.
30. Manafò E, Wong S. Assessing the eHealth literacy skills of older adults: a preliminary study. *Journal of Consumer Health on the Internet* 2012; **16**(4): 369-81.
31. Hyde LL, Boyes AW, Evans TJ, Mackenzie LJ, Sanson-Fisher R. Three-factor structure of the eHealth Literacy Scale among magnetic resonance imaging and computed tomography outpatients: a confirmatory factor analysis. *JMIR Human Factors* 2018; **5**(1): e6.
32. McDowell I. The Theoretical and Technical Foundations of Health Measurement. *Measuring Health: A Guide to Rating Scales and Questionnaires*. 3rd ed. New York: Oxford University Press; 2006: 10 - 54.
33. Hastie T, Tibshirani R, Friedman J. *The Elements of Statistical Learning: Data Mining, Inference, and Prediction*, Second Edition. 2nd ed. New York: Springer-Verlag; 2009.
34. Lanza ST, Rhoades BL. Latent class analysis: an alternative perspective on subgroup analysis in prevention and treatment. *Prevention Science: The Official Journal of the Society for Prevention Research* 2013; **14**(2): 157-68.

35. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *British Medical Journal* 2007; **335**(7624): 806-8.
36. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *Journal of Medical Internet Research* 2004; **6**(3): e34-e.
37. Hyde LL, Mackenzie LJ, Boyes AW, Evans T-J, Symonds M, Sanson-Fisher R. Prevalence and correlates of patient-centred preparatory information provision to computed tomography and magnetic resonance imaging outpatients: a cross-sectional study. *Patient Education and Counseling* 2018; **101**(10): 1814-22.
38. Paul D, Wallis M, Henskens F, Nolan K. QuON: A Generic Platform for the Collation and Sharing of Web Survey Data. WEBIST 2013 - 9th International Conference on Web Information Systems and Technologies. Aachen, Germany; 2013. p. 111-6.
39. Hugo Centre for Migration and Population Research. ARIA (Accessibility/Remoteness Index of Australia): The University of Adelaide, 2005.
40. Nylund KL, Asparouhov T, Muthén BO. Deciding on the number of classes in latent class analysis and growth mixture modeling: a monte carlo simulation study. *Structural Equation Modeling: A Multidisciplinary Journal* 2007; **14**(4): 535-69.
41. Celeux G, Soromenho G. An entropy criterion for assessing the number of clusters in a mixture model. *Journal of Classification* 1996; **13**(2): 195-212.
42. Clark S, Muthén BO. Relating Latent Class Analysis Results to Variables Not Included in the Analysis. 28/03/2014 2009.
<https://www.statmodel.com/download/relatinglca.pdf>.

43. R Development Core Team. R: A Language and Environment for Statistical Computing, R Foundation for Statistical Computing. Vienna, Austria; 2018.
44. Tein JY, Coxe S, Cham H. Statistical power to detect the correct number of classes in latent profile analysis. *Structural Equation Modeling: A Multidisciplinary Journal* 2013; **20**(4): 640-57.
45. Australian Bureau of Statistics. 8146.0 - Household Use of Information Technology, Australia, 2016-17. 2018.
<http://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0> (accessed 24 June 2018).
46. Paige SR, Krieger JL, Stellefson M, Alber JM. eHealth literacy in chronic disease patients: an item response theory analysis of the eHealth Literacy Scale (eHEALS). *Patient Education and Counseling* 2017; **100**(2): 320-6.
47. Clance PR, Imes SA. The imposter phenomenon in high achieving women: dynamics and therapeutic intervention. *Psychotherapy: Theory, Research & Practice* 1978; **15**(3): 241.
48. Ramsay I, Peters M, Corsini N, Eckert M. Consumer Health Information Needs and Preferences: A Rapid Evidence Review. Sydney: ACSQHC, 2017.
49. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. *Management Information Systems Quarterly* 1989: 319-40.
50. Car J, Lang B, Colledge A, Ung C, Majeed A. Interventions for enhancing consumers' online health literacy. *Cochrane Database of Systematic Reviews* 2011; (6): Cd007092.
51. Usher W. Gold Coast general practitioners' recommendations of health websites to their patients. *Medical Journal of Australia* 2007; **187**(2): 82-3.

52. Kelders SM, Kok RN, Ossebaard HC, Van Gemert-Pijnen JE. Persuasive system design does matter: a systematic review of adherence to web-based interventions. *Journal of Medical Internet Research* 2012; **14**(6): e152.
53. Van De Belt TH, Engelen LJ, Berben SA, Schoonhoven L. Definition of Health 2.0 and Medicine 2.0: a systematic review. *Journal of Medical Internet Research* 2010; **12**(2): e18.

DISCUSSION

Thesis overview

This body of research responds to two key priority areas for healthcare; namely, the requirement for patient-centred care and the application of information and communication technology to support healthcare. Patient-centred care is recognised as an integral component of high-quality service delivery¹⁻³, and eHealth is a key element of Australian and international health reform agendas^{4,5}. The internet provides a mechanism to deliver health information in a way that is standardised and scalable, and accommodates variability in patients' information preferences⁶. However, despite the importance of patient-centred care¹⁻³, it is uncertain whether patients' preferences for content and amount of preparatory information are met prior to undergoing high-technology medical imaging procedures. Magnetic Resonance Imaging (MRI) and Computed Tomography (CT) are common, potentially threatening diagnostic and surveillance medical imaging procedures conducted in Australian healthcare settings^{7,8}, but very few studies have assessed the extent to which preparatory information is delivered in a patient-centred manner to people undergoing these procedures. Furthermore, patients' eHealth literacy is an important consideration when determining the potential application of eHealth for patient-centred preparatory information provision. However, there are mixed findings about the accuracy of one of the most commonly used self-reported measures of eHealth literacy, the eHealth Literacy Scale (eHEALS)⁹. Thus, the implications of eHEALS findings for the development and implementation of eHealth are speculative.

This thesis comprises four publications that address gaps in knowledge about delivering patient-centred preparatory information to MRI and CT outpatients. This study is the first to simultaneously assess whether Australian MRI and CT outpatients receive

preparatory information that is linked to guideline recommendations (Paper One) and what their preferences are for receiving this information (Paper Two). Additionally, an analysis of the factorial validity of the eHEALS (Paper Three) and an assessment of subgroups of patients reporting similar eHealth literacy (Paper Four) have been completed. The findings provide a novel contribution to the field by identifying discrete preparatory information items and domains requiring improved provision of patient-centred information. Moreover, these findings identify eHealth literacy components and patient subgroups that should be supported to maximise patient engagement and the benefits of eHealth.

Key finding 1: There is discord between recommendations for preparatory information and patients' preferences for receiving this information

This study is the first in Australia, and one of few internationally, to involve dual assessment of medical imaging outpatients' experiences of receiving preparatory information (Paper One) and their preferences for receiving preparatory information (Paper Two). This novel approach allowed identification of the extent to which patients received information items linked to guideline recommendations¹⁰⁻¹³, and whether their preferences for receiving preparatory information were met by clinical practice.

Identification of the preparatory domains (i.e. procedural, behavioural, sensory and psychosocial) for information provision and the items of information that patients want but do not receive is useful in defining possible areas for intervention research and service modification.

There is room to improve patient-centred information provision across all four domains of preparation

Not all preparatory information assessed as part of this study was reported as being received by patients prior to undergoing MRI and CT procedures (Paper One). When patient preferences for information were not met, it was mostly because they received too little information, rather than too much (Paper Two). It is encouraging that one-quarter of participants reported no unmet information preferences. However, each of the 13 most prevalent unmet information preference items were reported by at least one-quarter of participants as not being delivered in accordance with their preferences.

These information items covered all domains of preparation (i.e. procedural, behavioural, sensory and psychosocial). Additionally, for each of these items, the proportions of participants wanting but not receiving information (16% to 28% of participants) exceeded those of participants receiving information that they did not want (3% to 9% of participants). The items that were most commonly delivered in discordance with patient preferences related to when to expect scan results, how to alert the radiographer during the scan, and how to receive scan results. Furthermore, despite pre-procedure risk information being required for informed patient consent¹⁰, one-quarter of participants reported unmet preferences regarding information about scan risks.

When taken together, the findings reported in Papers One and Two indicate that there is capacity to improve the provision of patient-centred preparatory information in the lead-up to patients' MRI and CT procedures. The need for improved patient-centred information provision applied to all domains of preparation, and commonly related to patient preferences to receive more information. Being provided too little information is conceivably more concerning than being provided too much information, given the

potential legal and ethical implications regarding informed patient consent¹⁰ and the clinical implications for patient preparation¹¹⁻¹³. These findings suggest that overall, efforts to provide more information in advance of MRI and CT procedures are needed.

The holistic assessment of discrete preparatory information items covering procedural, behavioural, sensory and psychosocial domains is a key strength of this study. Imaging research often focuses on one or only a few elements of preparation¹⁴⁻¹⁹, making it unclear whether a diverse range of information content items are offered to patients in accordance with their preferences. Pahade et al's (2018) multi-institutional US study of 1542 outpatients and carers attending for radiological examinations found that 78% of participants had received information about the scans before their appointments, and information about "how to prepare" was perceived as being most important to receive before arriving for the scans. However, the authors did not examine the content of information provided, or whether specific aspects about "how to prepare" were more or less preferred by patients²⁰. The studies that examine patients' information preferences typically relate to specific procedural or behavioural information¹⁷⁻¹⁹. For example, Thornton et al (2015) conducted one of a small number of studies examining whether patient preferences for defined procedural and behavioural information items were met. In line with Paper Two findings, it was reported that cancer patients undergoing medical imaging regularly needed to instigate patient-provider discussions to meet their preferences for more information¹⁷. Similarly, qualitative research suggests that medical imaging outpatients often want a greater amount of clear and simplified preparatory information²¹. Collectively, these findings are consistent with the study reported in this thesis, suggesting that some preparatory information is not received by patients before scans in a way they can recall and in the amount that they prefer.

However, as data for this study were collected in the waiting room prior to procedures, it is recognised that some elements of preparatory information may have been given to patients when they were called for their scans. Seven of the 10 most prevalent information items not received by patients (Paper One) and 12 of the 13 most prevalent unmet information preference items (Paper Two) related to information about the scan and post-scan periods. This suggests that, in relation to the 33 preparatory information items examined, patient preferences for information concerning the time leading up to the scan were generally met, but were unmet for information about subsequent points along the care trajectory. Anecdotal feedback from radiographers within the study setting indicated that information is regularly provided at the point of care, in the context of the scanning room and equipment. This feedback is consistent with findings of Lee et al (2006) who reported that radiology technologists are more likely than other health professionals to inform patients about the risks of CT scans, and they most commonly do so verbally²². Additionally, the study setting's practice of providing information immediately prior to patients' procedures reflects the guidance of the Australian Commission of Safety and Quality in Health Care, which indicates that consumers should be provided with information at time points that are relevant and specific to their stage of care²³. However, the study findings for unmet information preferences (Paper Two) suggest that, prior to arriving for an appointment, patients commonly want information that relates to the times before, during and after the scans. Early information provision has also been identified as important to allow sufficient time for patients to review information, consider its implications and use it to inform their medical decision-making²⁴.

Efforts to enhance patient-centred preparatory information provision should be directed at all patients

Contrary to expectations, no patient characteristics were associated with reporting a greater number of unmet information preferences (Paper Two). An absence of literature assessing correlates of unmet information preferences (i.e. receipt of too much and too little information) prevented the comparison of findings with wider research. However, as unmet information preferences in this study mostly related to receiving too little information (as opposed to too much), some similarities with unmet information needs research could be expected. Studies with patients undergoing cancer treatment have found that, unlike the results of this study (Paper Two), participant characteristics including age²⁵⁻²⁸ and health status²⁹⁻³¹ were associated with unmet information needs. Divergence in findings may indicate that different variables correlate with the receipt of too little information and too much information. Thus, effect sizes are reduced when assessing these groups in combination (i.e. as unmet information preferences), albeit with small proportions of participants indicating receipt of too much information. This notion is supported by research examining life expectancy discussions among Australian cancer patients, where it was reported that some patient variables (e.g. being anxious) were associated with receiving too little information but not too much³². Similarly, other variables (e.g. being younger) were associated with reporting too much information but not too little³². Whilst these results provide a possible explanation for the findings of Paper Two, the research design of this study was not adequately powered to separately assess the correlates of receiving too little and too much information.

The analyses examining characteristics associated with unmet information preferences were limited to nine dichotomised variables (e.g. health status was grouped into “poor or fair” versus “good or better than good” categories). A more granular analysis of

explanatory variables, maintaining the integrity of response options, might have resulted in the identification of correlates of unmet information preferences. The ability to identify characteristics associated with an outcome is also limited by the range of characteristics examined. It is therefore possible that other relevant characteristics which were not assessed in this study (e.g. stage of illness) are associated with unmet information preferences. Nevertheless, these findings indicate that efforts to improve patient-centred information provision should be targeted at all MRI and CT outpatients, irrespective of the sociodemographic, scan or disease characteristics that were assessed in this study.

It may not be possible to deliver information in accordance with patient preferences whilst meeting legal and ethical requirements for preparation and informed patient consent

The *Medical Imaging Informed Consent Guidelines* developed by the Royal Australian and New Zealand College of Radiologists (RANZCR, 2019) indicate that preparatory information provision is a shared responsibility, with the referring doctor providing information about clinical context and the radiologist providing information about the examination¹⁰. The item of information most commonly both wanted and received by participants related to why doctors had referred patients for a scan (78% of participants reported that their preference to receive this information was met). This suggests that patient preferences for information about the clinical context of the referral were often aligned with informed patient consent guidelines¹⁰ and addressed as part of clinical practice. However, 33% to 38% of participants did not want to receive information items that are mandated for informed patient consent (i.e. benefits of the procedure and who to speak to with questions)¹⁰. This highlights a mismatch between the patient-centred approach of providing information aligned with patients' wants and needs^{3,33},

and the clinical requirements for information provision¹⁰. These findings suggest that it would not be possible to fully meet patient preferences for the content and amount of information (particularly when there is a preference to not receive information items) whilst still satisfying legal and ethical responsibilities. Alternative patient-centred approaches to providing preparatory information may need to be considered, such as adapting the timing, source and format of information to be responsive to patients' preferences, rather than modifying the content itself. One approach to deliver such tailored information may be through the use of patient education websites^{6,34}.

Key finding 2: Improved assessment and interpretation of eHealth literacy is needed to guide targeted support for the use of eHealth

Accurate assessment and interpretation of patients' capabilities to use patient education websites (i.e. eHealth literacy) is key to determining whether eHealth may be a feasible vehicle for the patient-centred provision of preparatory information. This study contributes new knowledge about the validity of the most commonly used self-report measure of eHealth literacy, the eHEALS⁹. The use of advanced analytical techniques has also enabled insights into medical imaging outpatients' eHealth literacy and the related need for support to engage meaningfully with eHealth (Papers Three and Four).

It may be appropriate to assess eHealth literacy across multiple factors

Paper Three reported on the use of confirmatory factor analysis (CFA) to validate a recently proposed multidimensional eHEALS structure identified by Sudbury-Riley et al (2017) in a multinational sample of adult internet users³⁵. Three discrete eHEALS factors (i.e. awareness, skills and evaluation) were identified in the medical imaging study population. The validated structure differentiates between the following domains:

(i) awareness, i.e. understanding what health resources and information are available on the internet (eHEALS items 1 and 2); (ii) skills, i.e. knowing how to find and engage with these health resources and information (eHEALS items 3 to 5); and (iii) evaluation, i.e. the appraisal and effective application of online health resources and information (eHEALS items 6 to 8)³⁵. The finding regarding eHEALS multidimensionality was expected, since the self-efficacy and social-cognitive theories underpinning eHealth literacy^{9,36} indicate that many components (e.g. finding, applying and evaluating electronic health information) are needed to effectively engage with eHealth. Paper Three reported on the first study to replicate Sudbury-Riley et al's (2017) psychometric findings within a new population and setting. Replication of findings is important because it adds to evidence regarding scale adequacy, increases confidence in the validity of eHEALS multidimensionality findings, and provides a better indication of generalisability of findings to MRI and CT outpatients³⁷. The continued accumulation of psychometric evidence is necessary to inform the wider application of the three-factor eHEALS structure among populations^{37,38}.

This finding of a three-factor structure challenges a large volume of research which employs exploratory factor analysis (EFA) to conclude that the eHEALS measures a single construct^{9,39-45}. The difference in the number of constructs identified in this study compared with other research may be explained by differences in the analytical techniques used. EFA is most appropriate in the early phases of measure development when the number of dimensions needs to be reduced and there is no preconceived factor structure⁴⁶. Given that the eHEALS was developed a long time ago and has been extensively tested³⁵, the EFA approach may no longer be optimal. Confirmatory factor analysis is instead recommended when a hypothesised measurement model can be established⁴⁷. This type of analysis is advantageous as it can account for the underlying

theory that informs latent variable structures, and is less reliant than EFA on subjective decision-making processes⁴⁸.

In contrast to this study, the few studies that have applied CFA to examine the construct validity of the eHEALS commonly report single-factor⁴⁹⁻⁵² or two-factor⁵³⁻⁵⁵ structures. However, the conclusions of these studies are often flawed, as they are based on inadequate fit indices^{49,53} and seek to validate EFA findings of unidimensionality⁴⁹⁻⁵², despite a dearth of theoretical or empirical argument to support the notion that the eHEALS measures a single dimension. The difference in findings may also be attributed to three of seven identified studies using linguistic translations of the scale^{50,53,55}.

Translating the eHEALS from English, the language in which it was originally designed, to other languages may result in changed item meanings and interpretations, therefore producing different results with different translated versions⁵⁶.

Since Paper Three was published, two studies have been conducted which use CFA to propose and validate three-factor eHEALS structures^{57,58}. Reder et al (2019) administered a German translation of the scale to women over the age of 50 years, who were first-time invitees to a mammography screening program. The authors concluded that there are three eHEALS factors: (1) information seeking, i.e. ability to find health information on the internet (eHEALS items 1, 3 and 4); (2) information appraisal, i.e. ability to evaluate electronic health information sources (eHEALS items 6 and 7); and (3) information use, i.e. ability to use this information to make health decisions (eHEALS items 2, 5 and 8)⁵⁷. This eHEALS factor structure was based on empirical hypotheses formed from the eHEALS' item wording, as well as the authors' proposed model of health competence⁵⁷. Similarly, Paige et al (2018) used multi-group exploratory structural equation models, as opposed to eHealth literacy or other theories,

to identify four different eHEALS factor structures among a sample of multi-generational US adults⁵⁸. Confirmatory factor analysis was then applied to conclude that the three-factor structure demonstrated the best model fit. This structure comprised: (1) eHealth information awareness, i.e. understanding what health information is available on the internet and where it can be located (eHEALS items 1 and 2); (2) eHealth information seeking, i.e. knowledge about how to find and use helpful health resources on the internet (eHEALS items 3 and 4); and (3) eHealth information engagement, i.e. evaluating and using health information to answer health-related questions (eHEALS items 5 to 8)⁵⁸. The fit of this three-factor structure was acceptable and invariant across generations included in the study (i.e. millennials, generation X, and baby boomers and silent generation)⁵⁸. The grouping of items into factors was different in these studies^{57,58} and in Paper Three. Nevertheless, results from these studies and those reported in this thesis consistently suggest that the eHEALS measures multiple discrete factors, generally related to finding, using and applying online health information. The identification of similar findings despite sampling differences (e.g. patients versus general public; German, US and Australian participants) strengthens the reliability of conclusions. Hence, this new work adds further weight to the argument for eHEALS multidimensionality.

Identification of four eHealth literacy subgroups challenges the existing interpretations of eHEALS scores

Paper Four reports the findings of a cluster analysis to identify and characterise subgroups of patients reporting similar eHealth literacy, based on their eHEALS scores. Cluster analysis is used to identify natural groupings within data and does not impose a priori cluster structures⁵⁹. Thus, this analytical technique is ideal in the context of eHealth literacy, where data-driven approaches have not previously been applied to

inform hypotheses for the number and composition of eHealth literacy subgroups.

Furthermore, recommendations for the standardised interpretation of eHEALS scores are missing, and score thresholds constituting clinically important levels of eHealth literacy are unknown. For the first time, this study identified four subgroups of patients with similar levels of eHealth literacy: low (21.1% of participants); moderate (26.2% of participants); high (32.8% of participants); and very high (19.9% of participants). These findings indicate that substantial variability in eHealth literacy should be accounted for when interpreting eHEALS scores.

The findings reported in Paper Four are strengthened by the consistent results obtained when using both distance-based and latent class cluster analyses. Distance-based cluster analysis was initially completed as an unsupervised, exploratory, knowledge discovery technique⁵⁹. This approach was undertaken to explore whether a model was likely to exist; thus, obtaining definitive results was not the objective of this analysis. After distance-based clustering identified four hierarchical clusters, it was appropriate to proceed to secondary clustering using latent class analysis. Latent class analysis was selected as the primary analysis technique as it is less sensitive to choice of parameters, allows for uncertainty in class membership, and has greater power and lower type 1 error when compared with other clustering methods⁶⁰. Based on model fit, overall interpretability and model parsimony, latent class analysis findings also indicated a four-class structure, therefore increasing confidence that multiple, differentiated eHealth literacy subgroups existed within the population; this is a finding that has not been reported previously.

The identification of four meaningful eHealth literacy subgroups contradicts existing interpretations of eHEALS data. Common analytical approaches to the eHEALS have

included reporting overall eHEALS mean and median values^{50,61-65}, as well as item response frequencies^{64,66,67}. Furthermore, other studies arbitrarily and inconsistently assigned cut-points at the eHEALS item or global levels⁶⁸⁻⁷⁰, assuming a dichotomy of high versus low eHealth literacy. This assumption was not supported by the study findings reported in Paper Four. Caution should therefore be used when interpreting eHealth literacy findings based on such traditional analytical techniques. In particular, the findings reported in Paper Four reinforce the need for accurate and clinically meaningful guidelines for eHEALS score interpretation⁷¹, and suggest that such guidelines should account for multiple ranges of eHEALS scores (i.e. representing low, moderate, high and very high eHealth literacy). Score interpretation guidelines may enable comparisons among study findings, inform development and targeting of interventions to improve eHealth literacy, and inform decision-making about population readiness for eHealth implementation.

Targeted support is needed to maximise the benefits that can be achieved from eHealth

The ability to distinguish between multiple subgroups of eHealth literacy is a key strength of this study, as it can direct the provision of intensive and less intensive support for patient engagement with eHealth. Hence, resource utilisation may be more efficient, and there may be increased likelihood that support strategies align with patients' needs. A substantial proportion of the sample (47%) were classified as belonging to low and moderate eHealth literacy subgroups, therefore requiring a higher level of differentiated eHealth support. These findings were not surprising, as studies among other patient populations⁷²⁻⁷⁴, including outpatients diagnosed with gastrointestinal diseases, diabetes and other endocrine conditions⁷⁴, indicate that levels of eHealth literacy are in need of improvement. These findings also align with

statements by peak Australian healthcare bodies (e.g. Consumers Health Forum of Australia) that eHealth literacy is a significant barrier to achieving optimal benefits from eHealth⁵.

The findings reported in Paper Four suggest that frequency of internet use and preferences for amount of health information can be used to identify patients most in need of support to engage with eHealth. Participants who self-reported using the internet at least daily were significantly more likely to be in the “moderate” eHealth literacy class, compared with the “low” eHealth literacy class. Furthermore, participants who reported preferring to receive a lot of health information (versus not a lot of health information) were significantly more likely to be in the “high” eHealth literacy class, compared with the “low” eHealth literacy class. These findings are consistent with the small number of studies conducted with patients with chronic disease and with the general public, which report a significant yet weak positive correlation between internet use and eHealth literacy^{39,65,75}. No other research has examined the association between eHealth literacy and preferences for amount of health information. Other characteristics that are comparable to preferences for amount of health information have, however, been reported as factors associated with eHealth engagement^{76,77}. In particular, predictors of eHealth usage that have been identified in other studies include a belief that information can make a difference to health⁷⁶ and that there is a need for information to fill a void in knowledge⁷⁷. Whilst these predictors are not the same, they are both consistent with a preference to receive a lot of health information, and collectively suggest that those who want more health information may also have greater capabilities in engaging with eHealth.

This study provides the first assessment of variability in eHEALS factor scores (i.e. for awareness, skills and evaluation) across subgroups. Being able to assess awareness, skills and evaluation allows the identification of specific areas of low competency that require targeted improvement or support. Respondents in all subgroups perceived that they were most competent in terms of eHealth skills, followed by either awareness or evaluation. Room for improvement in awareness and evaluation was expected, given the abundance of poor-quality online health information⁷⁸, which creates difficulties in understanding which information can be retrieved and reliably used⁷⁹.

Limited awareness is reflected in reported online health-information-searching behaviours. Pahade et al's (2018) study of 1542 radiology outpatients and carers found that 31% of participants referred to general web sources such as Google and WebMD to independently source preparatory information, whereas only 5% referred to sources by national radiology organisations (e.g. RadiologyInfo)²⁰. The accuracy, completeness, readability, design, disclosures, and references provided in general imaging websites are often low, and these factors may contribute to patients' perceived difficulties in evaluation⁸⁰⁻⁸². van der Vaart et al (2013) also found suboptimal eHealth evaluation capabilities when observing how patients with rheumatic disease performed across a set of eHealth tasks⁸³. The largest number of problems encountered by participants related to assessing the relevance and reliability of information⁸³. No participants were observed verifying the quality of information on one website with that of another⁸³. These volume and quality issues are recognised by users, as qualitative research indicates that some of the greatest self-reported barriers to eHealth engagement pertain to issues with the information or presentation of information online, and the vast amount of information available⁷⁹. The current assessment of eHealth literacy by use of eHEALS factors, therefore, contributes to literature suggesting that whilst most people

have reasonable skills, awareness and evaluation should be targeted as areas requiring support.

Clinical implications: There is a need to better elicit and respond to patient's preparatory information preferences

Findings from Papers One and Two suggest a need to better elicit and respond to patient preferences across multiple domains of preparation (i.e. procedural, behavioural, sensory and psychosocial) whilst complying with duty of care requirements. A standardised approach to robust, patient-centred information provision may therefore be beneficial. Whilst eHealth holds promise as a sustainable mode for delivering information aligned to patient preferences^{6,34}, findings presented in Papers Three and Four suggest that not all patients are ready for online health information provision. A suite of preparatory information modes should therefore be considered to enable responsiveness to a range of patient preferences, and address patients' varied capacity to engage with online health information.

A shared understanding of patients' preparatory information preferences is an important first step to delivering patient-centred care

With up to 28% of the study sample reporting receipt of too little information (Paper Two), there are clinical and ethical requirements to deliver more information to patients. It may therefore be appropriate to implement strategies that facilitate greater patient-provider discussion of information preferences. It is widely accepted that asking patients about their preferences is a crucial first step to delivering patient-centred care^{84,85}. Nevertheless, this can be difficult to achieve within the context of large, multidisciplinary and resource-constrained healthcare systems, such as public medical imaging services^{86,87}. Question prompt lists are one scalable approach that may be

considered to address this need. This method involves patients being provided with the option to choose from an established list of questions, or being asked to generate their own list of questions to discuss with their healthcare providers⁸⁸. Sansoni et al's (2015) systematic review of 50 interventions found that, when endorsed by the physician and provided immediately prior to a consultation, question prompt lists are effective in increasing the amount of information provided by healthcare professionals⁸⁸. For the purpose of preparatory information provision prior to MRI and CT scans, these lists may provide patients with options about the content, amount, source, format and timing of information they can request. Moreover, there is an opportunity to feasibly integrate question prompt lists into booking confirmation letters that are routinely mailed to MRI and CT outpatients in this setting. Other approaches that may be considered for developing a shared understanding of patient information preferences include, for example, clinician training to improve the elicitation of patient information preferences at the time of booking appointments, offering patients additional consultations to discuss their information preferences, and coaching of patients before their appointments to help them develop skills in expressing information preferences^{89,90}.

Multiple modes of information provision should be offered to respond to patient preferences

In addition to greater discussion of patient preferences, there is also a need for greater responsiveness to patient preferences to enable provision of patient-centred information. Tailored interventions that are responsive to individual patient preferences have been proposed as the ultimate strategy to deliver patient-centred information⁹¹. eHealth programs hold promise, as branching algorithms can direct patients to their preferred type of information^{6,34}. Yet, in accordance with Vereni and Zdanis' (2018) meta-analysis of technology-informed and traditional methods of patient education⁹²,

delivering online preparatory information without responding to patients' eHealth literacy and preferences for receiving information may diminish the effectiveness and benefits of interventions. As approximately half of participants in this study reported low-to-moderate eHealth literacy, and a small minority (11%) referred to online health information to prepare for their scans, it may not be appropriate to rely on eHealth as a single solution to enhance patient-centred communication in this setting. Rather, multiple modes of preparatory information should be available to address patient preferences. These information modes should be responsive to patient preferences for content and amount of information, and also to patients' preferred source, format and timing for receiving preparatory information. Whilst not the focus of this thesis, supplementary unpublished data collected as part of this research project indicated that the majority of participants preferred to receive written information (66%), followed by verbal information (28%). Almost half of participants indicated that they would prefer to receive information about scans from their doctors (47%), followed by radiographers (16%) and receptionists (16%). Furthermore, most participants (63%) preferred to receive this information at least one week before an appointment. These findings provide initial insights into the preferences of patients in the study setting regarding other aspects of information provision, and are consistent with Australian studies that relate to medical imaging⁹³, general medical procedures⁹⁴ and radiotherapy⁹⁵. Thus, approaches that provide preparatory information in a way that patients prefer may include, for example, offering information through preparatory telephone calls, information booklets and patient education websites.

Methodological strengths and limitations

A series of methodological challenges that affect the veracity of findings from web-based cross-sectional studies need to be considered when interpreting the findings of this study, including non-representativeness of the sample and limited generalisability across broader healthcare settings⁹⁶. To increase transparency, enable replication and facilitate the evaluation of reliability, validity and generalisability of this study, the findings were described in accordance with relevant scientific reporting guidelines, including the Strengthening the Reporting of Observational studies in Epidemiology checklist for cross-sectional studies⁹⁷ and the Checklist for Reporting Results of Internet E-Surveys⁹⁸.

Generalisability

Generalisability refers to the extent to which the results of a study can be applied across other situations and to other people⁹⁹. When assessing generalisability, it is important to determine whether study participants are representative of the population of interest, and whether the study setting and procedures are indicative of real-world clinical practice⁹⁹. Findings suggest that participants recruited to this study were generally representative of MRI and CT outpatients attending the study department. Specifically, no significant differences were found between participants and potentially eligible patients attending the department during the study period in age, gender, geographic location and scan type. This may have been a result of the recruitment strategy, with in-person rather than passive online recruitment. In addition, there was a high consent rate (88%). Such findings are important; whilst not identified in this study, existing literature suggests that age and gender may influence patients' information preferences and eHealth literacy^{25,26,65}. In terms of wider representativeness, the age and gender profile of the

sample was similar to other Australian^{100,101} and international¹⁰² medical imaging studies which are representative of patients attending the public healthcare systems in those countries. Thus, confidence is increased that the study findings are generalisable to MRI and CT outpatients at this site, and potentially across broader medical imaging settings.

The Australian Institute of Health and Welfare highlights the diversity in size of facilities and types of services provided by Australia's public hospital sector¹⁰³. This likely results in differing operating models, governance arrangements and funding structures across hospitals¹⁰³, and may lead to differences in the way that information is communicated to patients. It is also possible that factors which vary across hospital locations, such as healthcare provider training and patient education¹⁰⁴, limit the generalisability of findings to patients attending other hospitals, particularly those in rural and remote regions. Furthermore, the generalisability of study findings to patients attending private practices is limited, given the differences in public versus private service characteristics, such as the volume of patients seen and the availability of funding⁸⁷. The convenience sample selected for this study, in which participants were consecutively recruited, was consistent with the sampling approach used by other studies in this field of research^{14,19,105}. However, it is acknowledged that recruitment from multiple centres, and random sampling of participants, are likely to produce findings that have greater generalisability to MRI and CT outpatients more broadly.

It is also important that study results are interpreted within the confines of the eligibility criteria. As the study sample was restricted to outpatients undergoing MRI and CT procedures, it is unclear whether the results can be generalised to other imaging

procedures with different preparatory needs (e.g. nuclear medicine services and positron emission tomography scans). Papers Three and Four report findings from participants who identified as internet users, although the difference in rates of internet access between the study sample (78%) and Australians aged 65 years and older (51%)¹⁰⁶ suggests that study findings may not be applicable to the general cohort of older-aged people, who may have lower levels of eHealth literacy. Whilst non-English speaking patients comprise a very small minority (<1%) of patients attending the medical imaging department, the study findings may not be generalisable to this group. These patients may have unique requirements when engaging with eHealth programs, such as language and cultural translation, which could impact their eHealth literacy. This also applies to patients with cognitive and physical impairments, who were excluded from the study, as the need for additional support (e.g. disability aids), may result in changed experiences in receiving preparatory information and engaging with online health information. It is possible that exclusion of these groups resulted in an under-estimation of patients' unmet information preferences.

Outcome measurement

Patients' experiences and preferences for information were assessed pre-procedure. On one hand, measuring outcomes in the waiting room at this time was advantageous as patients' responses were not affected by their experience of the procedure. On the other hand, data collection at this time means that information provided immediately before the procedure (e.g. by the nurse during preparation for the scan) was not captured. This may have resulted in under-estimation of information received and over-estimation of unmet information preferences. It is also possible that recall bias impacted participants' reported receipt of information. Items within the questionnaire related to information

that participants had received from a health professional or other imaging department staff before arriving for an MRI or CT procedure. As there was no specified timeframe during which information was received, participants might have inconsistently interpreted and responded to the items. For example, it is possible that some participants reported on information received in the days prior to the scan, whereas others reported on information received from the time of appointment booking. In addition, over one-third of participants had undergone the same procedures in the previous year. Hence, their responses might have reflected information provided as part of prior scan experiences, particularly as patients undergoing follow-up scans in close time proximity may be less likely to receive detailed preparatory information. To address potential recall issues, it might have been beneficial to verify the accuracy of patient self-report by comparing findings with objective measures of information receipt, such as clinician reports or audiotapes of consultations. However, this approach would need to be confined to specific health professionals (e.g. imaging department staff) and would therefore not capture information received from all the health professionals who may communicate with patients about having a scan (e.g. community nurses, specialists, general practitioners and physiotherapists).

Tablet computers were found to be an acceptable mode of data collection, with 93% of participants completing the survey electronically. Of these, 78% used the tablet computer independently and 22% required a level of assistance. Paper-and-pen administration of the questionnaire was usually due to internet connectivity issues, as opposed to participants being unwilling to complete the questionnaire electronically. It is not expected that this influenced survey results, as meta-analyses indicate that mode of administration does not cause bias in patient-reported outcome measures, particularly

when comparing self-completion with assisted-completion questionnaires¹⁰⁷.

Additionally, Lane et al's (2006) review of randomised controlled trials found that patients preferred tablet computers, compared with paper-and-pen questionnaires¹⁰⁸.

There are further advantages of tablet computers: (i) greater anonymity of participant responses, as researchers are not required to collect and enter individual respondent data, thus possibly reducing social desirability bias; (ii) less opportunity for manual data entry errors when transcribing answers on a paper-and-pen questionnaire to a database; and (iii) the ability to randomise item presentation, as used for information experience and preference items in this study, thus minimising order effects bias¹⁰⁹. Furthermore, tablet computer survey administration, and the use of no more than two researchers for recruitment and data collection, might have increased the likelihood that survey items were consistently understood by, administered to and communicated to participants.

At the time the study was conducted, there were no published, psychometrically robust tools available to assess information receipt and preferences in the medical imaging context. As a result, an author-developed, study-specific measure was developed. A methodical, scientific and multi-phased approach was taken to create the measure, using best practices for developing and validating scales for health and behavioural research^{110,111}. Firstly, general^{113,112} and imaging-specific guidelines¹¹³⁻¹¹⁶ (e.g. *Standards of Practice for Diagnostic and Interventional Radiology* by the RANZCR, *Medical Imaging Informed Consent Guidelines* by the RANZCR, and MRI and CT consumer materials) were reviewed to identify relevant preparatory domains and items, and to establish the content validity of the scale. Next, behavioural scientists, radiologists and health administrators reviewed the domains and items to ensure they were appropriate and addressed key elements of information that should be

communicated to patients. This step further strengthened content validity and established face validity of the scale. Finally, the tool was administered to health professionals in the ageing, disability and nursing sectors, as well as 134 MRI and CT outpatients attending the study setting across a two-week period. This testing was completed to ensure that items were understandable, easy to complete and feasible to administer in the study setting, and provided insights to further evaluate the content and face validity of the scale. Throughout each stage, the scale was iteratively refined, the item pool was reduced and revisions were made to item presentation and wording.

Whilst a robust approach was taken, additional steps could have been introduced to further increase the scientific rigour of measure development. In particular, item generation was based on deductive methods through thorough reviews of peer-reviewed and grey literature¹¹⁰, including the websites of relevant professional organisations (e.g. the RANZCR website)^{115,116}. To ensure a broad and comprehensive item pool, and increase content validity of the scale, it might have been beneficial to also use inductive approaches¹¹⁰. For example, focus groups could have been conducted to explore preparation from patients' and providers' perspectives, with their insights informing item development. Supplementing the views of experts with those of the target population during this process might have also improved the face validity of the scale.

Pilot testing was completed via behavioural observation during survey administration, and unstructured feedback from participants¹¹⁰. More structured exploration of whether patients understood the items and responded in a way that was intended would have been valuable. This could have been done by undertaking cognitive interviews, where participants "think aloud" as they complete the scale to share what they believed each

individual item was asking, the reason for selecting a response, and the relevance of the item. Such cognitive interviews would have built an understanding of the need for item modification to improve the scale's face validity and acceptability¹¹⁰.

A unique strength of the measure is the ability to assess information experiences and preferences with a single response scale, thereby minimising participant burden and maximising scale utility. Responses were combined to indicate receipt of information (*yes, and I wanted this information; yes, but I didn't want this information*) and non-receipt of information (*no, but I wanted this information; no, but I didn't want this information*), as well as unmet information preferences (*no, but I wanted this information; yes, but I didn't want this information*) and met information preferences (*yes, and I wanted this information; no, but I didn't want this information*). Internal consistency was strong across dichotomised experience (Kuder-Richardson coefficient = 0.96) and preference items (Kuder-Richardson coefficient = 0.94)¹¹⁷. Despite being robust, this measurement approach did not capture reasons for reporting unmet information preferences.

The rapidly evolving nature of technology creates challenges for developing psychometrically robust measures of eHealth literacy which remain relevant over time¹¹⁸. Whilst no instrument is unanimously considered a gold standard measure of eHealth literacy¹¹⁹, a wealth of research has used and continues to use the eHEALS, thus informing the approach to measurement in this study. The eHEALS was selected for use because it is brief, has demonstrated rigour across many psychometric properties and is applicable across settings^{9,35,119}. However, many have questioned the relevance of the eHEALS to the modern digital era¹¹⁹. As the eHEALS was developed from work in

the late 1990s and early 2000s¹²⁰, it precedes the “health 2.0” movement (i.e. interactive technologies that support people to communicate about their health, self-monitor their health and receive treatment via the internet¹²¹) and likely omits issues relevant to modern health technologies (e.g. social media). Anecdotal feedback obtained from researchers who were monitoring study participants when they were completing the eHEALS also suggests that, despite the fact that items were developed for individuals who use technology for a range of purposes⁹, some participants were unsure of how to respond to items if they did not use the internet to search for health information. These difficulties with item interpretation might have resulted in response bias.

Since this study was undertaken, new tools to measure eHealth literacy have emerged which attempt to address some of the limitations of the eHEALS¹¹⁹. These measures are theoretically-informed and multidimensional, thus aligning with the many literacy types, theories and engagement behaviours (e.g. finding, applying and evaluating electronic health information) that underpin eHealth literacy. van der Vaart et al’s (2017) Digital Health Literacy Instrument was designed to measure a broad spectrum of skills relevant to health 1.0 (e.g. information gathering) and health 2.0 (e.g. interactivity)¹²². Paige et al (2019) developed an 18-item instrument to measure functional, communicative, critical and translational eHealth literacies¹²³. Furthermore, Seckin et al (2016) developed the 19-item Electronic Health Literacy Scale to measure the elements of communication, trust and action regarding online health information¹²⁴. These tools are promising developments for improving the assessment of eHealth literacy, but were not published at the time that this study was conducted, and their psychometric properties have not been widely investigated.

The evaluation of the eHEALS' factorial validity (Paper Three) was based on confirmatory factor analysis, derived from Classical Test Theory (CTT)¹²⁵. This traditional psychometric model assumes that measurement instruments are fallible, and observed scores are therefore comprised of a true score and an error score^{125,126}. This error is random and normally distributed, meaning that it can be higher or lower across individuals and settings, with higher error reducing certainty about the attribute being measured^{125,126}. Despite being widely used, CTT has shortcomings, including a lack of population invariance and confounding parameters (e.g. common dependency between item difficulty and item discrimination)¹²⁵⁻¹²⁷. Item Response Theory (IRT) is a contemporary measurement model that overcomes these limitations, using stronger assumptions, probabilistic modelling and statistical adjustments to examine how item properties manifest into latent traits^{127,128}. Originally developed for analyses of unidimensionality with dichotomous response options, IRT advances now allow for the assessment of multidimensionality with multiple item responses^{127,128}, and may have been appropriate to apply as part of this study.

Future research directions

Whilst this study contributes new knowledge regarding patient-centred information provision and the psychometric quality of the eHEALS in the medical imaging setting, it also highlights opportunities for ongoing research. In particular, findings have identified new areas for investigation into the measurement of patient information preferences and eHealth literacy, approaches to facilitate patient-centred preparation, and strategies to enhance eHealth literacy. As conclusions were drawn from a single-site cross-sectional study, there is a need to replicate study findings across time, and in new

populations and settings, to build a body of evidence that can inform future research and be used to improve service delivery^{37,71}.

Continued psychometric analyses of measures of patient-centred preparatory information provision

As discussed in Papers One and Two, there is a need to build evidence regarding the measurement of patients' receipt of preparatory information within medical imaging settings. An absence of psychometrically tested measures of preparation for medical procedures at the time of study completion demonstrates that this field is in its infancy. A robust approach was taken to developing and testing the measure of patient-centred information provision that was reported in this thesis. However, further work is needed to evaluate the psychometric properties of this scale. This includes assessing the author-developed scale's construct validity (i.e. whether the items measure discrete concepts), factorial validity (i.e. degree to which scores are an adequate reflection of these concepts) and predictive validity (i.e. whether scores can be used to predict other patient outcomes)¹²⁹.

Since this study was conducted, a generic measure to assess patients' perceptions of the quality of preparation provided for medical interventions, MiPrep, has become available¹³⁰. Module 1 of MiPrep can be used to evaluate receipt and adequacy of preparatory information¹³⁰. Whilst this is a promising measure, some of the psychometric qualities of MiPrep (e.g. construct validity assessed via exploratory factor analysis) were derived from a single study, and further analyses of reliability and validity are required across time and settings^{71,130}. Additionally, MiPrep was developed for administration after medical procedures and would require adaptation for the pre-procedural assessment of the adequacy of preparation¹³⁰.

