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Review Article

Perspectives on access to imaging digital health records in oncology: A mixed methods systematic review

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ABSTRACT

Background: Digital Health Records (DHR) have become essential for managing patient data, including radiology and nuclear medicine reports. The wider adoption of DHR globally presents an opportunity to improve patient engagement and empowerment through effective access and sharing of imaging investigations. This review aims to synthesize literature on views, experiences, expectations, and preferences of oncology patients and healthcare professionals (HCP) when accessing imaging via DHR.

Materials and Methods: This review was conducted using recommended Cochrane Handbook databases (registration: CRD42021213808), focusing on English articles published from 2000 onwards. Three experienced reviewers critically appraised selected articles, thematic analysis and narrative synthesis were used to extract data.

Results: 493 unique articles were identified, with 451 excluded, resulting in 42 articles assessed for eligibility. Nine studies were included, eight from the USA, one from Canada, published between 2010 and 2020. Findings suggest patient portals can positively impact patient and HCP engagement, and patients desire access to their imaging reports. Factors such as timing of access, adequate consultation time, resources for HCP to discuss findings, and format of information are critical considerations that influence both patient and HCP perceptions and preferences.

Conclusion: Oncology patients want timely and understandable access to their imaging records. To ensure this, it is crucial to explore the appropriate timing, format, and methods to discuss these findings with patients. By involving all stakeholders in the planning process, we can develop DHR systems that provide personalised support for patients to manage their complex imaging results.

Introduction

In recent years, Digital Health Records (DHR) have emerged as an effective tool to allow patients independent access to their medical records and to manage their own health [1]. In the oncology setting, diagnostic imaging has substantially improved healthcare, patients undergo several scans from early diagnosis to follow-up as part of routine clinical practice and radiology and nuclear medicine reports are a critical element of a patient's medical records.

With the wider adoption of new DHR globally, there is a real opportunity to improve patient and Health Care Professionals (HCP) engagement to ensure imaging records not only report disease status for clinicians, but are also presented clearly to patients themselves, particularly in the oncological setting [2].

Several published studies have shown that patients want access to their imaging records, including images and preferably with detailed

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information and in a timely manner [3–6], to support their understanding and to contextualise their condition at that point in time. Alongside assessing patients' preferences there is also a growing interest and supporting literature to understand and evaluate the current model of reporting and communication of results to patients and referring clinicians, as patients themselves become end users of reports [1,7,8]. Earlier studies already addressed to whom and how scan results should be communicated, however this is an area of ongoing discussion and some studies have demonstrated that where patients have access to their medical records, including their scans it does not always translate to improved patient satisfaction [3,9–11].

We live in an exciting era of advanced and rapid technological developments in imaging with the introduction of Artificial Intelligence (AI), automated tools and interoperability of the whole of the patient's medical records to support diagnostic and treatment decision making. However, the question whether we fulfil the wishes of patients in this respect has not been addressed at the same pace, but it is reassuring that over recent years a significant improvement and emphasis on patient engagement and empowerment has been made. The implementation of DHR and its imaging component, to support both patients and HCP can play an indispensable role in the provision of care in the oncological setting.

This review aims to identify, appraise, and synthesise current available literature on independent patient access to medical imaging records in the oncology setting via DHR. This systematic review will identify patients and healthcare professionals' views, experiences, expectations and preferences and any intervention studies related to independent access to medical imaging records via DHR in an oncological setting.

Materials and methods

This mixed methods systematic review followed the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis Protocols (PRISMA - P) 2015 statement [12]. The literature review research question was developed using PICo [13]. (population; phenomena of interest; context) as opposed to the traditional PICO approach (population; interventions; comparators; outcomes). The former is a different approach for synthesis of qualitative research, to guide the research question.

The review was conducted by three reviewers experienced in systematic literature reviews: Lead reviewer (Ana Ribeiro, AR); Second reviewer (Milou Reuvers, MR), Third reviewer (Olga Husson, OH).

The protocol was registered with PROSPERO (registration no CRD42021213808). The study was exempt from ethical approval and no direct funding was received.

Search strategy

The review was performed using the recommended databases from the Cochrane Handbook Medline, Embase, Medline ALL, WEB OF SCIENCE Core Collection, Cochrane Central Register of Controlled Trials, CINAHL and Google Scholar. Only full English articles from 2000 onwards were included, the systematic search was conducted on the 31st of January 2022, full search strings can be found in supplementary material.

