Digital Portals for Individuals with a Cancer Diagnosis: A Scoping Review Co-Led by a Patient Partner

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Abstract

Background: Patient portals enable individuals to access their health information and data, facilitating self-management during outpatient care. Evidence highlights the impact of these digital portals on behavioral outcomes, but populations with cancer remain underexplored. These tools are generally associated with improvements in patient engagement and healthcare processes. However, their main functionalities, impact on various health outcomes, and accessibility across diverse populations remain insufficiently understood.

Objective: This study aims to identify the main functionalities of portals used by individuals with cancer, as well as the categories of outcomes assessed, including those related to the healthcare system. Our secondary objectives were to: 1) describe the diversity of participant groups in oncology portal research, and 2) identify individual characteristics associated with portal use.

Methods: We conducted a scoping review following JBI (formerly the Joanna Briggs Institute) guidelines, searching the Embase.com, Web of Science, Medline (Ovid), and CINAHL Plus with Full Text databases for studies published between 2014 and 2024. Pairs of reviewers independently screened titles and abstracts, applied the selection criteria, and performed full-text screening. The main inclusion criteria were participants with an active cancer diagnosis or a history of cancer, using a portal at home or in other outpatient settings, with access to personal health information, and with at least one outcome assessed. We excluded studies if they involved participants without a cancer diagnosis or mixed populations of cancer and non-cancer participants, where subgroup-specific results were not reported.

Results: At the end of the selection process, we included 44 studies. Regarding the main functionalities, e-messaging was reported in 73% of studies and access to health services in 59%. Technology experience and behavioral outcomes were the most frequently assessed categories of outcomes, while clinical, biopsychosocial, and healthcare system outcomes received less focus. Breast cancer was the most studied type (16/44, 36%), with metastasis being a feature in 25% (11/44) and caregiver involvement in 18% (8/44). Additionally, 43% (19/44) of studies investigated PROGRESS-Plus factor associations with the portal use. Age (12/19, 63%) and socioeconomic status (10/19, 53%) were most frequently explored, while social capital (2/19, 11%), occupation (1/19, 5%), disability (1/19, 5%), and religion (0/19, 0%) were less or not reported.

Conclusions: We showed the strong focus of studies on patient technology experience and behavioral outcomes, with limited exploration of healthcare system and clinical impacts. The current landscape in patient portals research for oncology underrepresent key equity-related factors and suggests a need for more inclusive research to optimize portal accessibility and usability for all individuals with cancer. Clinical Trial: Open Science Framework Registries (OSF) nrbt3; https://osf.io/nrbt3/

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Conclusions: We showed the strong focus of studies on patient technology experience and behavioral outcomes, with limited exploration of healthcare system and clinical impacts. The current landscape in patient portals research for oncology underrepresent key equity-related factors and suggests a need for more inclusive research to optimize portal accessibility and usability for all individuals with cancer.

Trial Registration: Open Science Framework Registries (OSF) nrbt3; https://osf.io/nrbt3/

Keywords: Cancer; Oncology; Personal health record; Patient portal; Electronic health records; Online access; Patient records; Scoping review

Introduction

Overview

Patient portals emerged as tools for healthcare delivery, offering individuals access to their personal health information and facilitating communication with healthcare providers **[1-7]**. These digital platforms have shown promise in enhancing some health outcomes, such as self-management or disease-related knowledge, and streamlining healthcare processes across various medical specialties **[1-5,7]**. In oncology, where patient engagement and effective information management are essential, the potential for impacts of digital portals are significant **[3,4,6,8]**. These portals facilitate communication between healthcare providers and their patients, empowering them to access and manage their health information and supporting informed decision-making throughout their care management.

Different Terminologies

Patient portals must not be mistaken for other types of digital information solutions. A Personal Health Record (PHR) and a ‘patient portal’, though similar, differ in several aspects **[9-11]**. PHRs are owned and controlled by the individuals, allowing them to input and manage health data from multiple sources. In contrast, ‘patient portals’ are managed by healthcare providers and typically contain data from a single provider or system **[9-11]**. While PHRs offer individuals broader control and integration of their personal health information, ‘patient portals’ primarily serve as tools for communication with healthcare providers and for accessing specific health data **[9-11]**.

Electronic Health Records (EHRs) are comprehensive digital records maintained by healthcare providers and shared across healthcare systems **[9]**. Patient portals, in comparison, provide individuals an access to these systems with a limited view of their health information **[7,9]**. While EHRs are designed to support clinical decision-making, ‘patient portals’ emphasize self-management and empowerment **[7]**.

Electronic Medical Records (EMRs) differ from EHRs in their scope **[12]**. EMRs are digital versions of paper charts used within a single practice, whereas EHRs consolidate information from multiple providers and offer greater interoperability **[7,9,12]**. Overall, while PHRs, ‘patient portals’, EHRs, and EMRs all contribute to improving health care delivery, they vary significantly in their scope, functionality, and degree of user control **[7-12]**.

Background

Patient portals can enhance oncology care by supporting self-management for individuals with cancer during outpatient care **[1,2,4-7]**. These secure online platforms provide 24-hour access to personal health information from any location with an internet connection **[1-8, 10-12]**. Typically integrated with healthcare providers' Electronic Health Record (EHR) systems, portals can improve behavioral outcomes, such as self-efficacy or chronic disease-related knowledge **[1,5,7]**. While impacts of portals for individuals with chronic disease such as diabetes is getting clearer, portals applied in the oncology setting has its own specificities and remains superficially explored **[3,4,6,8]**.