Continued exploration of patient-centred preparatory information provision

This study suggests there is room to better elicit and respond to patient information preferences, but the reliability and generalisability of these conclusions is unclear.

Further multi-site cross-sectional research is needed to determine whether these findings reflect patient-centred information provision across state, national and international medical imaging services. In addition to validating patients' preferred amount and content of preparatory information, ongoing research should assess whether medical imaging patients' preferences for the source, format and timing of preparatory information provision are met. This includes whether these preferences vary at different stages of care (e.g. before, during and after their procedures). An examination of service characteristics (e.g. the source, timing, mode and content of appointment confirmations) associated with reporting fewer unmet information preferences would also be useful in identifying optimal models of service provision. Future research should be adequately powered to explore characteristics associated with the receipt of too much versus too little information, in order to identify targeted patient groups that require differing approaches to information provision. Additionally, other potential correlates of unmet patient information preferences should be assessed, such as the source of referral (e.g. general practitioner versus specialist) and reason for referral (e.g. diagnostic versus follow-up). In accordance with the Transactional Model of Stress and Coping¹³¹ described in the Thesis Introduction, it is conceivable that these suggested correlates influence patient perceptions of their environment (e.g. scan process and risks) and the resultant need for information to facilitate coping¹³¹. Mixed methods could also be employed to examine the reasons for patients' unmet information preferences (e.g. providers' failure to elicit preferences, or change in preferences over time) and to better direct improvements in patient-centred communication. Furthermore, an examination of

patient preferences for online versus offline health information would be worthwhile, as this could inform the implementation of traditional and technologically-enabled media to provide preparatory information in line with patients' preferences.

Once multi-site cross-sectional research has been conducted, it may be appropriate to evaluate interventions to enhance patient-centred information provision. This could include examining whether question prompt lists are effective in eliciting patients' preparatory information preferences in the medical imaging context⁸⁸. For example, MRI and CT outpatients could be provided with a list of information items that can be requested from healthcare providers, in addition to providing options for the source, timing and format of information provision. Subsequently, information could be delivered in accordance with these preferences as part of intervention research. eHealth may be one option to deliver such information, but other information modes should be considered for those who do not want to receive online health information. These include, for example, extended written information leaflets, podcasts and face-to-face preparatory consultations. The impacts of interventions on patient outcomes (e.g. anxiety) and service outcomes (e.g. appointment non-attendance) should be evaluated, and process measures (e.g. time and cost of intervention delivery) assessed, to determine the potential benefits of these interventions and their ability for translation into standard clinical practice.

Refinement of eHealth literacy outcome measures

Despite being conceptualised more than a decade ago, the definition of eHealth literacy is still not agreed, and terminology is inconsistently applied¹¹⁹. This presents a fundamental challenge for measurement research: to rigorously evaluate content

validity, a clear definition of the concept being examined is needed¹²⁹. Digital health literacy, internet literacy and e-literacy are terms that are often used interchangeably and as a proxy for eHealth literacy¹¹⁹. This lack of definition is seen in scientific reporting guidelines (e.g. CONSORT), which state the need for eHealth trials to report on computer or internet literacy¹³². A focus on single literacies does not recognise the multiple literacy types which constitute the concept¹³³ and play important roles in facilitating engagement. Additionally, varying eHealth literacy definitions may be attributed, in part, to the emergence of “health 2.0” in 2004¹²¹ and the changing ways in which eHealth applications are intended to be used¹²⁰. Techniques such as Delphi methodology¹³⁴ should be applied to develop a standardised definition of eHealth literacy which recognises the multi-component nature of the concept, reflects “health 2.0” and can be used to validate the relevance of eHealth literacy measures, including the eHEALS, in the modern digital era.

Such work may inform the continued use of the eHEALS, its adaptation (e.g. addition of a module to assess “health 2.0”), or its replacement with more recently developed measures of eHealth literacy¹²²⁻¹²⁴. Whilst these more recently developed measures appear relevant in the modern digital era, more work is required to establish their psychometric properties and their potential for superseding the eHEALS. For example, van der Vaart et al (2017) reported that the Digital Health Literacy Instrument demonstrated internal consistency, construct validity and test-retest reliability, but some ceiling effects were identified, and educated respondents were overrepresented in the study¹²². Paige et al’s (2019) multidimensional instrument of transactional eHealth literacies was tested with a sample of mostly older respondents (>65 years), and some key psychometric properties (e.g. test-retest reliability) were not evaluated¹²³. Likewise,

items in Seckin et al's (2016) Electronic Health Literacy Scale were based on a review of existing literature, but were not validated by respondents or experts in the field, raising uncertainties about the scale's content validity¹²⁴. Additionally, recruitment and testing were completed via a web-based panel of participants, who likely have high levels of eHealth literacy¹²⁴. The use of non-representative samples from single studies limits generalisability and reinforces the need to replicate findings with diverse populations before measures are more widely applied⁷¹. Nevertheless, measures by van der Vaart (2017) and Paige et al (2019) have both demonstrated convergent validity with the eHEALS^{122,123}. This is encouraging as it suggests that these measures adequately assess behaviours originally identified as constituting eHealth literacy^{9,133}, as well as possibly providing new information about eHealth engagement capabilities.

The evaluation of concurrent and predictive validity is limited across eHealth literacy measurement research, including for that of the eHEALS⁹ and recently developed scales¹²²⁻¹²⁴. This likely reflects the absence of "gold standard" measures of eHealth literacy for comparison¹¹⁹. Weak-to-moderate correlations have been reported between perceived eHealth literacy, using the eHEALS, and performed eHealth literacy, using simulated computer tasks^{39,135}. Similarly, van der Vaart et al (2017) coupled the self-report Digital Health Literacy Scale with performance-based items, in which respondents were asked to apply skills in fictional scenarios¹²². However, performance items showed poor discriminant validity and internal consistency, thus restricting the conclusions that could be drawn¹²². A challenge with this research is that the performance tests were also author-developed, and behaviours constituting active eHealth engagement remain unclear¹³⁶. Short et al (2018) recently recommended that in the absence of valid and reliable measures, multiple methods be used to track eHealth

engagement, such as self-report, system usage data and sensor data (e.g. tracking eye movements)¹³⁶. Further research is needed to develop best-practice measures of eHealth engagement and compare the outputs with scores on eHealth literacy measures.

To maximise research and clinical utility of the eHEALS, guidance for the standardised interpretation of scores is needed⁷¹. Findings from Papers Three and Four suggest that score interpretation guidance should account for multiple subgroups and eHEALS factors, i.e. categorisation of scores constituting very high, high, moderate and low eHealth literacy across the components of awareness, skills and evaluation. It is acknowledged that, whilst other studies proposing eHEALS multidimensionality have since been published^{57,58}, Paper Three reports one of only two studies³⁵ validating this three-factor eHEALS structure. Additionally, Paper Four is the first to identify multiple eHEALS subgroups. A body of evidence is required for psychometrically rigorous guideline development⁷¹. To accumulate the necessary evidence, future research should focus on (i) the widespread validation of multidimensionality and multiple subgroups among populations; (ii) identification of minimal important differences in scores across factors; and (iii) determination of whether score interpretation varies across contexts and audiences⁷¹. Particularly, the examination of eHEALS multidimensionality using item response theory methods^{127,128} is a logical extension of the existing body of research, and should be considered when seeking to validate the three-factor eHEALS structure among populations.

Intervention research to enhance eHealth literacy

The identification of low and moderate eHealth literacy subgroups (Paper Four) suggests that improvement interventions are required to maximise potential benefits from eHealth in this setting. Norman and Skinner (2006) propose that core eHealth

literacy skills are not static and can therefore be improved with appropriate training and support¹³³. However, few studies have evaluated strategies to improve eHealth literacy, and those that have been conducted often include a high risk of bias¹³⁷. Interventions that hold promise are those that use human interaction to build meaning and commitment, such as classes to support the effective use of eHealth¹³⁷⁻¹⁴⁰. For example, Kalichman et al (2006) conducted a randomised controlled trial with people living with HIV/AIDs, and reported that eight bi-weekly training sessions designed to enhance participants' understanding, skills and evaluation of online health information, resulted in significantly greater use of the internet for health in the months following the intervention, compared with time-matched social support groups¹⁴⁰. More recently, Blakemore et al (2020) conducted a mixed-methods study which reported that massive open online courses were effective in significantly improving eHealth evaluation skills of learners, including those of cancer patients¹³⁹.

These results are supported by the Extended Health Valence Model¹⁴¹, which posits that an interaction between perceived susceptibility to a health-related threat and severity if that threat materialises, as well as risks and benefits associated with using patient education websites, influence eHealth engagement behaviours¹⁴¹. Classes in the effective use of eHealth provide an opportunity to use patient education websites without the potential danger of misinformation, therefore reducing perceived risks, and potentially increasing perceived engagement capabilities. Being able to identify specific components of eHealth literacy (i.e. awareness, skills, evaluation) across clearly defined participant subgroups, as indicated in this study (Paper Four), means that more targeted and potentially effective improvement interventions may be developed and tested. In particular, these findings suggest that structured classes designed to enhance eHealth

awareness and evaluation warrant investigation as part of high-quality intervention research, particularly for individuals who use the internet less than daily and who prefer not to receive a lot of health information.

Another strategy to increase awareness and reduce the need to evaluate content may be the introduction of doctor recommendations to view credible online health materials. In accordance with the Extended Health Valence Model¹⁴¹, increased efforts by doctors and other healthcare professionals to highlight the benefits of patient education websites may result in increased intentions and capabilities to engage with eHealth. Furthermore, this approach aligns with the preferences of a majority of participants to receive preparatory information from their doctors (unpublished results from this study).

Research suggests that the active promotion of eHealth using recommendations that draw on providers' sense of authority and credibility may result in greater eHealth use^{142,143}. In their cross-sectional study of 132 Australian parents of children with chronic coronary heart disease, Kasparian et al (2017) reported that 25% of participants had received eHealth recommendations from their doctors, 97% of whom had referred to the recommended information source¹⁴⁴. Additionally, 90% of participants indicated that they would definitely use a doctor's eHealth recommendation if it were provided to them in the future¹⁴⁴. These results reinforce the potential of doctor recommendations in increasing awareness of, and engagement with, credible patient education websites, but also indicate the under-utilisation of this approach across Australian healthcare practice. Thus, continued research may examine whether doctor eHealth recommendations may be effective in enhancing patients' self-reported eHealth literacy.

Conclusion

This body of research builds knowledge about patient-centred preparatory information provision among MRI and CT outpatients, and the potential utility of eHealth in responding to patient information preferences in this setting. The need for this research is emphasised by growing numbers of medical imaging outpatients^{7,8}, and the strategic focus on technologically-enabled⁵ and patient-centred¹⁻³ models of healthcare. Overall, findings indicate that greater efforts are needed to provide patient-centred preparatory information prior to MRI and CT procedures. In particular, patients often want but do not receive the recommended procedural, sensory, psychosocial and behavioural information prior to a scan. Whilst the internet provides a way of delivering tailored preparatory information^{6,34}, not all patients perceive that they have the capabilities to engage meaningfully with eHealth. Ongoing research is also needed to strengthen understandings of eHealth literacy assessment and interpretation. Such research may inform targeted approaches to maximise eHealth engagement and the possible benefits to be achieved from its use. Until such time, eHealth should co-exist alongside other options that provide patients with access to the preparatory information they prefer.

References

1. Australian Commission on Safety and Quality in Health Care. Person-Centred Care. 2019. <https://www.safetyandquality.gov.au/our-work/partnering-consumers/person-centred-care> (accessed 16 May 2020).
2. Agency for Healthcare Research and Quality. Six Domains of Health Care Quality. 2018. <https://www.ahrq.gov/talkingquality/measures/six-domains.html> (accessed 16 May 2020).
3. Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington D.C., 2001.
4. World Health Organization. WHO eHealth Resolution. 2020. <https://www.who.int/healthacademy/news/en/> (accessed 10 April 2020).
5. Australian Digital Health Agency. Australia's National Digital Health Strategy. Safe, Seamless and Secure: Evolving Health and Care to Meet the Needs of Modern Australia. Sydney: ADIA, 2018.
6. van Gemert-Pijnen JE, Peters O, Ossebaard HC. Improving eHealth. The Netherlands: Eleven International Publishing; 2013.
7. Organisation for Economic Co-operation and Development. Computed Tomography (CT) Exams (Indicator). 2020. <https://www.oecd-ilibrary.org/content/data/3c994537-en> (accessed 5 February 2020).
8. Organisation for Economic Co-operation and Development. Magnetic Resonance Imaging (MRI) Exams (Indicator). 2020. https://www.oecd-ilibrary.org/social-issues-migration-health/magnetic-resonance-imaging-mri-exams/indicator/english_1d89353f-en (accessed 5 February 2020).

9. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. *Journal of Medical Internet Research* 2006; **8**(4): e27.
10. The Royal Australian and New Zealand College of Radiologists. Medical Imaging Informed Consent Guidelines, Version 3. Sydney, Australia: RANZCR, 2019.
11. National Breast Cancer Centre and National Cancer Control Initiative. Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer. Camperdown, NSW: National Breast Cancer Centre, 2003.
12. Powell R, Scott NW, Manyande A, et al. Psychological preparation and postoperative outcomes for adults undergoing surgery under general anaesthesia. *Cochrane Database of Systematic Reviews* 2016; (5): CD008646.
13. Schofield MJ, Sanson-Fisher R. How to prepare cancer patients for potentially threatening medical procedures: consensus guidelines. NSW Cancer Council Cancer Education Research Program. *Journal of Cancer Education* 1996; **11**(3): 153-8.
14. Singh N, Mohacsy A, Connell DA, Schneider ME. A snapshot of patients' awareness of radiation dose and risks associated with medical imaging examinations at an Australian radiology clinic. *Radiography (Lond)* 2017; **23**(2): 94-102.
15. Busey JM, Soine LA, Yager JR, Choi E, Shuman WP. Patient knowledge and understanding of radiation from diagnostic imaging. *JAMA Internal Medicine* 2013; **173**(3): 239-41.
16. Sin Hk, Wong CS, Huang B, Yiu Kl, Wong Wl, Chu YCT. Assessing local patients' knowledge and awareness of radiation dose and risks associated with medical imaging: a questionnaire study. *Journal of Medical Imaging and Radiation Oncology* 2013; **57**(1): 38-44.

17. Thornton RH, Dauer LT, Shuk E, et al. Patient perspectives and preferences for communication of medical imaging risks in a cancer care setting. *Radiology* 2015; **275**(2): 545-52.
18. Ollivier L, Apiou F, Leclere J, et al. Patient experiences and preferences: development of practice guidelines in a cancer imaging department. *Cancer Imaging* 2009; **9**: S92-7.
19. Rosenkrantz AB, Flagg ER. Survey-based assessment of patients' understanding of their own imaging examinations. *Journal of the American College of Radiology* 2015; **12**(6): 549-55.
20. Pahade JK, Trout AT, Zhang B, et al. What patients want to know about imaging examinations: a multiinstitutional us survey in adult and pediatric teaching hospitals on patient preferences for receiving information before radiologic examinations. *Radiology* 2018; **287**(2): 554-62.
21. Munn Z, Jordan Z. The patient experience of high technology medical imaging: a systematic review of the qualitative evidence. *Radiography* 2011; **17**(4): 323-31.
22. Lee CI, Flaster HV, Haims AH, Monico EP, Forman HP. Diagnostic CT scans: institutional informed consent guidelines and practices at academic medical centers. *American Journal of Roentgenology* 2006; **187**(2): 282-7.
23. Ramsay I, Peters M, Corsini N, Eckert M. Consumer Health Information Needs and Preferences: A Rapid Evidence Review. Sydney: ACSQHC, 2017.
24. Waller A, Forshaw K, Bryant J, Carey M, Boyes A, Sanson-Fisher R. Preparatory education for cancer patients undergoing surgery: a systematic review of volume and quality of research output over time. *Patient Education and Counseling* 2015; **98**(12): 1540-9.

25. Mirošević Š, Prins JB, Selič P, Zaletel Kragelj L, Klemenc Ketiš Z. Prevalence and factors associated with unmet needs in post-treatment cancer survivors: a systematic review. *European Journal of Cancer Care* 2019; **28**(3): e13060.
26. Kowalski C, Lee S-YD, Ansmann L, Wesselmann S, Pfaff H. Meeting patients' health information needs in breast cancer center hospitals - a multilevel analysis. *BMC Health Services Research* 2014; **14**(1): 601.
27. Brütting J, Bergmann M, Garzarolli M, et al. Unmet information needs of patients with melanoma in Germany. *Melanoma Research* 2019; **29**(2): 196-204.
28. Sanson-Fisher R, Girgis A, Boyes A, et al. The unmet supportive care needs of patients with cancer. *Cancer* 2000; **88**(1): 226-37.
29. Zebrack B. Information and service needs for young adult cancer survivors. *Supportive Care in Cancer* 2009; **17**(4): 349-57.
30. Keegan TH, Lichtensztajn DY, Kato I, et al. Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study. *Journal of Cancer Survivorship* 2012; **6**(3): 239-50.
31. Faller H, Koch U, Brähler E, et al. Satisfaction with information and unmet information needs in men and women with cancer. *Journal of Cancer Survivorship* 2016; **10**(1): 62-70.
32. Zucca AC, Sanson-Fisher RW, Waller A, Carey M, Grady A, Mackenzie L. Life expectancy discussions in a multisite sample of Australian medical oncology outpatients. *The Medical Journal of Australia* 2015; **203**(10): 405.
33. The Royal Australian and New Zealand College of Radiologists Quality and Safety Committee. Strategic Planning Discussion Paper – Radiology Quality and Safety. Sydney, Australia: RANZCR, 2014.

34. Waller A, Forshaw K, Carey M, et al. Optimizing patient preparation and surgical experience using eHealth technology. *JMIR Medical Informatics* 2015; **3**(3): e29.
35. Sudbury-Riley L, FitzPatrick M, Schulz PJ. Exploring the measurement properties of the eHealth Literacy Scale (eHEALS) among baby boomers: a multinational test of measurement invariance. *Journal of Medical Internet Research* 2017; **19**(2): e53.
36. Bandura A. Social Cognitive Theory. In: Vasta R, ed. *Annals of child development*. Greenwich, CT: JAI Press; 1989.
37. Earp BD, Trafimow D. Replication, falsification, and the crisis of confidence in social psychology. *Frontiers in Psychology* 2015; **6**(621).
38. Cella D, Yount S, Rothrock N, et al. The Patient-Reported Outcomes Measurement Information System (PROMIS): progress of an NIH Roadmap cooperative group during its first two years. *Medical Care* 2007; **45**(5 Suppl 1): S3-S11.
39. van der Vaart R, van Deursen AJ, Drossaert CH, Taal E, van Dijk JA, van de Laar MA. Does the eHealth Literacy Scale (eHEALS) measure what it intends to measure? Validation of a Dutch version of the eHEALS in two adult populations. *Journal of Medical Internet Research* 2011; **13**(4): e86.
40. Nguyen J, Moorhouse M, Curbow B, Christie J, Walsh-Childers K, Islam S. Construct validity of the eHealth Literacy Scale (eHEALS) among two adult populations: a rasch analysis. *JMIR Public Health and Surveillance* 2016; **2**(1): e24.
41. Koo M, Norman CD, Hsiao-Mei C. Psychometric evaluation of a Chinese version of the eHealth Literacy Scale (eHEALS) in school age children. *Global Journal of Health Education and Promotion* 2012; **15**(1): 29-36.

42. Bazm S, Mirzaei M, Fallahzadeh H, Bazm R. Validity and reliability of the Iranian version of eHealth Literacy Scale. *Journal of Community Health Research* 2016; **5**(2): 121-30.
43. Chung SY, Nahm ES. Testing reliability and validity of the eHealth Literacy Scale (eHEALS) for older adults recruited online. *CIN: Computers, Informatics, Nursing* 2015; **33**(4): 150-6.
44. Sheng X, Simpson PM. Seniors, health information, and the Internet: motivation, ability, and Internet knowledge. *Cyberpsychology, Behavior, and Social Networking* 2013; **16**(10): 740-6.
45. Nahm E-S, Resnick B, Orwig D, et al. A theory-based online hip fracture resource center for caregivers: effects on dyads. *Nursing Research* 2012; **61**(6): 413-22.
46. O'Rourke N, Hatcher L. A Step-by-Step Approach to using SAS® for Factor Analysis and Structural Equation Modeling. Second ed. Cary, NC: SAS Institute Inc.; 2013.
47. Costello A, Osborne J. Best practices in exploratory factor analysis: four recommendations for getting the most from your analysis. *Practical Assessment Research and Evaluation* 2005; **10**(7): 1-9.
48. Henson RK, Roberts JK. Use of exploratory factor analysis in published research. *Educational and Psychological Measurement* 2006; **66**(3): 393-416.
49. Paige SR, Krieger JL, Stellefson M, Alber JM. eHealth literacy in chronic disease patients: an item response theory analysis of the eHealth Literacy Scale (eHEALS). *Patient Education and Counseling* 2017; **100**(2): 320-6.
50. Mitsutake S, Shibata A, Ishii K, Oka K. Association of eHealth literacy with colorectal cancer knowledge and screening practice among internet users in Japan. *Journal of Medical Internet Research* 2012; **14**(6): e153.

51. Ma Z, Wu M. The psychometric properties of the Chinese eHealth Literacy Scale (C-eHEALS) in a Chinese rural population: cross-sectional validation study. *Journal of Medical Internet Research* 2019; **21**(10): e15720.
52. Lin C-Y, Broström A, Griffiths MD, Pakpour AH. Psychometric evaluation of the Persian eHealth Literacy Scale (eHEALS) among elder Iranians with heart failure. *Evaluation & The Health Professions* 2019: 0163278719827997.
53. Soellner R, Huber S, Reder M. The concept of eHealth literacy and its measurement. *Journal of Media Psychology* 2014; **26**(1): 29-38.
54. Neter E, Brainin E, Baron-Epel O. The dimensionality of health literacy and eHealth literacy. *The European Health Psychologist* 2015; **17**(6): 275-80.
55. Diviani N, Dima AL, Schulz PJ. A psychometric analysis of the Italian version of the eHealth Literacy Scale using Item Response and Classical Test Theory methods. *Journal of Medical Internet Research* 2017; **19**(4): e114.
56. Harkness JA, Van de Vijver FJ, Mohler PP. Cross-Cultural Survey Methods: Wiley-Interscience Hoboken, NJ; 2003.
57. Reder M, Soellner R, Kolip P. Do women with high eHealth literacy profit more from a decision aid on mammography screening? Testing the moderation effect of the eHEALS in a randomized controlled trial. *Frontiers in Public Health* 2019; **7**: 46.
58. Paige SR, Miller MD, Krieger JL, Stellefson M, Cheong J. Electronic health literacy across the lifespan: measurement invariance study. *Journal of Medical Internet Research* 2018; **20**(7): e10434.
59. Hastie T, Tibshirani R, Friedman J. The Elements of Statistical Learning: Data Mining, Inference, and Prediction, Second Edition. 2nd ed. New York: Springer-Verlag; 2009.

60. Lanza ST, Rhoades BL. Latent class analysis: an alternative perspective on subgroup analysis in prevention and treatment. *Prevention Science: The Official Journal of the Society for Prevention Research* 2013; **14**(2): 157-68.
61. Shiferaw KB, Mehari EA, Eshete T. eHealth literacy and internet use among undergraduate nursing students in a resource limited country: a cross-sectional study. *Informatics in Medicine Unlocked* 2020; **18**: 100273.
62. Athanasopoulou C, Välimäki M, Koutra K, et al. Internet use, eHealth literacy and attitudes toward computer/internet among people with schizophrenia spectrum disorders: a cross-sectional study in two distant European regions. *BMC Medical Informatics and Decision Making* 2017; **17**(1): 136-.
63. Arcury TA, Sandberg JC, Melius KP, et al. Older adult internet use and eHealth literacy. *Journal of Applied Gerontology* 2020; **39**(2): 141-50.
64. Tennant B, Stellefson M, Dodd V, et al. eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults. *Journal of Medical Internet Research* 2015; **17**(3): e70.
65. Neter E, Brainin E. eHealth literacy: extending the digital divide to the realm of health information. *Journal of Medical Internet Research* 2012; **14**(1): e19.
66. Knapp C, Madden V, Wang H, Sloyer P, Shenkman E. Internet use and eHealth literacy of low-income parents whose children have special health care needs. *Journal of Medical Internet Research* 2011; **13**(3): e75.
67. Manafò E, Wong S. Assessing the eHealth literacy skills of older adults: a preliminary study. *Journal of Consumer Health on the Internet* 2012; **16**(4): 369-81.
68. Shiferaw KB, Mehari EA. Internet use and eHealth literacy among health-care professionals in a resource limited setting: a cross-sectional survey. *Advances in Medical Education and Practice* 2019; **10**: 563-70.

69. Richtering SS, Hyun K, Neubeck L, et al. eHealth literacy: predictors in a population with moderate-to-high cardiovascular risk. *JMIR Human Factors* 2017; **4**(1): e4.
70. Milne RA, Puts MT, Papadakos J, et al. Predictors of high eHealth literacy in primary lung cancer survivors. *Journal of Cancer Education* 2015; **30**(4): 685-92.
71. HealthMeasures. PROMIS® Instrument Maturity Model. 2013.
http://www.healthmeasures.net/images/PROMIS/PROMISStandards_Vers_2_0_MaturityModelOnly_508.pdf (accessed 5 May 2019).
72. Kim KA, Kim YJ, Choi M. Association of electronic health literacy with health-promoting behaviors in patients with type 2 diabetes: a cross-sectional study. *CIN: Computers, Informatics, Nursing* 2018; **36**(9).
73. Stelfox ML, Shuster JJ, Chaney BH, et al. Web-based health information seeking and eHealth literacy among patients living with chronic obstructive pulmonary disease (COPD). *Health Communication* 2017: 1-15.
74. Holt KA, Karnoe A, Overgaard D, et al. Differences in the level of electronic health literacy between users and nonusers of digital health services: an exploratory survey of a group of medical outpatients. *Interactive Journal of Medical Research* 2019; **8**(2): e8423.
75. Choi NG, Dinitto DM. The digital divide among low-income homebound older adults: Internet use patterns, eHealth literacy, and attitudes toward computer/Internet use. *Journal of Medical Internet Research* 2013; **15**(5): e93.
76. Hardiker NR, Grant MJ. Factors that influence public engagement with eHealth: a literature review. *International Journal of Medical Informatics* 2011; **80**(1): 1-12.

77. Morahan-Martin JM. How internet users find, evaluate, and use online health information: a cross-cultural review. *Cyberpsychology & Behaviour* 2004; **7**(5): 497-510.
78. Eysenbach G, Powell J, Kuss O, Sa ER. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. *Journal of the American Medical Association* 2002; **287**(20): 2691-700.
79. Lee K, Hoti K, Hughes JD, Emmerton L. Dr Google and the consumer: a qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. *Journal of Medical Internet Research* 2014; **16**(12): e262.
80. Hansberry DR, Ayyaswami V, Sood A, Prabhu AV, Agarwal N, Deshmukh SP. Abdominal imaging and patient education resources: enhancing the radiologist–patient relationship through improved communication. *Abdominal Radiology* 2017; **42**(4): 1276-80.
81. Smart JM, Burling D. Radiology and the internet: a systematic review of patient information resources. *Clinical Radiology* 2001; **56**(11): 867-70.
82. Bowden DJ, Yap L-C, Sheppard DG. Is the Internet a suitable patient resource for information on common radiological investigations? Radiology-related information on the internet. *Academic Radiology* 2017; **24**(7): 826-30.
83. van der Vaart R, Drossaert CH, de Heus M, Taal E, van de Laar MA. Measuring actual eHealth literacy among patients with rheumatic diseases: a qualitative analysis of problems encountered using Health 1.0 and Health 2.0 applications. *Journal of Medical Internet Research* 2013; **15**(2): e27.

84. Zucca A, Sanson-Fisher R, Waller A, Carey M, Boadle D. The first step in ensuring patient-centred quality of care: ask the patient. *European Journal of Cancer Care* 2017; **26**(1).
85. Dickinson D, Raynor DKT. Ask the patients - they may want to know more than you think. *British Medical Journal* 2003; **327**(7419): 861.
86. Australian National Audit Office. The Auditor-General, ANAO Report No.12 2014–15, Performance Audit: Diagnostic Imaging Reforms. Canberra: ANAO, 2014.
87. Australian Diagnostic Imaging Association. ADIA Budget Submission 2017-18: A Fairer and Smarter Medicare for Radiology Patients. Melbourne: ADIA, 2017.
88. Sansoni JE, Grootemaat P, Duncan C. Question Prompt Lists in health consultations: a review. *Patient Education and Counseling* 2015; **98**(12): 1454-64.
89. Kinnersley P, Edwards AG, Hood K, et al. Interventions before consultations for helping patients address their information needs. *Cochrane Database of Systematic Reviews* 2007; (3).
90. Halkett GKB, Merchant S, Jiwa M, et al. Effective communication and information provision in radiotherapy - the role of radiation therapists. *Journal of Radiotherapy in Practice* 2010; **9**(1): 3-16.
91. Kiesler DJ, Auerbach SM. Optimal matches of patient preferences for information, decision-making and interpersonal behavior: evidence, models and interventions. *Patient Education and Counseling* 2006; **61**(3): 319-41.
92. Veneri DA, Zdanis K. Are technology-informed methods better than traditional approaches in educating patients? A meta-analysis. *Health Education Journal* 2018; **77**(3): 261-76.

93. Younger CWE, Douglas C, Warren-Forward H. Medical imaging and informed consent – Can radiographers and patients agree upon a realistic best practice? *Radiography* 2018; **24**(3): 204-10.
94. Turon H, Wall L, Fakes K, Brown SD, Sanson-Fisher R. Cancer patient preferences for the provision of information regarding emotional concerns in relation to medical procedures: a discrete choice experiment. *Patient Education and Counseling* 2020.
95. Halkett G, Kristjanson L, Lobb E, O'driscoll C, Taylor M, Spry N. Meeting breast cancer patients' information needs during radiotherapy: what can we do to improve the information and support that is currently provided? *European Journal of Cancer Care* 2010; **19**(4): 538-47.
96. Ahern DK. Challenges and opportunities of eHealth research. *American Journal of Preventive Medicine* 2007; **32**(5): S75-S82.
97. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement: guidelines for reporting observational studies. *British Medical Journal* 2007; **335**(7624): 806-8.
98. Eysenbach G. Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). *Journal of Medical Internet Research* 2004; **6**(3): e34-e.
99. Kukull WA, Ganguli M. Generalizability: the trees, the forest, and the low-hanging fruit. *Neurology* 2012; **78**(23): 1886-91.
100. Gibson DA, Moorin RE, Semmens J, Holman DJ. The disproportionate risk burden of CT scanning on females and younger adults in Australia: a retrospective cohort study. *Australian and New Zealand Journal of Public Health* 2014; **38**(5): 441-8.

101. Gibson DA, Moorin RE, Holman CDAJ. Cohort study of Western Australia computed tomography utilisation patterns and their policy implications. *BMC Health Services Research* 2014; **14**(1): 526.
102. Dovalés AC, da Rosa LA, Kesminiene A, Pearce MS, Veiga LH. Patterns and trends of computed tomography usage in outpatients of the Brazilian public healthcare system, 2001–2011. *Journal of Radiological Protection* 2016; **36**(3): 547.
103. Australian Institute of Health and Welfare. Hospital Resources 2017–18: Australian Hospital Statistics. 2019. <https://www.aihw.gov.au/reports/hospitals/hospital-resources-2017-18-ahs/contents/diversity-of-public-hospitals> (accessed 17 May 2020).
104. Standing Committee on Community Affairs. Highway to Health: Better Access for Rural, Regional and Remote Patients Canberra: Parliament of Australia, 2007.
105. Horton KM, Garland MR, Fishman EK. The Internet as a potential source of information about radiological procedures for patients. *Journal of Digital Imaging* 2000; **13**(1): 46-7.
106. Australian Bureau of Statistics. 8146.0 - Household Use of Information Technology, Australia, 2016-17. 2018. <http://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0> (accessed 24 June 2018).
107. Rutherford C, Costa D, Mercieca-Bebber R, Rice H, Gabb L, King M. Mode of administration does not cause bias in patient-reported outcome results: a meta-analysis. *Quality of Life Research* 2016; **25**(3): 559-74.
108. Lane SJ, Heddle NM, Arnold E, Walker I. A review of randomized controlled trials comparing the effectiveness of hand held computers with paper methods for data collection. *BMC Medical Informatics and Decision Making* 2006; **6**(1): 23.

109. Singleton KW, Lan M, Arnold C, et al. Wireless data collection of self-administered surveys using tablet computers. *AMIA: Annual Symposium Proceedings* 2011; **2011**: 1261-9.
110. Boateng GO, Neilands TB, Frongillo EA, Melgar-Quinonez HR, Young SL. Best practices for developing and validating scales for health, social, and behavioral research: a primer. *Frontiers in Public Health* 2018; **6**: 149-.
111. O'Connor M, Halkett G. Designing surveys for radiography and radiation therapy. *Radiographer* 2010; **57**(3): 8-11.
112. Cockburn J., NSW Cancer Council. How to Prepare Patients for Potentially Threatening Clinical Procedures: An Interactional Skills Training Manual for General Practitioners, Junior Medical Officers, Nurses, Surgeons. Kings Cross, NSW: NSW Cancer Council, 1997.
113. The Royal Australian and New Zealand College of Radiologists. Standards of Practice for Diagnostic and Interventional Radiology, Version 10.1: RANZCR, 2016.
114. The Royal Australian and New Zealand College of Radiologists. Medical Imaging Consent Guidelines, Version 2. Sydney, Australia: RANZCR, 2013.
115. The Royal Australian and New Zealand College of Radiologists. Magnetic Resonance Imaging (MRI): Consumer Information. 2015.
<http://www.ranzcr.edu.au/resources/consumers> (accessed 26 June 2016).
116. The Royal Australian and New Zealand College of Radiologists. Computed Tomography: Consumer Information. 2015.
<http://www.ranzcr.edu.au/resources/consumers> (accessed 26 June 2016).
117. Kuder GF, Richardson MW. The theory of the estimation of test reliability. *Psychometrika* 1937; **2**(3): 151-60.

118. Baker TB, Gustafson DH, Shah D. How can research keep up with eHealth? Ten strategies for increasing the timeliness and usefulness of eHealth research. *Journal of Medical Internet Research* 2014; **16**(2): e36.
119. Griebel L, Enwald H, Gilstad H, Pohl A-L, Moreland J, Sedlmayr M. eHealth literacy research - quo vadis? *Informatics for Health and Social Care* 2018; **43**(4): 427-42.
120. Norman C. eHealth literacy 2.0: problems and opportunities with an evolving concept. *Journal of Medical Internet Research* 2011; **13**(4): e125-e.
121. Van De Belt TH, Engelen LJ, Berben SA, Schoonhoven L. Definition of Health 2.0 and Medicine 2.0: a systematic review. *Journal of Medical Internet Research* 2010; **12**(2): e18.
122. van der Vaart R, Drossaert C. Development of the Digital Health Literacy Instrument: measuring a broad spectrum of Health 1.0 and Health 2.0 skills. *Journal of Medical Internet Research* 2017; **19**(1): e27.
123. Paige SR, Stellefson M, Krieger JL, Miller MD, Cheong J, Anderson-Lewis C. Transactional eHealth Literacy: Developing and Testing a Multi-Dimensional Instrument. *Journal of Health Communication* 2019; **24**(10): 737-48.
124. Seckin G, Yeatts D, Hughes S, Hudson C, Bell V. Being an informed consumer of health information and assessment of electronic health literacy in a national sample of internet users: validity and reliability of the e-HLS Instrument. *Journal of Medical Internet Research* 2016; **18**(7): e161.
125. DeVellis RF. Classical Test Theory. *Medical Care* 2006; **44**(11 Suppl 3): S50-9.
126. Magno C. Demonstrating the difference between Classical Test Theory and Item Response Theory using derived test data *The International Journal of Educational and Psychological Assessment* 2009; **1**(1): 1-11.

127. Zickar MJ, Broadfoot AA. The Partial Revival of a Dead Horse? Comparing Classical Test Theory and Item Response Theory. *Statistical and Methodological Myths and Urban Legends: Doctrine, Verity and Fable in the Organizational and Social Sciences*. New York, NY, US: Routledge/Taylor & Francis Group; 2009: 37-59.
128. van der Linden W, Hambleton R, editors. *Handbook of Modern Item Response Theory*. New York: Springer Science+Business Media; 1997.
129. McDowell I. *The Theoretical and Technical Foundations of Health Measurement. Measuring Health: A Guide to Rating Scales and Questionnaires*. 3rd ed. New York: Oxford University Press; 2006: 10 - 54.
130. Fakes KL, Hall AE, Carey ML, et al. Development and validation of the MiPrep survey: an instrument assessing patients' perceived preparation for medical interventions including medical imaging, radiotherapy, and surgery. *Value in Health* 2019; **22**(6): 704-11.
131. Folkman S, Lazarus RS. *Stress, Appraisal, and Coping*: New York: Springer Publishing Company; 1984.
132. Eysenbach G, Consort-EHEALTH Group. CONSORT-EHEALTH: improving and standardizing evaluation reports of Web-based and mobile health interventions. *Journal of Medical Internet Research* 2011; **13**(4): e126.
133. Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. *Journal of Medical Internet Research* 2006; **8**(2): e9.
134. Okoli C, Pawlowski SD. The Delphi method as a research tool: an example, design considerations and applications. *Information & Management* 2004; **42**(1): 15-29.
135. Neter E, Brainin E. Perceived and performed eHealth literacy: survey and simulated performance test. *JMIR Human Factors* 2017; **4**(1): e2.

136. Short CE, DeSmet A, Woods C, et al. Measuring engagement in eHealth and mHealth behavior change interventions: viewpoint of methodologies. *Journal of Medical Internet Research* 2018; **20**(11): e292.
137. Car J, Lang B, Colledge A, Ung C, Majeed A. Interventions for enhancing consumers' online health literacy. *Cochrane Database of Systematic Reviews* 2011; (6): Cd007092.
138. Mitsuhashi T. Effects of two-week e-learning on eHealth literacy: a randomized controlled trial of Japanese Internet users. *PeerJ* 2018; **6**: e5251-e.
139. Blakemore LM, Meek SE, Marks LK. Equipping learners to evaluate online health care resources: longitudinal study of learning design strategies in a health care massive open online course. *Journal of Medical Internet Research* 2020; **22**(2): e15177.
140. Kalichman SC, Cherry C, Cain D, et al. Internet-based health information consumer skills intervention for people living with HIV/AIDS. *Journal of Consulting and Clinical Psychology* 2006; **74**(3): 545-54.
141. Mou J, Shin D-H, Cohen J. Health beliefs and the valence framework in health information seeking behaviors. *Information Technology & People* 2016; **29**(4): 876-900.
142. Flynn D, Gregory P, Makki H, Gabbay M. Expectations and experiences of eHealth in primary care: a qualitative practice-based investigation. *International Journal of Medical Informatics* 2009; **78**(9): 588-604.
143. Eysenbach G, Gray JM, Bonati M, et al. Towards quality management of medical information on the internet: evaluation, labelling, and filtering of information. *British Medical Journal* 1998; **317**(7171): 1496-502.

144. Kasparian N, Lieu N, Winlaw D, Cole A, Kirk E, Sholler G. eHealth literacy and preferences for eHealth resources in parents of children with complex CHD. *Cardiology in the Young* 2017; **27**(4): 722-30.

APPENDICES

Appendix 1: Ethics approvals

Appendix 1.1: Health Hunter New England Health Research Ethics Committee Low and Negligible Risk approval



25 October 2016

Dr Lisa Mackenzie
Health Behaviour Research Group
Level 4 West
HMRI Building

Dear Dr Mackenzie

Re: A cross-sectional descriptive study assessing CT & MRI medical imaging outpatients' experiences with, & preferences for, preparatory information: Preparing for CT & MRI scans: Patients' information preferences & experiences: (16/10/19/5.11)

HNEHREC Reference No: 16/10/19/5.11
NSW HREC Reference No: LNR/16/HNE/487
NSW SSA Reference No: LNRSSA/16/HNE/488

Thank you for submitting the above study for single ethical review. This project was considered to be eligible to be reviewed as Low and Negligible risk research, and so was reviewed at an Executive Meeting of the Hunter New England Human Research Ethics Committee on **24 October 2016**. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research (2007)* (National Statement) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review. The Committee's Terms of Reference are available from the Hunter New England Local Health District website.

I am pleased to advise, the Hunter New England Human Research Ethics Committee has determined that the above protocol meets the requirements of the *National Statement on Ethical Conduct in Human Research* and, following acceptance of the requested clarifications and revised participant information statement, receptionist log sheet, research assistant recruitment script and receptionist EOI script by Dr Nicole Gerrand Manager, Research Ethics & Governance, under delegated authority from the Committee, grants ethical approval of the above project.

The *National Statement on Ethical Conduct in Human Research (2007)*, to which the Committee is obliged to adhere, include the requirement that the Committee monitors the research protocols it has approved. Ethics Approval will be ongoing subject to the following conditions:

- A report on the progress of the above protocol is to be submitted at 12 monthly intervals, or, 2 months after the proposed closure date of the project, if this date is less than 12 months. A proforma for the annual report will be sent. Your review date is **October 2017** as per your anticipated closure date.
- All variations or amendments to this protocol must be forwarded to, and approved by, the Hunter New England Human Research Ethics Committee prior to their implementation.
- A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled.

Hunter New England Research Ethics & Governance Office
Locked Bag No 1
New Lambton NSW 2305
Telephone: (02) 49214950
Email: HNEHREC@hnehealth.nsw.gov.au
<http://www.hnehealth.nsw.gov.au/ethics/Pages/Research-Ethics-and-Governance-Unit.aspx>

- The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
 - Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009*
https://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e112_nhmrc_position_statement_monitoring_reporting_safety_clinical_trials.pdf
 - Unforeseen events that might affect continued ethical acceptability of the project.
- If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand as soon as possible.

The following documentation has been reviewed and approved by the Hunter New England Human Research Ethics Committee:

Document	Version	Date
Participant Information Statement	2.0	24 October 2016
Receptionist EOI Script	2.0	20 October 2016
Research Assistant Recruitment Script	3.0	24 October 2016
Participant Survey	1.0	16 September 2016
Receptionist Log Sheet	2.0	24 October 2016
Research Assistant Log Sheet	1.0	16 September 2016

Approval has been granted for this study to take place at the following sites:

- **John Hunter Hospital**

You are reminded that this letter constitutes ethical approval only. You must not commence this research project at a site until separate authorisation from the Chief Executive or delegate of that site has been obtained.

A copy of this letter must be forwarded to all site investigators for submission to the relevant Research Governance Officer.

Should you have any concerns or questions about your research, please contact Dr Gerrand as per the details at the bottom of the page. The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Please quote **16/10/19/5.11** in all correspondence.