Inclusion of 2 or more of the following terms in the title or abstract was mandated: electronic medical or health records; scans or reports or imaging tests; patient(s); health professional(s) or radiologist(s) or radiographer(s) or technologist(s) or referrer(s) or doctor(s) or physician (s) or provider(s); perspective(s) or attitude(s) or view(s) or perception (s) or experience(s) or understanding(s); medical imaging or imaging; radiology or radiologic or nuclear medicine; patient-centred imaging; shared decision making.

Reviewers AR and MR independently and blindly screened titles and abstracts of articles yielded by the above search strategy, using the online systematic review manager Rayyan [14]. Following unblinding, reasons for exclusion and non-concordance were documented and agreement between reviewers AR ad MR was reached, and third reviewer gave final approval.

Quality assessment

The review was conducted in adherence to the registered protocol and selected articles were critically appraised by reviewers AR and MR independently using the Mixed Methods Appraisal Tool (MMAT) [15]. This particular tool was considered the best fit for the nature of the review since it is designed to critically appraise a variety of study designs. Full articles were retrieved, and authors of papers were contacted for one clarification relating to two included articles by same author [16, 17]. Consensus was achieved and discussed with third independent reviewer.

Data extraction and synthesis

Study characteristics for all selected studies were tabulated in Excel (V2208) by reviewer AR, checked by reviewer MR and in agreement with reviewer OH, to include i) study design and focus; ii) methodology and data analysis; iii) sampling and setting; iv) key findings; v) practical implications; vi) ethical approval and vii) study limitations. (see Supplementary material - Tables 1 and 2)

Qualitative data was manually extracted from included qualitative and mixed methods studies using the thematic analysis framework according to Braun & Clarke [18]. Initial coding, sub-themes and themes development was performed by reviewer AR and subsequently checked and agreed with reviewers MR and OH. Supporting data from articles was used to provide context to the findings at code level and a global theme was co-developed by all three reviewers.

Quantitative data, comprising of descriptive and inferential statistical tests was extracted by reviewer AR and checked by reviewers MR and OH. Due to the reduced number of quantitative studies and mixed methods studies included, as well as it's heterogeneity, in study design, methodology, sample size and setting, a narrative synthesis was conducted as opposed to a meta-analysis.

Data synthesis followed the Joanna Briggs Institute convergent segregated approach [19,20], which consists of separate qualitative and quantitative analysis, followed by careful integration of results to gain a deeper understanding of the phenomenon of interest. This method was deemed as the most appropriate given the different aspects of the phenomenon such as patients versus healthcare professionals, different settings, and study designs. Qualitative and quantitative findings from selected studies have been juxtaposed and combined for an overall configured analysis of current evidence.

Results

The systematic search identified 571 manuscripts published between 2000 and 2021 eligible for screening (see Fig. 1, PRISMA flow diagram). After duplicates were removed, a total of 493 records were screened independently by reviewers AR and MR, which resulted in 451 exclusions. Full text review for eligibility assessment was performed on 40 studies by two independent reviewers (AR and MR). This resulted in further 31 exclusions, with reasons grouped as per Fig. 1 PRISMA diagram. A total of 9 studies were selected for inclusion in the review as per Table 1 study characteristics (Supplementary material -Table 2 for comprehensive details of included studies).

All included studies were conducted in an oncology setting, in either the USA or Canada between 2010 and 2020. Of the included studies, two were qualitative [16,17], three mixed methods [21-23] and four were quantitative studies [24-27]. Four studies were restricted to patients [21,24,26,27], two were restricted to oncologists [23,25] and three included both oncologists and patients [16,17,22], with one study also

