



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

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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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06/06/2020

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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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.