The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Ms M Hunter
Chair
Hunter New England Human Research Ethics Committee

Hunter New England Research Ethics & Governance Office

Locked Bag No 1

New Lambton NSW 2305

Telephone: (02) 49214950

Email: HNELHD-HREC@hnehealth.nsw.gov.au

<http://www.hnehealth.nsw.gov.au/ethics/Pages/Research-Ethics-and-Governance-Unit.aspx>

Appendix 1.2: University of Newcastle Low and Negligible Risk registration

RESEARCH INTEGRITY UNIT



Registration of External HREC Approval

To Chief Investigator or Project Supervisor:	Doctor Lisa Mackenzie
Cc Co-investigators / Research Students:	Laureate Professor Robert Sanson-Fisher Mr Michael Symonds Ms Lisa Richards Doctor Allison Boyes
Re Protocol:	A cross-sectional descriptive study assessing CT and MRI medical imaging outpatients' experiences with, and preferences for, preparatory information
Date:	22-Nov-2016
Reference No:	H-2016-0386
External HREC Reference No:	16/10/19/5.11

Thank you for your **Initial Application** submission to the Research Integrity Unit (RIU) seeking to register an External HREC Approval in relation to the above protocol.

Your submission was considered under an **Administrative Review** by the Ethics Administrator.

I am pleased to advise that the decision on your submission is **External HREC Approval Noted** effective **22-Nov-2016**.

As the approval of an External HREC has been noted, this registration is valid for the approval period determined by that HREC.

Your reference number is **H-2016-0386**.

PLEASE NOTE:

As the RIU has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University's RIU, via RIMS.

Linkage of ethics approval to a new Grant

Registered External HREC approvals cannot be assigned to a new grant or award (ie those that were not identified in the initial registration submission) without confirmation from the RIU.

Best wishes for a successful project.

Mr Alan Hales
Manager, Research Compliance, Integrity and Policy

For communications and enquiries:
Human Research Ethics Administration

Research Services
Research Integrity Unit
NIER, Block C
The University of Newcastle
Callaghan NSW 2308
T +61 2 492 17894
Human-Ethics@newcastle.edu.au

RIMS website - <https://RIMS.newcastle.edu.au/login.asp>

Linked University of Newcastle administered funding:

Funding body	Funding project title	First named investigator	Grant Ref

Appendix 1.3: Health Hunter New England Health Research Ethics Committee variation approval



12 December 2016

Dr Lisa Mackenzie
Health Behaviour Research Group
Level 4 West
HMRI Building

Dear Dr Mackenzie

Re: A cross-sectional descriptive study assessing CT & MRI medical imaging outpatients' experiences with, & preferences for, preparatory information: Preparing for CT & MRI scans: Patients' information preferences & experiences: (16/10/19/5.11)

HNEHREC Reference No: 16/10/19/5.11
NSW HREC Reference No: LNR/16/HNE/487
NSW SSA Reference No: LNRSSA/16/HNE/488

Thank you for submitting a request for an amendment to the above project. This amendment was reviewed at an Executive meeting of the Hunter New England Human Research Ethics Committee under the provisions of expedited review. This Human Research Ethics Committee is constituted and operates in accordance with the National Health and Medical Research Council's *National Statement on Ethical Conduct in Human Research (2007)* (National Statement) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*. Further, this Committee has been accredited by the NSW Department of Health as a lead HREC under the model for single ethical and scientific review. The Committee's Terms of Reference are available from the Hunter New England Local Health District website.

I am pleased to advise that the Hunter New England Human Research Ethics Committee has determined the variation meets the requirements of the National Statement on Ethical Conduct in Human Research and has granted ethical approval for the following amendment requests:

Document	Version	Date
Protocol	2	6 December 2106
Receptionist EOI Script	3	6 December 2016
Research Assistant Recruitment Script	4	6 December 2016
Patient Survey	2	6 December 2016
Recruitment Log Sheet	3	6 December 2016

Approval has been granted for this study to take place at the following site:

- **John Hunter Hospital**

Hunter New England Research Ethics & Governance Office
Locked Bag No 1
New Lambton NSW 2305
Telephone: (02) 49214950

Email: HNELHD-HREC@hnehealth.nsw.gov.au
<http://www.hnehealth.nsw.gov.au/ethics/Pages/Research-Ethics-and-Governance-Unit.aspx>

The *National Statement on Ethical Conduct in Human Research (2007)*, to which the Committee is obliged to adhere, include the requirement that the Committee monitors the research protocols it has approved. Ethics Approval will be ongoing subject to the following conditions:

- A report on the progress of the above protocol is to be submitted at 12 monthly intervals, or, 2 months after the proposed closure date of the project if this date is less than 12 months. A proforma for the annual report will be sent. Your review date is **October 2017**.
- All variations or amendments to this protocol must be forwarded to, and approved by, the Hunter New England Human Research Ethics Committee prior to their implementation.
- A final report must be submitted at the completion of the above protocol, that is, after data analysis has been completed and a final report compiled.
- The Principal Investigator will immediately report anything which might warrant review of ethical approval of the project in the specified format, including:
 - Notify the reviewing HREC of any adverse events that have a material impact on the conduct of the research in accordance with the NHMRC Position Statement: *Monitoring and reporting of safety for clinical trials involving therapeutic products May 2009*
https://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e112_nhmrc_position_statement_monitoring_reporting_safety_clinical_trials.pdf
 - Unforeseen events that might affect continued ethical acceptability of the project.
- If for some reason the above protocol does not commence (for example it does not receive funding); is suspended or discontinued, please inform Dr Nicole Gerrand as soon as possible.

Please quote **16/10/19/5.11** in all correspondence.

Should you have any queries about your project please contact Dr Nicole Gerrand as per the contact details at the bottom of the page. The Hunter New England Human Research Ethics Committee wishes you every success in your research.

Yours faithfully

For: Ms M Hunter
Chair
Hunter New England Human Research Ethics Committee

Hunter New England Research Ethics & Governance Office

Locked Bag No 1

New Lambton NSW 2305

Telephone: (02) 49214950

Email: HNELHD-HREC@hnehealth.nsw.gov.au

<http://www.hnehealth.nsw.gov.au/ethics/Pages/Research-Ethics-and-Governance-Unit.aspx>

Appendix 1.4: University of Newcastle variation registration

RESEARCH INTEGRITY UNIT



Registration of External HREC Approval

To Chief Investigator or Project Supervisor:	Doctor Lisa Mackenzie
Cc Co-investigators / Research Students:	Miss Georgia Garr Laureate Professor Robert Sanson-Fisher Mr Michael Symonds Ms Lisa Richards Doctor Allison Boyes
Re Protocol:	A cross-sectional descriptive study assessing CT and MRI medical imaging outpatients' experiences with, and preferences for, preparatory information
Date:	15-Dec-2016
Reference No:	H-2016-0386
External HREC Reference No:	16/10/19/5.11

Thank you for your **Variation** submission to the Research Integrity Unit (RIU) seeking to register an External HREC Approval in relation to the above protocol.

Variation to:

1. Protocol (V2 6 December 2106)
2. Receptionist EOI Script (V3 6 December 2016)
3. Research Assistant Recruitment Script (V4 6 December 2016)
4. Patient Survey (V2 6 December 2016) and
5. Recruitment Log Sheet (V3 6 December 2016)

Your submission was considered under an **Administrative Review** by the Ethics Administrator.

I am pleased to advise that the decision on your submission is **External HREC Approval Noted** effective **15-Dec-2016**.

As the approval of an External HREC has been noted, this registration is valid for the approval period determined by that HREC.

Your reference number is **H-2016-0386**.

PLEASE NOTE:

As the RIU has "noted" the approval of an External HREC, progress reports and reports of adverse events are to be submitted to the External HREC only. In the case of Variations to the approved protocol, or a Renewal of approval, you will apply to the External HREC for approval in the first instance and then Register that approval with the University's RIU, via RIMS.

Linkage of ethics approval to a new Grant

Registered External HREC approvals cannot be assigned to a new grant or award (ie those that were not identified in the initial registration submission) without confirmation from the RIU.

Best wishes for a successful project.

Mr Alan Hales
Manager, Research Compliance, Integrity and Policy

For communications and enquiries:

Human Research Ethics Administration

Research Services
Research Integrity Unit
NIER, Block C
The University of Newcastle
Callaghan NSW 2308
T +61 2 492 17894
Human-Ethics@newcastle.edu.au

RIMS website - <https://RIMS.newcastle.edu.au/login.asp>

Linked University of Newcastle administered funding:

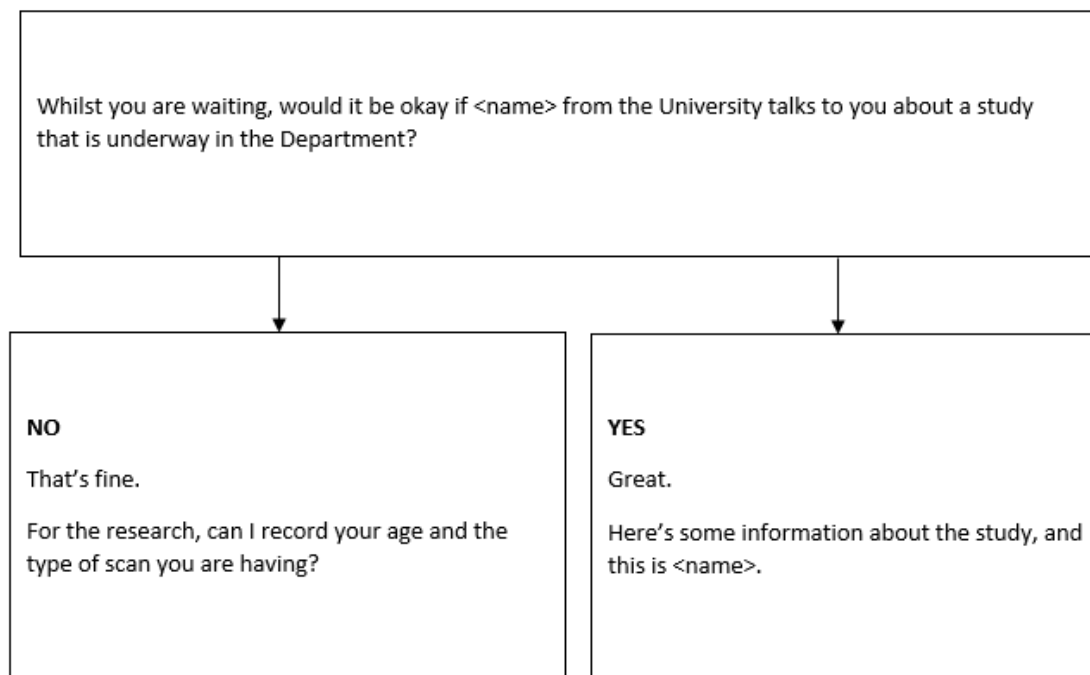
Funding body	Funding project title	First named investigator	Grant Ref
		.	

Appendix 2: Study materials

Appendix 2.1: Receptionist expression of interest script

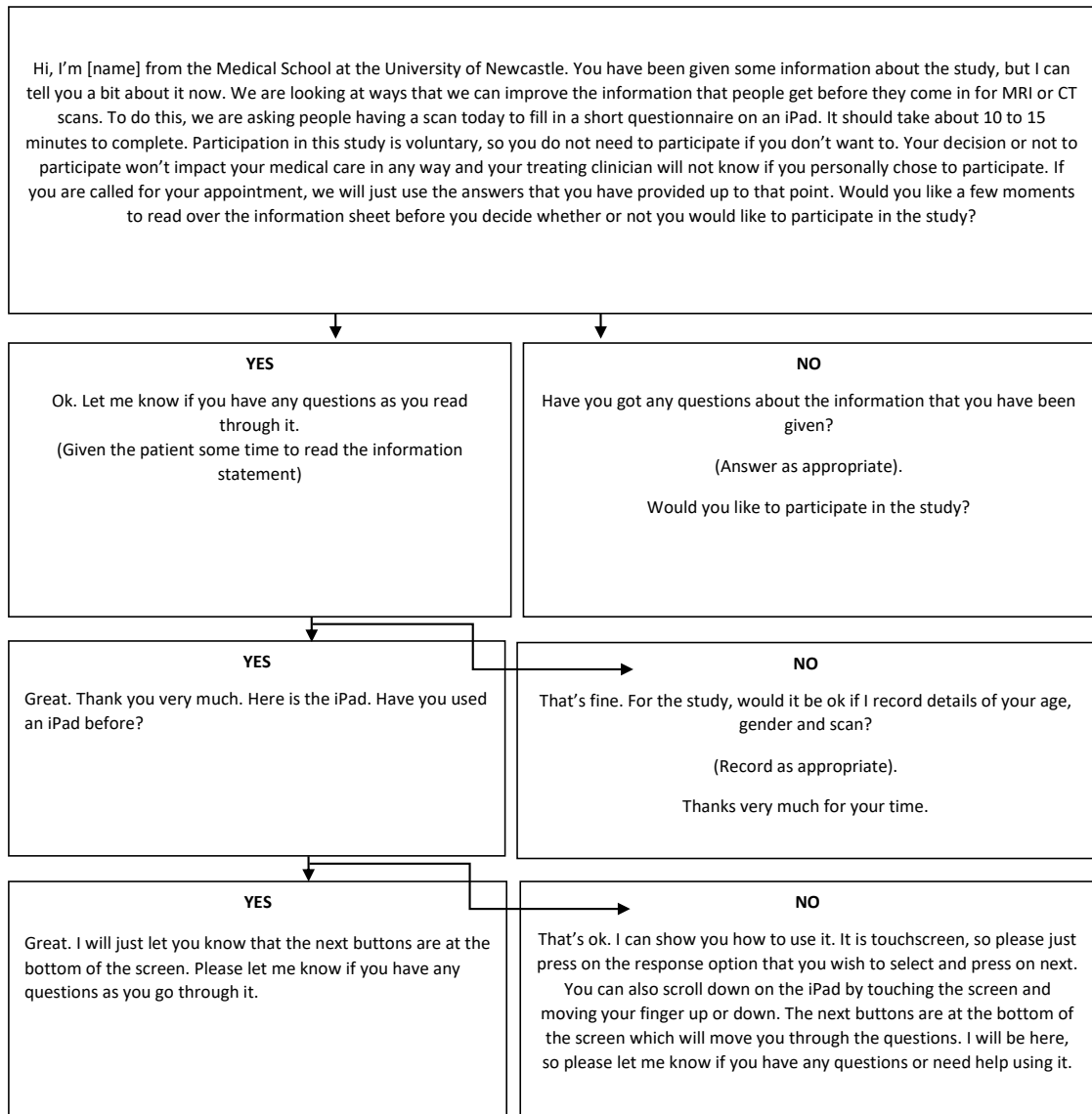
Receptionist EOI Script - Document Version 3.0; dated 06/12/2016

Text/Script:



Appendix 2.2: Research assistant recruitment script

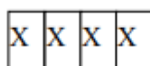
Research Assistant Recruitment Script - Document Version 4.0; dated 06/12/2016



Appendix 2.3: Participant information statement

Participant-Information-Statement--Document-Version-2.0;-dated-24/10/2016

FACULTY OF HEALTH AND MEDICINE



Dr Lisa Mackenzie
School of Medicine and Public Health
University of Newcastle
University Drive
Callaghan, NSW, 2308
T: (02) 4042 0710
E: Lisa.Mackenzie@newcastle.edu.au

Information Statement for the Research Project:

Preparing for CT and MRI scans: Patients' information preferences and experiences

You are invited to participate in the research project identified above which is being conducted by L/Prof Rob Sanson-Fisher, Dr Lisa Mackenzie, Dr Allison Boyes, Mr Michael Symonds and Ms Lisa Richards from the School of Medicine and Public Health at the University of Newcastle, and Hunter New England Imaging at the John Hunter Hospital.

The research is part of Lisa Richards' studies at the University of Newcastle, supervised by L/Prof Rob Sanson-Fisher, Dr Allison Boyes and Dr Lisa Mackenzie from the School of Medicine and Public Health.

Why is the research being done?

Information is important in helping patients prepare for medical procedures. However, patients receive and interpret information in different ways. For example, one person might understand written information, whereas another might prefer pictures or videos. If information is delivered in a way that is responsive to individual needs, it is more likely to be helpful for the patient. Health websites can be easily adapted, so are one way of providing this type of information. The purpose of this research is to determine patient experiences with, and preferences for, preparation information. We are also trying to better understand how skilled patients are in accessing and using online health information. This is important for making sure future patients have the information they need in advance of medical procedures.

Who can participate in the research?

We are seeking people 18 years of age and older, who are attending for a Magnetic Resonance Imaging (MRI) or Computed Tomography (CT) scan.

Unfortunately this study will not be suitable for you if: you are unable to speak and understand English competently, or you have a physical or cognitive impairment which restricts your ability to provide informed consent or answer survey questions.

What would you be asked to do?

If this study is suitable for you and you agree to participate, a researcher will provide you with a survey on an electronic tablet. The survey will ask about you, the information you have been given about your scan, your preferences for information and your internet use. The researcher will show you how to use the electronic tablet, but if you prefer, we can provide you with a paper and pen survey instead.

If this study is not suitable for you or you do not agree to participate, the researcher will ask you about your age, gender and scan type. Answering these questions is completely voluntary. You are not required to tell the researcher these details if you don't want to.

What choice do you have?

Participation in this research is entirely your choice. Only those people who give their informed consent will be included in the project. Whether or not you decide to participate, your decision will not disadvantage you or affect the care you receive from the John Hunter Hospital in any way.

If you do decide to participate, you may withdraw from the project at any time without giving a reason and have the option of withdrawing any data which identifies you.

How much time will it take?

The survey should take approximately 10 to 15 minutes to complete. If you are called in for your scan when you are completing the survey, we will just use the answers you have given us up to that point.

What are the risks and benefits of participating?

By participating in this research, you will be providing important information, which may improve the imaging experience for future patients.

There are few risks associated with this research. In some circumstances, the survey may make you feel anxious. In this instance, the research and medical imaging teams will be on hand to provide assistance. Where additional support is needed you are encouraged to discuss concerns with your doctor and/or contact the NSW Mental Health Line on 1800 011 511 (24-hour telephone service operating seven days a week).

How will your privacy be protected?

Any information collected by the researchers which might identify you will be stored securely and only accessed by the researchers unless you consent otherwise, except as required by law. Data which identifies you will be stored separately in a password protected file on the University of Newcastle network drive. A unique identification number will be used to link your information. Data will be retained at the University of Newcastle for a minimum of 7 years.

How will the information collected be used?

Data from this study will be reported in scientific journals, in a thesis to be submitted for Lisa Richards' doctoral studies at the University of Newcastle, and may be presented at scientific conferences. Individual participants will not be identified in any reports arising from this project. Non-identifiable data may also be shared with other parties to encourage scientific scrutiny, and to contribute to further research and public knowledge, or as required by law.

What do you need to do to participate?

Please read this Information Statement and be sure you understand its contents. If there is anything you do not understand, or you have questions, contact the researcher.

Further information

If you would like further information please contact Ms Lisa Richards on 1800 084 755 or Lisa.Richards@newcastle.edu.au.

Thank you for considering this invitation.

Dr Lisa Mackenzie
Research Fellow

Ms Lisa Richards
PhD candidate

Complaints about this research

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 16/10/19/5.11.

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, to Dr Nicole Gerrand, Manager, Research Ethics and Governance Unit, Hunter New England Human Research Ethics Committee, Hunter New England Local Health District, Locked Bag 1, New Lambton NSW 2305, telephone (02) 49214950, email Hnehrec@hnehealth.nsw.gov.au

Appendix 2.4: Patient survey

Patient Survey – Document Version 2.0; dated 06/12/2016

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Patient Survey

Thank you for taking the time to complete this survey entitled: Preparing for CT and MRI scans: Patients' information preferences and experiences

This survey should take 10 - 15 minutes to complete. If you are called in for your appointment before you have answered all of the questions, the researcher will collect the iPad from you. We will still use your answers to the questions you have completed.

- **Section A** asks about you and your scan
- **Section B** asks about your internet use
- **Section C** asks about the type of information you received about the scan
- **Section D** asks about you

If you have any questions, or would like to discuss this study further, please speak with the researcher who provided you with this iPad, or contact Ms. Lisa Richards by phone on 1800 084 755 (free call).

If any of the questions cause you distress, we encourage you to discuss your concerns with your doctor and/or contact the NSW Mental Health line on 1800 011 511 (free call).

SECTION A: ABOUT YOU AND YOUR SCAN

This section asks about you. Please circle the most appropriate response option.

A1. Are you male or female?

1 Male

2 Female

A2. What is your age?

*Please click the response box to
access the number pad and select
your age.*

____ _

A3. What is your postcode?

____ _

A4. What type of scan are you having
today?

1 CT

2 MRI

3 Don't know *(go to Section B)*

A5. Have you had this type of scan
before?

1 No, I have not had this scan before

2 Yes, less than one year ago

3 Yes, one year or more ago

4 Don't know

SECTION B: YOUR INTERNET USE

The following questions ask about your experience using the internet. Please circle the most appropriate response option.

B1.	Do you have access to the internet for personal use? <i>Personal use includes, for example, email, banking, social networking, purchasing goods or services, entertainment and educational activities.</i>	1 No (<i>progress to Section C</i>) 2 Yes
B2.	How often do you access the internet for personal use? <i>Personal use includes, for example, email, banking, social networking, purchasing goods or services, entertainment and educational activities.</i>	1 Less than once a month 2 Once a month 3 A few times a month 4 A few times a week 5 About once a day 6 Several times a day
B3.	Have you searched the internet for information to help you prepare for your scan?	1 No 2 Yes 3 Don't know

The following questions ask you for your opinion and about your experience using the Internet for health information. For each statement, please circle the response that best reflects your opinion and experience right now.

		Strongly disagree	Disagree	Undecided	Agree	Strongly agree
B4.	I know what health resources are available on the internet	1	2	3	4	5
B5.	I know where to find helpful health resources on the internet	1	2	3	4	5
B6.	I know how to find helpful health resources on the internet	1	2	3	4	5
B7.	I know how to use the internet to answer my questions about health	1	2	3	4	5
B8.	I know how to use the health information I find on the Internet to help me	1	2	3	4	5

B9.	I have the skills I need to evaluate the health resources I find on the internet	1	2	3	4	5
B10.	I can tell high quality from low quality health resources on the internet	1	2	3	4	5
B11.	I feel confident in using information from the internet to make health decisions	1	2	3	4	5

SECTION C: INFORMATION ABOUT THE SCAN

The following questions ask about information you were given **when arriving** for your scan today.

C1.	Since arriving at your appointment, have you received information about your scan?	1	No, but I wanted some information
		2	No, but I didn't want any information
		3	Yes, and I wanted this information
		4	Yes, but I didn't want this information
C2.	Since arriving at your appointment, have you received information about the risks associated with your scan?	1	No, but I wanted some information
		2	No, but I didn't want any information
		3	Yes, and I wanted this information
		4	Yes, but I didn't want this information

The next section asks about the information you were **given** by a health professional or other imaging department staff **before arriving** for your scan today. Please **do not** include information that you sourced by yourself. Please circle the answer that best reflects your experience.

	Before arriving for your scan today, were you <u>given</u> any information about:	No, but I wanted this information	No, but I didn't want this information	Yes, and I wanted this information	Yes, but I didn't want this information
C3.	Why your doctor referred you for a CT or MRI scan?	1	2	3	4
C4.	The benefits of having a CT or MRI scan?	1	2	3	4
C5.	Steps you needed to take to prepare for your scan in the day(s) before your appointment (e.g. blood tests)?	1	2	3	4
C6.	Who to speak to if you had any questions about the scan in the week(s) before your appointment?	1	2	3	4
C7.	Where to find information about any aspects related to the scan?	1	2	3	4
C8.	How to manage scan-related fear or anxiety before the scan?	1	2	3	4
C9.	What to eat or drink on the day of the scan?	1	2	3	4

	<u>Before arriving for your scan today, were you given any information about:</u>	No, but I wanted this information	No, but I didn't want this information	Yes, and I wanted this information	Yes, but I didn't want this information
C10.	Where to park in the hospital?	1	2	3	4
C11.	How to find the imaging department in the hospital?	1	2	3	4
C12.	What to bring with you to the scan appointment (e.g. prior scan results)?	1	2	3	4
C13.	Whether someone should come with you to the scan?	1	2	3	4
C14.	How long you will have to wait in the department before having the scan?	1	2	3	4
C15.	Whether you will need an injection at the scan?	1	2	3	4
C16.	What you will be asked to wear during the scan?	1	2	3	4
C17.	What the scanner looks like?	1	2	3	4
C18.	Being required to lie on a table that moves in and out of the scanner?	1	2	3	4
C19.	Who will be with you during the scan?	1	2	3	4
C20.	How the scanner takes images of the body?	1	2	3	4
C21.	What you will see during the scan?	1	2	3	4
C22.	What you will hear during the scan?	1	2	3	4
C23.	Any physical sensations you may feel during the scan?	1	2	3	4
C24.	Whether you can move during the scan?	1	2	3	4
C25.	How long the scan will take?	1	2	3	4
C26.	Any risks associated with the scan?	1	2	3	4

	<u>Before arriving</u> for your scan today, were you <u>given</u> any information about:	No, but I wanted this information	No, but I didn't want this information	Yes, and I wanted this information	Yes, but I didn't want this information
C27.	What to do if you suffer from claustrophobia? <i>Claustrophobia is a fear of confined spaces</i>	1	2	3	4
C28.	How to manage scan-related fear or anxiety <u>during</u> the scan?	1	2	3	4
C29.	How to alert the radiographer if you have questions or concerns during the scan? <i>A radiographer is a healthcare professional who specialises in imaging the body.</i>	1	2	3	4
C30.	How long you will have to stay at the department after the scan?	1	2	3	4
C31.	Whether you can drive home from the scan?	1	2	3	4
C32.	Any after-effects in the day(s) following the scan?	1	2	3	4
C33.	How to manage scan-related fear or anxiety <u>after</u> the scan?	1	2	3	4
C34.	When to expect the results of the scan?	1	2	3	4
C35.	How you will receive the results of the scan?	1	2	3	4

The following questions are about your preferences for being given information about your scan.

C36.	Who would <u>you have preferred</u> to receive <i>most</i> of the information from about preparing for your scan? <i>(Please circle one response only)</i>	1 General Practitioner / Doctor 2 Radiographer 3 Nurse 4 Physiotherapist 5 Medical Imaging Receptionist 6 Don't know 7 Other (please specify) _____
-------------	---	--

<p>C37. In what format would <u>you have preferred</u> to have receive <i>most</i> of the information about preparing for your scan?</p> <p><i>(Please circle one response only)</i></p>	<p>1 Listen to information being spoken to me</p> <p>2 Read written information</p> <p>3 Look at pictures or diagrams</p> <p>4 Look at and listen to video clips</p>
<p>C38. How long before the scan would <u>you have preferred</u> to receive <i>most</i> of the information about preparing for your appointment?</p>	<p>1 Less than one week before the scan</p> <p>2 One week or more before the scan</p>

SECTION D: ABOUT YOU

This section asks about you. Please circle the most appropriate response option.

D1.	What is your marital status?	1 Single, never married 2 Married or living with partner 3 Separated or divorced 4 Widowed
D2.	What is the highest level of education you have completed?	1 Year 10/School Certificate or lower 2 Higher School Certificate 3 Diploma / Trade Certificate 4 Bachelor degree 5 Postgraduate degree 6 Other (please specify)
D3.	In general, how much information do you like to have about your health?	1 No information 2 Some information 3 A lot of information
D4.	In general, how would you rate your overall health?	1 Poor 2 Fair 3 Good 4 Very good 5 Excellent

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If reading these questions cause you any distress, we encourage you to discuss your concerns with your doctor and/or contact the NSW Mental Health Line on Ph: 1800 011 511

END OF SURVEY

THANK YOU!

Appendix 3: Paper One

Appendix 3.1: Statements of contribution for Paper One

Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (v) completion of statistical analyses; (vi) interpretation of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

Hyde L, Mackenzie L, Boyes A, Symonds M, Brown S & Sanson-Fisher R. Medical imaging outpatients' experiences with receiving information required for informed consent and preparation: A cross-sectional study. Journal of Patient Experience 2018:1-7. doi: 10.1177/2374373518765794.

8-1-2020
Dr Lisa Mackenzie (Co-Author) Date

08/01/2020
Mrs Lisa Hyde (Candidate) Date

24/2/20
A/Prof Lesley MacDonald-Wicks (Assistant Dean Research Training) Date

Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (v) completion of statistical analyses; (vi) interpretation of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

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13/01/2020
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15/01/2020
Mrs Lisa Hyde (Candidate) Date

24/2/20
A/Prof Lesley MacDonald-Wicks (Assistant Dean Research Training) Date

Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (v) completion of statistical analyses; (vi) interpretation of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

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Date *8 January 2020*

Mrs Lisa Hyde (Candidate)

Date *09/01/2020*

24/2/20

A/Prof Lesley MacDonald-Wicks (Assistant Dean Research Training)

Date

Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (v) completion of statistical analyses; (vi) interpretation of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

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Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (v) completion of statistical analyses; (vi) interpretation of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

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24/2/20

Date

Medical Imaging Outpatients' Experiences With Receiving Information Required for Informed Consent and Preparation: A Cross-Sectional Study

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Journal of Patient Experience
2018, Vol. 5(4) 296-302
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sagepub.com/journals-permissions
DOI: 10.1177/2374373518765794
journals.sagepub.com/home/jpx
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Abstract

Background: Medical imaging outpatients often experience inadequate information provision and report high levels of anxiety. However, no studies have assessed patients' receipt of preparatory information in this setting. **Objective:** To examine medical imaging outpatients' perceived receipt or non-receipt of preparatory information from health professionals and imaging department staff prior to their procedure. **Method:** Computed tomography and magnetic resonance imaging outpatients at one Australian hospital self-completed a touchscreen computer survey assessing their perceived receipt of 33 guideline-recommended preparatory information items. **Results:** Of 317 eligible patients, 280 (88%) consented to participate. Eight percent (95% confidence interval: 5%-12%) of participants reported receiving all information items. The median number of information items not received was 18 (interquartile range: 8-25). Items most frequently endorsed as "not received" were: *how to manage anxiety after* (74%) and *during the scan* (69%). Items most commonly endorsed as "received" were: *reason for referral* (85%) and *how to find the imaging department* (74%). **Conclusion:** Few medical imaging outpatients recalled receiving recommended preparatory information. Preparatory communication needs to be improved to better meet patient-centered service imperatives.

Keywords

communication, patient education, imaging, survey data

Introduction

International medical imaging bodies endorse the importance of appropriately communicating procedural risks and benefits to patients before the point of care (1-5). Providing comprehensive preparatory information is a legal and ethical imperative, as it supports patient autonomy, quality of care, and informed patient consent (1-7). The provision of this information may also improve patient outcomes, such as reducing anxiety and distress (8). General recommendations regarding preparation for potentially threatening medical procedures highlight the need to communicate procedural, behavioral, sensory, and psychosocial information (9,10). This information refers, respectively, to the sequence of events and equipment to be used, the patient's role in facilitating the procedure, the sensations that will be felt, and the management of emotions and should relate to the time before, during, and after the procedure (9-12).

Magnetic resonance imaging (MRI) and computed tomography (CT) medical imaging outpatients are an increasing population undergoing a potentially threatening, high technology medical procedure, who require such preparatory

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information. For example, in Australia, the four year service growth rate since 2010 for MRI and CT scans was 47.4% and 29.4%, respectively (13). Similar growth has been seen internationally, including in the United States, Canada, and Turkey (14,15). Although these procedures occur frequently, they are considered potentially threatening because of their association with high levels of anxiety (16–19). Consistent with broader international literature, a recent Australian study found that 56% of MRI and 59% of CT outpatients reported raised state anxiety (using the short-form state scale of the State-Trait Anxiety Inventory) prior to undergoing their procedure (20). Such anxiety contributes to patients feeling a loss of control during the procedure (17,19). Research findings in France, the United States, and Scotland suggest that communication could be improved for these patients (16,21,22). Inadequate communication prior to diagnostic medical procedures contributes to negative patient experiences (23), and efforts are being made to enhance patient–provider communication within medical imaging settings (24–26). However, very limited research has assessed MRI and CT medical imaging outpatients' experiences with receiving preparatory information, and no Australian-based studies have been completed. Therefore, this study examined MRI and CT medical imaging outpatients' perceived receipt and non-receipt of preparatory information from health professionals and imaging department staff prior to their imaging procedure.

Methods

Design and Setting

A cross-sectional survey of medical imaging outpatients scheduled for MRI or CT examinations was conducted in one medical imaging clinic within the John Hunter Hospital located in Newcastle, New South Wales, Australia. In this setting, MRI and CT medical imaging outpatients are typically provided with mailed written preparatory information and verbal information when scheduling and attending their appointment.

Sample

Eligible patients were: (a) attending for an outpatient MRI or CT appointment at the Hunter New England Medical Imaging Department at John Hunter Hospital and (b) 18 years or older. Patients were excluded if they had (a) insufficient English language proficiency or (b) a cognitive or physical impairment that precluded informed consent and/or survey completion.

Procedure

Medical imaging receptionists identified potentially eligible patients when they presented for their appointment, informed them about the research, and invited them to speak with a trained researcher. The researcher provided interested

patients with written and verbal information about the study and gained verbal informed consent to participate. The age, gender, and scan type of non-consenting patients was recorded with their permission.

Patients who consented to participate were provided with a tablet computer and asked to self-complete an online questionnaire prior to their scan. The researcher was available to help participants who had difficulties using the tablet computer, and paper and pen versions of the questionnaire were available for those who requested it. If the patient was called for their procedure prior to finishing the questionnaire, only those questions that had been completed were used for data analysis. Ethics approval was obtained from the Human Research Ethics Committees of the Hunter New England Local Health District (16/10/19/5.11) and University of Newcastle (H-2016-0386).

Measure

Patient perceived receipt of information. Patient perceived receipt of information was measured using a series of investigator-developed items. General standards addressing patient preparation for potentially threatening medical procedures were initially used to identify the preparatory domains (ie, procedural, behavioral, sensory, and psychosocial) that items should address (9,10,27). Domain-related items were developed using these general standards (9,10,27). As this study was based in Australia, items were also informed by the Royal Australian and New Zealand College of Radiologists (RANZCR) Standards of Practice (2), consumer materials (28,29), and informed consent guidelines (1). Behavioral scientists, radiographers, and imaging department management staff initially reviewed and agreed upon the face validity of the questionnaire. This version was then reviewed by members of the general public and health professionals in the aging, disability, and nursing sector, for ease of comprehension and completion time. Minor amendments to survey item wording and screen presentation were made. The revised questionnaire was pilot-tested with patients across a two week period in the medical imaging department, which resulted in further changes to item structure and presentation. The final questionnaire included 33 items that asked participants whether they had received information from imaging department staff or health care professionals prior to arriving for the scan procedure, with response options: “no, but I wanted this information”, “no, but I didn't want this information”, “yes, but I didn't want this information”, and “yes, and I wanted this information”. This analysis was centered on patient experiences with receiving information, given the legal and ethical implications, as well as the requirement for information delivery to facilitate patient preparation. As such, “no” responses and “yes” responses were combined to indicate the non-receipt and receipt of preparatory information, respectively. The internal consistency (Kuder-Richardson

coefficient) of these dichotomized preparatory information items was 0.96 (30).

Study Factors

Sociodemographic and scan characteristics. Standard items assessed age, gender, marital status, highest level of education completed, postcode, scan type, and prior scans. Postcode was mapped to the Accessibility/Remoteness Index of Australia Plus (ARIA + 2011) classification to examine remoteness (31).

Data Analysis

The gender, age group (<65 years vs ≥ 65 years), and scan type of consenters and non-consenters were compared using chi-square tests. The median number of received and non-received items (and interquartile range [IQR]) were reported due to non-normally distributed data. The proportion of participants reporting (a) non-receipt of each information item and (b) 0 to 33 non-received information items was calculated with 95% confidence intervals (CIs). Due to an absence of theoretically or empirically sound hypotheses, this study was not powered to explore patient characteristics associated with perceived receipt or non-receipt of information.

Results

Sample

Of the 394 patients considered for the study during the six week recruitment period, 317 were eligible and invited to speak with the researchers. Of eligible patients, 280 (88%) consented to take part in the study. There was no significant difference between consenters and non-consenters based on gender ($\chi^2 = 2.200$; $P = .138$) and age group ($\chi^2 = 0.003$; $P = .956$). Significantly more CT patients than MRI patients declined the study participation invitation ($\chi^2 = 6.565$; $P = .010$). Of consenting participants, 273 (98%) started the survey, 234 (84%) started "information received" items, 218 (78%) completed these items, and 208 (74%) completed all survey items. There were no significant differences in participant characteristics between those who did and did not complete all survey items (gender: $\chi^2 = 0.614$, $P = .433$; age: $\chi^2 = 0.537$, $P = .464$; scan: $\chi^2 = 0.095$, $P = .758$). Table 1 provides a summary of the sociodemographic and scan characteristics of participants who started the survey.

Self-Reported Non-Receipt of Preparatory Information Items

The median number of preparatory information items received was 15 (IQR 8-25) and non-received information items was 18 (IQR 8-25). Eight percent (95% CI: 5%-12%) of participants reported receiving all preparatory information items, whereas 69% (95% CI: 63%-75%) reported not having received at least 10 information items, and 45% (95% CI:

Table 1. Participant Sociodemographic, Scan, and Information Preference Profile.^a

Characteristic	n (%)
Mean years of age (SD)	57 (14)
Gender	
Male	130 (48%)
Female	142 (52%)
Marital status	
Married or living with partner	133 (63%)
Single or never married	28 (13%)
Divorced or separated	34 (16%)
Widowed	17 (8%)
Education completed	
High school or less	195 (71%)
More than high school	78 (29%)
Geographic location	
Metropolitan	209 (78%)
Nonmetropolitan	59 (22%)
Scan type	
CT	108 (40%)
MRI	157 (59%)
Don't know	3 (1%)
Prior scans	
Not had scan before	66 (25%)
Had scan <1 year ago	93 (35%)
Had scan ≥ 1 year ago	97 (37%)
Don't know	8 (3%)

Abbreviations: CT, computed tomography; MRI, magnetic resonance imaging; SD, standard deviation.

^aN = 273, completed at least 1 item. Item sample sizes vary due to missing data.

39%-52%) reported not having received at least 20 information items. As shown in Table 2, the proportion of respondents who reported not having received each preparatory information item from health professionals prior to their scan ranged between 15% and 74%.

Discussion

This study explored patient experiences in relation to preparatory information communication in an Australian medical imaging setting. MRI and CT medical imaging outpatients perceived that they received approximately half of the assessed preparatory information items from health professionals and imaging department staff prior to their scan. These findings suggest that future improvements are needed to better meet patient-centered, legal, and ethical imperatives associated with preparatory information delivery.

Most Patients Received Information About Scan Type, Reason for Referral, and Appointment Practicalities

Consistent with Chesson et al.'s (2002) Scottish cross-sectional study of 372 medical imaging outpatients, which reported that 82% of respondents were aware of why their examination was required, 85% of participants in this study

Table 2. Prevalence of Patient Perceived Nonreceipt of Preparatory Information Items.^a

Rank	Item	Prevalence of Patient Perceived Non-Receipt of Preparatory Information Items
1	How to manage scan-related fear or anxiety after the scan?	150 (74%)
2	How to manage scan-related fear or anxiety during the scan?	151 (69%)
3	Who will be with you during the scan?	149 (66%)
4	How to manage scan-related fear or anxiety before the scan?	151 (65%)
	What you will see during the scan?	147 (65%)
6	Any after-effects in the day/s following the scan?	129 (63%)
	Whether someone should come with you to the scan?	144 (63%)
8	Where to find information about any aspects related to the scan?	144 (62%)
9	How to alert the radiographer if you have questions or concerns during the scan?	135 (61%)
10	How the scanner takes images of the body?	132 (59%)
12	Any physical sensations you may feel during the scan?	130 (58%)
	Whether you can drive home from the scan?	127 (58%)
14	What to do if you suffer from claustrophobia?	125 (56%)
	How long you will have to stay at the department after the scan?	123 (56%)
15	What the scanner looks like?	124 (55%)
18	What you will hear during the scan?	122 (54%)
	Where to park in the hospital?	124 (54%)
	Whether you can move during the scan?	122 (54%)
20	When to expect the results of the scan?	105 (51%)
	What you will be asked to wear during the scan?	117 (51%)
21	Any risks associated with the scan?	113 (50%)
23	Whether you will need an injection at the scan?	102 (45%)
	Who to speak to if you had any questions about the scan in the week/s before your appointment?	104 (45%)
24	Being required to lie on a table that moves in and out of the scanner?	99 (43%)
26	How you will receive the results of the scan?	84 (41%)
	How long the scan will take?	92 (41%)
28	The benefits of having a CT or MRI scan?	86 (37%)
	How long you will have to wait in the department before having the scan?	84 (37%)

(continued)

Table 2. (continued)

Rank	Item	Prevalence of Patient Perceived Non-Receipt of Preparatory Information Items
29	Steps you needed to take to prepare for your scan in the day/s before your appointment?	80 (34%)
30	What to eat or drink on the day of the scan?	78 (33%)
31	What to bring to the scan (eg, prior scan results)?	70 (31%)
32	How to find the imaging department in the hospital?	60 (26%)
33	Why your doctor referred you for a CT or MRI scan?	35 (15%)

Abbreviations: CT, computed tomography; MRI, magnetic resonance imaging.

^aN = 234, completed at least 1 item. Item sample sizes vary due to missing data.

had received information about the reason for referral (22). Similarly, when arriving for their procedure, 99% of participants in this study were able to self-report the type of scan they were attending for. Information addressing the type and requirement for the scan was therefore received by patients, indicating appropriate service delivery in this element of preparatory communication.

At least two-thirds of patients reported they had received information that could facilitate timely appointment attendance and enhanced imaging quality: how to find the imaging department (74%), what to bring to the scan (69%), what to eat or drink (67%), and steps to prepare beforehand (66%). These findings align with a small US-based study conducted with patients undergoing diagnostic medical interventions, where a majority of participants, or their families, recalled receiving procedural (97.9%) or behavioral (100%) information about the intervention (23). Our study findings may reflect that the appointment letter received by patients specifies how to find the imaging department and what to bring to the scan. Alternatively, these findings may indicate that patients place a higher level of importance on practical aspects of preparation, which is reflected in higher rates of recall of this information. Future research is needed to assess the concordance between information delivery and patient-reported information needs, as well as the impact of patient-centered information provision on patient outcomes.

Some Imaging-Specific and General Preparatory Information Items Were Commonly Not Received

Up to 74% of respondents perceived that they *had not received* preparatory information items from medical imaging department staff or other health professionals prior to their scan. This included between 37% and 50% reporting not having received items required for informed

consent (ie, procedural risks, benefits, and who to speak to with questions), despite being recommended by RANZCR Medical Imaging Consent Guidelines (1), and literature suggesting that receipt of the right amount of such information can reduce pre-procedural anxiety (32). However, these findings mirror those of otorhinolaryngology head and neck surgery patients preparing for invasive diagnostic or therapeutic medical procedures, in which patient recall of risk-related information ranged between 35% and 54% (33). While factors including patient age, education, time since information provision, and perceived relevance of information may influence recall rates (33), these findings indicate that there is room to improve information provision prior to medical imaging procedures and current practices may not be meeting medical imaging-specific standards.