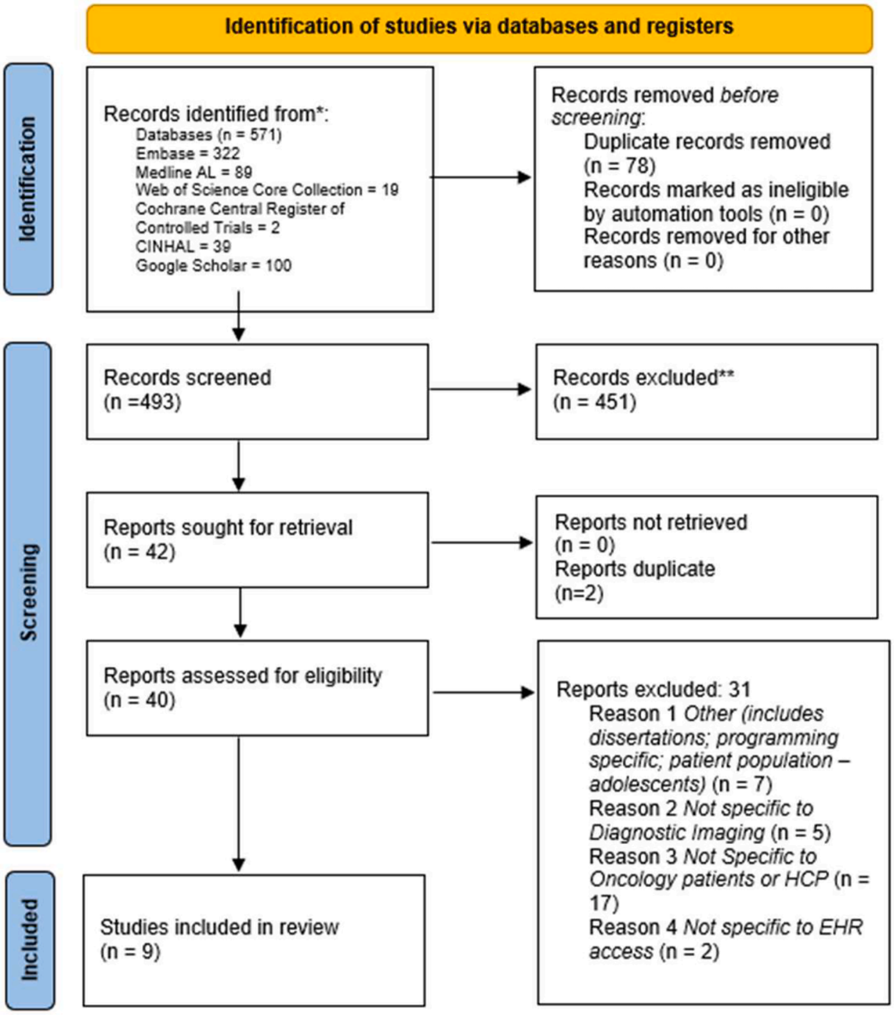

Fig. 1. PRISMA flow diagram.

Table 1
PICo table- PICo framework [13].

Population:	Oncology patients, healthcare professionals
Phenomenon of interest:	Views, experiences, expectations, and preferences
Context:	Radiology and nuclear medicine reports in Electronic Health Records

including medical informaticians [16].

Qualitative synthesis

Thematic analysis [18] of qualitative studies and mixed method studies (qualitative component), resulted in eight sub-themes across patients and HCP, leading to three themes and one global theme (see Table 2). Full thematic analysis can be seen in supplementary material Table 3.

The findings suggested a positive effect during consultation, with patients reporting the benefits of prior access to results [16,17]. The study by Alpert et al. 2019 [17] highlights how particularly for upsetting results, patients (and oncologists) still prefer in-person communication, emphasising the need to provide support and ensuring accessibility to all when navigating new portals.

Alpert et al. 2018 [16] explored and described the different perceptions of portals as communication tools, from patients, clinicians and medical informaticians. Clinicians [21] presented concerns regarding patients viewing their results without a consultation and favoured in person discussions, to note, at the time this study was conducted there was no function available to release scans only after consultation. Similarly, the mixed methods study of oncologist's views on electronic release of radiology and pathology reports [23] reported that clinicians' feel that reports are written for clinicians. Consequent patient research of clinical terminology and/or diagnoses in reports was felt to cause misunderstanding and anxiety as descried by two oncologists. Positive changes were also highlighted by clinicians [17], where they referred to an improved patient engagement during consultations. The mixed methods study by Henshaw et al. 2015 [22], focusing on experiences of patients and referring physicians with sending and receiving radiology reports via patient portal, suggests that online portals can be beneficial for radiology reports. During the decision-making and execution process of deploying portals, involvement of all stakeholders, including oncologists, can impact their attitude towards patient portals.

Quantitative synthesis

Narrative synthesis of quantitative data, including mixed methods quantitative data was summarised from five themes across patients and HCP, (Table 3 and Supplementary material Table 4).

Patients deem access to their imaging reports as important [24,25, 27], with the study from McNamara et al. 2015 [24] for non-small cell lung cancer patients also reporting that it leads to a better health

Table 2
Qualitative synthesis – patients and healthcare professionals.