Some general standards for preparation for potentially threatening medical procedures were also commonly not met in this medical imaging setting. Despite MRI and CT medical imaging outpatients experiencing high levels of anxiety (16–18), which is associated with procedure terminations, motion artifacts, and reduced diagnostic utility of images (18,34), information on how to manage anxiety before, during, and after the scan were among the most commonly non-received items (ie, by 65%–74% of respondents). This gap in patient-reported receipt of information may be a result of misalignment between medical imaging guidelines (which do not explicitly mandate the provision of such information) (2,4,5) and broader preparatory guidelines (which do recommend the delivery of anxiety-related information) (9,10). Although Australian and international medical imaging bodies advocate the importance of emotional support and alleviation of patient anxiety (3,29,35), these findings suggest a need for standards that more clearly guide communication of psychosocial information to patients.

The pre-procedural timing of survey completion is another important consideration for information provision findings. It is likely that the information required for informed consent is provided when patients attend for their scan. Additionally, anxiety management strategies, such as telling the patient that they can press the alert buzzer if they become uncomfortable, may be provided at the point of care when presenting the scan room and equipment. However, providing information in advance of potentially threatening medical procedures has been suggested to increase patient preparation and participation in health care (36). Further research is needed to assess medical imaging outpatients' post-procedural perceptions of information provision and whether the timing of information delivery meets patients' needs. There is also a lack of clarity about what low intensity, evidence-based approaches may assist patients to self-manage imaging-related anxiety (8,37). Consequently, we are undertaking a randomized controlled trial to test the impact of an information intervention on reducing anxiety among medical imaging outpatients.

Most Imaging Patients Are Left to Self-Source Information About Their Scan

Over half (62%) of the respondents reported not being informed of where to find further information about the scan. Medical imaging outpatients who self-source information most commonly do so from family and friends, drawing the accuracy of sourced information into question (22). To ensure information seekers' needs are met by credible sources, there is a need to enhance patient awareness of reliable information materials that are developed by peak medical imaging bodies.

Limitations

This research was designed to establish current patterns of preparatory information receipt, in order to inform service-wide improvements that may benefit all MRI and CT outpatients. This study was not intended to assess preparatory information receipt among medical imaging inpatients nor was it designed to test for differences in information receipt by specific CT or MRI scan type. Although the sample size was small relative to the volume of outpatients attending the department annually, it was sufficient for detecting prevalence estimates with 95% CIs with 7% margin of error. Findings may not generalize beyond the single, large metropolitan medical imaging department study setting. However, the age and gender profile of the sample was similar to that of participants in other large Australian (38,39) and international studies (40,41) with medical imaging outpatients.

Significantly more CT patients than MRI patients refused study participation, suggesting that the sample is less representative of CT patients. This may be due to some CT patients being asked to arrive at least 15 minutes in advance of their scheduled appointment (vs 30 minutes for MRI patients), thus perceiving they have insufficient time to participate in the research prior to their scan. The exclusion of those with insufficient English to allow survey completion may have led to an underestimation of the proportion of medical imaging patients who didn't receive information items (42). Patient self-report may have been influenced by recall bias, however, patient perceptions of past communication have been suggested to influence present health behaviors (43). While further evaluation of the psychometric properties of the information receipt measure is required, item development was informed by relevant guidelines, standards, and expert views and demonstrated excellent internal consistency.

Conclusion

This study contributes important knowledge regarding key preparatory information items that are commonly received and not received by MRI and CT medical imaging outpatients, and may inform enhanced medical imaging preparation guidelines and improved forms of information delivery.

Although information relating to scan type, reason for referral, and practicalities are commonly received, these findings suggest that not all recommended preparatory information is provided to patients. Further research is needed to assess whether current information provision is aligned with patient preferences for this information and determine the impact that preparatory information has on patient outcomes.

Acknowledgments

The authors thank the patients for their involvement in this study, as well as the practice and managerial staff at Hunter New England Imaging for assistance with recruitment and data collection.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Mrs Lisa Hyde is supported by an Australian Government Research Training Program Scholarship. Dr Lisa Mackenzie is supported by a Postdoctoral Fellowship grant [PF-16-011] from the Australian National Breast Cancer Foundation. Dr Allison Boyes is supported by a National Health and Medical Research Council Early Career Fellowship [APP1073317] and Cancer Institute New South Wales Early Career Fellowship [13/ECF/1-37].

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References

1. The Royal Australian and New Zealand College of Radiologists. Medical Imaging Consent Guidelines, Version 2. Sydney, Australia: The Royal Australian and New Zealand College of Radiologists; 2013.
2. The Royal Australian and New Zealand College of Radiologists. Standards of practice for diagnostic and interventional radiology, Version 10.1. Faculty of Clinical Radiology, The Royal Australian and New Zealand College of Radiologists; 2016.
3. European Society of Radiology. Patient information. The most important stakeholder in radiology: the patient. 2017. <https://www.mysr.org/quality-safety/patient-information> (accessed 7 July 2017).
4. The Royal College of Radiologists. Standards for Patient Consent Particular to Radiology. 2nd ed. London, UK: The Royal College of Radiologists; 2012.
5. American College of Radiologists. ACR-SIR-SPR practice parameter on informed consent for Image-Guided Procedure. Res. 17. Virginia, USA: American College of Radiologists; 2016.
6. Niveltstein RA, Frush DP. Should we obtain informed consent for examinations that expose patients to radiation? *Am J Roentgenol*. 2012;199:664-9.
7. Törnqvist E, Månsson Å, Larsson EM, Hallström I. Impact of extended written information on patient anxiety and image motion artifacts during magnetic resonance imaging. *Acta Radiol*. 2006;47:474-80.
8. Munn Z, Jordan Z. Interventions to reduce anxiety, distress and the need for sedation in adult patients undergoing magnetic resonance imaging: a systematic review. *Int J Evid Based Healthc*. 2013;11:265-74.
9. Cockburn J; N.S.W. Cancer Council. How to Prepare Patients for Potentially Threatening Clinical Procedures: An Interactional Skills Training Manual for General Practitioners, Junior Medical Officers, Nurses, Surgeons. Kings Cross, Australia: N. S.W. Cancer Council; 1997.
10. Schofield MJ, Sanson-Fisher R. How to prepare cancer patients for potentially threatening medical procedures: Consensus Guidelines. NSW Cancer Council Cancer Education Research Program. *J Cancer Educ*. 1996;11:153-8.
11. Powell R, Scott NW, Manyande A, Bruce J, Vögele C, Byrne-Davis LM, et al. Psychological preparation and postoperative outcomes for adults undergoing surgery under general anaesthesia. *Cochrane Database Syst Rev*. 2016;CD008646.
12. Henwood SM, Munro L. Principles of communication. In: Ramlal A, Vosper M, eds. *Patient Centered Care in Medical Imaging and Radiotherapy*. London, UK: Churchill Livingstone; 2013:3-6.
13. Department of Health and Ageing. Review of funding for diagnostic imaging services: Final Report. Canberra, Australia: Department of Health and Ageing; 2011.
14. Organisation for Economic Co-operation and Development. Health at a Glance 2015: Organisation for Economic Co-operation and Development Indicators. Paris, France: Organisation for Economic Co-operation and Development; 2015.
15. Organisation for Economic Co-operation and Development. Geographic Variations in Health Care: What Do We Know and What Can Be Done to Improve Health System Performance? Paris, France: Organisation for Economic Co-operation and Development Health Policy Studies; 2014.
16. Ollivier L, Apiou F, Leclerc J, Sévellec M, Asselain B, Brédart A, et al. Patient experiences and preferences: development of practice guidelines in a cancer imaging department. *Cancer Imaging*. 2009;9: S92-97.
17. Heyer CM, Thuring J, Lemburg SP, Kreddig N, Hasenbring M, Dohna M, et al. Anxiety of patients undergoing CT imaging—an underestimated problem? *Acad Radiol*. 2015;22:105-12.
18. Dewey M, Schink T, Dewey CF. Claustrophobia during magnetic resonance imaging: cohort study in over 55,000 patients. *J Magn Reson Imaging*. 2007;26:1322-7.
19. Törnqvist E, Månsson A, Larsson EM, Hallström I. It's like being in another world—patients' lived experience of magnetic resonance imaging. *J Clin Nursing*. 2006;15:954-61.
20. Forshaw K, Boyes A, Carey M, Hall A, Symonds M, Brown S, et al. Raised anxiety levels among outpatients preparing to undergo a medical imaging procedure: prevalence and correlates. *J Am Coll Radiol*. 2018;S1546-1440:31675-7.
21. Thornton RH, Dauer LT, Shuk E, Carma LB, Smita CB, Erin M, et al. Patient perspectives and preferences for communication of medical imaging risks in a cancer care setting. *Radiology*. 2015;275:545-52.

22. Chesson RA, McKenzie GA, Mathers SA. What do patients know about ultrasound, CT and MRI? *Clin Radiol*. 2002;57:477-82.
23. Jacob DA, Franklin L, Bernstein B, Pall H. Results from a patient experience study in pediatric gastrointestinal endoscopy. *J Patient Exp*. 2015;2:23-8.
24. Creagh C, Flamm SD, Madonia H, O'Keefe P, Ricaurte F, Triner J. Cleveland clinic imaging institute's "commitment to respect" and impact on quality of care and patient satisfaction. *J Patient Exp*. 2017;4:88-94.
25. Williams G, Greene S. From analogue to apps—developing an app to prepare children for medical imaging procedures. *J Vis Commun Med*. 2015;38:168-76.
26. Bolejko A, Sarvik C, Hagell P, Brinck A. Meeting patient information needs before magnetic resonance imaging: development and evaluation of an information booklet. *J Radiol Nurs*. 2008;27:96-102.
27. Forshaw KL, Carey ML, Hall AE, Boyes AW, Sanson-Fisher R. Preparing patients for medical interventions: a systematic review of the psychometric qualities of published instruments. *Patient Educ Couns*. 2016;99:960-73.
28. The Royal Australian and New Zealand College of Radiologists. Computed tomography: Consumer Information. 2015. <http://www.ranzcr.edu.au/resources/consumers> (accessed 26 June 2016).
29. The Royal Australian and New Zealand College of Radiologists. Magnetic resonance imaging (MRI): Consumer Information. 2015. <http://www.ranzcr.edu.au/resources/consumers> (accessed 26 June 2016).
30. Kuder GF, Richardson MW. The theory of the estimation of test reliability. *Psychometrika*. 1937;2:151-60.
31. Hugo Centre for Migration and Population Research. ARIA (Accessibility/Remoteness Index of Australia). Adelaide, Australia: The University of Adelaide; 2005.
32. Yucel A, Gecici O, Emul M, Oyar O, Gulsoy UK, Dayanir YO, et al. Effect of informed consent for intravascular contrast material on the level of anxiety: how much information should be given? *Acta Radiol*. 2005;46:701-7.
33. Laccourreye O, Garabedian EN, Samad MA, Dubreuil C. Medical information prior to invasive medical procedures in otorhinolaryngology-head and neck surgery in France. *Eur Ann Otorhinolaryngol Head Neck Dis*. 2012;129:38-43.
34. Thompson MB, Coppens NM. The effects of guided imagery on anxiety levels and movement of clients undergoing magnetic resonance imaging. *Holist Nurs Pract*. 1994;8:59-69.
35. Itri JN. Patient-centered radiology. *Radiographics*. 2015;35:1835-46.
36. Waller A, Forshaw K, Bryant J, Carey M, Boyes A, Sanson-Fisher R. Preparatory education for cancer patients undergoing surgery: a systematic review of volume and quality of research output over time. *Patient Educ Couns*. 2015;98:1540-9.
37. Munn Z, Jordan Z. The effectiveness of interventions to reduce anxiety, claustrophobia, sedation and non-completion rates of patients undergoing high technology medical imaging. *JBI Libr Syst Rev*. 2012;10:1122-85.
38. Gibson DA, Moorin RE, Holman CDAJ. Cohort study of Western Australia computed tomography utilisation patterns and their policy implications. *BMC Health Serv Res*. 2014;14:526.
39. Gibson DA, Moorin RE, Semmens J, Holman DJ. The disproportionate risk burden of CT scanning on females and younger adults in Australia: a retrospective cohort study. *Aust N Z J Public Health*. 2014;38:441-8.
40. Boone JM, Brunberg JA. Computed tomography utilization in a tertiary care university hospital. *J Am Coll Radiol*. 2008;5:132-8.
41. Davales AC, da Rosa LA, Kesminiene A, Pearce MS, Veiga LH. Patterns and trends of computed tomography usage in outpatients of the Brazilian public healthcare system, 2001-2011. *J Radiol Prot*. 2016;36:547-60.
42. Schenker Y, Wang F, Selig SJ, Ng R, Fernandez A. The impact of language barriers on documentation of informed consent at a hospital with on-site interpreter services. *J Gen Intern Med*. 2007;22:294-9.
43. Sutherland J. Patient information in radiation therapy: strategies to meet patient needs. *J Radiation Oncol*. 2014;3:223-8.

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Michael Symonds has over 30 years experience in both public and private sector health, in clinical, management and leadership roles, and has previously held the position of Director, Hunter New England Imaging and BreastScreen.

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Appendix 4: Paper Two

Appendix 4.1: Statements of contribution for Paper Two

Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (vi) interpretation of statistical analyses; (vii) identification of study findings; and (viii) manuscript development and submission, to the paper/publication entitled:

Hyde L, Mackenzie L, Boyes A, Evans T, Symonds M & Sanson-Fisher R. Prevalence and correlates of patient-centred preparatory information provision to computed tomography and magnetic resonance imaging outpatients: A cross-sectional study. Patient Education and Counseling 2018; 101(10):1814-1822. doi: 10.1016/j.pec.2018.05.025

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By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (vi) interpretation of statistical analyses; (vii) identification of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

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Statement of Contribution

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Appendix 4.2: Paper Two

Patient Education and Counseling 101 (2018) 1814–1822



Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou



Prevalence and correlates of patient-centred preparatory information provision to computed tomography and magnetic resonance imaging outpatients: A cross-sectional study

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ARTICLE INFO

Article history:

Received 12 September 2017

Received in revised form 23 May 2018

Accepted 30 May 2018

Keywords:

Computed tomography

Cross-sectional study

Information preferences

Magnetic resonance imaging

Patient-centred care

ABSTRACT

Objective: Responsiveness to information preferences is key to high-quality, patient-centred care. This study examined the top ten preparatory information items not delivered in accordance with medical imaging outpatients' preferences, and patient characteristics associated with reporting a greater number of unmet information preferences.

Methods: Magnetic resonance imaging and computed tomography outpatients were recruited consecutively in one major public hospital waiting room. Participants self-administered a touchscreen computer questionnaire assessing their sociodemographic and scan characteristics, and unmet preferences for 33 guideline-endorsed preparatory information items.

Results: Of 317 eligible patients, 280 (88%) consented to participate. Given equal rankings, the top ten unmet information preferences included 13 items which were endorsed by at least 25% of participants, and commonly related to receiving 'too little' information. One item related to the pre-scan period, seven items to the scan period and five items to the post-scan period. None of the patient characteristics examined were significantly associated with reporting a greater number of unmet information preferences.

Conclusion: There is room to improve responsiveness to medical imaging outpatients' preparatory information preferences. Improvements should be targeted at individuals, rather than groups defined by sociodemographic or scan characteristics.

Practice Implications: A standardised approach to addressing individual patient's information preferences is needed.

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1. Introduction

1.1. How can we assess whether health information provision is patient-centred?

A key pillar of high-quality patient-centred care is responsiveness to patient needs, values and preferences [1–3]. This includes the delivery of patients' preferred format, amount and timing of health-related information [1–3]. Patient-centred communication

styles are typically associated with higher rates of patient satisfaction than more paternalistic, provider-centred approaches [4,5], and may lead to improved health outcomes, including enhanced medical decision-making, and improved physical and emotional health [6,7]. Whilst it is increasingly acknowledged that information should be made available to patients in a variety of formats, less is known about how to improve responsiveness to patient's preferences for *amount* of information, including how much information patients want at key points in the trajectory of care [3,8]. Patients who receive less information than they want can be characterised as having an unmet information need, whilst patients who receive either too much or too little information can be characterised as having an unmet information preference. Too little information can result in heightened anxiety and distress

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<https://doi.org/10.1016/j.pec.2018.05.025>

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[9,10], and too much information can overwhelm patients and increase anxiety levels [11,12]. As such, assessment of patient's unmet information preferences can help to identify areas where patient-centred communication could be improved. Despite this, research has tended to focus on patients' unmet information needs [13–16].

1.2. Does patient-centred information provision vary by patient subgroup?

Studies in oncology and rheumatology settings have indicated that patients' unmet needs for more information vary according to patient characteristics such as age [14–17], stage of illness [17–19] and physical functioning [14,16,17]. The assessment of factors associated with a greater number of unmet information preferences is important for informing the development of targeted strategies to improve care, yet remains under-studied. Furthermore, despite findings which suggest that the most frequent information needs are treatment-related [19], little research has been conducted with general populations undergoing anxiety-provoking medical procedures. The research that has been conducted commonly focuses on preparatory information provision prior to surgery [20–24]. There is a need for research assessing patient-centred information delivery relating to other potentially threatening medical procedures.

1.3. Is preparatory information provision prior to medical imaging procedures patient-centred?

Adequate communication of preparatory information prior to potentially threatening medical procedures is important, as it allows the patient to anticipate what is coming and reassures them of the normality of their experience [9]. Preparatory information should address procedural, sensory, psychosocial and behavioural aspects of care, which refers, respectively, to the sequence of events and equipment to be used, sensations that will be felt, management of emotions and patient's role in facilitating the procedure [25–27]. The number of patients undergoing potentially threatening medical imaging procedures, such as magnetic resonance imaging (MRI) and computed tomography (CT) scans, has increased over time [28]. These procedures are associated with high anxiety levels [29,30] which has been suggested to increase procedure delays or terminations, and resultantly impacts on patient wellbeing, and service timeliness, coordination and quality [31,32]. However, little research assesses whether information provision aligns with patient preferences in this setting. Thornton and colleagues' USA-based qualitative study of cancer patients found that participants often wanted a wide range of medical imaging information yet were regularly left to initiate these discussions themselves [33]. Similarly, Ollivier and colleagues reported that French cancer patients undergoing MRI and CT scans needed greater reassurance and procedural explanations [30]. These findings highlight that most of the research in this area has focused on cancer and emphasise the need for studies assessing unmet information preferences across general CT and MRI outpatient settings. This research should identify specific information items commonly reported as unmet preferences, so that findings translate to clearly defined areas for future practice improvement.

This study aims to identify, among MRI and CT medical imaging outpatients:

1. The ten most prevalent preparatory information content items reported as unmet information preferences (i.e. participants perceived they were given too little or too much information); and

2. Sociodemographic, scan and information preference characteristics associated with reporting a greater number of unmet information preferences.

2. Methods

2.1. Design and setting

A cross-sectional survey of CT and MRI medical imaging outpatients was conducted over six weeks in one medical imaging clinic in the John Hunter Hospital located in Newcastle, NSW, Australia. This study is reported in accordance with the STROBE checklist of observational studies in epidemiology [34].

2.2. Participants

Eligible participants were: (i) attending for an outpatient CT or MRI appointment at the Hunter New England Medical Imaging Department at John Hunter Hospital; and (ii) 18 years or older. Inclusion was not restricted to specific medical conditions being investigated by these diagnostic scans. Participants were excluded if they (i) had poor English proficiency as determined by medical imaging reception staff; or (ii) had a cognitive or physical impairment precluding informed consent and/or survey completion.

2.3. Procedure

Medical imaging receptionists identified potentially eligible patients presenting for their appointment, informed them about the research and invited them to speak with a trained researcher. The researcher provided interested patients with written and verbal study information, and gained verbal consent to participate. The age, gender and scan type of non-consenting patients was recorded with their permission.

Patients who consented to participate were provided with a tablet computer and asked to self-complete an online questionnaire prior to their scan. The researcher was available to help participants who had difficulties using the tablet computer, and paper-and-pen versions of the questionnaire were available upon request. If the patient was called for their procedure prior to finishing the questionnaire, only those questions that had been completed were analysed. Ethics approval was obtained from the Human Research Ethics Committees of the Hunter New England Local Health District (16/10/19/5.11) and University of Newcastle (H-2016-0386).

2.4. Unmet information preferences measure

2.4.1. Development

Unmet information preferences were measured using a series of investigator-developed items. General standards addressing patient preparation for potentially threatening medical procedures were initially used to identify preparatory domains (i.e. procedural, behavioural, sensory, psychosocial) that items should address [25–27]. Domain-related items were developed using these general standards [25–27], as well as Royal Australian and New Zealand College of Radiologists (RANZCR) Standards of Practice [35], consumer materials [36,37] and informed consent guidelines [38]. The items were applicable to patients having MRI or CT scans. Behavioural scientists, radiographers and health administrators initially reviewed and agreed upon the face validity of the questionnaire.

2.4.2. Pilot testing

Members of the general public and health professionals in the ageing, disability and nursing sector reviewed the questionnaire for item comprehension and completion time. Minor amendments to item wording and screen presentation were made based on the feedback. Prior to data collection, the revised questionnaire and recruitment protocol were tested with 134 MRI and CT outpatients [mean years of age (SD) = 53.6 (15.8); 61% female; 51.6% MRI] in the medical imaging department over a two week period. This timeframe ensured that the recruitment protocol was appropriately tested given high rotation of medical imaging receptionists in the study setting. Further changes to item structure and presentation were made.

2.4.3. Final version

The final questionnaire included an explanation indicating that the items related to information that participants were given by a health professional or other imaging department staff before arriving for their scan. The item stem "Before arriving for your scan today, were you given any information about . . .", was followed by a list of 33 items of information (refer Appendix A). Participants were asked to respond either: 'no, but I wanted this information', 'no, but I didn't want this information', 'yes, but I didn't want this information', and 'yes, and I wanted this information'. Item presentation was randomised using computer algorithms to reduce systematic bias in missing data and account for potential order effects [39]. An unmet information preference was defined as items where there was discordance between patient preferences and experiences [40]. Responses indicating the receipt of too little (no, but I wanted this information) and too much (yes, but I didn't want this information) information were therefore combined to indicate an unmet information preference. The internal consistency (Kuder-Richardson coefficient) of these dichotomised information items was 0.94 [41].

2.5. Study factors

Sociodemographic, scan and information preference characteristics included: age, gender, residential postcode, scan type, prior

scans, marital status, highest level of education completed, perceived overall health, and preference for amount of health information. Postcode was mapped to the Accessibility/Remoteness Index of Australia Plus (ARIA + 2011) classification to examine remoteness [42], and categorised as metropolitan (major cities of Australia) or non-metropolitan (inner regional, outer regional, remote or very remote Australia).

2.6. Data analysis

To investigate consent bias, the gender, age group (< 65 years; ≥ 65 years) and scan type of consenters and non-consenters were compared using chi-squared tests. To investigate sampling bias, t-tests and chi-squared tests were used to compare the gender, age, scan type and geographic location profile of participants, versus all patients seen in the department during the study period. The proportion of participants reporting an unmet information preference for each item was calculated with 95% confidence intervals (CIs). The distribution of total number of unmet information preferences for all participants who had completed all 33 items (i.e. all items with non-missing values) were summarised as percentages. Data for patients having MRI and CT scans were analysed together, however scan type was included as a study factor in regression analyses. Zero-inflated negative binomial regression was used to model the counts of unmet preferences across 33 items. This model was used due the possibility that zeros occur by two different methods and due to over dispersion of the count outcome variable. Model fit was assessed using the Vuong test and the likelihood ratio test for the over dispersion coefficient $\alpha = 0$. A zero-inflated model assumes that the zero outcome may be due to two different processes. The same predictors were used to model the counts and the excess zeros: gender, age (< 65 years; ≥ 65 years), marital status (married or living with partner; not married or living with partner), geographic location (metropolitan; non-metropolitan), education (high school or less; more than high school), information amount preference (not a lot of information; a lot of information), overall health (poor or fair; good or better than good), scan type (MRI; CT), and prior scans (had scan before; don't know or not had

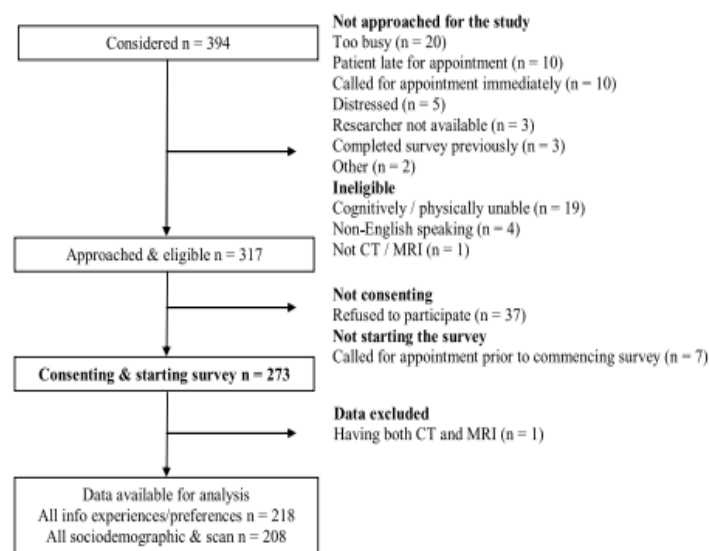


Fig. 1. Flow diagram of recruitment.

scan before). Available case analysis was conducted. All analyses used a significance level of 5%. Analysis was conducted using STATA Version 13.1.

2.7. Sample size

Sample size was calculated based on an intent to dichotomise the outcome variable, for which a sample size of 200 would be sufficient to detect differences of approximately 20% in characteristics between those who were classified as having at least one unmet preparatory information preference (versus no unmet preparatory information preferences) with 80% power and a 5% significance level. However, after data collection, the analysis was refined to investigate the more meaningful and quantitative outcome of number of unmet information preferences. Modelling of a count outcome is generally more powerful than a binary outcome and this change is expected to have increased the statistical power of the study.

3. Results

3.1. Sample

Of the 394 patients considered for the study during the six week recruitment period, 317 were eligible and invited to speak with the researcher (Fig. 1). Of eligible patients, 280 (88%) consented to participate, 273 (86%) started the full survey, and 234 (74%) started information preference items. There was no significant difference between consenters and non-consenters based on gender and age group. Significantly more CT patients than MRI patients did not consent to participate ($\chi^2 = 6.565$; $p = 0.010$). The gender, age, scan type and geographic location of participants who commenced the survey was not significantly different from that of all potentially eligible patients seen in the department during the study period

(Table 1). Two hundred and eighteen (78%) participants completed all of the unmet information preference items and 208 (74%) completed the full questionnaire. There were no significant differences in gender, age and scan type between those who did and did not complete the full questionnaire. Table 1 provides a summary of the sociodemographic and scan characteristics of the included sample.

3.2. Top 10 ranked preparatory information items reported as unmet information preferences

Each of the top ten ranked information items delivered in discordance with patient preferences were endorsed by at least one quarter of participants (Table 2). Five of these commonly unmet information preference items were procedural, four behavioural, two psychosocial and two sensory. Of the thirteen items reported as the most common unmet information preferences, one related to the pre-scan period, seven to the scan period and five to the post-scan period. Across the 33 information items, the proportion of respondents reporting unmet information preferences ranged from 12%–33%. Among those reporting unmet information preferences, the proportion receiving too little information ranged from 38%–90%, while the proportion receiving too much information ranged from 10%–62%.

3.3. Characteristics associated with reporting a greater number of unmet information preferences

Fig. 2 shows the distribution of number of unmet information preferences as a percentage of the 218 participants who completed all 33 items. Twenty five percent of participants reported no unmet information preferences ($n = 54$; 95% CI 19%–31%). The Table 3 zero inflated negative binomial model (count equation) shows that there was no significant association between participants'

Table 1
Participant sociodemographic, scan and information preference profile.

Characteristic		Participants who commenced the survey ($n = 273^a$)	Potentially eligible patients seen in the department during the study period ($n = 754$)	Test statistic, p
			n (%)	
Mean years of age, (SD)		57 (14)	55 (17)	$t = 1.72$
Gender	Male	130 (48%)	352 (47%)	$p = 0.08$
	Female	142 (52%)	402 (53%)	$\chi^2 = 0.75$
Marital status	Married or living with partner	133 (63%)	–	$p = 0.10$
	Single or never married	28 (13%)	–	–
	Divorced or separated	34 (16%)	–	–
	Widowed	17 (8%)	–	–
Education completed	High school or less	195 (71%)	–	–
	More than high school	78 (29%)	–	–
Geographic location	Metropolitan	209 (78%)	557 (74%)	$\chi^2 = 1.55$
	Non-metropolitan	59 (22%)	197 (26%)	$p = 0.21$
Overall health	Fair or worse	151 (55%)	–	–
	Good or better than good	122 (45%)	–	–
Scan type	CT	108 (40%)	329 (44%)	$\chi^2 = 0.66$
	MRI	157 (59%)	425 (56%)	$p = 0.41$
	Don't know	3 (1%)	–	–
Scan experience	Not had scan before	66 (25%)	–	–
	Had scan <1 year ago	93 (35%)	–	–
	Had scan ≥ 1 year ago	97 (37%)	–	–
	Don't know	8 (3%)	–	–
Information amount preferences	Not a lot of information	121 (44%)	–	–
	A lot of information	152 (56%)	–	–

^a Not all items add to 273 due to missing data from incomplete surveys.

Table 2Top ten ranked items for which CT and MRI medical imaging outpatients reported not receiving their preferred amount of information (n = 234^a).

Rank	Item	Domain	Unmet preference option endorsed		Sum of unmet preference percentages ^b
			No, but I wanted this information "Too little information"	Yes, but I didn't want this information "Too much information"	
			n (%)	n (%)	
1	When to expect the results of the scan?	Procedural	61 (28%)	10 (5%)	71 (33%)
2	How to alert the radiographer if you have questions or concerns during the scan?	Behavioural	59 (27%)	10 (5%)	69 (32%)
3	How you will receive the results of the scan?	Procedural	51 (23%)	15 (7%)	66 (30%)
4	Whether you can drive home from the scan?	Behavioural	50 (23%)	13 (6%)	63 (29%)
5	How to manage scan-related fear or anxiety during the scan?	Psychosocial	49 (22%)	12 (6%)	61 (28%)
	Any after-effects in the day/s following the scan?	Sensory	54 (25%)	6 (3%)	60 (28%)
7	How long you will have to stay at the department after the scan?	Behavioural	48 (22%)	12 (5%)	60 (27%)
8	Where to find information about any aspects related to the scan?	Behavioural	43 (18%)	15 (6%)	58 (25%)
	Any risks associated with the scan?	Procedural	44 (20%)	13 (5%)	57 (25%)
	What you will see during the scan?	Sensory	39 (17%)	17 (8%)	56 (25%)
	What to do if you suffer from claustrophobia?	Psychosocial	36 (16%)	20 (9%)	56 (25%)
	How long the scan will take?	Procedural	38 (17%)	18 (8%)	56 (25%)
	What you will be asked to wear during the scan?	Procedural	40 (18%)	16 (7%)	56 (25%)

^a Not all items were completed by 234 participants due to missing data.^b Percentages don't add to 100% due to met preference responses being omitted.

sociodemographic and scan characteristics, and reporting a greater number of unmet information preferences. The inflation model shows that there was no significant association between participants' sociodemographic and scan characteristics, and reporting zero unmet information preferences. Despite this, the Vuong test indicated that the zero inflated model was an improvement over the standard negative binomial model ($p = 0.004$). The test for $\alpha = 0$ was highly significant ($p < 0.001$) indicating that the model was more appropriate than Poisson.

4. Discussion and conclusion

Patient-centred care is a strategic priority across peak Australian and international medical imaging bodies [43,44]. This study is the first to assess the extent to which preparatory information delivery meets the preferences of patients attending a large, Australian metropolitan medical imaging department. Whilst patient-centred care is important for quality improvement within diagnostic services [43,44], this study found that there is room to improve responsiveness to individual patient's preferences for information across all assessed sociodemographic and scan characteristics.

4.1. Which information items are most commonly not delivered in accordance with patient preferences?

4.1.1. Patients more commonly receive too little information, as opposed to too much information

MRI and CT medical imaging outpatients more commonly reported receiving too little information relating to the "top ten" unmet information preferences, as opposed to too much information. This aligns with earlier findings indicating that many benefit and risk-related information items are reported as not received across medical imaging patients [33]. Collectively these findings suggest that efforts are needed to ensure that those who want information are receiving it. Provider responsiveness to those who don't want information comes with greater complexity, as legal and ethical imperatives mandate the provision of certain information items for informed consent [38]. Obligations at the patient- and service- level are therefore not always aligned, and it is not always possible to provide all information in a patient-centred manner. Further efforts are needed to ensure improved responsiveness to patient preferences for information, where legally and ethically appropriate.

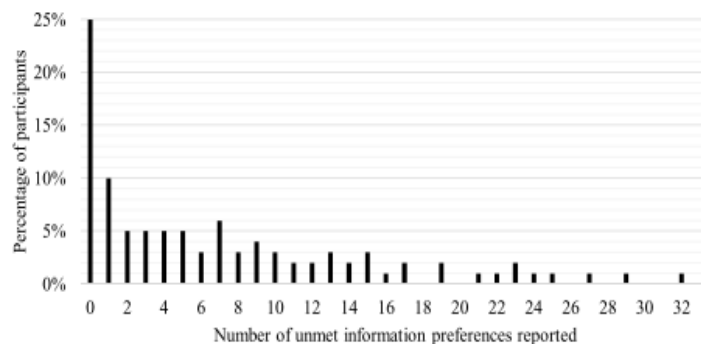
**Fig. 2.** Proportion of participants reporting 0–33 unmet preferences for preparatory information content items (n = 218).

Table 3

Zero-inflated negative binomial regression of sociodemographic and scan characteristics associated with reporting a greater number of unmet information preferences (n = 208).

Variable	Count equation (IRR for number of unmet needs)		Inflation (binary) equation (Odds of zero count)	
	IRR ^a (95% CI)	p	OR ^b (95% CI)	p
Gender				
Male	1.00		1.00	
Female	1.15 (0.84 – 1.60)	0.38	0.64 (0.24 – 1.70)	0.37
Age				
Less than 65 years	1.00		1.00	
65 years or older	0.80 (0.54 – 1.17)	0.25	2.20 (0.72 – 6.68)	0.16
Marital status				
Married / living with partner	1.00		1.00	
Not married / living with partner	1.27 (0.91 – 1.76)	0.16	0.84 (0.31 – 2.24)	0.73
Geographic location				
Metropolitan	1.00		1.00	
Non-metropolitan	1.26 (0.86 – 1.84)	0.24	2.36 (0.90 – 6.17)	0.08
Education				
High school or less	1.00		1.00	
More than high school	0.99 (0.72 – 1.37)	0.96	0.97 (0.36 – 2.60)	0.96
Information amount preference				
Not a lot of information	1.00		1.00	
A lot of information	0.78 (0.55 – 1.12)	0.18	0.58 (0.22 – 1.54)	0.28
Overall health				
Fair or worse	1.00		1.00	
Good or better than good	0.91 (0.66 – 1.26)	0.57	1.82 (0.65 – 5.08)	0.25
Scan				
CT	1.00		1.00	
MRI	0.78 (0.55 – 1.10)	0.16	3.86 (0.82 – 18.06)	0.09
Scan experience				
Not had scan before / don't know	1.00		1.00	
Had scan before	0.74 (0.51 – 1.08)	0.12	1.02 (0.33 – 3.18)	0.97

^a Incidence rate ratio.^b Odds ratio.

4.1.2. The most frequently endorsed unmet information preferences related to all types of preparatory information

All preparatory domains (i.e. procedural, behavioural, sensory, psychosocial) were represented in the “top ten” unmet information preference items, suggesting that limited responsiveness to patient preferences is not isolated to one information type. Unmet preferences across multiple preparatory domains has also been reported in other research, particularly amongst those undergoing potentially threatening medical procedures [45–47]. Mackenzie and colleagues’ study of radiation oncology outpatients, found that better care could be provided with respect to information about patients’ cancer (procedural and behavioural information), emotional and spiritual support (psychosocial information) and management of physical symptoms (behavioural information) [45]. A holistic approach to providing preparatory information is important, as such information has been found to work synergistically [9], and therefore unmet preferences in one preparatory domain may reduce the effectiveness of information provision within another domain. Hence, strategies are needed to concurrently respond to individual patient preferences for information across the behavioural, procedural, sensory and psychosocial aspects of care. This is increasingly difficult given time and resource constraints impacting healthcare delivery [48] and indicates a requirement for standardised approaches that ensure holistic patient-centred information provision.

4.1.3. Information about the time during and after the scan was most commonly not delivered in accordance with patient preferences

Our findings indicate that unmet information preferences often relate to the procedural and post-procedural period. It is possible that information relating to the time during and after the scan is

provided at the point of care, however this does not reflect best-practice recommendations [35,49], and is not meeting patients’ expressed need for information prior to their examination. Early information provision, addressing all phases of the procedure, is important as many patients experience high anxiety levels before their procedure [30], and information at this time can empower the patient, facilitate active care management [24] and allow them to anticipate what is coming [50]. Greater efforts are therefore needed to ensure prompt responsiveness to patient preferences for information relating to the whole trajectory of care, from referral to receipt of results.

4.2. Which patient characteristics are associated with having a greater number of unmet information preferences?

Surprisingly, none of the sociodemographic or scan characteristics examined in this study were associated with the number of unmet information preferences reported. Whilst mixed findings exist regarding factors associated with unmet information needs in other fields of research [14–19], findings relating to the health status measure used in this study did not support the link between physical and psychological health status and unmet need that has been reported across other settings and patient groups [14,16,17,51]. Adult, adolescent and young adult patients across oncology and rheumatology settings have been reported to experience a higher number of unmet information and service needs when experiencing poorer physical health or requiring psychological support [14,16,51]. The discrepancy between existing supportive care literature and our findings may be attributable to measurement differences, with the majority of studies focused on unmet information needs [14,16,17,51], as opposed to unmet information preferences.

Of the small number of studies assessing patient-perceived receipt of too much information [52–55], few examine patient characteristics associated with unmet information preferences (i.e. by examining the receipt of too much and too little information in combination). Zucca and colleagues examined the correlates of oncology patients' perceived receipt of too much or too little life expectancy information [52]. Particular patient characteristics were related to perceived receipt of too much information (e.g. stage of illness, being younger) and too little information (e.g. stage of illness, being anxious or depressed). Although, as is commonly the case across the field, too much and too little information were examined separately rather than in combination [52], hence limiting capacity for comparisons with this study. Zucca and colleagues' findings [52] do, however, indicate that other factors which we did not examine, such as psychological distress and illness progression (where applicable), may be related to unmet information preferences. These factors, as well as those relevant to the delivery and receipt of information but not examined in our study (e.g. quality of referrer, health condition under examination), may warrant further investigation.

Multiple approaches can, and have been, used to assess patient-centred communication, including observation, physician and student experiences, and patient perception questionnaires [40]. Whilst patient self-report has potential limitations, such as possible recall bias or patient misunderstanding, it is recommended as the gold standard measure in this field, as the patient is conceivably the best person to assess whether their preferences have been met [40,56]. The current study, and others [52], attempt to capture the mismatch between preferred and actual information delivery concurrently in a single self-report scale (as opposed to comparing agreement between two measures), hence reducing participant burden. This approach builds on unmet needs and preference literature and has promise, given the high survey completion rate, participant ease in responding to the items and endorsement by behavioural scientists. As such, the reliability and validity of data captured by this type of hybrid assessment is also worth exploring in future research.

4.3. Practice implications

As no sociodemographic characteristics were associated with reporting a greater number of unmet information preferences, patient-centred information provision may vary at an individual rather than a group level. This highlights the need for health professionals and other imaging department staff to elicit and respond to individual patient's information preferences at each touch point in the care trajectory. Given that the majority of commonly unmet preferences related to receiving 'too little' information, strategies are needed to support healthcare professionals to identify and respond to patients who want more information. This may include communication training and question aids to prompt clinicians in eliciting unique information preferences [57], followed by the use of widely used information provision approaches, such as information sheets targeted to specific aspects of preparation (i.e. procedural, behavioural, sensory, psychosocial), for those seeking more information [58]. It is recognised that these approaches may be challenging to implement given time and resource constraints impacting healthcare [59,60].

An alternative and potentially feasible strategy may be supplementing existing information provision practices with online information delivery. The internet provides tailoring functionality so that individuals can indicate their preferences for format, timing and amount of information, and materials can be adapted accordingly [61]. Additional benefits include wide accessibility and high interactivity of online information [61].

However, this approach assumes that patients have an ability to seek, find, understand and appraise online health resources (otherwise termed eHealth literacy) [62] as well as decide how much and what information they would like to receive. Research may be needed to assess patient eHealth literacy, and identify strategies or aids which may assist patients in expressing personal information preferences. High-quality research is also needed to assess the impact of the internet in facilitating patient-centred communication on outcomes for imaging services (e.g. appointment terminations) and imaging patients (e.g. anxiety and distress).

4.4. Limitations

Findings may not generalise beyond the single, metropolitan medical imaging department study setting, and may not apply to groups that were excluded (i.e. non-English speaking patients, cognitively and physically impaired patients) or underrepresented (CT patients). The sociodemographic and scan profile of study participants did, however, reflect that of all patients seen through the department in the study period (Table 1). In the absence of a standardised measure of patient-centred preparatory information provision in medical imaging settings, this study used an investigator-developed patient self-report measure to determine alignment between patients' preferred and actual receipt of preparatory information [56]. Whilst the instrument has demonstrated internal consistency [41], further evaluation of its psychometric properties is needed. The reason for reporting an unmet information preference was not explored. It is therefore unclear whether health professionals or other imaging department staff failed to elicit and respond to patient information preferences, or whether alternative factors, such as changing preferences over time, contributed to study findings.

4.5. Conclusion

There is room to improve responsiveness to patients' preferences for preparatory information within the medical imaging setting. The number of unmet information preferences did not vary significantly based on participants' sociodemographic and scan characteristics, suggesting that health care professionals and imaging department staff should be supported and encouraged to elicit and respond to information preferences at an individual patient level. A standardised approach to patient-centred information exchange that elicits patient preferences, and tailors information delivery accordingly, may be an important first step to improving the quality of preparatory communication prior to medical imaging procedures.

Informed consent and patient details

All patient/personal identifiers have been removed so the patient/person(s) described are not identifiable and cannot be identified through the details of the manuscript.

Conflicts of interest

None.

Acknowledgements

The authors thank the patients for their involvement in this study, as well as the practice and managerial staff at Hunter New England Imaging for assistance with recruitment and data collection.

Funding

Mrs Lisa Hyde is supported by an Australian Government Research Training Program Scholarship. Dr Lisa Mackenzie is supported by a Postdoctoral Fellowship grant [PF-16-011] from the Australian National Breast Cancer Foundation. Dr Allison Boyes is supported by a National Health and Medical Research Council Early Career Fellowship (APP1073317) and Cancer Institute New South Wales Early Career Fellowship (13/ECF/1-37).

Appendix A. Supplementary data

Supplementary material related to this article can be found, in the online version, at doi:<https://doi.org/10.1016/j.pec.2018.05.025>.

References

- [1] A. Kitson, A. Marshall, K. Bassett, K. Zeitz, What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing, *J. Adv. Nurs.* 69 (2013) 4–15.
- [2] Institute of Medicine, Crossing the Quality Chasm: A New Health System for the 21st Century, Institute of Medicine, Washington D.C., 2001.
- [3] M. Gerteis, S. Edgman-Levitan, J. Daley, T. Delbanco, *Through the Patient's Eyes: Understanding and Promoting Patient-Centered Care*, Jossey-Bass, San Francisco, 1993.
- [4] P. Kinnersley, N. Stott, T.J. Peters, I. Harvey, The patient-centredness of consultations and outcome in primary care, *Br. J. Gen. Pract.* 49 (1999) 711–716.
- [5] N. Mead, P. Bower, M. Hann, The impact of general practitioners' patient-centredness on patients' post-consultation satisfaction and enablement, *Soc. Sci. Med.* 55 (2002) 283–299.
- [6] R.M. Epstein, R.L. Street, Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering, National Cancer Institute, NIH, Bethesda, MD, 2007.
- [7] M. Stewart, J.B. Brown, A. Donner, L.R. McWhinney, J. Oates, W.W. Weston, J. Jordan, The impact of patient-centered care on outcomes, *J. Fam. Pract.* 49 (2000) 796–804.
- [8] I. Ramsay, M. Peters, N. Corsini, M. Eckert, Consumer Health Information Needs and Preferences: A Rapid Evidence Review, ACSQHC, Sydney, 2017.
- [9] J. Suls, C.K. Wan, Effects of sensory and procedural information on coping with stressful medical procedures and pain: a meta-analysis, *J. Consult. Clin. Psychol.* 57 (1989) 372–379.
- [10] M. Jefford, M. Tattersall, Informing and involving cancer patients in their own care, *Lancet Oncol.* 3 (2002) 629–637.
- [11] S.M. Miller, C.E. Mangan, Interacting effects of information and coping style in adapting to gynecologic stress: should the doctor tell all? *J. Pers. Soc. Psychol.* 45 (1983) 223–236.
- [12] S. Miller, Individual differences in the coping process: what to know and when to know it, in: B. Carpenter (Ed.), *Personal Coping: Theory, Research and Application*, Praeger Publishers/Greenwood Publishing Group, Westport, CT, US, 1992, pp. 77–91.
- [13] O. Husson, F. Mols, W.A. Oranje, H.R. Haak, W.A. Nieuwlaat, R.T. Netea-Maier, J. W. Smit, L.V. van de Poll-Franse, Unmet information needs and impact of cancer in (long-term) thyroid cancer survivors: results of the PROFILES registry, *Psychooncology* 23 (2014) 946–952.
- [14] T.H. Keegan, D.Y. Lichtensztajn, I. Kato, E.E. Kent, X.-C. Wu, M.M. West, A.S. Hamilton, B. Zebrack, K.M. Bellizzi, A.W. Smith, Unmet adolescent and young adult cancer survivors information and service needs: a population-based cancer registry study, *J. Cancer Surviv* 6 (2012) 239–250.
- [15] C. Kowalski, S.D. Lee, L. Ansmann, S. Wesselmann, H. Pfaff, Meeting patients' health information needs in breast cancer center hospitals - a multilevel analysis, *BMC Health Serv. Res.* 14 (2014) 601.
- [16] J. Meesters, I. de Boer, M. van den Berg, M. Fiocco, T. Vliet Vlieland, Unmet information needs about the delivery of rheumatology health care services: a survey among patients with rheumatoid arthritis, *Patient Educ. Couns.* 85 (2011) 299–303.
- [17] D. Pieper, F. Jülich, S.-L. Antoine, C. Bächle, N. Chernyak, J. Genz, M. Eikermann, A. Icks, Studies analysing the need for health-related information in Germany - a systematic review, *BMC Health Serv. Res.* 15 (2015) 407.
- [18] S.C. Chen, Y.H. Lai, C.T. Liao, J.T. Chang, C.C. Lin, Unmet information needs and preferences in newly diagnosed and surgically treated oral cavity cancer patients, *Oral Oncol.* 45 (2009) 946–952.
- [19] L.J. Rutten, N.K. Arora, A.D. Bakos, N. Aziz, J. Rowland, Information needs and sources of information among cancer patients: a systematic review of research (1980–2003), *Patient Educ. Couns.* 57 (2005) 250–261.
- [20] L. Sjostedt, R. Hellstrom, M.W. Stomberg, Patients' need for information prior to colonic surgery, *Gastroenterol. Nurs.* 34 (2011) 390–397.
- [21] A. Steptoe, J. O'Sullivan, Monitoring and blunting coping styles in women prior to surgery, *Br. J. Clin. Psychol.* 25 (1986) 143–144.
- [22] N.K. King, G.A. Cheeseman, A.K. Siriwardena, Development of procedure-specific patient information sheets for acute abdominal surgery and validation in patients undergoing urgent cholecystectomy or appendicectomy, *Int. J. Clin. Pract.* 58 (2004) 559–563.
- [23] S. Garretson, Benefits of pre-operative information programmes, *Nurs. Stand.* 18 (2004) 33–37.
- [24] A. Waller, K. Forshaw, J. Bryant, M. Carey, A. Boyes, R. Sanson-Fisher, Preparatory education for cancer patients undergoing surgery: a systematic review of volume and quality of research output over time, *Patient Educ. Couns.* 98 (2015) 1540–1549.
- [25] M.J. Schofield, R. Sanson-Fisher, How to prepare cancer patients for potentially threatening medical procedures: consensus guidelines. NSW Cancer Council Cancer Education Research Program, *J. Cancer Educ.* 11 (1996) 153–158.
- [26] J. Cockburn, NSW Cancer Council, How to Prepare Patients for Potentially Threatening Clinical Procedures: an Interactional Skills Training Manual for General Practitioners, Junior Medical Officers, Nurses, Surgeons, NSW Cancer Council, Kings Cross, NSW, 1997.
- [27] K.L. Forshaw, M.L. Carey, A.E. Hall, A.W. Boyes, R. Sanson-Fisher, Preparing patients for medical interventions: a systematic review of the psychometric qualities of published instruments, *Patient Educ. Couns.* 99 (2016) 960–973.
- [28] Organisation for Economic Co-Operation and Development, Health at a Glance 2015: OECD Indicators, OECD, Paris, 2015.
- [29] C.M. Heyer, J. Thuring, S.P. Lemburg, N. Kreddig, M. Hasenbring, M. Dohna, V. Nicolas, Anxiety of patients undergoing CT imaging-an underestimated problem? *Acad. Radiol.* 22 (2015) 105–112.
- [30] L. Ollivier, F. Apiou, J. Leclerc, M. Sévellec, B. Asselain, A. Brédart, S. Neuwenschwander, Patient experiences and preferences: development of practice guidelines in a cancer imaging department, *Cancer Imaging* 9 (2009) S92.
- [31] Z. Munn, Z. Jordan, Interventions to reduce anxiety, distress and the need for sedation in adult patients undergoing magnetic resonance imaging: a systematic review, *Int. J. Evid Based Healthc* 11 (2013) 265–274.
- [32] M. Dewey, T. Schink, C.F. Dewey, Claustrophobia during magnetic resonance imaging: cohort study in over 55,000 patients, *J. Magn. Reson. Imaging* 26 (2007) 1322–1327.
- [33] R.H. Thornton, L.T. Dauer, E. Shuk, C.L. Bylund, S.C. Banerjee, E. Maloney, L.B. Fox, C.M. Beattie, H. Hricak, J. Hay, Patient perspectives and preferences for communication of medical imaging risks in a cancer care setting, *Radiology* 275 (2015) 545–552.
- [34] E. von Elm, D.G. Altman, M. Egger, S.J. Pocock, P.C. Gotsche, J.P. Vandenbroucke, The strengthening of reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies, *J. Clin. Epidemiol.* 61 (2008) 344–349.
- [35] The Royal Australian and New Zealand College of Radiologists, Standards of Practice for Diagnostic and Interventional Radiology, Version 10.1, RANZCR, Faculty of Clinical Radiology, (2016).
- [36] The Royal Australian and New Zealand College of Radiologists, Computed Tomography: Consumer Information, (2015). (Accessed 26 June 2016) <http://www.ranzcr.edu.au/resources/consumers>.
- [37] The Royal Australian and New Zealand College of Radiologists, Magnetic Resonance Imaging (MRI): Consumer Information, (2015). (Accessed 26 June 2016) <http://www.ranzcr.edu.au/resources/consumers>.
- [38] The Royal Australian and New Zealand College of Radiologists, Medical Imaging Consent Guidelines, Version 2, RANZCR, Sydney, Australia, 2013.
- [39] F. Strack, "Order effects" in survey research: activation and information functions of preceding questions, in: N. Schwarz, S. Sudman (Eds.), *Context Effects in Social and Psychological Research*, Springer New York, New York, NY, 1992, pp. 23–34.
- [40] M. Stewart, Towards a global definition of patient centred care, *BMJ* 322 (2001) 444.
- [41] G.F. Kuder, M.W. Richardson, The theory of the estimation of test reliability, *Psychometrika* 2 (1937) 151–160.
- [42] Hugo Centre for Migration and Population Research, ARIA (Accessibility/Remoteness Index of Australia), The University of Adelaide, 2005.
- [43] The Royal Australian and New Zealand College of Radiologists Quality and Safety Committee, Strategic Planning Discussion Paper – Radiology Quality and Safety, RANZCR, Sydney, Australia, 2014.
- [44] European Society of Radiology, Patient Information. The Most Important Stakeholder in Radiology: the Patient., (2017). (Accessed 8 June 2017) <https://www.mysr.org/quality-safety/patient-information>.
- [45] L.J. Mackenzie, R.W. Sanson-Fisher, M.L. Carey, C.A. Este, Radiation oncology outpatient perceptions of patient-centred care: a cross-sectional survey, *BMJ Open* 3 (2013) e001265.
- [46] V. Tsiakanas, G. Robert, J. Maben, A. Richardson, C. Dale, T. Wiseman, Implementing patient-centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services, *Support Care Cancer* 20 (2012) 2639–2647.
- [47] P. Sinfield, R. Baker, S. Agarwal, C. Tarrant, Patient-centred care: what are the experiences of prostate cancer patients and their partners? *Patient Educ. Couns.* 73 (2008) 91–96.
- [48] J. Verheijde, Health Care Costs and Scarcity of Health Care Resources, Managing Care: A Shared Responsibility, Springer, Netherlands, 2006, pp. 1–30.
- [49] S.M. Henwood, L. Munro, Principles of communication, in: A. Ramlal, M. Vosper (Eds.), *Patient Centred Care in Medical Imaging and Radiotherapy*, Churchill Livingstone, London, 2013, pp. 3–6.
- [50] D. Poroch, The effect of preparatory patient education on the anxiety and satisfaction of cancer patients receiving radiation therapy, *Cancer Nurs.* 18 (1995) 206–214.

- [51] B. Zebrack, Information and service needs for young adult cancer survivors, *Support Care Cancer* 17 (2009) 349–357.
- [52] A.C. Zucca, R.W. Sanson-Fisher, A. Waller, M. Carey, A. Grady, L. Mackenzie, Life expectancy discussions in a multisite sample of Australian medical oncology outpatients, *Med. J. Aust.* 203 (2015) 405.
- [53] M. Oldman, D. Moore, S. Collins, Drug patient information leaflets in anaesthesia: effect on anxiety and patient satisfaction, *Br. J. Anaesth.* 92 (2004) 854–858.
- [54] S.J. Katz, L.P. Wallner, P.H. Abrahamse, N.K. Janz, K.A. Martinez, D.A. Shumway, A.S. Hamilton, K.C. Ward, K.A. Resnicow, S.T. Hawley, Treatment experiences of Latinas after diagnosis of breast cancer, *Cancer* 123 (2017) 3022–3030.
- [55] N. Gaucher, S. Nadeau, A. Barbier, A. Janvier, A. Payot, Personalized antenatal consultations for preterm labor: responding to mothers' expectations, *J. Pediatr.* 178 (2016) 130–134.
- [56] F. Tzelepis, R.W. Sanson-Fisher, A.C. Zucca, E.A. Fradgley, Measuring the quality of patient-centered care: why patient-reported measures are critical to reliable assessment, *Patient Prefer. Adherence* 9 (2015) 831–835.
- [57] F. Dwamena, M. Holmes-Rovner, C.M. Gauden, S. Jorgenson, G. Sadigh, A. Sikorskii, S. Lewin, R.C. Smith, J. Coffey, A. Olomu, Interventions for Providers to Promote a Patient-Centred Approach in Clinical Consultations, *The Cochrane Library*, 2012CD003267.
- [58] A. Bolejko, C. Sarvik, P. Hagell, A. Brinck, Meeting patient information needs before magnetic resonance imaging: development and evaluation of an information booklet, *J. Radiol. Nurs.* 27 (2008) 96–102.
- [59] D.G. Kirch, M.K. Henderson, M.J. Dill, Physician workforce projections in an era of health care reform, *Annu. Rev. Med.* 63 (2012) 435–445.
- [60] Department of Health, Review of Australian Government Health Workforce Programs, Department of Health, Canberra, Australia, 2013.
- [61] R.J.W. Cline, K.M. Haynes, Consumer health information seeking on the internet: the state of the art, *Health Educ. Res.* 16 (2001) 671–692.
- [62] C.D. Norman, H.A. Skinner, eHealth literacy: essential skills for consumer health in a networked world, *J. Med. Internet Res.* 8 (2006) e9.

Appendix 4.3: Paper Two supplementary materials

APPENDIX A: UNMET INFORMATION PREFERENCE MEASURE

The next section asks about the information you were given by a health professional or other imaging department staff before arriving for your scan today. Please do not include information that you sourced by yourself. Please circle the answer that best reflects your experience.

	Before arriving for your scan today, were you <u>given</u> any information about:	No, but I wanted this information	No, but I didn't want this information	Yes, and I wanted this information	Yes, but I didn't want this information
1.	Why your doctor referred you for a CT or MRI scan?	1	2	3	4
2.	The benefits of having a CT or MRI scan?	1	2	3	4
3.	Steps you needed to take to prepare for your scan in the day(s) before your appointment (e.g. blood tests)?	1	2	3	4
4.	Who to speak to if you had any questions about the scan in the week(s) before your appointment?	1	2	3	4
5.	Where to find information about any aspects related to the scan?	1	2	3	4
6.	How to manage scan-related fear or anxiety <u>before</u> the scan?	1	2	3	4
7.	What to eat or drink on the day of the scan?	1	2	3	4
8.	Where to park in the hospital?	1	2	3	4
9.	How to find the imaging department in the hospital?	1	2	3	4
10.	What to bring with you to the scan appointment (e.g. prior scan results)?	1	2	3	4
11.	Whether someone should come with you to the scan?	1	2	3	4
12.	How long you will have to wait in the department before having the scan?	1	2	3	4
13.	Whether you will need an injection at the scan?	1	2	3	4

	Before arriving for your scan today, were you given any information about:	No, but I wanted this information	No, but I didn't want this information	Yes, and I wanted this information	Yes, but I didn't want this information
14.	What you will be asked to wear during the scan?	1	2	3	4
15.	What the scanner looks like?	1	2	3	4
16.	Being required to lie on a table that moves in and out of the scanner?	1	2	3	4
17.	Who will be with you during the scan?	1	2	3	4
18.	How the scanner takes images of the body?	1	2	3	4
19.	What you will see during the scan?	1	2	3	4
20.	What you will hear during the scan?	1	2	3	4
21.	Any physical sensations you may feel during the scan?	1	2	3	4
22.	Whether you can move during the scan?	1	2	3	4
23.	How long the scan will take?	1	2	3	4
24.	Any risks associated with the scan?	1	2	3	4
25.	What to do if you suffer from claustrophobia? <i>Claustrophobia is a fear of confined spaces</i>	1	2	3	4
26.	How to manage scan-related fear or anxiety <u>during</u> the scan?	1	2	3	4
27.	How to alert the radiographer if you have questions or concerns during the scan? <i>A radiographer is a healthcare professional who specialises in imaging the body.</i>	1	2	3	4
28.	How long you will have to stay at the department after the scan?	1	2	3	4

	Before arriving for your scan today, were you <u>given</u> any information about:	No, but I wanted this information	No, but I didn't want this information	Yes, and I wanted this information	Yes, but I didn't want this information
29.	Whether you can drive home from the scan?	1	2	3	4
30.	Any after-effects in the day(s) following the scan?	1	2	3	4
31.	How to manage scan-related fear or anxiety <u>after</u> the scan?	1	2	3	4
32.	When to expect the results of the scan?	1	2	3	4
33.	How you will receive the results of the scan?	1	2	3	4

Appendix 4.4: Paper Two copyright clearance



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Prevalence and correlates of patient-centred preparatory information provision to computed tomography and magnetic resonance imaging outpatients: A cross-sectional study

Author:
Lisa Hyde, Lisa Mackenzie, Allison W. Boyes, Tiffany-Jane Evans, Michael Symonds, Rob Sanson-Fisher

Publication: Patient Education and Counseling

Publisher: Elsevier

Date: October 2018

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Appendix 5: Paper Three

Appendix 5.1: Statements of contribution for Paper Three

Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (vi) interpretation of statistical analyses; (vii) identification of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

Hyde L, Boyes A, Evans T, Mackenzie L & Sanson-Fisher R. Three-Factor Structure of the eHealth Literacy Scale Among Magnetic Resonance Imaging and Computed Tomography Outpatients: A Confirmatory Factor Analysis. JMIR: Human Factors 2018; 5(1);e6. doi: 10.2196/humanfactors.9039.



Dr Allison Boyes (Co-Author)

13/01/2020

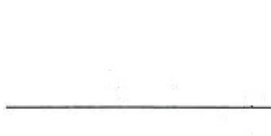
Date



Mrs Lisa Hyde (Candidate)

15/01/2020

Date



A/Prof Lesley MacDonald-Wicks (Assistant Dean Research Training)

24/2/20

Date

Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (vi) interpretation of statistical analyses; (vii) identification of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

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8th January 2020

Ms Tiffany-Jane Evans (Co-Author)

Date

08/01/2020

Mrs Lisa Hyde (Candidate)

Date

24/2/20

A/Prof Lesley MacDonald-Wicks (Assistant Dean Research Training)

Date

Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (vi) interpretation of statistical analyses; (vii) identification of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

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Dr Lisa Mackenzie (Co-Author) Date

_____ 08/01/2020
Mrs Lisa Hyde (Candidate) Date

_____ 24/2/20
A/Prof Lesley MacDonald-Wicks (Assistant Dean Research Training) Date

Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (vi) interpretation of statistical analyses; (vii) identification of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

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Appendix 5.2: Paper Three

Original Paper

Three-Factor Structure of the eHealth Literacy Scale Among Magnetic Resonance Imaging and Computed Tomography Outpatients: A Confirmatory Factor Analysis

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Abstract

Background: Electronic health (eHealth) literacy is needed to effectively engage with Web-based health resources. The 8-item eHealth literacy scale (eHEALS) is a commonly used self-report measure of eHealth literacy. Accumulated evidence has suggested that the eHEALS is unidimensional. However, a recent study by Sudbury-Riley and colleagues suggested that a theoretically-informed three-factor model fit better than a one-factor model. The 3 factors identified were awareness (2 items), skills (3 items), and evaluate (3 items). It is important to determine whether these findings can be replicated in other populations.

Objective: The aim of this cross-sectional study was to verify the three-factor eHEALS structure among magnetic resonance imaging (MRI) and computed tomography (CT) medical imaging outpatients.

Methods: MRI and CT outpatients were recruited consecutively in the waiting room of one major public hospital. Participants self-completed a touchscreen computer survey, assessing their sociodemographic, scan, and internet use characteristics. The eHEALS was administered to internet users, and the three-factor structure was tested using structural equation modeling.

Results: Of 405 invited patients, 87.4% (354/405) were interested in participating in the study, and of these, 75.7% (268/354) were eligible. Of the eligible participants, 95.5% (256/268) completed all eHEALS items. Factor loadings were 0.80 to 0.94 and statistically significant ($P < .001$). All reliability measures were acceptable (indicator reliability: awareness=.71-.89, skills=.78-.80, evaluate=.64-.79; composite reliability: awareness=.89, skills=.92, evaluate=.89; variance extracted estimates: awareness=.80, skills=.79, evaluate=.72). Two out of three goodness-of-fit indices were adequate (standardized root mean square residual (SRMR)=.038; comparative fit index (CFI)=.944; root mean square error of approximation (RMSEA)=.156). Item 3 was removed because of its significant correlation with item 2 (Lagrange multiplier [LM] estimate 104.02; $P < .001$) and high loading on 2 factors (LM estimate 91.11; $P < .001$). All 3 indices of the resulting 7-item model indicated goodness of fit ($\chi^2_{11}=11.3$; SRMR=.013; CFI=.999; RMSEA=.011).

Conclusions: The three-factor eHEALS structure was supported in this sample of MRI and CT medical imaging outpatients. Although further factorial validation studies are needed, these 3 scale factors may be used to identify individuals who could benefit from interventions to improve eHealth literacy awareness, skill, and evaluation competencies.

KEYWORDS

eHealth; literacy; factor analysis; measures; psychometrics

Introduction**Consumer eHealth Literacy is Critical to Maximizing the Benefits of eHealth**

Technologically-enabled health care is important at both the patient and service level, given the increasing resource and timing pressures on the health care system [1], the digital transformation of health-related industries [2], and changing consumer expectations about their role in care [3]. Electronic health (eHealth) refers to the organization and delivery of health services and information using the internet and related technologies [4]. eHealth holds potential as a scalable form of service delivery that is accessible, low-cost, promotes patient empowerment, and enhances patient-provider information exchange [5]. However, to reap the possible benefits, patients must be eHealth literate [6]. eHealth literacy refers to an individual's ability to seek, find, understand, and appraise health information from electronic sources, and apply the knowledge gained to addressing or solving a health problem [6]. Limited ability to seek, find, understand, and appraise electronic health information has been recognized as a key self-reported barrier to the utilization of the internet for health purposes [7]. The first step in identifying individuals who may benefit from improved eHealth literacy is the development of valid and reliable tools assessing this construct.

The eHealth Literacy Scale Is a Standardized and Widely Used Measure

The eHealth literacy scale (eHEALS) was among the first and continues to be one of the most commonly used self-reported measures of eHealth literacy [8,9]. The scale comprises 8 items, which assess consumers' combined knowledge, comfort, and perceived skills at finding, evaluating, and applying electronic health information to health problems [8]. Consistent with the current definition of eHealth [4], all eHEALS items are specific to health information access via the Internet, as opposed to other electronic forms of information provision (eg, Compact Disc Read-Only Memory [CD-ROM], computer games). The scale was developed to address the need for an easily self-administrable eHealth literacy measure that could be applied across a wide range of populations and contexts [8]. Widespread adoption of the scale has been demonstrated, with the measure translated into multiple languages [10-17] and used across participants with diverse sociodemographic [10,15,16,18], ethnic [11,14,19], and disease profiles [13,20,21]. Items were originally developed and validated among Canadian youths more than a decade ago [8], and subsequent studies have demonstrated test-retest reliability across younger [14] and older age cohorts [10], internal consistency across populations of varying age and ethnicity [10,11,14,15,19,22], and measurement invariance across English-speaking countries [23]. However, inconsistent findings exist regarding the convergent and predictive validity of the scale [10,11,24], and debate continues about its factor

structure [10-17,22,23,25-28]. We sought to contribute to this knowledge by assessing the factorial validity and internal consistency of a three-factor structure of the eHEALS.

The Factor Structure of the eHealth Literacy Scale Is Uncertain

Norman and Skinner's original factorial validation of the eHEALS found that the scale assesses a single dimension [8]. Numerous studies with the general public have supported this finding [10,11,14-16,22,25,26], including those specific to children [15], university students [14,16], and older adults [10,22]. However, the strength of these conclusions is limited by the common use of exploratory factor analysis (EFA) [8,10,11,14,15,22,25,26]. EFA originates from classical test theory and holds value in the early stages of scale development when factor structure is unknown and latent variable structures need to be identified [29]. EFA does, however, have some limitations. For example, it often involves subjective decision-making processes and does not account for the theory which may inform latent variable structures [30].

Confirmatory factor analysis (CFA) is an alternative analysis technique, also derived from classical test theory, which allows models to be tested via theoretically or empirically-driven hypotheses [31]. However, studies assessing a unidimensional eHEALS structure using CFA commonly report poor fit indices [13,23,27,28]. This may be because a single factor structure does not account for the multifaceted nature of the concept of eHealth literacy, such as its inherent literacy types (ie, traditional, health, information, scientific, media, and computer) or the multiple components of information retrieval and use (ie, finding, applying and evaluating electronic health information) [6]. Paige and colleagues [13] completed one of the only studies of the construct validity of the eHEALS using CFA with chronically ill patients and found evidence for a three-factor structure. Despite this, multidimensionality of the eHEALS was refuted on the basis that a large proportion of variance loaded on one factor only. The authors applied the partial credit model, which is a unidimensional item response theory technique, to conclude that a single structure exists, despite CFA values indicating a poor unidimensional fit [13]. A two-factor model based on the concepts of information-seeking and appraisal has also been tested [12,27,28]. Although this model has a strong theoretical basis, 2 of the 3 studies testing this structure reported inadequate fit indices [12,27]. Furthermore, all were based on translated versions of the scale, which can result in varied item meaning and interpretation [32].

Recent Literature Proposes That the eHealth Literacy Scale Has a Three-Factor Structure

Sudbury-Riley and colleagues [23] used CFA to test a three-factor structure of the English-language version of the eHEALS with a multinational sample of adult internet users from the United Kingdom (n=407), New Zealand (n=276), and the United States (n=313). A hypothesis-driven approach was

adopted, whereby 2 eHEALS items were mapped to an “awareness” factor, 3 items to a “skills” factor, and 3 items to an “evaluate” factor. These factors were derived from the self-efficacy and social-cognitive theoretical constructs underpinning eHealth literacy [8,23]. Self-efficacy theory is based on the premise that goal achievement is mediated by self-belief and confidence, and social cognitive theory states that social context influences goal achievement [33]. Sudbury-Riley and colleagues [23] therefore proposed that an individual’s awareness is shaped by their environment (eg, exposure to Web-based health information), their skills are influenced by social factors (eg, modeling, instruction, and social persuasion), and their ability to evaluate eHealth resources is mediated by their confidence and persistence. CFA fit indices supported the hypothesized three-factor eHEALS structure across all 3 countries [23].

Further Research Is Needed to Verify the Three-Factor Structure of the Standardized eHealth Literacy Scale With Patient Populations

Sudbury-Riley and colleagues’ [23] study contributes to our understanding of the underlying structures of the eHEALS, however, it has some limitations. In particular, a modified version of the scale was used, based on feedback from the authors’ family, friends, and colleagues, in which “and information” was added to items to address the increasing interactivity of eHealth materials. It is therefore unclear whether the three-factor structure also applies to the original version of the scale. The study was also conducted with middle-aged members of the general population, restricting the generalizability of findings across medical populations and age cohorts. This adds to the common underrepresentation of chronically ill patients in the eHEALS measurement literature, despite the potential benefits of eHealth to this population [13].

Given that evidence about the properties of a measure is accumulated over a number of studies, the appropriate next step is to determine whether Sudbury-Riley and colleagues’ [23] findings can be replicated in a different population. To address this need, and also overcome some of the limitations of Sudbury-Riley and colleagues’ work [23], this factorial validation study was conducted with patients, using the standardized eHEALS. Magnetic resonance imaging (MRI) and computed tomography (CT) medical imaging outpatients represent a high volume of patients with diverse demographic characteristics and medical diagnoses [34,35], and as such, research completed with these patients may have high generalizability. Furthermore, MRI and CT medical imaging outpatients require substantial preparatory information that could potentially be delivered online [36]. Hence, this study aimed to test the factorial validity and internal consistency of the three-factor structure of the eHEALS, identified by Sudbury-Riley and colleagues [23], among MRI and CT medical imaging outpatients.

Methods

Design and Setting

A cross-sectional survey of CT and MRI medical imaging outpatients was conducted in a medical imaging clinic at a tertiary referral hospital located in regional New South Wales, Australia.

Participants

Eligible participants were attending for an outpatient CT or MRI appointment at the tertiary referral hospital, were 18 years or older, and had access to the internet for personal use. Participants were excluded from the study if they had a cognitive or physical impairment that precluded them from providing informed consent or participating in the study, or if they were unable to complete the questionnaire because of poor English proficiency. These criteria mean that a diversity of participants in terms of frequency, confidence, and reasons for personal use of the internet were eligible to participate. Consistent with the original eHEALS validation study [8], use of the internet for health was not an eligibility requirement.

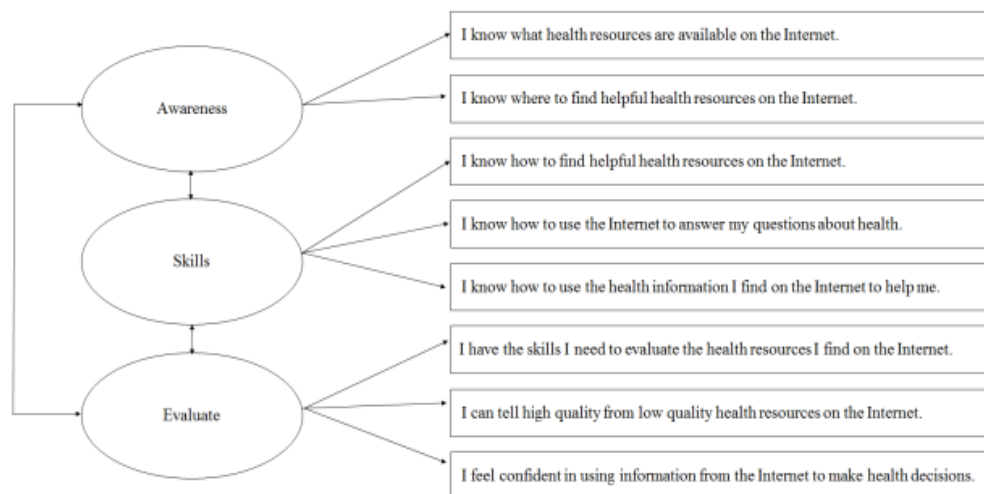
Procedure

Patients who were potentially eligible for the study were identified by medical imaging reception staff when they presented for their outpatient appointment. These patients were informed about the research and invited to speak with a trained research assistant. Interested patients were provided with a written information sheet and introduced to the research assistant, who gave an overview of the study and obtained patients’ verbal consent to participate. The age, gender, and scan type of noninterested and nonconsenting patients were recorded. Consenting participants were provided with a tablet computer and asked to complete a Web-based questionnaire before their scan. A paper version of the questionnaire was provided to participants who requested it. Ethics approval was obtained from the Hunter New England Human Research Ethics Committee (16/10/19/5.11) and University of Newcastle (H-2016-0386).

Measures

Participants’ eHealth literacy was assessed using the 8-item English-language version of the eHEALS [8]. Respondents indicated their level of agreement with each statement on a 5-point Likert scale, which was scored from 1 “strongly disagree” to 5 “strongly agree.”

Sociodemographic, scan, and information preference characteristics were examined using standard items. These items assessed participant age, gender, marital status, highest level of education completed, postcode, and scan type. Postcodes were mapped to the Accessibility/Remoteness Index of Australia Plus 2011 classification to examine remoteness [37] and categorized as metropolitan (major cities of Australia) or nonmetropolitan (inner regional, outer regional, remote, or very remote Australia). One item, adapted from an existing health information wants questionnaire [38], assessed how much information participants liked to have about their health. Response options were “no information,” “some information,” and “a lot of information.”

Figure 1. eHealth Literacy Scale three-factor model proposed by Sudbury-Riley and colleagues.

Internet characteristics were assessed by 2 items. Use of the internet for scan preparation was assessed by an author-developed item: *Have you searched the internet for information to help you prepare for your scan?* with response options “no,” “yes,” and “don’t know.” Frequency of internet use was measured with a single item used in existing informatics literature [39], in which participants respond on a 6-point scale ranging from “less than once a month” to “several times a day.”

Sample Size

Rules of thumb for CFA recommend a sample size of at least 200 participants [40,41] or 10 participants per parameter estimated [42]. Wolf and colleagues [43] found that a sample size of at least 150 is required for three-factor models with fewer than 4 indicator variables per factor and assuming strong factor loadings of 0.80. To accommodate deviation from these assumptions, and given that 19 parameters were estimated for the eHEALS CFA, the more conservative estimate of at least 200 participants was applied to this study.

Statistical Analyses

Participant characteristics and eHEALS responses were summarized as frequencies and percentages, or means and standard deviations. Consent bias was assessed for gender, scan type, and age group using chi-square tests. CFA was undertaken using the CALIS procedure of SAS software v9.4 (SAS Institute, Cary, NC, USA). We chose CFA as it is the same theoretically-sound technique used by Sudbury-Riley and colleagues [23] and therefore allowed for a direct comparison of results. Given the high completion rate (98.1% [256/261] of participants who started the eHEALS completed all items), this analysis was restricted to participants with complete eHEALS data. The relationship between latent variables (ie, awareness, skills, evaluate) and manifest variables (eHEALS items 1-8), as proposed by Sudbury-Riley and colleagues [23], was tested using structural equation modeling (Figure 1). All loadings were standardized, with variances fixed at 1. The model was estimated using the full information maximum likelihood method.

Standardized factor loadings and covariances were calculated with 95% CIs.

Reliability measures included indicator reliability to determine the percentage of variation in the item explained by each factor, composite reliability to assess internal consistency ($>.70$ ideal) [29], and variance extracted estimates (VEEs) to determine the amount of variance captured by factors with regard to variance attributable to measurement error ($>.50$ ideal) [44]. Discriminant validity was assessed following the method proposed by Anderson and Gerbing [45].

Model goodness of fit was assessed using a range of metrics. Absolute indices included the chi-square statistic, the chi-square to degrees of freedom ratio (<2 ideal) [46], and the standardized root mean square residual (SRMR; $<.055$ ideal) [29]. The incremental index was reported as the comparative fit index (CFI; $>.95$ good fit) [47]. The parsimony index used was the root mean square error of approximation (RMSEA; $<.05$ close approximate fit, $.05-.08$ acceptable fit, $>.10$ poor fit) [29,47]. Lagrange multiplier (LM) estimates of items on different factors were assessed to identify complex items and possible ways to improve the model.

Results

Sample

A total of 405 potentially eligible patients were invited to discuss the study with a research assistant during the 7-week recruitment period. Of the invited patients, 87.4% (354/405) were interested in participating in the study, and of these, 75.7% (268/354) were eligible. Of these eligible participants, 97.4% (261/268) started the eHEALS, and 95.5% (256/268) completed all eHEALS items. There were no significant differences between patients who were and were not interested in participating in the study based on gender, scan type, or age group. Table 1 provides a summary of the sociodemographic, scan, and internet

characteristics of eligible participants. [Multimedia Appendix 1](#) provides a summary of participant responses to eHEALS items.

Confirmatory Factor Analysis

Convergence between the implied and observed variance covariance matrices was achieved within 10 iterations. As shown in [Table 2](#), all factor loadings were at or above 0.80 and were statistically significant ($P<.001$). All CRs exceeded .70, indicating good reliability, and all VEEs exceeded the cutoff of .50, indicating convergent validity. Discriminant validity of the

model was demonstrated, with statistically significant chi-square difference-tests ($P<.001$) for each pair of factors. The absolute index SRMR was .038, indicating adequate fit to the hypothesized model. The incremental index CFI was .944 and therefore close to the .95 threshold of acceptability ([Table 3](#)). However, the chi-square statistic ($\chi^2_{17}=124.2$) was highly significant and suggestive of poor fit, and the chi-square statistic to degrees of freedom ratio of 7.3 exceeded the acceptability cutoff of 2 [46]. The parsimony index RMSEA was .16, indicating poor fit.

Table 1. Participant sociodemographic, scan, and internet characteristics (N=268).

Characteristic	n (%) ^a
Mean age years (SD)	53 (15)
Gender	
Male	120 (44.8)
Female	148 (55.2)
Marital status	
Married or partner	148 (64.9)
Not married/living with partner	80 (35.1)
Education completed	
High school or less	169 (63.1)
More than high school	99 (36.9)
Geographic location	
Metropolitan	212 (79.1)
Nonmetropolitan	56 (20.9)
Scan type	
CT	104 (38.8)
MRI	160 (59.7)
Don't know	4 (1.5)
Used internet for scan	
Yes	29 (10.9)
No	237 (88.8)
Don't know	1 (0.3)
Frequency of internet use	
Less than once a month	11 (4.1)
Once a month	5 (1.8)
A few times a month	14 (5.2)
A few times a week	36 (13.5)
About once a day	51 (19.1)
Several times a day	150 (56.2)
Information amount preference	
No information	2 (0.8)
Some information	59 (26.0)
A lot of information	166 (73.1)

^aNumber of observations for each characteristic may not total 268 because of missing data.

Table 2. Factor loading and residual error estimates for confirmatory factor analysis of hypothesized model.

Factor-variable	Factor loadings (95% CI)	Error estimates (95% CI)	IR ^a	CR ^b	VEE ^c
Awareness					
I know what health resources are available on the Internet	0.85 (0.80-0.89) ^d	0.29 (0.21-0.36) ^d	.71	.89	.80
I know where to find helpful health resources on the Internet	0.94 (0.91-0.97) ^d	0.11 (0.05-0.17) ^d	.89		
Skills					
I know how to find helpful health resources on the Internet ^e	0.90 (0.86-0.93) ^d	0.20 (0.14-0.26) ^d	.80	.92	.79
I know how to use the internet to answer my questions about health	0.88 (0.85-0.92) ^d	0.22 (0.16-0.28) ^d	.78		
I know how to use the information I find on the internet to help me	0.88 (0.85-0.92) ^d	0.22 (0.16-0.28) ^d	.78		
Evaluate					
I have the skill I need to evaluate the health resources I find on the Internet	0.89 (0.85-0.92) ^d	0.21 (0.15-0.28) ^d	.79	.89	.72
I can tell high quality from low quality health resources on the Internet	0.86 (0.82-0.90) ^d	0.26 (0.19-0.33) ^d	.74		
I feel confident in using information from the internet to make health decisions	0.80 (0.75-0.85) ^d	0.36 (0.28-0.44) ^d	.64		

^aIR: indicator reliability.^bCR: composite reliability.^cVEE: variance extracted estimate.^d $P < .001$.^eThis item was dropped in the alternative 7-item model.**Table 3.** Goodness-of-fit indices for tested models.

Index type and fit index	Statistics for hypothesized 8-item model	Statistics for tested 7-item model
Absolute index		
Chi-square	124.2	11.3
Chi-square degrees of freedom	17	11
P -value for the chi-square statistic	<.001	.417
SRMR ^a	.038	.012
Incremental index		
Bentler CFI ^b	.944	.999
Parsimony index		
RMSEA ^c estimate	.156	.011
RMSEA lower 90% CI	.131	.000
RMSEA upper 90% CI	.182	.066

^aSRMR: standardized root mean square residual.^bCFI: comparative fit index.^cRMSEA: root mean square error of approximation.

When investigating the possible reasons for less than ideal fit, LM estimates provided strong evidence for a path between item 3 “I know how to find helpful health resources on the Internet” and the awareness factor (LM estimate 107.66; $P < .001$). There was also strong evidence for a path between item 2 “I know where to find helpful health resources on the Internet” and item 3 “I know how to find helpful health resources on the Internet” (LM estimate 91.11; $P < .001$). Given apparent overlap between items 2 and 3, a 7-item model which excluded item 3 was tested, which indicated good model fit (Table 3). See Multimedia

Appendix 2 for factor loading and residual error estimates for this altered model.

Discussion

Principal Findings

This study was the first to examine the theoretically-derived three-factor structure of the eHEALS, as proposed by Sudbury-Riley and colleagues [23], among a sample of MRI

and CT medical imaging outpatients. This three-factor structure was supported, with 2 out of 3 goodness-of-fit indices indicating adequate fit to the hypothesized model. Although these findings oppose accumulated evidence for a unidimensional structure of the eHEALS [8,10,11,14-16,22,25,26], they are consistent with the social cognitive and self-efficacy theory underpinning eHealth literacy [8,23,33]. As a result, it may be timely for researchers to examine patients' eHealth literacy across eHEALS factors to inform targeted eHealth literacy improvement interventions. This study contributes important knowledge about the structure of the eHEALS, yet further factorial analyses, including multidimensional item response theory analyses, are required across populations to increase the reliability of these findings.

Findings Broadly Support the Proposed Three-Factor Structure of the eHEALS

The proposed model demonstrated strong internal consistency and discriminant validity, suggesting that items within each factor measured the same general construct, and these constructs were sufficiently different from one another. Similarly, 2 out of 3 fit indices demonstrated good fit to the proposed three-factor model. Factor loadings were high and statistically significant, similar to that reported by Sudbury-Riley and colleagues [23]. This finding contrasts to the majority of existing literature, where it is argued that a single factor structure exists [8,10-16,19,22,25,26]. Most such prior research is based on data-driven EFA techniques [8,10,11,14,15,22,25,26], which may indicate that limited reference to the theoretical underpinnings of eHealth literacy has resulted in inaccurate interpretations of eHEALS data in the past.

Not all Goodness-of-Fit Indices Were Ideal

Poor fit of the parsimony index suggests that complexity exists within the three-factor model. RMSEA estimates have also been identified as a poor performing goodness-of-fit metric in other CFA eHEALS literature [12,13,27] and are rarely reported as being a close approximate fit, indicating that relationships among items need to be interrogated. When we investigated further, it was found that item 3 "I know how to find helpful health resources on the Internet" loaded on both "skills" and "awareness" domains, and correlated significantly with item 2 "I know where to find helpful health resources on the Internet." This finding supports that of Sudbury-Riley and colleagues [23], who identified substantial overlap between items 2 and 3. Potential item homogeneity is also evident in prior literature, as measures of internal consistency have commonly been reported to be approaching the .95 threshold of acceptability for Cronbach alpha [10,11,15,19], with some reported to have reached .97 [22]. The redundancy of items 2 and 3 is unsurprising, given their similar structure and meaning (ie, about how and where to find helpful health resources on the Internet). It is also possible that the low education level of the sample [48], and the distressing setting of a hospital waiting room [49], contributed to participants' difficulties in differentiating between item meanings. However, patient understanding of eHEALS items has been questioned previously, and the need for further research investigating item interpretation across populations has been indicated [11].

For this study, we did not restrict our sample to health-related internet users. This aligns with the majority of studies assessing the factorial validity of the eHEALS, including Norman and Skinner's original validation study [8,10-17,19,22,26-28]. Furthermore, Norman and Skinner [8] highlight the potential application of the scale to those with varying levels of technology use. eHEALS response options of *disagree* and *strongly disagree* provide for those who do not use the internet for health. Despite this, some participants within this study voluntarily reported being unsure of how to respond to each item as they did not use the internet for health. This anecdotal feedback suggests that items within the scale may not be interpretable to the wide population for which it was originally intended [8], and further research is needed to investigate the face and content validity of the scale among those who do and do not use the internet for health purposes.