	Global theme	DHR systems are largely seen as a positive change in the provision of healthcare, however, they must be carefully implemented, with appropriate engagement and ongoing support to patients and healthcare professionals, to promote partnership in care
	Themes	**Supporting Information**
Qualitative and mixed methods analysis (qualitative data)	**Partner in care, change in HCP-patient dynamics**	Patients
		"When I am in the doctors' office, I'm not blindsided by information…there's no surprises." [16]
		"[The portal] helped me because now when I walk into his office, he's not giving me information that I don't already have access to. I can be ready to ask him specific questions rather than generalising everything." [17]
		Healthcare professionals
		Clinicians referred to improved patient engagement during consultations, acknowledged that the portal gives patients more ownership, making them, "A little bit more of a partner." [17]
		"Making sure that the reports are easy to read, in layman's terms as much as possible, could decrease the amount of call backs and patient concerns. It's helpful and much more efficient to see it online." [22]
	Accessibility, ongoing support and acknowledging individual preferences	Patients
		"I do not want to read on an MRI that my diagnosis is cancer. I would rather have a doctor discuss that with me before I have to review it online. [Patient, Sarcoma]" [16]
		Healthcare Professionals
		"I think we just need to have systems to support us. I do believe that release of results is important, but we need to work with patients to get appointments coordinated in a timely fashion for discussion, or we need to have credit for time spent on the phone in discussion." [23]
	Comprehensive and explainable information available on DHR	Patients
		"…would like retroactive results to be posted,"; "… having an online dictionary to define unfamiliar medical terms." [21]
		Healthcare professionals
		"Currently, the language of these reports contains code that informs us physicians but confuses the patients"; "Radiologists need to stop using vague terminology that alarms patients." [23]

management, and although patients acknowledge it may lead to more questions, it does not necessarily lead to more anxiety. Overall patients preferred to receive results to a possible cancer diagnosis as soon as possible; however, the subgroup analysis of oncology patients demonstrated that this group prefers to communicate directly with clinicians over portals and as soon as possible [26].

The study from Sadigh et al. 2015 [25], looking at the satisfaction of HCP with a Multimedia Enhanced Radiology Report (MERR) platform and its potential impact, suggests that combining text and images, is a beneficial change and would lead to more engaging consultations. In an early study from 2016 [23], oncologists agree that patient access to reports before consultation is harmful to patients, particularly for abnormal results suggesting that results should only be released if there is sufficient time to discuss with patients.

Discussion

Qualitative analysis of included studies suggests patient access to digital health care records for imaging results are largely seen as a positive change in the provision of healthcare [16,17,21–23], however, they must be carefully implemented [21], with appropriate engagement and ongoing support to patients and HCPs to promote partnership in care [23].

Data derived from quantitative analysis [21,22,24–27] indicates oncology patients would like timely access to their imaging results, together with the opportunity to discuss the results with clinicians for better health management [24,26]. As portals become commonplace, it's crucial to synchronize imaging workflows with the release of imaging results in oncology. The timing of report availability, especially for abnormal results, remains a topic of debate [22]. Increasingly advanced imaging modalities also pose additional challenges for patient comprehension and interpretation [23,27].

Whilst earlier studies included in this review report on HCP apprehension towards independent patient access [16,23] there are recent considerations on how to address these challenges and support patient independent access [30]. Ranging from Artificial Intelligence (AI) to support with lay summaries for patients, to redesigning the appointments schedule, ensuring clinic appointments are <48 h from receipt of imaging reports [31]. Advances to support inclusiveness are also equally important and highlighted by an oncologist in the included study by Alpert et al. 2019 – "patients without the ability to log-in to the portal would be left out" [17]. Emerging literature regarding the content of imaging reports and both patient and HCP interpretation broadly corroborates above findings [32,33], however these are not specific to oncology. A particularly good example is seen in one of the included studies [26] where the overall preference was to receive imaging results as soon as possible ($p < 0.001$) and over the telephone ($p < 0.001$) after results were seen by the clinician, however, the subgroup analysis of cancer patients (26.6 %) preferred direct communication with clinician over an online portal. In recent study published in March 2023 [34], addressing patient attitudes and perceptions of immediate release of test results (where 18.6 % respondents were oncology patients, with 48.5 % of the tests referring to imaging or biopsy tests), 95.7 % of patients want

Table 3
Qualitative synthesis – patients and healthcare professionals.