As model fit improved when item 3 "I know how to find helpful health resources on the Internet" was excluded, an adapted 7-item eHEALS may be appropriate to consider. Reducing the number of items would result in two factors containing 2 items, which could create difficulties with model identification and convergence [29]. Likewise, it is unknown whether a reduced 2-item "skill" factor would adequately measure the construct and appropriately detect changes over time. As such, further research is needed to test the psychometric properties (specifically content validity, test-retest reliability, predictive validity, and responsiveness) of a 7-item eHEALS. Until this point, it is recommended that the standardized 8-item scale is used, with consideration of preliminary evidence supporting a three-factor structure.

The Three-Factor Structure of the eHEALS May Reflect an eHealth Literacy Pathway Among internet Users

Despite some fit indices being less than ideal, considering eHealth literacy by factor may help to guide Web-based health information provision in research and clinical practice. Furthermore, in accordance with the eHealth literacy continuum proposed by Diviana and colleagues [12], the eHEALS may measure an eHealth literacy pathway. In this instance, eHEALS factors are structured sequentially, and a user gradually demonstrates proficiency in more complex tasks. That is, a user must first be aware of eHealth resources before they can use their skills to navigate and interact with electronic content, and finally evaluate content quality and applicability to their health situation. Only once a user has undertaken all 3 of these steps, will they be able to effectively engage with eHealth resources and reap related benefits. This proposed pathway structure is supported by findings of Neter and colleagues [24], who reported that success rates gradually declined for older adults performing health-related computerized simulation tasks, as they stepped through the process of accessing, understanding, appraising, applying, and generating new health information. These findings may, however, be influenced by order effects of the simulated tasks [50], and further research is needed to validate such a causal pathway.

Important Implications for the Future Development and Evaluation of eHealth Literacy Improvement Strategies

On the basis of these findings, researchers and health care professionals have the opportunity to identify areas (ie, awareness, skills, or evaluate) where competency is low and target eHealth literacy improvement interventions accordingly. These interventions may, for example, include clinician recommendations to Web-based materials to increase awareness and reduce the need to evaluate content [51], training sessions to enhance eHealth literacy skills [52], or the promotion of checklists to aid in the evaluation of Web-based resources [53]. Additionally, user characteristics such as sociodemographic, health, and Internet use attributes that are associated with lower competency across eHEALS factors could be identified, so that assistance is directed toward those most in need. No studies have been conducted to determine the competency of individuals across eHEALS awareness, skill, and evaluate domains, and further research is needed.

Limitations

CFA was selected as it represents an understudied yet rigorous aspect of classical test theory and logically extends on the existing body of EFA and CFA measurement literature. The recent emergence of item response theory analyses of the eHEALS [12,13,16] has advantages over classical test theory approaches, including the capacity to establish increased item level psychometric information (eg, item difficulty). The application of multidimensional item response theory techniques to validate the three-factor eHEALS structure should be explored further. Furthermore, this study assessed one psychometric

property (ie, factorial validity), and more research is needed to investigate other understudied measurement properties of the eHEALS, such as its predictive validity.

It is possible that findings may not be generalizable beyond the medical imaging context. Similarly, as most participants reported using the internet at least daily (75.3%, 201/267), study findings may not be generalizable to those who use the internet less frequently. As we did not ask participants about the activities they undertook online, it is unclear whether the results are applicable to those who do or do not use the internet for health. Future research is consequently needed to validate study findings across patients with diverse demographics, medical diagnoses, and internet use patterns. Additionally, our study was based on the standardized version of the eHEALS. As recognized in prior research [12,23], this version may not sufficiently capture competency in using Web 2.0 (eg, social networking) for health. Further research is needed to determine whether scale modifications are needed to reflect the evolving nature of eHealth interventions.

Conclusions

Although potential item redundancy impacted fit indices, the three-factor structure of the eHEALS was broadly supported. On the basis of these findings, the eHEALS could be used to inform the development of tailored eHealth literacy enhancement strategies, which may in turn increase engagement with Web-based health resources. Further research is needed to confirm the three-factor structure across other medical settings and populations to support the generalizability of these findings.

Acknowledgments

The authors thank the patients for their involvement in this study, as well as the administrative and clinical staff at Hunter New England Imaging for assistance with recruitment and data collection. This research was supported by a Hunter Cancer Research Alliance statistical support grant (HCRA 157) and has received funding support from the Hunter Cancer Research Alliance Implementation Science Flagship Program as part of the 2018 HDR Student Award initiative. LH is supported by an Australian Government Research Training Program Scholarship. AB is supported by a National Health and Medical Research Council Early Career Fellowship (APP1073317) and Cancer Institute New South Wales Early Career Fellowship (13/ECF/1-37). LM is supported by a Postdoctoral Fellowship (PF-16-011) from the Australian National Breast Cancer Foundation.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Participant responses to eHEALS items (n=261).

[\[PDF File \(Adobe PDF File\), 26KB - humanfactors_v5i1e6_app1.pdf\]](#)

Multimedia Appendix 2

Factor loading and residual error estimates for the confirmatory factor analysis of the 7-item model.

[\[PDF File \(Adobe PDF File\), 31KB - humanfactors_v5i1e6_app2.pdf\]](#)

References

1. Zurn P, Dal Poz MR, Stilwell B, Adams O. Imbalance in the health workforce. *Hum Resour Health* 2004 Dec 17;2(1):13 [FREE Full text] [doi: [10.1186/1478-4491-2-13](https://doi.org/10.1186/1478-4491-2-13)] [Medline: [15377382](https://pubmed.ncbi.nlm.nih.gov/15377382/)]

2. Agarwal R, Gao G, DesRoches C, Jha AK. The digital transformation of healthcare: current status and the road ahead. *Inf Syst Res* 2010 Dec;21(4):796-809. [doi: [10.1287/isre.1100.0327](https://doi.org/10.1287/isre.1100.0327)]
3. Ball MJ, Lillis J. E-health: transforming the physician/patient relationship. *Int J Med Inform* 2001 Apr;61(1):1-10. [Medline: [11248599](https://pubmed.ncbi.nlm.nih.gov/11248599/)]
4. Pagliari C, Sloan D, Gregor P, Sullivan F, Detmer D, Kahan JP, et al. What is eHealth (4): a scoping exercise to map the field. *J Med Internet Res* 2005;7(1):e9 [FREE Full text] [doi: [10.2196/jmir.7.1.e9](https://doi.org/10.2196/jmir.7.1.e9)] [Medline: [15829481](https://pubmed.ncbi.nlm.nih.gov/15829481/)]
5. Eysenbach G. What is e-health? *J Med Internet Res* 2001 Jun;3(2):e20. [doi: [10.2196/jmir.3.2.e20](https://doi.org/10.2196/jmir.3.2.e20)] [Medline: [11720962](https://pubmed.ncbi.nlm.nih.gov/11720962/)]
6. Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. *J Med Internet Res* 2006 Jun;8(2):e9 [FREE Full text] [doi: [10.2196/jmir.8.2.e9](https://doi.org/10.2196/jmir.8.2.e9)] [Medline: [16867972](https://pubmed.ncbi.nlm.nih.gov/16867972/)]
7. Lee K, Hoti K, Hughes JD, Emmerton L. Dr Google and the consumer: a qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. *J Med Internet Res* 2014;16(12):e262 [FREE Full text] [doi: [10.2196/jmir.3706](https://doi.org/10.2196/jmir.3706)] [Medline: [25470306](https://pubmed.ncbi.nlm.nih.gov/25470306/)]
8. Norman CD, Skinner HA. eHEALS: the eHealth literacy scale. *J Med Internet Res* 2006 Nov;8(4):e27 [FREE Full text] [doi: [10.2196/jmir.8.4.e27](https://doi.org/10.2196/jmir.8.4.e27)] [Medline: [17213046](https://pubmed.ncbi.nlm.nih.gov/17213046/)]
9. Karnoe A, Kayser L. How is eHealth literacy measured and what do the measurements tell us? A systematic review. *Knowl Manag ELearn* 2015;7(4):576-600.
10. Chung SY, Nahm ES. Testing reliability and validity of the eHealth Literacy Scale (eHEALS) for older adults recruited online. *Comput Inform Nurs* 2015 Apr;33(4):150-156. [doi: [10.1097/CIN.0000000000000146](https://doi.org/10.1097/CIN.0000000000000146)] [Medline: [25783223](https://pubmed.ncbi.nlm.nih.gov/25783223/)]
11. Van der Vaart R, van Deursen AJ, Drossaert CH, Taal E, van Dijk JA, van de Laar MA. Does the eHealth Literacy Scale (eHEALS) measure what it intends to measure? Validation of a Dutch version of the eHEALS in two adult populations. *J Med Internet Res* 2011;13(4):e86 [FREE Full text] [doi: [10.2196/jmir.1840](https://doi.org/10.2196/jmir.1840)] [Medline: [22071338](https://pubmed.ncbi.nlm.nih.gov/22071338/)]
12. Diviani N, Dima AL, Schulz PJ. A psychometric analysis of the Italian version of the eHealth literacy scale using item response and classical test theory methods. *J Med Internet Res* 2017 Apr 11;19(4):e114 [FREE Full text] [doi: [10.2196/jmir.6749](https://doi.org/10.2196/jmir.6749)] [Medline: [28400356](https://pubmed.ncbi.nlm.nih.gov/28400356/)]
13. Paige SR, Krieger JL, Stellefson M, Alber JM. eHealth literacy in chronic disease patients: an item response theory analysis of the eHealth literacy scale (eHEALS). *Patient Educ Couns* 2017 Feb;100(2):320-326. [doi: [10.1016/j.pec.2016.09.008](https://doi.org/10.1016/j.pec.2016.09.008)] [Medline: [27658660](https://pubmed.ncbi.nlm.nih.gov/27658660/)]
14. Bazm S, Mirzaei M, Fallahzadeh H, Bazm R. Validity and reliability of the Iranian version of eHealth literacy scale. *J Commun Health Res* 2016;5(2):121-130.
15. Koo M, Norman CD, Hsiao-Mei C. Psychometric evaluation of a Chinese version of the eHealth literacy scale (eHEALS) in school age children. *Int Electron J Health Educ* 2012;15(1):29-36.
16. Nguyen J, Moorhouse M, Curbow B, Christie J, Walsh-Childers K, Islam S. Construct validity of the eHealth literacy scale (eHEALS) among two adult populations: a Rasch analysis. *JMIR Public Health Surveill* 2016 May;2(1):e24 [FREE Full text] [doi: [10.2196/publichealth.4967](https://doi.org/10.2196/publichealth.4967)] [Medline: [27244771](https://pubmed.ncbi.nlm.nih.gov/27244771/)]
17. Cardoso Tomás C, Pina Queirós PJ, Rodrigues Ferreira TJ. Analysis of the psychometric properties of the Portuguese version of an eHealth literacy assessment tool. *Rev Enf Ref* 2014 Jun 30;IV Série(2):19-28. [doi: [10.12707/RIV14004](https://doi.org/10.12707/RIV14004)]
18. Tennant B, Stellefson M, Dodd V, Chaney B, Chaney D, Paige S, et al. eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults. *J Med Internet Res* 2015;17(3):e70 [FREE Full text] [doi: [10.2196/jmir.3992](https://doi.org/10.2196/jmir.3992)] [Medline: [25783036](https://pubmed.ncbi.nlm.nih.gov/25783036/)]
19. Mitsutake S, Shibata A, Ishii K, Oka K. Association of eHealth literacy with colorectal cancer knowledge and screening practice among internet users in Japan. *J Med Internet Res* 2012;14(6):e153 [FREE Full text] [doi: [10.2196/jmir.1927](https://doi.org/10.2196/jmir.1927)] [Medline: [23149453](https://pubmed.ncbi.nlm.nih.gov/23149453/)]
20. Stellefson ML, Shuster JJ, Chaney BH, Paige SR, Alber JM, Chaney JD, et al. Web-based health information seeking and eHealth literacy among patients living with chronic obstructive pulmonary disease (COPD). *Health Commun* 2017 Sep 05:1-15. [doi: [10.1080/10410236.2017.1353868](https://doi.org/10.1080/10410236.2017.1353868)] [Medline: [28872905](https://pubmed.ncbi.nlm.nih.gov/28872905/)]
21. Lee K, Hoti K, Hughes JD, Emmerton LM. Consumer use of "Dr Google": a survey on health information-seeking behaviors and navigational needs. *J Med Internet Res* 2015;17(12):e288 [FREE Full text] [doi: [10.2196/jmir.4345](https://doi.org/10.2196/jmir.4345)] [Medline: [26715363](https://pubmed.ncbi.nlm.nih.gov/26715363/)]
22. Sheng X, Simpson PM. Seniors, health information, and the Internet: motivation, ability, and Internet knowledge. *Cyberpsychol Behav Soc Netw* 2013 Oct;16(10):740-746. [doi: [10.1089/cyber.2012.0642](https://doi.org/10.1089/cyber.2012.0642)] [Medline: [23679569](https://pubmed.ncbi.nlm.nih.gov/23679569/)]
23. Sudbury-Riley L, FitzPatrick M, Schulz PJ. Exploring the measurement properties of the eHealth literacy scale (eHEALS) among baby boomers: a multinational test of measurement invariance. *J Med Internet Res* 2017 Feb 27;19(2):e53 [FREE Full text] [doi: [10.2196/jmir.5998](https://doi.org/10.2196/jmir.5998)] [Medline: [28242590](https://pubmed.ncbi.nlm.nih.gov/28242590/)]
24. Neter E, Brainin E. Perceived and performed eHealth Literacy: survey and simulated performance test. *JMIR Hum Factors* 2017 Jan 17;4(1):e2 [FREE Full text] [doi: [10.2196/humanfactors.6523](https://doi.org/10.2196/humanfactors.6523)] [Medline: [28096068](https://pubmed.ncbi.nlm.nih.gov/28096068/)]
25. Nahm ES, Resnick B, Orwig D, Magaziner J, Bellantoni M, Sterling R, et al. A theory-based online hip fracture resource center for caregivers: effects on dyads. *Nurs Res* 2012;61(6):413-422 [FREE Full text] [doi: [10.1097/NNR.0b013e318270712a](https://doi.org/10.1097/NNR.0b013e318270712a)] [Medline: [23052420](https://pubmed.ncbi.nlm.nih.gov/23052420/)]
26. Neter E, Brainin E. eHealth literacy: extending the digital divide to the realm of health information. *J Med Internet Res* 2012 Jan;14(1):e19 [FREE Full text] [doi: [10.2196/jmir.1619](https://doi.org/10.2196/jmir.1619)] [Medline: [22357448](https://pubmed.ncbi.nlm.nih.gov/22357448/)]

27. Soellner R, Huber S, Reder M. The concept of eHealth literacy and its measurement. *J Media Psychol* 2014 Jan;26(1):29-38. [doi: [10.1027/1864-1105/a000104](https://doi.org/10.1027/1864-1105/a000104)]
28. Neter E, Brainin E, Baron-Epel O. The dimensionality of health literacy and eHealth literacy. *Eur Health Psychologist* 2015;17(6):275-280.
29. O'Rourke N, Hatcher L. *A Step-by-Step Approach to Using SAS® for Factor Analysis and Structural Equation Modeling*. Second ed. Cary, NC: SAS Institute Inc; 2013:444.
30. Henson RK, Roberts JK. Use of exploratory factor analysis in published research. *Educ Psychol Meas* 2016 Jul 02;66(3):393-416. [doi: [10.1177/0013164405282485](https://doi.org/10.1177/0013164405282485)]
31. Costello A, Osborne J. Best practices in exploratory factor analysis: four recommendations for getting the most from your analysis. *Pract Assess Res Eval* 2005;10(7):1-9.
32. Harkness JA, Van de Vijver FJ, Mohler PP. *Cross-Cultural Survey Methods*. Hoboken, NJ: Wiley-Interscience; 2003.
33. Bandura A. Social cognitive theory. In: Vasta R, editor. *Annals of Child Development*. Greenwich, CT: JAI Press; 1989.
34. Smith-Bindman R, Miglioretti DL, Larson EB. Rising use of diagnostic medical imaging in a large integrated health system. *Health Aff (Millwood)* 2008 Nov;27(6):1491-1502 [FREE Full text] [doi: [10.1377/hlthaff.27.6.1491](https://doi.org/10.1377/hlthaff.27.6.1491)] [Medline: [18997204](https://pubmed.ncbi.nlm.nih.gov/18997204/)]
35. Medical Benefits Reviews Task Group, Diagnostic Imaging Review Team. RANZCR. Australia: Department of Health and Ageing; 2012. Review of funding for diagnostic imaging services: final report URL: <https://www.ranzcr.com/documents/1281-review-of-funding-for-diagnostic-imaging/file> [accessed 2017-11-05] [WebCite Cache ID 6ul5n2TNl]
36. Horton KM, Garland MR, Fishman EK. The Internet as a potential source of information about radiological procedures for patients. *J Digit Imaging* 2000 Feb;13(1):46-47 [FREE Full text] [Medline: [10696601](https://pubmed.ncbi.nlm.nih.gov/10696601/)]
37. Hugo Centre for Migration and Population Research. The University of Adelaide. Adelaide, Australia: The University of Adelaide; 2005. ARIA (Accessibility/Remoteness Index of Australia) URL: https://www.adelaide.edu.au/hugo-centre/spatial_data/aria/ [accessed 2017-11-05] [WebCite Cache ID 6ul5tZ11A]
38. Xie B, Wang M, Feldman R, Zhou L. Internet use frequency and patient-centered care: measuring patient preferences for participation using the health information wants questionnaire. *J Med Internet Res* 2013 Jul 01;15(7):e132 [FREE Full text] [doi: [10.2196/jmir.2615](https://doi.org/10.2196/jmir.2615)] [Medline: [23816979](https://pubmed.ncbi.nlm.nih.gov/23816979/)]
39. Anandarajan M, Simmers C, Igbadia M. An exploratory investigation of the antecedents and impact of internet usage: an individual perspective. *Behav Inf Technol* 2000 Jan;19(1):69-85. [doi: [10.1080/014492900118803](https://doi.org/10.1080/014492900118803)]
40. Kline R. *Principles and Practice of Structural Equation Modeling*. 2nd ed. New York: The Guilford Press; 2005.
41. Boomsma A. Robustness of Lisrel against small sample sizes in factor analysis models. In: Jöreskog KG, Wold HO, editors. *Systems Under Indirection Observation: Causality, Structure, Prediction (Part I)*. Amsterdam, Netherlands: North-Holland; 1982.
42. Floyd FJ, Widaman KF. Factor analysis in the development and refinement of clinical assessment instruments. *Psychol Assess* 1995;7(3):286-299. [doi: [10.1037/1040-3590.7.3.286](https://doi.org/10.1037/1040-3590.7.3.286)]
43. Wolf EJ, Harrington KM, Clark SL, Miller MW. Sample size requirements for structural equation models. *Educ Psychol Meas* 2013 Jul 09;73(6):913-934. [doi: [10.1177/0013164413495237](https://doi.org/10.1177/0013164413495237)]
44. Fornell C, Larcker DF. Evaluating structural equation models with unobservable variables and measurement error. *J Mark Res* 1981 Feb;18(1):39-50. [doi: [10.2307/3151312](https://doi.org/10.2307/3151312)]
45. Anderson JC, Gerbing DW. Structural equation modeling in practice: a review and recommended two-step approach. *Psychol Bull* 1988;103(3):411-423 [FREE Full text]
46. Carmines E, McIver J. Unobserved variables. In: Bohrnstedt GW, Borgatta EF, editors. *Social Measurement: Current Issues*. Beverly Hills, CA: Sage Publications; 1981.
47. Hu L, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Struct Equ Modeling Multidiscip J* 1999 Jan;6(1):1-55. [doi: [10.1080/10705519909540118](https://doi.org/10.1080/10705519909540118)]
48. Sheehan-Holt JK, Smith MC. Does basic skills education affect adults' literacy proficiencies and reading practices. *Read Res Q* 2000;35(2):226-243. [doi: [10.1598/RRQ.35.2.2](https://doi.org/10.1598/RRQ.35.2.2)]
49. Podsakoff PM, MacKenzie SB, Lee J, Podsakoff NP. Common method biases in behavioral research: a critical review of the literature and recommended remedies. *J Appl Psychol* 2003 Oct;88(5):879-903. [doi: [10.1037/0021-9010.88.5.879](https://doi.org/10.1037/0021-9010.88.5.879)] [Medline: [14516251](https://pubmed.ncbi.nlm.nih.gov/14516251/)]
50. Strack F. Order effects in survey research: activation and information functions of preceding questions. In: Schwarz N, Sudman S, editors. *Context Effects in Social and Psychological Research*. New York: Springer; 1992:23-34.
51. Usher WT. Australian health professionals' health website recommendation trends. *Health Promot J Austr* 2011 Aug;22(2):134-141. [Medline: [21819357](https://pubmed.ncbi.nlm.nih.gov/21819357/)]
52. Watkins I, Xie B. eHealth literacy interventions for older adults: a systematic review of the literature. *J Med Internet Res* 2014;16(11):e225 [FREE Full text] [doi: [10.2196/jmir.3318](https://doi.org/10.2196/jmir.3318)] [Medline: [25386719](https://pubmed.ncbi.nlm.nih.gov/25386719/)]
53. Bernstam EV, Shelton DM, Walji M, Meric-Bernstam F. Instruments to assess the quality of health information on the World Wide Web: what can our patients actually use. *Int J Med Inform* 2005 Jan;74(1):13-19. [doi: [10.1016/j.ijmedinf.2004.10.001](https://doi.org/10.1016/j.ijmedinf.2004.10.001)] [Medline: [15626632](https://pubmed.ncbi.nlm.nih.gov/15626632/)]

Abbreviations

CFA: confirmatory factor analysis
CFI: comparative fit index
CT: computed tomography
EFA: exploratory factor analysis
LM: Lagrange multiplier
eHEALS: 8-item eHealth literacy scale
eHealth: electronic health
MRI: magnetic resonance imaging
RMSEA: root mean square error of approximation
SRMR: standardized root mean square residual
VEE: variance extracted estimate

Edited by P Santana-Mancilla; submitted 03.10.17; peer-reviewed by L Sudbury-Riley, O Montesinos; comments to author 23.10.17; revised version received 21.11.17; accepted 13.12.17; published 19.02.18

Please cite as:

Hyde LL, Boyes AW, Evans TJ, Mackenzie LJ, Sanson-Fisher R
Three-Factor Structure of the eHealth Literacy Scale Among Magnetic Resonance Imaging and Computed Tomography Outpatients: A Confirmatory Factor Analysis
JMIR Hum Factors 2018;5(1):e6
URL: <http://humanfactors.jmir.org/2018/1/e6/>
doi: [10.2196/humanfactors.9039](https://doi.org/10.2196/humanfactors.9039)
PMID: [29459356](https://pubmed.ncbi.nlm.nih.gov/29459356/)

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Appendix 5.3: Paper Three supplementary materials

Appendix 5.3.1: Paper Three Multimedia Appendix 1

Multimedia Appendix Table 1: Participant responses to eHEALS items (N = 261)

Factor Variable	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
	n (%) ^a				
Awareness					
I know what health resources are available on the internet	12 (5)	50 (19)	55 (21)	115 (44.1)	29 (11)
I know where to find helpful health resources on the internet	10 (4)	50 (19)	47 (18)	121 (46.4)	33 (13)
Skills					
I know how to find helpful health resources on the internet	9 (4)	41 (16)	37 (14)	135 (51.9)	38 (15)
I know how to use the internet to answer my questions about health	12 (5)	28 (11)	36 (14)	132 (51.2)	50 (19)
I know how to use the information I find on the internet to help me	10 (4)	34 (13)	48 (19)	126 (49.8)	40 (16)
Evaluate					
I have the skill I need to evaluate the health resources I find on the internet	14 (5)	48 (19)	53 (21)	93 (36)	49 (19)

Factor Variable	Strongly disagree	Disagree	Undecided	Agree	Strongly agree
	n (%)^a				
I can tell high quality from low quality health resources on the internet	11 (4)	59 (23)	63 (25)	79 (31)	44 (17)
I feel confident in using information from the internet to make health decisions	21 (8)	52 (20)	72 (28)	81 (32)	30 (12)

^a Number of observations for each eHEALS item may not total 261 due to missing data

Appendix 5.3.2: Paper Three Multimedia Appendix 2

Multimedia Appendix Table 2: Factor loading and residual error estimates for the confirmatory factor analysis of the 7-item model

Factor Variable	Factor loadings (95% CI)	Error estimates (95% CI)	IR ^a	CR ^b	VEE ^c
Awareness					
I know what health resources are available on the internet	.85 (.80 to .89) ^e	.28 (.20 to .36) ^e	.72	.89	.80
I know where to find helpful health resources on the internet	.94 (.90 to .98) ^e	.12 (.05 to .19) ^f	.89		
Skills					
I know how to use the internet to answer my questions about health	.90 (.86 to .93) ^e	.20 (.14 to .25) ^e	.80	.90	.82
I know how to use the information I find on the internet to help me	.92 (.89 to .94) ^e	.16 (.11 to .22) ^e	.84		
Evaluate					
I have the skills I need to evaluate the health resources I find on the internet	.89 (.86 to .93) ^e	.21 (.14 to .27) ^e	.79	.89	.72
I can tell high quality from low quality health resources on the internet	.86 (.82 to .90) ^e	.26 (.19 to .33) ^e	.74		
I feel confident in using information from the internet to make health decisions	.80 (.75 to .85) ^e	.36 (.28 to .44) ^e	.64		

^a IR: Indicator Reliability

^b CR: Composite Reliability

^c VEE: Variance Extracted Estimate

^e $P < .001$ ^f $P = .001$

Appendix 6: Paper Four

Appendix 6.1: Statements of contribution for Paper Four

Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (v) completion of statistical analyses; (vi) identification of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

Hyde L, Boyes A, Mackenzie L, Leigh L, Oldmeadow C, Riveros C & Sanson-Fisher, R. Electronic Health Literacy Among Magnetic Resonance Imaging and Computed Tomography Medical Imaging Outpatients: Cluster Analysis. *Journal of Medical Internet Research*; 2019; 21(8):e13423. doi: 10.2196/13423

Statement of Contribution

By signing below I confirm that Lisa Hyde contributed substantially to: (i) study conceptualisation and design; (ii) development and submission of ethics applications; (iii) training and liaison with clinical staff for research procedures; (iv) collection of research data; (v) completion of statistical analyses; (vi) identification of study findings; and (vii) manuscript development and submission, to the paper/publication entitled:

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Appendix 6.2: Paper Four

Original Paper

Electronic Health Literacy Among Magnetic Resonance Imaging and Computed Tomography Medical Imaging Outpatients: Cluster Analysis

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Abstract

Background: Variations in an individual's electronic health (eHealth) literacy may influence the degree to which health consumers can benefit from eHealth. The eHealth Literacy Scale (eHEALS) is a common measure of eHealth literacy. However, the lack of guidelines for the standardized interpretation of eHEALS scores limits its research and clinical utility. Cut points are often arbitrarily applied at the eHEALS item or global level, which assumes a dichotomy of high and low eHealth literacy. This approach disregards scale constructs and results in inaccurate and inconsistent conclusions. Cluster analysis is an exploratory technique, which can be used to overcome these issues, by identifying classes of patients reporting similar eHealth literacy without imposing data cut points.

Objective: The aim of this cross-sectional study was to identify classes of patients reporting similar eHealth literacy and assess characteristics associated with class membership.

Methods: Medical imaging outpatients were recruited consecutively in the waiting room of one major public hospital in New South Wales, Australia. Participants completed a self-report questionnaire assessing their sociodemographic characteristics and eHealth literacy, using the eHEALS. Latent class analysis was used to explore eHealth literacy clusters identified by a distance-based cluster analysis, and to identify characteristics associated with class membership.

Results: Of the 268 eligible and consenting participants, 256 (95.5%) completed the eHEALS. Consistent with distance-based findings, 4 latent classes were identified, which were labeled as low (21.1%, 54/256), moderate (26.2%, 67/256), high (32.8%, 84/256), and very high (19.9%, 51/256) eHealth literacy. Compared with the low class, participants who preferred to receive a lot of health information reported significantly higher odds of moderate eHealth literacy (odds ratio 16.67, 95% CI 1.67-100.00; $P=.02$), and those who used the internet at least daily reported significantly higher odds of high eHealth literacy (odds ratio 4.76, 95% CI 1.59-14.29; $P=.007$).

Conclusions: The identification of multiple classes of eHealth literacy, using both distance-based and latent class analyses, highlights the limitations of using the eHEALS global score as a dichotomous measurement tool. The findings suggest that eHealth literacy support needs vary in this population. The identification of low and moderate eHealth literacy classes indicate that the design of eHealth resources should be tailored to patients' varying levels of eHealth literacy. eHealth literacy improvement

interventions are needed, and these should be targeted based on individuals' internet use frequency and health information amount preferences.

(*J Med Internet Res* 2019;21(8):e13423) doi: [10.2196/13423](https://doi.org/10.2196/13423)

KEYWORDS

internet; health; literacy; cluster analysis; medical imaging

Introduction

Electronic Health Literacy Is Important for the Use and Receipt of Benefits From Electronic Health Programs

Web-based interventions have been reported to be consistently more effective than non-Web-based modalities in changing patient health behaviors and health-related knowledge [1]. Information and communication technology is also recognized as a promising enabler of safe, integrated, and high-quality health care, yet more scientifically rigorous research is needed [2,3]. Accordingly, internet-enabled health care is a strategic priority globally [4-7]. Electronic health (eHealth) literacy is one important factor influencing the use and receipt of benefits from Web-based health resources [8-10]. eHealth literacy refers to an individual's ability to seek, find, understand, and appraise health information from electronic sources, and apply the knowledge gained to addressing or solving a health problem [11]. The concept is derived from 6 literacy types (ie, health, computer, media, science, information, traditional literacy, and numeracy), which play an important role in facilitating engagement with Web-based health resources [11]. Inadequate eHealth literacy has been self-reported as a barrier to use of the internet for health information seeking purposes among the chronically ill [12]. Furthermore, descriptive research indicates that eHealth literacy is associated with positive cognitive (eg, understanding of health status) [8], instrumental (eg, self-management, physical exercise, and dieting) [8-10], and interpersonal (eg, physician interaction) [8] outcomes from Web-based health information searches. Individuals with lower eHealth literacy have been suggested to be older [8,13,14], less educated [8,14,15], have lower access to, or use of, the internet [15-17], and have poorer health [8].

Interpretations of Electronic Health Literacy Data are Inconsistent

Approaches used to assess eHealth literacy have included objective performance testing [18,19] and self-reported measurement [20-23]. The most commonly used self-reported measure is the 8-item, eHealth Literacy Scale (eHEALS) [20]. Compared with other self-report measures of eHealth literacy, strengths of the eHEALS include its psychometric rigor, brevity, ease of administration, and availability in a number of languages [17,19,20,24-26]. One of the key issues limiting the utility of the eHEALS is the lack of information about interpretation of these data. Although there is a convention that higher scores represent a higher level of eHealth literacy [20], there is an absence of guidance for the standardized interpretation of these scores. This guidance is needed to inform decision-making and follow-up actions [27]. eHEALS mean and median scores

[8,13,14,28], as well as item response frequencies [14,29,30], are typically reported. Cut points have been arbitrarily applied at the item level [15], which disregards scale constructs. Furthermore, the common use of a single cut point to the global scale [8,16,28] implies a dichotomy of high versus low eHealth literacy and does not account for respondent self-perceived competency across the multiple eHEALS factors (ie, awareness, skills, and evaluation) [24,31]. These factors have only recently been identified [24,31], demonstrating that our understanding of the eHEALS and its psychometric properties is continuing to evolve more than a decade after the scale was published.

A Robust Approach to Analyzing Electronic Health Literacy Data Is Required

Shortcomings in the interpretation of eHEALS scores highlight the need for a robust approach to analyzing and interpreting eHealth literacy data. In line with the principles of scale development [27,32], measures should be refined as new data about a scale's properties accumulates. This includes retesting a scale when it is used in new populations and as new analytical techniques become available [27,32]. Cluster analysis is a sophisticated analytical approach, which has not previously been applied to eHealth literacy research. This powerful technique is used to identify natural groupings or structures within data and can therefore classify individuals who score similarly on an outcome measure, such as the eHEALS [33]. It has several strengths including: First, it is a data-driven exploratory technique and therefore not dependent on scoring thresholds, which are arbitrarily imposed by the author(s). Second, being able to observe and characterize natural structures or groupings means that researchers have a better understanding of subgroups of eHealth literacy in the sample population. If classes (or clusters) exist, ignoring their presence by analyzing the data as a single group could lead to an averaging out of any effects of interest [34]. Third, this approach allows for the multiple eHEALS domains (ie, skill, awareness, and evaluate) to be considered simultaneously across subgroups. For example, it can be known if one subgroup self-rates their *awareness* as highest, whereas another subgroup self-rates their *skills* as highest. Finally, regression analyses can be completed to examine patient characteristics associated with assignment to each eHealth literacy class.

By understanding the number and characteristics of groupings, it can be known whether a one size fits all approach to eHealth literacy improvement is appropriate, or whether more tailored interventions are required. If tailoring is needed, understanding how different classes scored across the eHEALS factors allows researchers and clinicians to ensure interventions are designed to specifically address the needs of that subgroup. Furthermore, understanding patient characteristics associated with class membership allows the identification of individuals who should

be targeted for interventions, or who will require more intensive support throughout periods of eHealth delivery. A cluster analysis of eHEALS data is therefore an important next step to better understand the multicomponent nature of eHealth literacy and how these eHEALS factors coexist in subgroups of patients.

This study aimed to determine (1) whether there are identifiable eHealth literacy classes among magnetic resonance imaging (MRI) and computed tomography (CT) medical imaging outpatients; and (2) sociodemographic and internet use characteristics associated with each eHealth literacy class.

Methods

Design and Setting

This cross-sectional study was completed with MRI and CT medical imaging outpatients attending the imaging department of a large, tertiary hospital, located within New South Wales, Australia. The results of this study have been reported in accordance with the Strengthening the Reporting of Observational Studies in Epidemiology checklist [35] and the Checklist for Reporting Results of Internet E-Surveys [36].

Participants

Eligible participants were: (1) attending for an outpatient MRI or CT scan; (2) 18 years or older; and (3) reported having access to the internet for personal use. Participants were excluded if they were: (1) non-English speaking; (2) deemed by reception staff to be cognitively or physically unable to consent or complete the survey; or (3) identified as having completed the survey previously. MRI and CT medical imaging outpatients were the focus of this research because they have high unmet information preferences, which could potentially be met by eHealth capabilities [37].

Procedure

Medical imaging department receptionists identified potentially eligible participants when they presented for their outpatient appointment. Potentially eligible participants were informed about the research and invited to speak with a trained research assistant. Interested patients were provided with a written information sheet and introduced to the research assistant, who gave an overview of the study and obtained the patient's verbal consent to participate. During this overview, interested patients were told that the Web-based questionnaire would take approximately 10-15 mins to complete, participation was voluntary, and responses would remain confidential. The age, gender, and scan type of noninterested and nonconsenting patients were recorded. Consenting patients were provided with a tablet computer and asked to complete a Web-based questionnaire before their scan. Participants' study identification number, assigned by the receptionist and entered by the research assistant, provided access to the questionnaire. Each participant could move freely through each screen using next and back buttons. The questionnaire was pilot tested with MRI and CT medical imaging outpatients 2 weeks before study commencement, which confirmed the acceptability and feasibility of electronic survey administration in this study setting. A paper-and-pen version of the questionnaire was available to participants who requested it. If the patient was

called for their procedure before finishing the questionnaire, only those questions that had been completed were used for data analysis. Electronic responses were deidentified, collected using the QuON platform [38], and stored securely on an access-restricted part of the University of Newcastle server. Ethics approval was obtained from the Human Research Ethics Committees of the Hunter New England Local Health District (16/10/19/5.11) and University of Newcastle (H-2016-0386).

Measure

eHealth literacy was assessed using the 8-item eHEALS. All 8 eHEALS items were administered on 1 screen within the Web-based questionnaire, and the presentation of these items was not random. Respondents indicated their level of agreement with each statement on a 5-point Likert scale from 1 *strongly disagree* to 5 *strongly agree*. Responses were summed to give a final score ranging from 8 to 40, with higher scores indicating higher eHealth literacy. The tool has demonstrated test-retest reliability [17], internal consistency [17,19,28], and measurement invariance across English speaking countries [24]. Previous studies, largely employing exploratory factor analysis, have suggested that the scale measures a single factor [8,17,19,20]. Emerging research using confirmatory factor analysis and based on the theoretical underpinnings of eHealth literacy suggests that the scale measures 3 factors: awareness, skills, and evaluate [24,31]. This 3-factor eHEALS structure has been identified in the medical imaging study setting (standardized root mean residual=0.038; confirmatory fit index=0.944; and root mean square error of approximation=0.156) [31]. As such, self-rated awareness, skills, and evaluate competencies of patients within each subgroup were explored within this study.

Study Factors

On the basis of previous research indicating an association with eHealth literacy, standard self-report items assessed participant gender, age, marital status, education, internet use frequency, and overall health status [8,13-17]. Remoteness of residence, health information amount preference (no information; some information; and a lot of information), and internet use for scan preparation (yes; no; and don't know) were hypothesized to influence eHealth literacy and were, therefore, included as covariates. Participant postcodes were mapped to the Accessibility/Remoteness Index of Australia Plus to categorize participant remoteness as metropolitan (major cities of Australia) or nonmetropolitan (inner regional, outer regional, remote, or very remote Australia) [39].

Data Analysis

Participant characteristics were summarized as frequencies and percentages or means and standard deviations. Consent bias was assessed for gender, scan type, and age group using Chi-square tests. Given the high completion rate (98.1%, 256/261 for individuals starting eHEALS items), only complete eHEALS data were included in the analyses. Items relating to each eHEALS factor were summed to generate separate awareness, skill, and evaluate factor scores.

Identification of Electronic Health Literacy Classes

Cluster analysis was completed using a 2-phased approach. Distance-based unsupervised clustering was undertaken as an initial exploratory knowledge discovery technique, to identify natural clusters of patients according to their responses (refer [Multimedia Appendix 1](#) for methods and results). Secondary clustering of patients, using latent class analysis (LCA) as a statistical modeling approach, was to be completed as a follow-up if distance-based cluster structures were observed. LCA was subsequently performed to verify the 4-cluster structure identified. LCA is less sensitive to choice of parameters (eg, distance metric), allows for uncertainty in class membership, and has greater power and lower type 1 error rates when compared with other clustering techniques [34], and was, therefore, selected as the primary analysis technique. Latent class membership probabilities were calculated to determine the proportion of the sample that belonged to each of the classes. Item response probabilities were calculated to determine the probability of endorsing each response option, conditional on class membership. The Bayesian Information Criterion (BIC) and G^2 -statistic were computed to aid in determining the optimal number of classes (with plateauing indicating no improvements to model fit) [40], as were overall class interpretability and model parsimony. Model entropy was computed, with values closer to 1 representing clear class delineation [41]. The maximum posterior probability of class membership was also calculated for each participant, based on the optimal number of classes, with values greater than .5 indicating adequate probability for class assignment [42].

Characteristics Associated With Class Membership

An LCA regression analysis was performed to identify participant sociodemographic and internet use characteristics associated with class membership. Given the exploratory nature of data analysis, all covariates were initially cross-tabulated with class membership (assigned according to maximum

posterior probability) to identify model sparseness, and then analyzed using univariate LCA regression: gender; age (<65 years vs 65+ years); geographic location of residence (major city vs regional or rural); marital status (married or living with partner vs not married); education (high school or less vs more than high school); overall health (fair or worse; good or better than good); information amount preference (a lot of information vs not a lot of information); internet use for scan preparation; and internet use frequency (daily vs less than daily). Likelihood ratio tests (based on the univariate results) were performed to determine whether each predictor significantly improved the fit of the model. Covariates with a statistically significant likelihood ratio test ($P<.05$) were included in the final multivariable LCA regression. Distance-based and latent class analyses were performed in R 3.4 [43]. Descriptive statistics were computed in STATA v13.

Sample Size

Sample sizes of at least 200 have been suggested as adequate for LCA, dependent on subsequent model fit and number of classes [40,44]. As such, a sample of at least 200 was deemed appropriate for this study.

Results

Sample

A total of 405 potentially eligible patients were invited to discuss the study with a research assistant during the 7-week recruitment period, of which 354 (87.4%) were interested in participating. Of 268 eligible participants, 261 (97.4%) started the eHEALS, 256 (95.5%) completed all eHEALS items, and 222 (82.8%) completed all eHEALS and study factor items. There were no significant differences between patients who were and were not interested in participating in the study based on gender, scan type, or age group. [Table 1](#) provides a summary of the sociodemographic, scan, and internet characteristics of the study sample.

Table 1. Participant sociodemographic, scan, and internet characteristics (N=256). Number of observations for each characteristic may not total 256 because of missing data.

Characteristic	Value
Age (years), mean (SD)	53 (15.0)
Electronic Health Scale (eHEALS) domain score, mean (SD)	
Awareness (possible total=10)	6.9 (2.0)
Skills (possible total=15)	10.9 (2.9)
Evaluate (possible total=15)	10.0 (3.1)
Gender, n (%)	
Male	112 (43.8)
Female	144 (56.3)
Marital status, n (%)	
Married or living with partner	146 (64.6)
Not married or living with partner	80 (35.4)
Education completed, n (%)	
High school or less	128 (56.6)
More than high school	98 (43.4)
Geographic location, n (%)	
Metropolitan	200 (78.1)
Nonmetropolitan	56 (21.9)
Overall health, n (%)	
Poor	17 (7.7)
Fair	75 (34.1)
Good	94 (42.7)
Very good	34 (15.5)
Scan type, n (%)	
Computed tomography	101 (39.4)
Magnetic resonance imaging	152 (59.4)
Don't know	3 (1.2)
Used internet for scan, n (%)	
Yes	27 (10.5)
No	228 (89.1)
Don't know	1 (0.4)
Frequency of internet use, n (%)	
Less than once a month	11 (4.3)
Once a month	5 (1.9)
A few times a month	14 (5.5)
A few times a week	33 (12.9)
About once a day	47 (18.4)
Several times a day	146 (57.0)
Information amount preference, n (%)	
No information	2 (0.8)
Some information	58 (25.9)
A lot of information	165 (73.3)

Identification of Electronic Health Literacy Classes

The BIC and G^2 -statistic continued to decrease as the number of classes (K) increased, but the improvement was progressively smaller after 3 classes (see Table 2). On the basis of the interpretability of the latent classes, the reduction in class size beyond K=4, and parsimony, the 4 class model was selected as the optimal class structure. The lowest maximum posterior probability under this 4 class model was .516. As such, all participants exceeded the threshold of .5 for maximum posterior probability and were assigned to a class. Hence, LCA findings on number of classes were consistent with that of distance-based clustering (see Multimedia Appendix 1).

Multimedia Appendix 2 shows the unconditional item response probabilities of each eHEALS response option based on class assignment. Classes were named according to likely level of eHealth literacy, with respect to that of other classes identified in the analysis:

- Class 1—*low eHealth literacy* (21.1% of respondents, 54/256): when compared with other classes, class 1 had the highest probability of responding *disagree* and *strongly disagree* across all eHEALS items. The probability of this group responding either *disagree* or *strongly disagree* was highest for awareness items (0.88 and 0.89), followed by evaluate items (0.79, 0.81, and 0.88) and skills items (0.66, 0.75, and 0.84).
- Class 2—*moderate eHealth literacy* (26.2% of respondents, 67/256): when compared with other classes, class 2 had the highest probability of responding *undecided* across all eHEALS items, and the second highest probability of responding *agree* across awareness and skills items. This group was most likely to respond *undecided* to awareness items (0.56 and 0.59), either *agree* (0.54 and 0.58) or *undecided* (0.48) to skills items, and *undecided* to evaluate items (0.55, 0.61, and 0.63).
- Class 3—*high eHealth literacy* (32.8% of respondents, 84/256): when compared with other classes, class 3 had the highest probability of responding *agree* across all eHEALS items. The probability of this class responding *agree* was

greatest for skills items (0.97, 0.97, and 1.00), followed by awareness (0.80 and 0.91), and evaluate items (0.68, 0.71, and 0.81).

- Class 4—*very high eHealth literacy* (19.9% of respondents, 51/256): when compared with other classes, class 4 had the highest probability of responding *strongly agree* across all eHEALS items. The probability of this class responding *strongly agree* was greatest for skills items (0.71, 0.79 and 0.90), followed by evaluate (0.57, 0.74, and 0.86), and awareness items (0.53 and 0.61).

Characteristics Associated With Class Membership

Internet use for scan preparation was not included in regression analyses because of sparseness (ie, 10.5%, 27/256 of participants responded *yes* to internet use for scan preparation). Following univariate analyses, likelihood ratio difference tests indicated that age; education, marital status, overall health status, information amount preference, and internet use frequency all significantly improved the fit of the model ($P<.05$; see Multimedia Appendix 3) and were included in the multivariable regression analysis (see Table 3).

Class 1 (low eHealth literacy) was selected as a reference class for multivariable regression. This was because these participants likely need additional support to engage with eHealth, making identification of the characteristics of participants in this subgroup a priority. As shown in Table 3, participants who indicated that they preferred not to receive a lot of information about their health had 0.06 times the odds of belonging to class 2 (moderate eHealth literacy), compared with class 1 (low eHealth literacy), and this difference was statistically significant. Furthermore, participants who reported using the internet less than daily had 0.21 times the odds of belonging to class 3 (high eHealth literacy), compared with class 1 (low eHealth literacy), and this difference was statistically significant. There were no other significant differences in sociodemographic or internet use attributes between participants in class 1 (low eHealth literacy) and classes 2, 3, and 4 (moderate, high, and very high eHealth literacy, respectively).

Table 2. Goodness of fit indices for 1 to 5 class structures.

Class structure	BIC ^a	G^2 -statistic	Entropy
1 class structure	5893.74	3402.83	1.00
2 class structure	5148.66	2474.76	0.97
3 class structure	4651.68	1794.79	0.98
4 class structure	4556.81	1516.93	0.92
5 class structure	4545.21	1322.34	0.90

^aBIC: Bayesian Information Criterion.

Table 3. Adjusted odds ratios associated with membership of classes 2, 3, and 4, compared with class 1.

Variable	Class 1 versus class 2 (low vs moderate)		Class 1 versus class 3 (low vs high)		Class 1 versus class 4 (low vs very high)	
	Odds ratio (95% CI)	P value	Odds ratio (95% CI)	P value	Odds ratio (95% CI)	P value
Age						
<65 years	Ref ^a	Ref	Ref	Ref	Ref	Ref
65 years or older	0.37 (0.06-2.11)	.26	0.32 (0.10-1.03)	.06	0.37 (0.07-2.00)	.25
Education						
High school or less	Ref	Ref	Ref	Ref	Ref	Ref
More than high school	1.09 (0.15-7.65)	.93	2.21 (0.52-9.47)	.29	3.89 (0.67-22.76)	.14
Marital status						
Married or living with partner	Ref	Ref	Ref	Ref	Ref	Ref
Not married or living with partner	1.63 (0.26-10.23)	.60	0.96 (0.27-3.41)	.96	0.91 (0.14-6.01)	.92
Information amount preference						
A lot of information	Ref	Ref	Ref	Ref	Ref	Ref
Not a lot of information	0.06 (0.01-0.60)	.02 ^b	0.61 (0.18-2.04)	.43	0.23 (0.04-1.29)	.10
Overall health						
Fair or worse	Ref	Ref	Ref	Ref	Ref	Ref
Good or better than good	1.10 (0.24-5.02)	.91	1.16 (0.35-3.87)	.81	1.48 (0.33-6.68)	.61
Internet use frequency						
Daily	Ref	Ref	Ref	Ref	Ref	Ref
Less than once a day	0.62 (0.14-2.67)	.52	0.21 (0.07-0.63)	.007 ^b	0.17 (0.02-1.76)	.14

^aRef: reference category.^bStatistically significant.

Discussion

Principal Findings

This study was the first to identify classes of patients based on eHealth literacy, and to assess characteristics associated with class membership. The identification of multiple classes, using both distance-based and latent class analyses, highlights issues with using the eHEALS global score as a dichotomous measurement tool. In particular, these findings suggest that it may be important to account for multiple eHealth literacy subgroups when developing standardized guidance for the interpretation of eHEALS scores. Furthermore, the identification of multiple classes suggests that the design and delivery of eHealth resources may need to be tailored based on eHealth literacy. Patient characteristics, such as internet use frequency and health-related information amount preferences, may provide an indication of eHealth literacy, and related support needs.

Multiple Electronic Health Literacy Subgroups Were Identified

In total, 4 eHealth literacy classes were identified, and the probabilities of belonging to each of the 4 classes were similar (ie, range 19.9%-32.8%). The finding that eHealth literacy varied substantially in this population suggests that MRI and CT medical imaging outpatients may have differing support needs relating to the use of eHealth technology. Subgroups of

patients were characterized by having either very high, high, moderate, or low eHealth literacy. Within the very high eHealth literacy subgroup, awareness was the lowest scoring competency. This may be because consumers who are familiar with eHealth also understand the masses of Web-based information that is available and the common difficulty of locating valid and reliable information sources [12]. Across all classes, participants reported being most competent in their skills using eHealth resources. Such skills may be perceived highly because they align to the computer and media literacy types, which comprise eHealth literacy [11]. These literacy types are increasingly used in the digital era, with 87% of Australians being identified as internet users in 2016-2017 [45].

In total, 2 out of 4 classes, comprising 52.7% of respondents, had the highest probability of responding either agree or strongly agree to eHEALS items, reflecting high and very high eHealth literacy. Despite this, there was room for improvement in awareness, skills, and evaluation competencies for the remaining 2 classes, comprising 47.3% of respondents and reflecting low and moderate eHealth literacy. This approximately even split in eHealth literacy capabilities is also apparent in other studies completed with cardiovascular disease patients [16] and chronic disease patients [46], which used arbitrary cut points to dichotomize high versus low eHealth literacy. It is possible that the application of dichotomous cut points prevented the identification of such diverse eHealth literacy subgroups. Further

research using cluster analyses should be conducted to determine whether multiple eHealth literacy subgroups exist across other health consumer populations. This information may inform the development of more targeted eHealth literacy improvement interventions.

Internet Use Frequency and Health Information Amount Preferences Predicted Class Membership

Those who had used the internet less than daily had approximately 5 times the odds of belonging to the low eHealth literacy class compared with the high eHealth literacy class. Although mixed findings exist [19], an association between internet use and eHealth literacy has been reported in studies with chronically ill patients and the general public [15-17]. Our findings may suggest that frequent internet users do use the internet for health, and this may result in greater self-reported eHealth literacy. Alternatively, they may indicate that frequent internet users self-perceive that their ability to engage with and evaluate general internet resources is transferable to health-related content.

Those with a preference not to receive a lot of information about their health had over 16 times the odds of belonging to the low eHealth literacy class, compared with the moderate eHealth literacy class. To the authors' knowledge, this study is the first to explore the association between preferred amount of information and eHealth literacy. It is possible that the inclusion of an *undecided* response option resulted in imposter syndrome for those in the moderate class [47]. In this case, participants underestimate their competency, opting for a neutral response option, to prevent being perceived as overconfident. Therefore, those in the moderate class may be more eHealth literate than findings suggest, which could contribute to a significant finding when comparing low and moderate classes. It may also be possible that those who prefer to receive a lot of information about their health are Web-based health-related information seekers, hence requiring eHealth literacy. An evidence review completed by the Australian Commission on Quality and Safety in Health Care found that patients typically use the internet as a supplement to advice from a health professional [48]. It is therefore likely that those who have greater preferences for health-related information require and develop the awareness, skills, and evaluation abilities needed to use this Web-based supplementary information. An analysis of the potentially moderating effects of Web-based health-related information seeking on the association between information amount preference and eHealth literacy should be explored in the future. This analysis should include an examination of the types of eHealth resources being accessed and used.

The technology acceptance model provides a theoretical justification for the characteristics related to a subgroup assignment [49]. Under this model, technology acceptance is influenced by perceived ease of use, and usefulness of the internet [49]. Accordingly, those who use the internet more frequently may be more likely to perceive ease of use of Web-based health resources. Similarly, those who prefer to receive a lot of health-related information may be more likely to deem eHealth as useful. Such perceived acceptability may result in greater self-rated eHealth literacy. Continued studies

are needed to investigate this association and determine whether other factors not explored in this study, which promote perceived ease of use and usefulness of eHealth (eg, speed and availability of the internet, and self-management of chronic conditions, respectively), are associated with eHealth literacy. Contrary to expectations and inconsistent with previous studies [8,13-15], no other examined sociodemographic characteristics significantly influenced class membership. Inconsistencies with existing literature may indicate that the predictors of eHealth literacy differ across populations, settings, or cut points applied.

Practice Implications

The identification of low and moderate eHealth literacy classes suggests that eHealth literacy improvement interventions may be warranted within this population. However, there is minimal high-quality research investigating the effectiveness of such interventions, highlighting a need for continued research in this area [50]. Given their association with low class membership, those who use the internet less than daily and prefer not to receive a lot of health information should be the focus of such eHealth literacy improvement interventions. In the interim, researchers and clinicians should tailor the design and delivery of eHealth resources to patients' eHealth literacy, to maximize engagement and potential receipt of benefits. As skills were the highest rated competency across all classes within this study population, future eHealth interventions should be designed with a focus on promoting awareness and reducing the need to evaluate eHealth resources within the imaging setting. A written provider recommendation, which directs consumers toward credible eHealth resources, may be one scalable strategy to do this [31,51]. In cases where skills are low, alternative strategies may be needed, such as clear instructions on how to appropriately navigate Web-based content, reduced click-through requirements to retrieve Web-based materials, and the use of persuasive system design elements to enhance usability and maintain engagement [52].

Limitations and Future Research

To aid in the interpretation of findings, labels (ie, very high, high, moderate, and low) were arbitrarily assigned to eHealth literacy classes. It is therefore unclear whether, for example, those classified as very high eHealth literacy were indeed very high. As this study applied a novel approach to data analysis and interpretation, the generalizability of findings across medical imaging settings and to other patient groups is unknown. This class structure and the predictors of class membership should be studied and replicated in other populations. Furthermore, it is possible that the setting influenced responses as participants may have assumed that eHEALS questions related to scan-specific information on the internet rather than general eHealth resources.

The eHEALS was selected because of its established psychometric properties, emerging research proposing a 3-factor structure, and wide application [17,19,20,24,28,31]. However, it has been criticized for not measuring health 2.0. (ie, user-generated content and interactivity) and, therefore, lacking relevance to modern technology [21,24,53]. Some studies have adapted the scale to address this limitation, yet the body of research is small and as a result, the impacts on scale

psychometric properties remain unclear [21,24]. The generation of new Web-based content is, however, not highly relevant within the context of preparatory information provision for medical imaging procedures and this limitation is, therefore, not expected to influence our study.

Conclusions

This study used sophisticated analytical techniques to add to evidence about the nature of eHEALS scores within a clinical population. Cluster analyses were used to identify 4 classes of patients with differing eHealth literacy within this sample of MRI and CT medical imaging outpatients. The proportion of participants assigned to each latent class was similar, suggesting

that eHealth literacy varies within this study setting. Across all classes, skills were perceived as the highest rated competency followed by either awareness or evaluation. The frequency of participants' personal internet use and their health-related information preferences predicted class membership. Tools such as the eHEALS may need to be administered to identify class assignment, and inform eHealth literacy improvement interventions, as well as the design and delivery of eHealth resources. Findings from this study should also contribute to the development of guidance for eHEALS scoring interpretation, which is a necessary next step to improve scale utility [27]. Study findings should be replicated in other populations and settings to increase the generalizability of results.

Acknowledgments

The authors thank the patients for their involvement in this study, as well as the administrative and clinical staff at Hunter New England Imaging for assistance with recruitment and data collection. This paper is supported by a Priority Research Centre for Health Behaviour Small Grant, and Hunter Cancer Research Alliance Implementation Science Flagship 2018 Student Award. LH is supported by an Australian Government Research Training Program Scholarship. AB is supported by a National Health and Medical Research Council Early Career Fellowship (APP1073317) and Cancer Institute New South Wales Early Career Fellowship (13/ECF/1-37). LM is supported by a postdoctoral fellowship (PF-16-011) from the Australian National Breast Cancer Foundation.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Distance-based cluster analysis.

[PDF File (Adobe PDF File), 330KB-Multimedia Appendix 1]

Multimedia Appendix 2

Unconditional item response probabilities for a 4-class model of electronic health literacy.

[PDF File (Adobe PDF File), 159KB-Multimedia Appendix 2]

Multimedia Appendix 3

Log likelihood difference tests.

[PDF File (Adobe PDF File), 12KB-Multimedia Appendix 3]

References

1. Wantland DJ, Portillo CJ, Holzemer WL, Slaughter R, McGhee EM. The effectiveness of web-based vs non-web-based interventions: a meta-analysis of behavioral change outcomes. *J Med Internet Res* 2004 Nov 10;6(4):e40 [FREE Full text] [doi: 10.2196/jmir.6.4.e40] [Medline: 15631964]
2. Car J, Black A, Anandan C, Cresswell K, Pagliari C, McKinstry B, et al. University of Birmingham. 2008. The Impact of eHealth on the Quality & Safety of Healthcare: A Systemic Overview & Synthesis of the Literature. Report for the NHS Connecting for Health Evaluation Programme URL: <https://www.birmingham.ac.uk/Documents/college-mds/haps/projects/cfhep/projects/001/NHSCFHEP001FinalReport.pdf> [accessed 2019-08-08]
3. Black AD, Car J, Pagliari C, Anandan C, Cresswell K, Bokun T, et al. The impact of ehealth on the quality and safety of health care: a systematic overview. *PLoS Med* 2011 Jan 18;8(1):e1000387 [FREE Full text] [doi: 10.1371/journal.pmed.1000387] [Medline: 21267058]
4. Queensland Health. 2015. eHealth Investment Strategy URL: <https://www.health.qld.gov.au/system-governance/strategic-direction/plans/ehealth-investment-strategy> [accessed 2018-12-13] [WebCite Cache ID 74d1NO9Lh]
5. Health and Social Care Board. 2016. eHealth and Care Strategy for Northern Ireland: Improving Health and Wealth Through the Use of Information and Communication Technology URL: http://www.hscboard.hscni.net/download/Consultations/2014-15%20eHealth_and_Care_Strategy_Consultation/Consultation_Document-e-Health_and_Care-PDF_2mb.pdf [accessed 2019-08-08]

6. NHS Scotland. 2015. eHealth Strategy 2014-2017 URL:<https://www.gov.scot/publications/ehealth-strategy-2014-2017/> [accessed 2019-08-08]
7. United States Department of Health and Human Services. 2015. Federal Health IT Strategic Plan: 2015-2020 URL:https://www.healthit.gov/sites/default/files/9-5-federalhealthitstratplanfinal_0.pdf [accessed 2019-08-08]
8. Neter E, Brainin E. eHealth literacy: extending the digital divide to the realm of health information. *J Med Internet Res* 2012 Jan 27;14(1):e19 [FREE Full text] [doi: [10.2196/jmir.1619](https://doi.org/10.2196/jmir.1619)] [Medline: [22357448](https://pubmed.ncbi.nlm.nih.gov/22357448/)]
9. Kim SH, Son YJ. Relationships between ehealth literacy and health behaviors in Korean adults. *Comput Inform Nurs* 2017 Feb;35(2):84-90. [doi: [10.1097/CIN.0000000000000255](https://doi.org/10.1097/CIN.0000000000000255)] [Medline: [27258808](https://pubmed.ncbi.nlm.nih.gov/27258808/)]
10. Mitsutake S, Shibata A, Ishii K, Oka K. Associations of ehealth literacy with health behavior among adult internet users. *J Med Internet Res* 2016 Jul 18;18(7):e192 [FREE Full text] [doi: [10.2196/jmir.5413](https://doi.org/10.2196/jmir.5413)] [Medline: [27432783](https://pubmed.ncbi.nlm.nih.gov/27432783/)]
11. Norman CD, Skinner HA. eHealth literacy: essential skills for consumer health in a networked world. *J Med Internet Res* 2006 Jun 16;8(2):e9 [FREE Full text] [doi: [10.2196/jmir.8.2.e9](https://doi.org/10.2196/jmir.8.2.e9)] [Medline: [16867972](https://pubmed.ncbi.nlm.nih.gov/16867972/)]
12. Lee K, Hoti K, Hughes JD, Emmerton L. Dr Google and the consumer: a qualitative study exploring the navigational needs and online health information-seeking behaviors of consumers with chronic health conditions. *J Med Internet Res* 2014 Dec 2;16(12):e262 [FREE Full text] [doi: [10.2196/jmir.3706](https://doi.org/10.2196/jmir.3706)] [Medline: [25470306](https://pubmed.ncbi.nlm.nih.gov/25470306/)]
13. Choi NG, Dinitto DM. The digital divide among low-income homebound older adults: internet use patterns, ehealth literacy, and attitudes toward computer/internet use. *J Med Internet Res* 2013 May 2;15(5):e93 [FREE Full text] [doi: [10.2196/jmir.2645](https://doi.org/10.2196/jmir.2645)] [Medline: [23639979](https://pubmed.ncbi.nlm.nih.gov/23639979/)]
14. Tennant B, Stellefson M, Dodd V, Chaney B, Chaney D, Paige S, et al. eHealth literacy and web 2.0 health information seeking behaviors among baby boomers and older adults. *J Med Internet Res* 2015 Mar 17;17(3):e70 [FREE Full text] [doi: [10.2196/jmir.3992](https://doi.org/10.2196/jmir.3992)] [Medline: [25783036](https://pubmed.ncbi.nlm.nih.gov/25783036/)]
15. Milne RA, Puts MT, Papadakis J, Le LW, Milne VC, Hope AJ, et al. Predictors of high ehealth literacy in primary lung cancer survivors. *J Cancer Educ* 2015 Dec;30(4):685-692. [doi: [10.1007/s13187-014-0744-5](https://doi.org/10.1007/s13187-014-0744-5)] [Medline: [25355524](https://pubmed.ncbi.nlm.nih.gov/25355524/)]
16. Richtering SS, Hyun K, Neubeck L, Coorey G, Chalmers J, Usherwood T, et al. eHealth literacy: predictors in a population with moderate-to-high cardiovascular risk. *JMIR Hum Factors* 2017 Jan 27;4(1):e4. [doi: [10.2196/humanfactors.6217](https://doi.org/10.2196/humanfactors.6217)] [Medline: [28130203](https://pubmed.ncbi.nlm.nih.gov/28130203/)]
17. Chung SY, Nahm ES. Testing reliability and validity of the ehealth literacy scale (eHEALS) for older adults recruited online. *Comput Inform Nurs* 2015 Apr;33(4):150-156 [FREE Full text] [doi: [10.1097/CIN.0000000000000146](https://doi.org/10.1097/CIN.0000000000000146)] [Medline: [25783223](https://pubmed.ncbi.nlm.nih.gov/25783223/)]
18. Neter E, Brainin E. Perceived and performed ehealth literacy: survey and simulated performance test. *JMIR Hum Factors* 2017 Jan 17;4(1):e2 [FREE Full text] [doi: [10.2196/humanfactors.6523](https://doi.org/10.2196/humanfactors.6523)] [Medline: [28096068](https://pubmed.ncbi.nlm.nih.gov/28096068/)]
19. van der Vaart R, van Deursen A, Drossaert C, Taal E, van Dijk J, van de Laar M. Does the ehealth literacy scale (eHEALS) measure what it intends to measure? Validation of a Dutch version of the eHEALS in two adult populations. *J Med Internet Res* 2011 Nov 9;13(4):e86 [FREE Full text] [doi: [10.2196/jmir.1840](https://doi.org/10.2196/jmir.1840)] [Medline: [22071338](https://pubmed.ncbi.nlm.nih.gov/22071338/)]
20. Norman CD, Skinner HA. eHEALS: the ehealth literacy scale. *J Med Internet Res* 2006 Nov 14;8(4):e27 [FREE Full text] [doi: [10.2196/jmir.8.4.e27](https://doi.org/10.2196/jmir.8.4.e27)] [Medline: [17213046](https://pubmed.ncbi.nlm.nih.gov/17213046/)]
21. van der Vaart R, Drossaert C. Development of the digital health literacy instrument: measuring a broad spectrum of Health 1.0 and Health 2.0 skills. *J Med Internet Res* 2017 Jan 24;19(1):e27 [FREE Full text] [doi: [10.2196/jmir.6709](https://doi.org/10.2196/jmir.6709)] [Medline: [28119275](https://pubmed.ncbi.nlm.nih.gov/28119275/)]
22. Hsu W, Chiang C, Yang S. The effect of individual factors on health behaviors among college students: the mediating effects of ehealth literacy. *J Med Internet Res* 2014 Dec 12;16(12):e287 [FREE Full text] [doi: [10.2196/jmir.3542](https://doi.org/10.2196/jmir.3542)] [Medline: [25499086](https://pubmed.ncbi.nlm.nih.gov/25499086/)]
23. Koopman RJ, Petroski GF, Canfield SM, Stuppy JA, Mehr DR. Development of the PRE-HIT instrument: patient readiness to engage in health information technology. *BMC Fam Pract* 2014 Jan 28;15:18 [FREE Full text] [doi: [10.1186/1471-2296-15-18](https://doi.org/10.1186/1471-2296-15-18)] [Medline: [24472182](https://pubmed.ncbi.nlm.nih.gov/24472182/)]
24. Sudbury-Riley L, FitzPatrick M, Schulz PJ. Exploring the measurement properties of the ehealth literacy scale (eHEALS) among baby boomers: a multinational test of measurement invariance. *J Med Internet Res* 2017 Feb 27;19(2):e53 [FREE Full text] [doi: [10.2196/jmir.5998](https://doi.org/10.2196/jmir.5998)] [Medline: [28242590](https://pubmed.ncbi.nlm.nih.gov/28242590/)]
25. Diviani N, Dima AL, Schulz PJ. A psychometric analysis of the Italian version of the ehealth literacy scale using item response and classical test theory methods. *J Med Internet Res* 2017 Apr 11;19(4):e114 [FREE Full text] [doi: [10.2196/jmir.6749](https://doi.org/10.2196/jmir.6749)] [Medline: [28400356](https://pubmed.ncbi.nlm.nih.gov/28400356/)]
26. Chung S, Park BK, Nahm ES. The Korean ehealth literacy scale (K-eHEALS): reliability and validity testing in younger adults recruited online. *J Med Internet Res* 2018 Apr 20;20(4):e138 [FREE Full text] [doi: [10.2196/jmir.8759](https://doi.org/10.2196/jmir.8759)] [Medline: [29678800](https://pubmed.ncbi.nlm.nih.gov/29678800/)]
27. HealthMeasures. 2013. PROMIS® Instrument Maturity Model URL:http://www.healthmeasures.net/images/PROMIS/PROMISStandards_Vers_2_0_MaturityModelOnly_508.pdf [accessed 2019-06-07] [WebCite Cache ID 78wZrh3Z]
28. Mitsutake S, Shibata A, Ishii K, Oka K. Association of ehealth literacy with colorectal cancer knowledge and screening practice among internet users in Japan. *J Med Internet Res* 2012 Nov 13;14(6):e153 [FREE Full text] [doi: [10.2196/jmir.1927](https://doi.org/10.2196/jmir.1927)] [Medline: [23149453](https://pubmed.ncbi.nlm.nih.gov/23149453/)]

29. Knapp C, Madden V, Wang H, Sloyer P, Shenkman E. Internet use and ehealth literacy of low-income parents whose children have special health care needs. *J Med Internet Res* 2011 Sep 29;13(3):e75 [FREE Full text] [doi: [10.2196/jmir.1697](https://doi.org/10.2196/jmir.1697)] [Medline: [21960017](https://pubmed.ncbi.nlm.nih.gov/21960017/)]
30. Manafò E, Wong S. Assessing the ehealth literacy skills of older adults: a preliminary study. *J Consum Health Internet* 2012 Oct;16(4):369-381. [doi: [10.1080/15398285.2012.701163](https://doi.org/10.1080/15398285.2012.701163)]
31. Hyde LL, Boyes AW, Evans TJ, Mackenzie LJ, Sanson-Fisher R. Three-factor structure of the ehealth literacy scale among magnetic resonance imaging and computed tomography outpatients: a confirmatory factor analysis. *JMIR Hum Factors* 2018 Feb 19;5(1):e6 [FREE Full text] [doi: [10.2196/humanfactors.9039](https://doi.org/10.2196/humanfactors.9039)] [Medline: [29459356](https://pubmed.ncbi.nlm.nih.gov/29459356/)]
32. McDowell I. The theoretical and technical foundations of health measurement. In: *Measuring Health: A Guide to Rating Scales and Questionnaires*. Third Edition. New York: Oxford University Press; 2006:10-46.
33. Hastie T, Tibshirani R, Friedman J. *The Elements of Statistical Learning: Data Mining, Inference, and Prediction*. Second Edition. New York: Springer-Verlag; 2009.
34. Lanza ST, Rhoades BL. Latent class analysis: an alternative perspective on subgroup analysis in prevention and treatment. *Prev Sci* 2013 Apr;14(2):157-168 [FREE Full text] [doi: [10.1007/s11121-011-0201-1](https://doi.org/10.1007/s11121-011-0201-1)] [Medline: [21318625](https://pubmed.ncbi.nlm.nih.gov/21318625/)]
35. von Elm E, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP, STROBE Initiative. The strengthening of reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies. *PLoS Med* 2007 Oct 16;4(10):e296 [FREE Full text] [doi: [10.1371/journal.pmed.0040296](https://doi.org/10.1371/journal.pmed.0040296)] [Medline: [17941714](https://pubmed.ncbi.nlm.nih.gov/17941714/)]
36. Eysenbach G. Improving the quality of web surveys: the checklist for reporting results of internet e-surveys (CHERRIES). *J Med Internet Res* 2004 Sep 29;6(3):e34 [FREE Full text] [doi: [10.2196/jmir.6.3.e34](https://doi.org/10.2196/jmir.6.3.e34)] [Medline: [15471760](https://pubmed.ncbi.nlm.nih.gov/15471760/)]
37. Hyde L, Mackenzie L, Boyes AW, Evans TJ, Symonds M, Sanson-Fisher R. Prevalence and correlates of patient-centred preparatory information provision to computed tomography and magnetic resonance imaging outpatients: a cross-sectional study. *Patient Educ Couns* 2018 Oct;101(10):1814-1822. [doi: [10.1016/j.pec.2018.05.025](https://doi.org/10.1016/j.pec.2018.05.025)] [Medline: [29884532](https://pubmed.ncbi.nlm.nih.gov/29884532/)]
38. Paul D, Wallis M, Henskens F, Nolan K. QuON: A Generic Platform for the Collation and Sharing of Web Survey Data. In: *Proceedings of the 9th International Conference on Web Information Systems and Technologies*. 2013 Presented at: WEBIST'13; May 8-10, 2013; Aachen, Germany p. 111-116 URL: <https://ogma.newcastle.edu.au/vital/access/manager/Repository/uon:15474>
39. The University of Adelaide. 2005. Accessibility/Remoteness Index of Australia (ARIA) URL: <https://www.adelaide.edu.au/hugo-centre/services/aria> [accessed 2019-08-08]
40. Nylund KL, Asparouhov T, Muthén BO. Deciding on the number of classes in latent class analysis and growth mixture modeling: a Monte Carlo simulation study. *Struct Equ Modeling* 2007 Dec 5;14(4):535-569. [doi: [10.1080/10705510701575396](https://doi.org/10.1080/10705510701575396)]
41. Celeux G, Soromenho G. An entropy criterion for assessing the number of clusters in a mixture model. *J Classif* 1996 Sep;13(2):195-212. [doi: [10.1007/BF01246098](https://doi.org/10.1007/BF01246098)]
42. Clark S, Muthén B, Muthén & Mplus. 2009. Relating Latent Class Analysis Results to Variables not Included in the Analysis URL: <https://www.statmodel.com/download/relatinglca.pdf> [accessed 2019-06-07] [WebCite Cache ID [78wb4hBuw](https://www.webcitation.org/78wb4hBuw)]
43. R Project. 2018. The R Project for Statistical Computing URL: <https://www.r-project.org/> [accessed 2019-08-09]
44. Tein JY, Coxe S, Cham H. Statistical power to detect the correct number of classes in latent profile analysis. *Struct Equ Modeling* 2013 Oct 1;20(4):640-657 [FREE Full text] [doi: [10.1080/10705511.2013.824781](https://doi.org/10.1080/10705511.2013.824781)] [Medline: [24489457](https://pubmed.ncbi.nlm.nih.gov/24489457/)]
45. Australian Bureau of Statistics, Australian Government. 2018. 8146.0 - Household Use of Information Technology, Australia, 2016-17 URL: <http://www.abs.gov.au/ausstats/abs@.nsf/mf/8146.0> [accessed 2019-06-24] [WebCite Cache ID [74d1a0s3q](https://www.webcitation.org/74d1a0s3q)]
46. Paige SR, Krieger JL, Stellefson M, Alber JM. eHealth literacy in chronic disease patients: an item response theory analysis of the ehealth literacy scale (eHEALS). *Patient Educ Couns* 2017 Feb;100(2):320-326 [FREE Full text] [doi: [10.1016/j.pec.2016.09.008](https://doi.org/10.1016/j.pec.2016.09.008)] [Medline: [27658660](https://pubmed.ncbi.nlm.nih.gov/27658660/)]
47. Clance PR, Imes SA. The imposter phenomenon in high achieving women: dynamics and therapeutic intervention. *Psychotherapy* 1978;15(3):241-247. [doi: [10.1037/h0086006](https://doi.org/10.1037/h0086006)]
48. Ramsay I, Peters M, Corsini N, Eckert M. Australia Commission on Safety and Quality in Healthcare. 2017. Consumer Health Information Needs and Preferences: A Rapid Evidence Review URL: <https://www.safetyandquality.gov.au/sites/default/files/migrated/Consumer-health-information-needs-and-preferences-A-rapid-evidence-review.pdf> [accessed 2019-08-08]
49. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. *MIS Q* 1989 Sep;13(3):319-340. [doi: [10.2307/249008](https://doi.org/10.2307/249008)]
50. Car J, Lang B, Colledge A, Ung C, Majeed A. Interventions for enhancing consumers' online health literacy. *Cochrane Database Syst Rev* 2011 Jun 15(6):CD007092 [FREE Full text] [doi: [10.1002/14651858.CD007092.pub2](https://doi.org/10.1002/14651858.CD007092.pub2)] [Medline: [21678364](https://pubmed.ncbi.nlm.nih.gov/21678364/)]
51. Usher W. Gold Coast general practitioners' recommendations of health websites to their patients. *Med J Aust* 2007;187(2):82-83. [doi: [10.5694/j.1326-5377.2007.tb01145.x](https://doi.org/10.5694/j.1326-5377.2007.tb01145.x)]

52. Kelders SM, Kok RN, Ossebaard HC, van Gemert-Pijnen JE. Persuasive system design does matter: a systematic review of adherence to web-based interventions. *J Med Internet Res* 2012 Nov 14;14(6):e152 [FREE Full text] [doi: [10.2196/jmir.2104](https://doi.org/10.2196/jmir.2104)] [Medline: [23151820](https://pubmed.ncbi.nlm.nih.gov/23151820/)]
53. van de Belt TH, Engelen LJ, Berben SA, Schoonhoven L. Definition of Health 2.0 and Medicine 2.0: a systematic review. *J Med Internet Res* 2010 Jun 11;12(2):e18 [FREE Full text] [doi: [10.2196/jmir.1350](https://doi.org/10.2196/jmir.1350)] [Medline: [20542857](https://pubmed.ncbi.nlm.nih.gov/20542857/)]

Abbreviations

BIC: Bayesian Information Criterion

CT: computed tomography

eHEALS: eHealth Literacy Scale

eHealth: electronic health

LCA: latent class analysis

MRI: magnetic resonance imaging

Edited by G Eysenbach; submitted 16.01.19; peer-reviewed by PJ Schulz, S Antani; comments to author 01.05.19; revised version received 20.06.19; accepted 19.07.19; published 30.08.19

Please cite as:

Hyde LL, Boyes AW, Mackenzie LJ, Leigh L, Oldmeadow C, Riveros C, Sanson-Fisher R

Electronic Health Literacy Among Magnetic Resonance Imaging and Computed Tomography Medical Imaging Outpatients: Cluster Analysis

J Med Internet Res 2019;21(8):e13423

URL: <http://www.jmir.org/2019/8/e13423/>

doi: [10.2196/13423](https://doi.org/10.2196/13423)

PMID:

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Appendix 6.3: Paper Four supplementary materials

Appendix 6.3.1: Paper Four Multimedia Appendix 1: Distance-based cluster analysis

Method

Distance-based cluster analysis was used as an unsupervised, exploratory, knowledge discovery technique to identify natural clusters of participants reporting similar eHealth literacy. Euclidean distance (i.e. straight line distance between coordinates) and Cosine distance (angular distance between coordinates) was computed. Hierarchical and kmeans clustering was computed on the optimal distance metric [1].

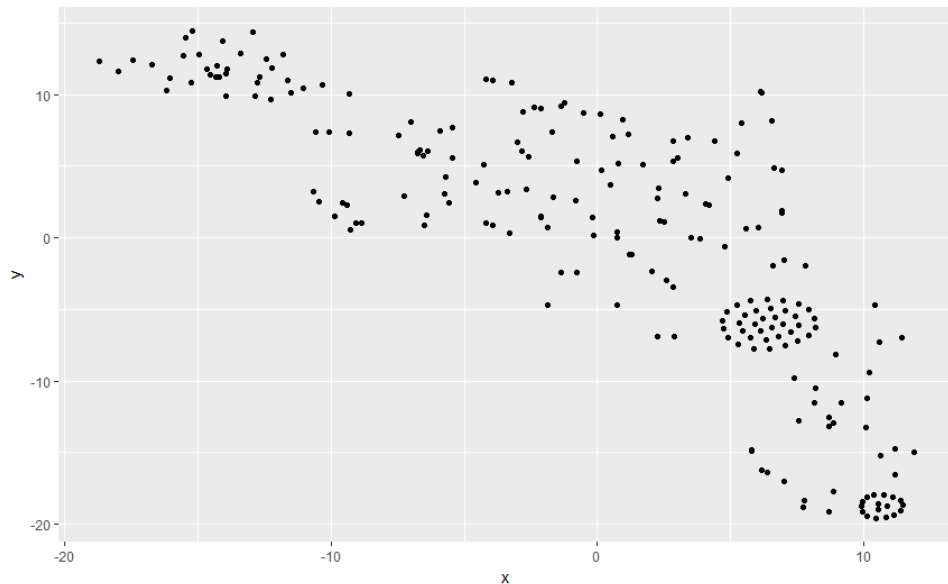
Hierarchical clustering is an approach in which points with the closest distance are gradually combined in a tree structure, and (in the simplest case) a fixed-depth cut point is selected, hence establishing clusters following the branches of the tree [1]. Kmeans clustering starts from a number of k samples randomly chosen, and iteratively adds samples to one of each k groups by choosing the group with the closest mean to the sample. After a sample is added to a group, the group mean position is updated. The procedure is repeated several times with different random starting points to robustly estimate group assignment [1].

The gap statistic, which uses bootstrapping to compare within cluster dispersion for a varying number of clusters to that of a reference uniform distribution, was computed for kmeans and hierarchical clustering. The point at which the gap statistic was greatest, was taken to indicate the optimal number of clusters. Clustering structure was visually appraised by a t-distribution stochastic network embedding (TSNE) projection [2, 3], with clusters indicated in different colours.

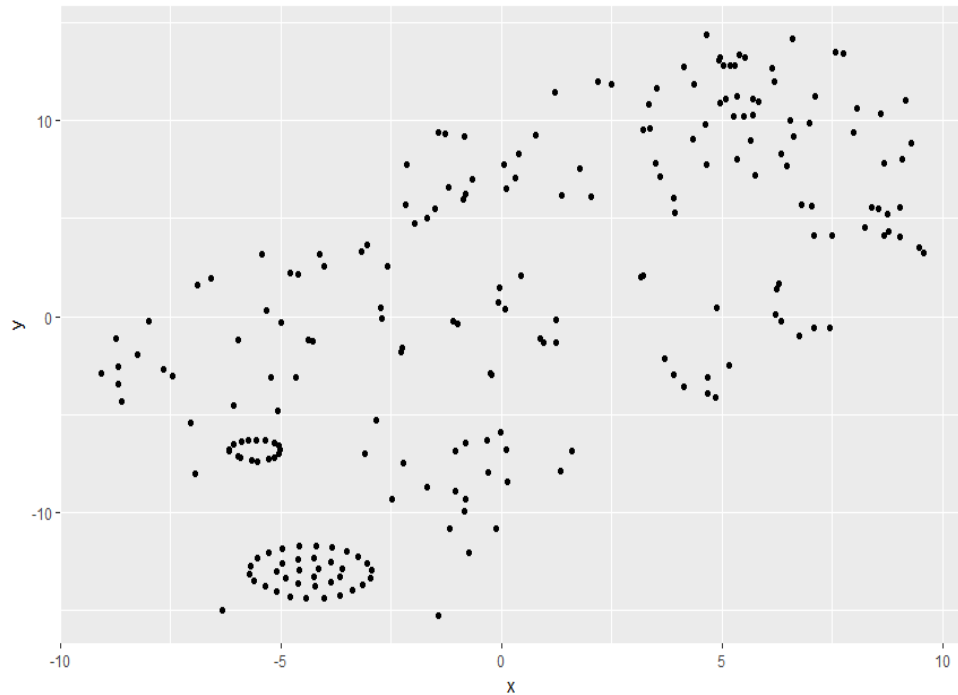
Results

Euclidean distance provided an optimal distance metric

Plots indicated a more compact and differentiated model using Euclidean distance (refer Suppl. Figure 1), with the overall dispersion of the points narrower when compared to that of the Cosine distance plot (refer Suppl. Figure 2). In both cases, distinctive cluster structures were visually apparent. This may be because the eHEALS response scale is ordinal (i.e. participants had only 5 response options), and distance between samples can only take discrete rather than continuous values.



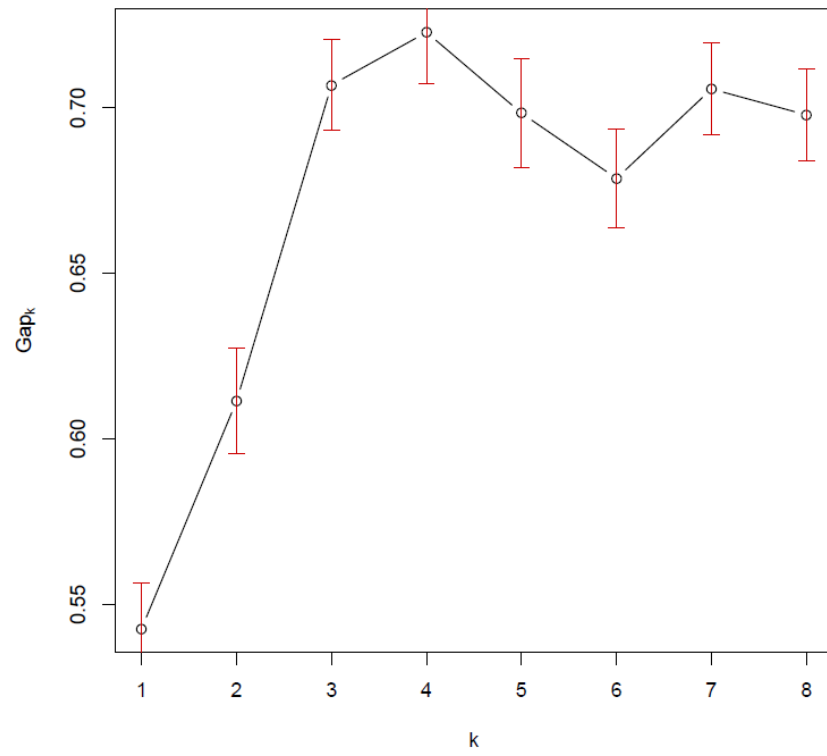
Suppl. Figure 1: Euclidean TSNE Projection



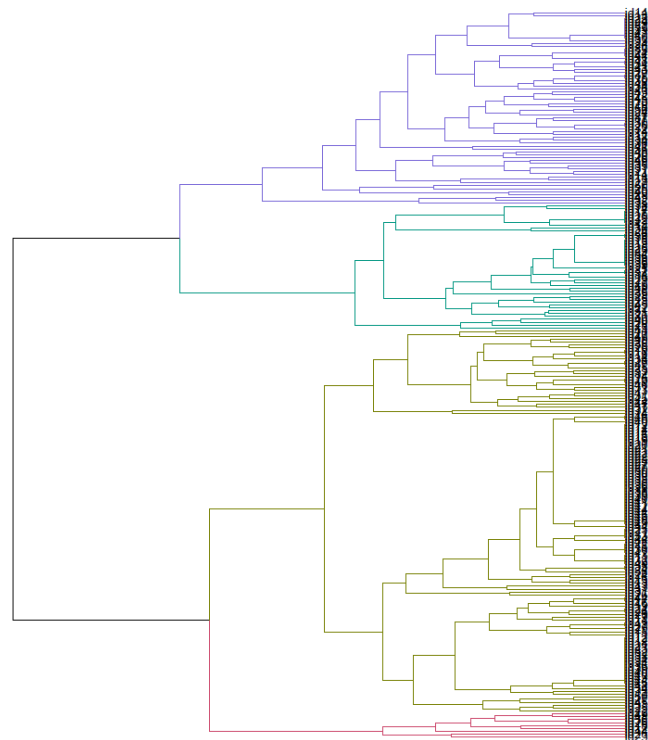
Suppl. Figure 2: Cosine TSNE Projection

The gap statistic for hierarchical clustering indicated a four-cluster structure

The gap statistic computed for hierarchical clustering of the Euclidean distance metric indicated a four cluster structure (refer Suppl. Figure 3): cluster 1: $n = 135$; cluster 2: $n = 9$; cluster 3: $n = 44$; cluster 4: $n = 68$. This cluster structure was apparent based on both firstmax (i.e. first maximum of the gap statistic) and globalmax (i.e. highest gap statistic in the range analysed) criteria. The hierarchical clustering dendrogram illustrates this four-cluster structure (refer Suppl. Figure 4), with high branch joining points demonstrating clear delineation between clusters. This four cluster structure was also apparent when plotted against TSNE projections (refer Suppl. Figure 5). The gap statistic computed for kmeans clustering did not indicate an optimal number of clusters (refer Suppl. Figure 6).