Quantitative analysis (including mixed methods quantitative data)	**Narrative synthesis**	Oncology patients want timely access to their imaging results, together with the opportunity to discuss with the clinician, to better manage their health. As portals become common ground timing of release in the oncology setting is still subject to debate, particularly for abnormal results, with the additional challenge for advanced imaging modalities when it comes to patient understanding of the report. Multimedia reports present an opportunity to improve understanding and facilitate discussion of imaging results.
	Themes	**Supporting information**
	Access to information	**Patients**
		90 % (37/41) of patients reported a desire to access information related to their diagnosis and imaging. [37]
		98.4 % (125/127) of patients agreed it would be helpful to have online access to their imaging report [21]
		Manual release of radiology reports via online patient portal was important to 88 % (446/508) of patients [22]
	Interactive and user-friendly reports	**Healthcare Professionals**
		80 % (159/200) of referring physicians agreed that multimedia-enhanced radiology reporting (MERR) is an improvement over traditional text-only radiology reporting [25]
	Timely access to imaging results related to cancer diagnosis as soon as possible from their clinician.	**Patients**
		Overall patient preference, across all ages and no effect from gender, was to receive imaging results related to cancer diagnosis as soon as possible from their physician ($p < 0.001$). [26]
	Imaging results from advanced imaging modalities are less understood by patients.	**Patients**
		Patients undergoing advanced imaging, MRI and CT had a lower understanding of their results 29.3 % (85/290) versus *40.3 % (83/206) for ultrasound and 38.2 % (99/259) for x-rays ($p < 0.02$).* [38]
		Healthcare Professionals
	Patient access to imaging reports before consultation is not beneficial	*35 % (29/82) of oncologists agreed patients should never see reports before consultation; 87 % (72/82) agreed it would be somewhat or very harmful for patients to receive abnormal results before consultation* [23]

immediate access and 95.3 % of patients who received abnormal results would still prefer immediate access.

Access to diagnostic imaging information via DHR is not intended as a replacement to the relationship with the clinician, particularly when receiving less favourable results. Patient – HCP relationship is fundamental for both [16,17,29]. These findings are also in line with studies focusing on changes brought by the wider adoption of DHR and the need for HCP to adapt to the technological changes and more importantly how HCP communicate with oncology patients [35]. In the recent editorial from the American Society of Clinical Oncology [35], authors present opportunities and challenges with regards to communication with patients, proposing topics for future research with a view to integrate recommendations in medical training curriculum, such as identification of barriers to portal use and understanding how initial portal interpretation can influence patient understanding.

Limited literature is available with regards to advanced imaging and interpretation of reports and images via DHR access [2,6,36]. It is acknowledged that patient preferences should be considered, together with potential modifications to reports as patients have direct access. Often referred as enhanced radiology reporting [2] or simplified reporting for patients [28], this is an unexplored area particularly for the oncology setting. Further research and evidence are needed to develop reporting recommendations for imaging professionals in view of widespread adoption of DHR and patient portals.

The scope and results derived from this systematic literature review is limited, despite this substantial change in clinical practice, at the time of this review only 9 studies addressed the oncological setting. All studies included were conducted in North America, with only two studies from 2019 onwards, highlighting the current lack of published European data with regards to patient access to diagnostic imaging information via DHR in oncology.

Digital Transformation across the healthcare sector worldwide, possibly brought forward due to the Covid pandemic have facilitated and promoted independent patient access and use of patient portals. This presents an excellent opportunity to explore patients and HCP preferences and to develop recommendations for DHR good practice and impact on patient reported outcomes in the oncology setting.

As patients become active end-users of the radiology and nuclear medicine reports and in view of the changing dynamics between patients and HCP, several considerations must be addressed when planning implementation of DHR and independent patient access to imaging records. Patient accessibility and usability, with considerations towards privacy, security, and wider population access; staff resources and impact on imaging departments, namely with extended reporting, accuracy of reports and records, direct patient communication, legal implications of lay/AI summaries; interaction and coordination with wider healthcare professionals for better patient experience.

In the European context, there is a pressing need for evidence-based research, especially within the public health sector. To fully leverage the rich diversity across European countries and their unique experiences in oncology, it is essential to foster a collaborative approach that promotes the sharing of best practices and implementation strategies. European perspectives are key to the successful implementation of DHR and encouraging the adoption of patient portals for oncological imaging.

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CRediT authorship contribution statement

Ana S.F. Ribeiro: Conceptualization, Data curation, Formal analysis, Methodology, Writing – original draft, Writing – review & editing. **Olga Husson:** Conceptualization, Formal analysis, Methodology, Supervision, Writing – review & editing. **Milou Reuvers:** Data curation, Formal analysis, Writing – review & editing. **Wim J.G. Oyen:** Conceptualization, Methodology, Supervision, Writing – review & editing. **Christina Messiou:** Conceptualization, Methodology, Supervision, Writing – review & editing. **Winette T.A. van der Graaf:** Conceptualization, Methodology, Supervision, Writing – review & editing.

Declaration of interests

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Supplementary materials

Supplementary material associated with this article can be found, in the online version, at doi:10.1016/j.hlpt.2024.100915.

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