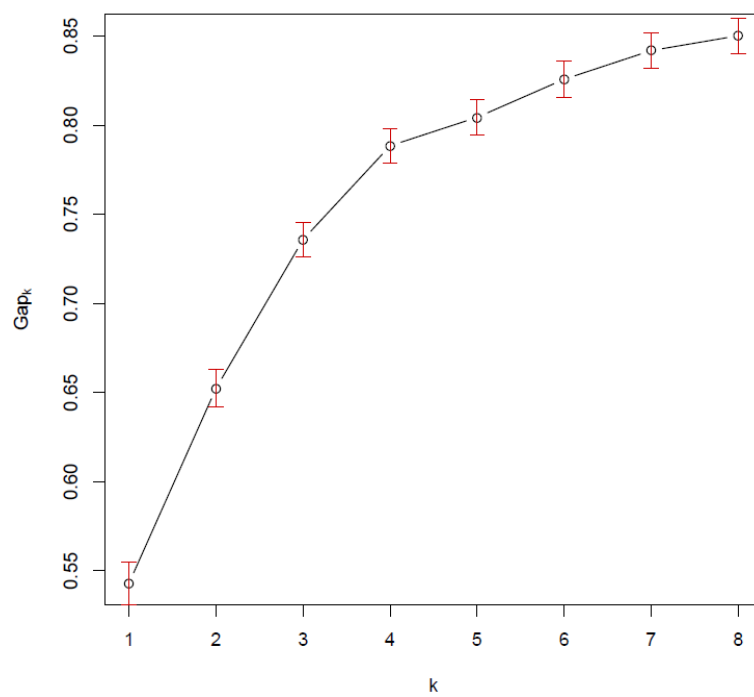
Suppl. Figure 3: Gap statistic computed for hierarchical clustering of eHEALS items



Suppl. Figure 4: Hierarchical clustering dendrogram (K=4) on Euclidean distance



Suppl. Figure 5: Hierarchical clusters (K=4) mapped against Euclidean TSNE projections



Suppl. Figure 6: Gap statistic computed for kmeans clustering of eHEALS items

References

1. Hastie T, Tibshirani R, Friedman J. The Elements of Statistical Learning: Data Mining, Inference, and Prediction, Second Edition. 2nd ed. New York: Springer-Verlag; 2009.
2. Van der Maaten L, Hinton G. Visualizing Data using t-SNE. J Mach Learn Res. 2008;9:2579–605
3. van der Maaten L, Hinton G. Visualizing non-metric similarities in multiple maps. Machine Learning. 2012;87(1):33-55. doi: 10.1007/s10994-011-5273-4.

Appendix 6.3.2: Paper Four Multimedia Appendix 2: Unconditional item response probabilities for a 4-class model of electronic health literacy

Suppl. Table 1. Unconditional item response probabilities for a 4-class model of electronic health literacy (column headings in brackets are the names allocated to electronic health literacy classes by the authors; text in italics is used to indicate the eHealth Literacy Scale response option within each item with the highest probability of endorsement for each class).

eHEALS ^a factor	eHEALS item	Class 1 (low)	Class 2 (moderate)	Class 3 (high)	Class 4 (very high)
	Responses (score)	ρ (SE ^b)			
Awareness	I know what health resources are available on the internet				
	Strongly agree (5)	0.00 (0.00)	0.00 (0.00)	0.02 (0.00)	0.53 (0.14)
	Agree (4)	0.08 (0.06)	0.41 (0.09)	0.80 (0.06)	0.27 (0.14)
	Undecided (3)	0.04 (0.03)	0.56 (0.09)	0.12 (0.04)	0.10 (0.05)
	Disagree (2)	0.72 (0.13)	0.02 (0.02)	0.06 (0.05)	0.08 (0.12)
	Strongly disagree (1)	0.16 (0.13)	0.02 (0.02)	0.00 (0.00)	0.02 (0.02)
	I know where to find helpful health resources on the internet				
	Strongly agree (5)	0.00 (0.00)	0.00 (0.00)	0.02 (0.01)	0.61 (0.19)
	Agree (4)	0.08 (0.07)	0.40 (0.10)	0.91 (0.06)	0.26 (0.16)
	Undecided (3)	0.04 (0.05)	0.59 (0.10)	0.00 (0.00)	0.06 (0.00)
	Disagree (2)	0.74 (0.18)	0.01 (0.03)	0.07 (0.05)	0.06 (0.08)
	Strongly disagree (1)	0.15 (0.20)	0.00 (0.02)	0.00 (0.00)	0.02 (0.02)
Skills	I know how to find helpful health resources on the internet				
	Strongly agree (5)	0.00 (0.00)	0.03 (0.02)	0.00 (0.00)	0.71 (0.16)
	Agree (4)	0.08 (0.08)	0.54 (0.10)	0.97 (0.03)	0.22 (0.11)

eHEALS ^a factor	eHEALS item	Class 1 (low)	Class 2 (moderate)	Class 3 (high)	Class 4 (very high)
	Responses (score)	ρ (SE ^b)			
	Undecided (3)	0.07 (0.05)	0.44 (0.10)	0.02 (0.02)	0.04 (0.07)
	Disagree (2)	0.73 (0.16)	0.00 (0.00)	0.01 (0.01)	0.00 (0.00)
	Strongly disagree (1)	0.11 (0.15)	0.00 (0.00)	0.00 (0.00)	0.04 (0.07)
	I know how to use the internet to answer my questions about health				
	Strongly agree (5)	0.02 (0.01)	0.03 (0.05)	0.01 (0.01)	0.90 (0.08)
	Agree (4)	0.15 (0.13)	0.58 (0.10)	0.97 (0.03)	0.08 (0.06)
	Undecided (3)	0.17 (0.07)	0.38 (0.09)	0.00 (0.00)	0.02 (0.04)
	Disagree (2)	0.48 (0.17)	0.00 (0.00)	0.02 (0.02)	0.00 (0.00)
	Strongly disagree (1)	0.18 (0.19)	0.02 (0.02)	0.00 (0.00)	0.00 (0.00)
	I know how to use the health information I find on the internet to help me				
	Strongly agree (5)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)	0.79 (0.10)
	Agree (4)	0.08 (0.09)	0.47 (0.08)	1.00 (0.00)	0.12 (0.09)
	Undecided (3)	0.17 (0.08)	0.48 (0.07)	0.00 (0.00)	0.10 (0.10)
	Disagree (2)	0.57 (0.19)	0.05 (0.04)	0.00 (0.00)	0.00 (0.00)
	Strongly disagree (1)	0.18 (0.15)	0.00 (0.00)	0.00 (0.00)	0.00 (0.00)
Evaluate	I have the skills I need to evaluate the health resources I find on the internet				
	Strongly agree (5)	0.00 (0.00)	0.03 (0.04)	0.04 (0.03)	0.86 (0.10)
	Agree (4)	0.06 (0.09)	0.24 (0.07)	0.81 (0.05)	0.10 (0.07)
	Undecided (3)	0.13 (0.08)	0.55 (0.09)	0.09 (0.04)	0.04 (0.05)
	Disagree (2)	0.57 (0.19)	0.18 (0.09)	0.05 (0.03)	0.00 (0.00)
	Strongly disagree (1)	0.24 (0.22)	0.00 (0.00)	0.01 (0.02)	0.00 (0.00)

eHEALS ^a factor	eHEALS item	Class 1 (low)	Class 2 (moderate)	Class 3 (high)	Class 4 (very high)
	Responses (score)	ρ (SE ^b)			
	I can tell high-quality from low-quality health resources on the internet				
	Strongly agree (5)	0.02 (0.01)	0.03 (0.02)	0.04 (0.03)	<i>0.74 (0.10)</i>
	Agree (4)	0.04 (0.05)	0.14 (0.06)	<i>0.71 (0.07)</i>	0.16 (0.07)
	Undecided (3)	0.07 (0.10)	<i>0.63 (0.09)</i>	0.15 (0.05)	0.10 (0.09)
	Disagree (2)	<i>0.69 (0.16)</i>	0.19 (0.09)	0.10 (0.05)	0.00 (0.00)
	Strongly disagree (1)	0.19 (0.14)	0.01 (0.02)	0.00 (0.00)	0.00 (0.00)
	I feel confident in using information from the internet to make health decisions				
	Strongly agree (5)	0.02 (0.04)	0.00 (0.00)	0.00 (0.00)	<i>0.57 (0.13)</i>
	Agree (4)	0.06 (0.06)	0.14 (0.06)	<i>0.68 (0.06)</i>	0.22 (0.09)
	Undecided (3)	0.13 (0.06)	<i>0.61 (0.08)</i>	0.21 (0.05)	0.14 (0.09)
	Disagree (2)	<i>0.48 (0.12)</i>	0.21 (0.08)	0.10 (0.04)	0.06 (0.04)
	Strongly disagree (1)	0.31 (0.12)	0.03 (0.03)	0.01 (0.01)	0.02 (0.04)

^aeHEALS: eHealth Literacy Scale.

^bSE: standard error.

Appendix 6.3.3: Paper Four Multimedia Appendix 3: Log likelihood difference tests

Suppl. Table 2: Log likelihood difference tests to identify covariates that significantly improved model fit

Variable	Chi-Squared (DF)	P-value
Age	9.61 (3)	$P = .02$
Gender	4.55 (3)	$P = .21$
Education	508.01 (3)	$P < .001$
Geographic location	2.28 (3)	$P = .52$
Marital status	489.70 (3)	$P < .001$
Information amount preference	526.26 (3)	$P < .001$
Overall health	508.53 (3)	$P < .001$
Internet use frequency	23.95 (3)	$P < .001$

Appendix 7: Publication relevant to, but not included in, the thesis

Appendix 7.1: Additional publication

Supportive Care in Cancer (2019) 27:1509–1517

<https://doi.org/10.1007/s00520-018-4525-2>

ORIGINAL ARTICLE



Do haematological cancer patients get the information they need about their cancer and its treatment? Results of a cross-sectional survey

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Received: 28 January 2018 / Accepted: 19 October 2018 / Published online: 30 October 2018

© Springer-Verlag GmbH Germany, part of Springer Nature 2018

Abstract

Purpose To explore the experiences of haematological cancer outpatients in obtaining information about their cancer and its treatment.

Methods A cross-sectional survey of adult haematological cancer outpatients was conducted. Participants completed two pen-and-paper questionnaires: the first examined demographics and disease characteristics; the second, completed four weeks later, asked about the cancer information received. Participants indicated whether they received the information they needed about medical procedures and self-management, experiences regarding doctor-patient communication, and self-efficacy in seeking information and support. Where possible, items were derived from Australian psychosocial cancer care guidelines.

Results Two hundred and ninety-three (84%) patients consented to participate, with 170 (58%) completing both questionnaires. Most participants reported receiving information in accordance with guidelines. Areas identified as requiring improvement included difficulty recalling information (28%); information overload (26%); insufficient opportunity to ask questions (23%); and insufficient information about managing anxiety related to medical procedures (20%).

Conclusion While many haematological cancer patients report receiving adequate information, there is room for improvement. Implementation of evidence-based strategies, such as decision aids or audiotapes of the consultation, may help to improve information experiences.

Practice implications A patient-centred approach to information provision is essential for ensuring information addresses the needs and preferences of the patient.

Keywords Cancer · Information provision · Patient experiences · Communication

Electronic supplementary material The online version of this article (<https://doi.org/10.1007/s00520-018-4525-2>) contains supplementary material, which is available to authorized users.

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Introduction

Impact of a diagnosis of haematological cancer

Haematological malignancies account for approximately 9% of all annual cancer diagnoses globally [1]. In 2017, the estimated incidence of leukaemia and lymphoma in Australia was estimated to be 3875 and 6232 new cases, respectively, ranking in the top 10 most commonly diagnosed cancers [2]. A diagnosis of haematological cancer is often associated with poor survival outcomes. Common treatment options, such as bone marrow transplantation, peripheral blood cell transplantation and high dose chemotherapy, are lengthy and invasive and often lead to debilitating side effects, including fatigue, nausea, infection and bleeding [3, 4]. As a result, patients often have poor psychosocial outcomes. Approximately 20% of haematological cancer patients attending treatment centres experience clinically significant levels of anxiety and/or depression [5]. Prior to first treatment, the prevalence of anxiety increases to approximately 45% and to 25% for depression [6]. This leads to poorer quality of life, a higher number of unmet needs and greater likelihood of adverse treatment outcomes [7, 8].

Benefits of effective information provision

Patient-centred care, which is respectful of and responsive to patients' needs, values and preferences, is a central component of quality health care [9]. To enable patients to become active and engaged partners in their health care, it has been argued that patients must receive clear and explicit information regarding the options available to them [10]. Appropriate information may influence patients' treatment choice and facilitate collaborative decision-making based on the patient's informed preferences [11, 12].

Enabling informed and active decision-making

Many haematological cancer patients have to make numerous decisions along the cancer trajectory, such as choosing between alternative treatments [13, 14]. There is considerable evidence to suggest that patients who are involved in decision-making regarding their health care to the degree they want have better outcomes than those that do not, including reduced decisional conflict and increased satisfaction with care [15, 16]. Patients who are actively involved in decision-making have also been shown to have higher physical and social functioning, significantly less fatigue and improved quality of life [17–19]. However, there are numerous barriers to patient involvement in decision-making that operate at the patient (e.g. poor health, lower level of education), physician

(e.g. interpersonal skills, presumptions about the patient) and system levels (e.g. lack of continuity of care, time restraints) [20].

Preparing patients for potentially threatening procedures

Poor preparation for medically threatening procedures can hinder treatment decision-making and increase patients' levels of anxiety and concerns prior to treatment [21]. It is important that patients are adequately prepared and understand the implications of their treatment decisions. For optimal care, it is recommended that a multi-disciplinary network of health care professionals provide consistent and timely information about the sensory, procedural, psychosocial and behavioural aspects of treatment [21–24]. This includes what patients will see or feel, the sequence of events, the patient's role in facilitating the procedure and how patients can best manage anxiety before, during and after treatment. The provision of such information has been found to reduce patients' levels of pain and psychological distress prior to cancer treatment [21, 25], as well as improving patients' satisfaction with care [24].

Equipping patients with self-management strategies

The delivery of preparatory information is also integral in establishing patients' skills in the self-management of ongoing side effects of treatment [24]. Self-management information, which describes what the patient can do to help themselves get well, is recognised as the fourth largest unmet need for all cancer patients [26] and one of the basic information needs of haematological cancer patients [27]. The provision of this information promotes a patient-centred approach to health care [28]. It allows patients to actively manage their own care and facilitates the acquisition of skills fundamental to the maintenance of health, including problem solving, resource utilisation, action planning and goal setting [29]. The provision of self-management information has been found to increase cancer patients' perceived level of control and to improve fatigue, depression, anxiety and quality of life [28, 29].

Various factors influence the effectiveness of information provision

Patients vary in their preferences for the type and amount of information they wish to receive, as well as the way information should be presented to them [18, 30]. Patient age, the amount of information provided, high levels of anxiety and a negative prognosis have also been shown to be associated with difficulties remembering information provided during medical consultations [31, 32]. Strategies to improve recall and understanding include categorisation

and prioritisation of information, using common and concrete terms and presenting information in multiple formats, such as written, face-to-face or video information [33]. Clinical practice guidelines recommend that patients be continually informed about their disease, symptom management and service availability, and that this information be adapted to the wishes of the individual [34]. Tailoring information to the unique circumstances and preferences of individual patients can improve anxiety levels, recall of information, self-perceived preparedness for treatment and satisfaction with care [34, 35]. This is likely to be particularly important for haematological cancer patients given the diversity of diagnoses within this group, which often require complex and rapidly changing treatment regimes [36].

Aims

There is very little information from previous studies about the extent to which haematological cancer patients receive information in line with these guidelines. The aim of this study was therefore to explore the views of haematological cancer outpatients regarding their experiences of receiving and obtaining information about their cancer and its treatment.

Methods

Design and setting

A cross-sectional questionnaire of haematological cancer outpatients was conducted in three metropolitan hospitals, each treating at least 300 patients for haematological cancer per year. Participating hospitals were located in three different Australian states.

Participants

Eligible patients were adults (aged 18 years or older) who had a diagnosis of any type of haematological cancer and were attending an outpatient clinic appointment at a participating hospital in relation to their cancer. Patients were excluded if they were unable to read or write English sufficiently to complete the questionnaire, were attending their first appointment at the clinic or were unable to provide informed consent or meet the requirements of participation, as judged by clinic staff.

Recruitment

Appropriate ethics approval was obtained from the University of Newcastle Human Research Ethics Committee and the relevant governing bodies at the

participating hospitals. Trained research assistants were responsible for participant recruitment and data collection at each hospital. A haematologist or nurse employed at the participating hospital assisted the research assistant to identify potentially eligible patients from the daily clinic appointment schedule. Patients identified as eligible were provided with a written information sheet and a verbal explanation of the study by the research assistant. Patients who were willing to participate were asked to complete a consent form and return it to the research assistant. To enable the examination of consent bias, the research assistant recorded the gender and age of non-consenters on a study log sheet with their permission.

Data collection

Consenting participants were asked to complete two pen-and-paper questionnaires; one at the time of recruitment and one approximately four weeks later in order to reduce patient burden and survey fatigue. The initial questionnaire was provided to participants in the clinic waiting room and included questions about participants' demographics, their cancer diagnosis and treatments received. The second questionnaire was sent to participants via mail along with a pre-addressed reply paid envelope to return their completed questionnaire to the research team. This follow-up questionnaire contained items exploring chemotherapy side effects (reported elsewhere) and experiences of receiving and obtaining information about their cancer and its treatment. A reminder letter and another copy of the questionnaire was sent via mail to participants who did not return their completed questionnaire after two weeks, with a second reminder sent following a further two weeks of non-response. All data was de-identified by the use of a unique ID number for each participant. This allowed the research team to track return rates and to link responses between the two questionnaires.

Measures

Participants were asked to indicate whether they received the information they needed in relation to preparation for potentially threatening medical procedures or treatments and self-management when leaving hospital. Items were also included to explore participants' experiences regarding doctor-patient communication, and self-efficacy regarding information and support seeking. Participants provided responses to all questions on a five-point Likert scale (1 = *strongly disagree* to 5 = *strongly agree*). A 'not applicable' response option was also available. A copy of these items is included in Appendix 1.

Development of the measure involved searching the available literature to identify existing measures related to

information seeking, provision and doctor-patient communication. From this search, a list of potential domains was constructed to broadly capture the experiences of patients in receiving and obtaining information about cancer and its treatment. Guidelines for information provision to cancer patients were then mapped against these domains to identify relevant aspects of care and were used to develop individual survey items. Where no or few guidelines were available in relation to a domain, items were adapted from existing measures and created based on issues reported by clinicians and patients in previous pilot work by the authors (unpublished).

Interpersonal communication

Nine items were included to explore patients' experiences regarding the conversations they had with their doctor and family members about disease and treatment information. Items were derived from clinical practice guidelines for the psychosocial care of cancer patients [34] and experiences reported by haematological cancer patients in pilot work conducted by the authors (unpublished).

Preparation for potentially threatening procedures

Eleven items were included to examine the type of information provided to patients prior to having medical procedures or treatments. These items were directly related to the clinical practice guidelines regarding preparation for potentially threatening procedures [34] and included questions addressing sensory and procedural aspects of treatment, anxiety management and after-care.

Post-discharge self-management

Six items were included to explore information provided following discharge from hospital to support self-management of symptoms and side effects of treatment. Items were derived from the clinical practice guidelines for the psychosocial care of cancer patients [34] and recommendations from a multi-disciplinary panel of experts in haematological cancer care regarding the information required by patients in the post-discharge phase.

Information-seeking self-efficacy

Four items were included to examine patients' confidence in their ability to seek support and information from family, friends and their health care team.

Demographic, disease and treatment characteristics

The following demographic, disease and treatment characteristics were reported by participants: date of birth, gender, marital status, highest level of education, employment status, country of birth, haematological cancer type, stage of disease at diagnosis, time since diagnosis and treatments received.

Statistical analysis

Statistical analyses were conducted using SAS v9.4 [37]. Age and gender of participants and non-consenters were compared to examine consent bias using F-adjusted Rao-Scott chi-square tests. Participant characteristics (age, gender, education, country of birth, cancer type) of those that completed both questionnaires were also compared with those who completed the first questionnaire only using F-adjusted Rao-Scott chi-square tests. Frequencies and percentages were calculated for each item with responses regrouped as Agree (*Strongly Agree* and *Agree*), Neutral, Disagree (*Strongly Disagree* and *Disagree*) and not applicable. Multivariate analysis to explore potential associations between patient characteristics and information experiences was not possible due to a high number of participants having 'not applicable' responses ($n = 58$). These participants could not be included in such analyses, therefore resulting in very limited power due to the small sample available.

Results

Sample

Of the 349 patients identified as eligible to participate, 293 (84%) consented to take part in the study. Two hundred and thirty-six (81%) consenters completed and returned the first questionnaire. There was no indication of consent bias, with no significant differences in age ($p = 0.14$) or gender ($p = 0.31$) between completers and non-consenters. One hundred and seventy participants (72%) also completed the second questionnaire and are included in the following analyses. There were no significant differences in age ($p = 0.24$) or gender ($p = 0.56$) between those who completed the first questionnaire only and those who completed both questionnaires. Table 1 provides a summary of the socio-demographic, disease and treatment characteristics for the included sample.

Patient experiences of obtaining information related to their disease and treatment

Overall, self-reported information experiences were largely positive. Data from items assessing participant experiences

Table 1 Participant socio-demographic and disease profile (*n* = 170)

Characteristic		<i>N</i> (%) ^a
Gender	Male	99 (58%)
	Female	71 (42%)
Age (years)	18–34	8 (5%)
	35–54	42 (25%)
	55–74	94 (57%)
	75+	22 (13%)
Marital status	Married or partner	112 (67%)
	Single, divorced, separated or widowed	55 (33%)
Education completed	High school or below	75 (45%)
	Vocational training or University	91 (55%)
Place of birth	Australia	113 (68%)
	Other	54 (32%)
Cancer type	Non-Hodgkin lymphoma	51 (30%)
	Chronic leukaemia	34 (20%)
	Myeloma	27 (16%)
	Acute leukaemia	22 (13%)
	Hodgkin lymphoma	12 (7%)
	Other	22 (13%)
Time since diagnosis (months)	0–6	14 (8%)
	7–12	25 (15%)
	13–24	23 (14%)
	24+	107 (63%)
Stage of cancer	Early	54 (33%)
	Advanced	37 (22%)
	In remission	29 (18%)
	Do not know	45 (27%)
Treatment received ^b	Chemotherapy	141 (85%)
	Radiation therapy	36 (21%)
	Stem cell transplant	37 (22%)
	Surgery	31 (19%)
	Other	12 (7%)
	No treatment	66 (39%)

^a Not all columns sum to 170 due to missing data; ^b not mutually exclusive categories

regarding information about diagnosis and treatment are presented in Table 2.

Interpersonal communication

When asked about their discussions with their doctor and family regarding their cancer, a substantial minority of participants indicated problems recalling information provided by their doctor (28%), experiencing information overload (26%) and insufficient opportunity to seek further information and clarification regarding their diagnosis and treatment (23%). Further, 15–18% of participants reported differing opinions amongst their family members regarding the information received and decisions about care.

Preparation for potentially threatening procedures

Most participants reported that guideline-recommended information was provided regarding the procedural and most sensory aspects of medical procedures. However, provision of information about strategies for managing stress and anxiety associated with these procedures was identified as being suboptimal for 20–22% of patients.

Post-discharge self-management

While information provision regarding post-discharge self-management was perceived to be adequate, a small proportion of participants reported receiving insufficient information about

Table 2 Patient experiences of obtaining information related to their disease and treatment

Item	Agree <i>N (%)^a</i>	Disagree	Neutral
When being told information about my disease and treatment:			
The way the doctor discussed the information was confusing	24 (14%) ^b	120 (71%)	23 (14%)
I felt my doctor told me everything s/he could	130 (77%)	18 (11%)	19 (11%)
I forgot important details of what the doctor told me	47 (28%) ^b	73 (44%)	44 (26%)
I felt too overwhelmed by the amount of information to make sense of it	43 (26%) ^b	84 (51%)	36 (22%)
There wasn't enough time to discuss all my questions with the doctor	38 (23%) ^b	106 (63%)	20 (12%)
There have been differing opinions among my family about:			
What the doctor has told us	29 (18%) ^b	94 (57%)	26 (16%)
The meaning of the information we have received	28 (17%) ^b	91 (55%)	31 (19%)
Decisions made regarding treatment	24 (15%) ^b	98 (59%)	29 (18%)
What is best for me	29 (18%) ^b	92 (56%)	31 (19%)
When having medical procedures or treatments, I got the information I needed about:			
Purpose of the procedure	148 (88%)	6 (4%)	8 (5%)
Benefits and risks of the procedure	142 (84%)	10 (6%)	10 (6%)
What the procedure involved	144 (85%)	6 (4%)	11 (7%)
Where the procedure would take place	150 (89%)	1 (1%)	9 (5%)
Who would perform the procedure	114 (69%)	10 (6%)	30 (18%)
How long it would take to recover from the procedure	106 (63%)	19 (11%)	29 (17%)
What care I would need after the procedure	116 (69%)	12 (7%)	23 (14%)
How to manage anxiety and stress before the procedure	59 (35%)	37 (22%)	56 (34%)
What I might feel during the procedure	124 (74%)	10 (6%)	20 (12%)
What I should do if I experienced pain or discomfort during the procedure	120 (71%)	6 (4%)	23 (14%)
How to manage anxiety or stress during the procedure	72 (43%)	33 (20%)	44 (26%)
When leaving hospital, I got the information I needed about:			
Who to call if I experienced worrying symptoms	135 (81%)	6 (4%)	14 (8%)
Which symptoms I should report to my health care team immediately	132 (79%)	7 (4%)	19 (11%)
How to manage symptoms and side effects	110 (65%)	11 (7%)	37 (22%)
Situations or activities I should avoid to reduce risk of infection or developing complications	125 (75%)	10 (6%)	18 (11%)
Foods I should avoid to reduce risk of infection or developing complications	98 (58%)	26 (15%)	24 (14%)
How to prepare food safely to reduce risk of infection or developing complications	90 (54%)	28 (17%)	29 (17%)
I feel confident in my ability to:			
Ask my family/friends for emotional support when I need it	113 (68%)	20 (12%)	27 (16%)
Ask my family/friends for practical support when I need it	128 (77%)	14 (8%)	20 (12%)
Ask my health care team questions about my disease and treatment options	143 (86%)	7 (4%)	12 (7%)
Be involved in making decisions about my care	137 (82%)	9 (5%)	17 (10%)

^a Not all rows sum to 170 due to missing data or 'not applicable' responses; ^b agreement indicates a negative patient experience as item was reverse-worded; Note: Areas where more than 15% of participants perceived care was not received in accordance with guidelines or indicated there was scope for improvement in information provision are presented in italic text

foods to avoid (15%) and how to prepare food safely to reduce risk of infection or developing complications (17%).

Information-seeking self-efficacy

Most participants (68–86%) reported feeling confident in their ability to seek support and information from their family, friends, and health care team.

Discussion and conclusion

Discussion

The results of this study indicate that haematological cancer outpatients have positive overall experiences in relation to obtaining required information about their cancer and its treatment. Despite 15–18% of participants reporting disagreement amongst family in terms of cancer information provision and

decision-making, more than half of participants had a positive experience in terms of family involvement in these processes. This finding is consistent with the literature. A systematic review of patient-physician-companion communication found that cancer patients appreciated the emotional and information support roles fulfilled by their companions during cancer consultations [38]. This included taking notes, asking questions, recalling essential information post-consultation, and assistance with decision-making [38].

There is room for improvement in the provision of some aspects of guideline-recommended psychosocial care for haematological cancer patients. A substantial minority of participants forgot information they were given during the consultation with their doctor, did not feel they had enough time to ask questions and felt too overwhelmed by the amount of information presented to them to make sense of it. Previous research has reported that patients forgot or remembered incorrectly approximately 40–80% of medical information provided during a consultation [39]. In addition, higher levels of anxiety also have a negative impact on information recall [39, 40], which is of particular importance for haematological cancer patients where the prevalence of anxiety may be as high as 45% [6]. Patient-centred information provision recommends that clinicians ask patients what information they would like to know and in how much detail [41]. This allows for information provision to be tailored according to patients' preferences and may minimise information overload [41]. Decision aids, question prompt lists and patient coaching might also be useful strategies to improve recall and decision-making. Such interventions have been shown to decrease patient anxiety and help patients become engaged in decision-making regarding their care [42, 43]. Additional strategies to aid recall of information post-consultation, minimise information overload and provide additional opportunities to seek clarification regarding the information might include having two consultations to discuss diagnosis and treatment information, or information to take home [33], such as audiotapes of the consultation.

Approximately one fifth of participants indicated that they did not receive the information they needed about managing stress and anxiety associated with a potentially threatening procedure or treatment. This finding may be due to a prioritisation of medical aspects of the procedure in preparatory information provision, highlighted by the comparatively better perception of information received in these areas. Alternatively, it may be that patients place a higher level of importance on procedural, behavioural and sensory aspects of care, leading to lower rates of patient recall of psychosocial information. A multi-disciplinary model of cancer care may be effective at addressing this issue, where various clinical staff are involved in the coordinated delivery of both medical and psychosocial preparatory information. This may result in greater opportunities for discussion, clarification and

reinforcement of information [44]. Previous research has also found that providing information aids, such as educational videos and audiotapes, may assist in reducing anxiety and increasing satisfaction with preparatory information [21, 44, 45]. The internet provides one highly accessible and cost-effective modality in which to provide such multimedia information. However, further research is needed to explore the potential use of interactive technology in delivering preparatory information to cancer patients [45].

Several limitations should be considered when interpreting the study findings. Firstly, there was potential for recall bias in survey responses. Over 60% of participants were diagnosed more than 24 months ago and, therefore, may be in the follow-up phase of care rather than undergoing diagnosis and active treatment to which many of the survey items relate. Future research could examine responses of cancer patients who are closer to the time of diagnosis. Sensitivity of the items regarding preparation for potentially threatening procedures may be limited due to the framing of the item stem. Participants were asked to respond taking into account all of the procedures and tests they had received rather than referring to a specific or most recent procedure. There were also a substantial number of neutral responses which were difficult to interpret. Future research may employ an alternative response scale which elicits more discrete responses in terms of whether specific information was received and what patients' preferences for receiving information are. Information provision in Australian haematological cancer treatment centres is likely impacted by a number of factors including clinician preferences and communication skills, patient preferences and learning styles and the availability of information resources. Such factors were not explored in the current study, however may have influenced the experience of patients, particularly if there was a mismatch between information delivery and patient preferences. Future research may benefit from a more in-depth exploration of the interaction between information provision, patient preferences and learning styles, and the patient experience.

Conclusion

While many haematological cancer patients report receiving adequate information, there is room for improvement in relation to some aspects of information provision. Findings highlight the need for implementation of effective strategies to minimise information overload, aid recall of information post-consultation and manage anxiety and stress related to medical procedures.

Practice implications

The majority of haematological cancer patients get the information they need about their cancer and its treatment.

Communication and provision of information by health professionals could be improved for some haematological cancer patients. The implementation of evidence-based strategies, such as decision aids [42, 43], audiotapes of the consultation and multimedia preparatory information [45] may be useful in addressing issues of poor information recall and information overload reported by participants in this study. While there are a number of tools that may be harnessed to improve patients' understanding of their diagnosis and treatment, the use of such strategies should be patient-centred to ensure the type and amount of information provided by health care professionals addresses the needs and preferences of the patient [41].

Author contributions All authors contributed to preparation and review of the manuscript. In addition, HT was the project manager responsible for overseeing data collection. RW, JB, and RSF were responsible for development of the measure.

Funding information This research was funded by the Cancer Council New South Wales (CSR 11-02) and infrastructure funding from the Hunter Medical Research Institute. The development of the survey instrument was also supported by the Cancer Institute New South Wales (10/THS/2-14). Dr. Jamie Bryant was supported by an Australian Research Council Post-Doctoral Industry Fellowship. Mrs. Lisa Hyde is supported by an Australian Government Research Training Program Scholarship. Ms. Anne Herrmann is supported by a University of Newcastle International Postgraduate Research Scholarship, a University of Newcastle/Hunter Cancer Research Alliance Research Scholarship and has received funding support from the Hunter Cancer Research Alliance Implementation Science Flagship Program as part of the 2017 Research Higher Degree Student Award initiative.

Compliance with ethical standards

Appropriate ethics approval was obtained from the University of Newcastle Human Research Ethics Committee and the relevant governing bodies at the participating hospitals.



Competing interests All authors declare that they have no competing interests.


References


- Smith A, Howell D, Patmore R, Jack A, Roman E (2011) Incidence of haematological malignancy by sub-type: a report from the Haematological Malignancy Research Network. *Br J Cancer* 105(11):1684–1692
- Australian Institute of Health and Welfare & Australasian Association of Cancer Registries (2017) Cancer in Australia: in brief 2017. Cancer series no. 102. Cat. no. CAN 101. AIHW, Canberra
- Montgomery C, Pocock M, Titley K, Lloyd K (2002) Individual quality of life in patients with leukaemia and lymphoma. *Psycho-Oncology* 11(3):239–243
- National Cancer Institute (2010) Fact Sheet 7.41: bone marrow transplantation and peripheral blood stem cell transplantation. <http://www.cancer.gov/about-cancer/treatment/types/stem-cell-transplant/stem-cell-fact-sheet#q14>. Accessed 6 June 2016
- Clinton-McHarg T, Carey M, Sanson-Fisher R, Tzelepis F, Bryant J, Williamson A (2014) Anxiety and depression among haematological cancer patients attending treatment centres: prevalence and predictors. *J Affect Disord* 165:176–181. <https://doi.org/10.1016/j.jad.2014.04.072>
- Breen SJ, Baravelli CM, Schofield PE, Jefford M, Yates PM, Aranda SK (2009) Is symptom burden a predictor of anxiety and depression in patients with cancer about to commence chemotherapy? *Med J Aust* 190(7):S99
- Allart P, Soubeyran P, Cousson-Gélie F (2013) Are psychosocial factors associated with quality of life in patients with haematological cancer? A critical review of the literature. *Psycho-Oncology* 22(2):241–249. <https://doi.org/10.1002/pon.3026>
- Swash B, Hulbert-Williams N, Bramwell R (2014) Unmet psychosocial needs in haematological cancer: a systematic review. *Support Care Cancer* 22(4):1131–1141
- Institute of Medicine, Committee on Quality of Health Care in America (2001) Crossing the quality chasm: a new health system for the 21st century Committee on Quality of Health Care in America, Washington, DC
- Tutty L, O'Connor G (1999) Patient information leaflets: some pertinent guidelines. *Radiography* 5(1):11–14. [https://doi.org/10.1016/S1078-8174\(99\)90003-2](https://doi.org/10.1016/S1078-8174(99)90003-2)
- Charles C, Gafni A, Whelan T (1997) Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). *Soc Sci Med* 44(5):681–692. [https://doi.org/10.1016/S0277-9536\(96\)00221-3](https://doi.org/10.1016/S0277-9536(96)00221-3)
- Coulter A, Entwistle V, Gilbert D (1999) Sharing decisions with patients: is the information good enough? *BMJ* 318(7179):318–322. <https://doi.org/10.1136/bmj.318.7179.318>
- Alexanian R, Dimopoulos M (1994) The treatment of multiple myeloma. *N Engl J Med* 330(7):484–489. <https://doi.org/10.1056/NEJM199402173300709>
- Pui CH, Evans WE (2006) Treatment of acute lymphoblastic leukemia. *N Engl J Med* 354(2):166–178. <https://doi.org/10.1056/NEJMra052603>
- Gattellari M, Butow PN, Tattersall MH (2001) Sharing decisions in cancer care. *Soc Sci Med* 52(12):1865–1878
- Shay LA, Lafata JE (2015) Where is the evidence? A systematic review of shared decision making and patient outcomes. *Med Decis Mak* 35(1):114–131
- Coulter A, Ellins J (2007) Effectiveness of strategies for informing, educating, and involving patients. *BMJ* 335(7609):24–27. <https://doi.org/10.1136/bmj.39246.581169.80>
- Leydon GM, Boulton M, Moynihan C, Jones A, Mossman J, Boudioni M, McPherson K (2000) Cancer patients' information needs and information seeking behaviour: in depth interview study. *BMJ* 320(7239):909–913
- Hack TF, Degner LF, Watson P, Sinha L (2006) Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psycho-Oncology* 15(1):9–19. <https://doi.org/10.1002/pon.907>
- Joseph-Williams N, Elwyn G, Edwards A (2014) Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Educ Couns* 94(3):291–309. <https://doi.org/10.1016/j.pec.2013.10.031>
- Schofield P, Jefford M, Carey M, Thomson K, Evans M, Baravelli C, Aranda S (2008) Preparing patients for threatening medical treatments: effects of a chemotherapy educational DVD on anxiety, unmet needs, and self-efficacy. *Support Care Cancer* 16(1):37–45
- Powell R, Bruce J, Johnston M, Vögele C, Scott N, Shehmar M, Roberts T (2010) Psychological preparation and postoperative outcomes for adults undergoing surgery under general anaesthesia. The Cochrane Library

23. Schofield MJ, Walkom S, Sanson-Fisher R (1997) Patient-provider agreement on guidelines for preparation for breast cancer treatment. *Behav Med* 23(1):36–45
24. Schofield P, Gough K, Ugalde A, Carey M, Aranda S, Sanson-Fisher R (2012) Cancer Treatment Survey (CaTS): development and validation of a new instrument to measure patients' preparation for chemotherapy and radiotherapy. *Psycho-Oncology* 21(3):307–315. <https://doi.org/10.1002/pon.1896>
25. Burish TG, Snyder SL, Jenkins RA (1991) Preparing patients for cancer chemotherapy: effect of coping preparation and relaxation interventions. *J Consult Clin Psychol* 59(4):518–525
26. Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P, Supportive Care Review G (2000) The unmet supportive care needs of patients with cancer. *Cancer* 88(1):226–237. [https://doi.org/10.1002/\(SICI\)1097-0142\(20000101\)88:1<226::AID-CNCR30>3.0.CO;2-P](https://doi.org/10.1002/(SICI)1097-0142(20000101)88:1<226::AID-CNCR30>3.0.CO;2-P)
27. Rood JA, Eeltink CM, van Zuuren FJ, Verdonck-de Leeuw IM, Huijgens PC (2015) Perceived need for information of patients with haematological malignancies: a literature review. *J Clin Nurs* 24(3–4):353–369. <https://doi.org/10.1111/jocn.12630>
28. Kim AR, Park HA (2015) Web-based self-management support interventions for cancer survivors: a systematic review and meta-analysis. *Stud Health Technol Inform* 216:142–147
29. Schulman-Green D, Bradley EH, Nicholson NR, George E, Indeck A, McCorkle R (2012) One step at a time: self-management and transitions among women with ovarian cancer. *Oncol Nurs Forum* 39(4):354–360. <https://doi.org/10.1188/12.ONF.354-360>
30. Cox A, Jenkins V, Catt S, Langridge C, Fallowfield L (2006) Information needs and experiences: an audit of UK cancer patients. *Eur J Oncol Nurs* 10(4):263–272. <https://doi.org/10.1016/j.ejon.2005.10.007>
31. Jansen J, Butow PN, van Weert JC, van Dulmen S, Devine RJ, Heeren TJ, Bensing JM, Tattersall MH (2008) Does age really matter? Recall of information presented to newly referred patients with cancer. *J Clin Oncol* 26(33):5450–5457. <https://doi.org/10.1200/jco.2007.15.2322>
32. Stark DPH, House A (2000) Anxiety in cancer patients. *Br J Cancer* 83(10):1261–1267. <https://doi.org/10.1054/bjoc.2000.1405>
33. Watson PW, McKinstry B (2009) A systematic review of interventions to improve recall of medical advice in healthcare consultations. *J R Soc Med* 102(6):235–243. <https://doi.org/10.1258/jrsm.2009.090013>
34. National Breast Cancer and National Cancer Control Initiative (2003) Clinical practice guidelines for psychosocial care of adults with cancer. National Breast Cancer Centre, Camperdown
35. McPherson CJ, Higginson IJ, Hearn J (2001) Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials. *J Public Health* 23(3):227–234. <https://doi.org/10.1093/pubmed/23.3.227>
36. Bryant J, Sanson-Fisher R, Stevenson W, Smits R, Henskens F, Wei A, Tzelepis F, D'Este C, Paul C, Carey M (2015) Protocol of a multi-centre randomised controlled trial of a web-based information intervention with nurse-delivered telephone support for haematological cancer patients and their support persons. *BMC Cancer* 15(1):1–13. <https://doi.org/10.1186/s12885-015-1314-x>
37. SAS Institute (2002–2011) SAS software, version 9.4 of the SAS system for Windows. Copyright SAS Institute Inc, Cary
38. Laidsaar-Powell RC, Butow PN, Bu S, Charles C, Gafni A, Lam WWT, Jansen J, McCaffery KJ, Shepherd HL, Tattersall MHN, Juraskova I (2013) Physician–patient–companion communication and decision-making: a systematic review of triadic medical consultations. *Patient Educ Couns* 91(1):3–13. <https://doi.org/10.1016/j.pec.2012.11.007>
39. Kessels RP (2003) Patients' memory for medical information. *J R Soc Med* 96(5):219–222
40. van Osch M, Sep M, van Vliet LM, van Dulmen S, Bensing JM (2014) Reducing patients' anxiety and uncertainty, and improving recall in bad news consultations. *Health Psychol* 33(11):1382–1390
41. Zucca A, Sanson-Fisher R, Waller A, Carey M, Boadle D (2017) The first step in ensuring patient-centred quality of care: ask the patient. *Eur J Cancer Care* 26(1). <https://doi.org/10.1111/ecc.12435>
42. Holmes-Rovner M, Nelson WL, Pignone M, Elwyn G, Rovner DR, O'Connor AM, Coulter A, Correa-de-Araujo R (2007) Are patient decision aids the best way to improve clinical decision making? Report of the IPDAS Symposium. *Med Decis Mak* 27(5):599–608
43. Kinnersley P, Edwards AG, Hood K, Cadbury N, Ryan R, Prout H, Owen D, MacBeth F, Butow P, Butler C (2007) Interventions before consultations for helping patients address their information needs. *The Cochrane Library*
44. Jefford M, Tattersall MH (2002) Informing and involving cancer patients in their own care. *Lancet Oncol* 3(10):629–637
45. Waller A, Forshaw K, Bryant J, Mair S (2014) Interventions for preparing patients for chemotherapy and radiotherapy: a systematic review. *Support Care Cancer* 22(8):2297–2308

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