Cancer care presents distinct challenges and opportunities for portal utilization **[3,4,6,8]**. The complex nature of cancer treatment, involving multiple specialists and frequent clinical evaluations, highlights the need for effective information management and communication. Portal use demonstrate significant potential to address these needs by empowering individuals living with chronic diseases to actively participate in their care and improving care coordination **[1-8]**. Portals enable people involvement through two main functionalities: (1) e-messaging, which facilitates communication with the healthcare team, and (2) access to health services, such as prescription renewals or appointment scheduling **[1,2,7]**.

Beyond behavioral outcomes, such as self-efficacy or disease-related knowledge, other categories of health outcomes should also be considered, including clinical outcomes such as weight, blood pressure, sleep duration, and quality; technology experience outcomes such as satisfaction with platform usability or user experience; biopsychosocial outcomes, such as health-related quality of life or physical well-being; and healthcare system outcomes, including measures of effectiveness, cost-effectiveness, and hospital readmissions **[13]**.

Social determinants of health and dimensions of inequity, as outlined in the PROGRESS-Plus framework **[14]**, are known to influence portal use. Existing research has identified factors such as age, gender (or sex), race (or ethnicity), socioeconomic status, and digital literacy as being associated with portal usage **[3-5, 15-17]**. Despite the growing adoption of digital portals in oncology, there is limited understanding of which functionalities are used, the outcomes they influence, and which diverse patient populations engage with them, hindering their optimal integration into cancer care.

Objectives

Our main objective was to identify the main functionalities of digital portals used by individuals with cancer and the categories of outcomes assessed, including those related to the healthcare system. As secondary objectives, we also seek to (1) describe the diversity of participant groups in oncology portal research and (2) identify individual characteristics associated with portal use.

Methods

Patient Engagement

Aligned with the Canadian Institutes of Health Research (CIHR)'s Strategy for Patient-Oriented Research and Patient Engagement Framework **[18]**, ‘patient partners’ (SO and CC) were members of the team and included in all aspects of the project, such as providing lived experience expertise in the orientation of the objectives, and in the results interpretation. We co-developed the workplan and the research protocol with all the other authors of this manuscript. The ‘patient partner’ co-leader (SO) participated in the meeting with the corresponding author and the librarian, providing input on the search strategy. Team members co-developed the data extraction form and participated in its pilot testing. The ‘patient partner’ co-leader (SO) held meetings with the corresponding author and other team members to support the analysis and interpretation of the data. The ‘patient partner’ co-leader (SO) wrote the first draft of this manuscript, integrating valuable insights from all other authors.

Study Design and Search Strategy

We conducted a scoping review guided by the JBI (formerly the Joanna Briggs Institute) guidelines **[19]** and registered the review protocol in the Open Science Framework (OSF) Registries (https://osf.io/nrbt3/) **[20]**. Our results are reported following the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) checklist **[21].** We used the PCC (Population [or Participant], Concept, and Context) framework **[22,23]** to define the elements applied in this review **(Table 1)**.

Table 1. Inclusion and exclusion criteria, study design, study type, and time frame

PCC Elements [23], study design, and time frame	**Inclusion criteria**	**Exclusion criteria**
Population	- Individuals diagnosed with cancer (any cancer including cancer survivors). - Children, teenagers and adults, as well as their caregivers or family caregivers.	- Participants with cancer alongside others (eg, healthy individuals or those with other chronic diseases) without presenting subgroup results. - Breast, prostate, or lung cancer screening studies involving populations without a formal cancer diagnosis. - Studies focused solely on clinicians' perceptions or the impact on their workload (clinician-only studies).
Concept	- Digital portal use and the main functionalities (e-messaging and access to health services) **[1,2,4-7]**.	- Use of a portal for a specific purpose, such as surveying patients on a topic unrelated to the portal itself. - Studies only addressing usability tests or

	- At least one health outcome or healthcare system outcome **[13]**.	portal development outcomes.
Context	- At home or in another outpatient setting.	- Hospitalized.
Study design, study type, and time frame	- Randomized controlled trials, quasi-randomized controlled trials, prospective cohort studies, pretest-posttest studies, observational studies, mixed methods studies, qualitative studies, and quantitative descriptive (surveys presenting participant characteristics). - Published between 2014-01-01 and 2024-02-27.	- Reviews, opinions, editorials, commentaries, book chapters, and conference papers.

We co-developed a search strategy with an experienced librarian in four databases (Embase.com, Web of Science (SCI-EXPANDED, SSCI, AHCI, ESCI), Medline (Ovid), and CINAHL Plus with Full Text (EBSCOhost)) identifying sources published between 2014-01-01 and 2024-02-27. We focused exclusively on original studies from the last 10 years. We used 10 relevant sources suggested by the 'patient partner' co-leader (SO) to test the sensitivity of the search strategies detailed in **[Appendix 1]**. The librarian imported the references into the web-based collaborative tool Covidence **[24]**, where duplicates were removed using both the automated function and manually.

Data Collection

We used the same criteria for data collection across all references. The main inclusion criteria were participants with an active cancer diagnosis or a history of cancer, using a portal at home or in other outpatient settings, with access to personal health information, and with at least one outcome assessed. For example, portals specifically offered to hospitalized patients and available only during hospitalization were excluded. The hospital setting was excluded because cancer patients in this environment are fully managed by the care team, which addresses all aspects of care, including basic needs like eating and bathing, as well as more complex clinical processes such as monitoring and testing. Studies were also excluded if they involved participants without a cancer diagnosis or mixed populations of cancer and non-cancer participants (eg, healthy individuals or those with other chronic diseases) where subgroup-specific results were not reported.

We conducted a calibration exercise with four reviewers and an experienced reviewer using a sample of 20 identical sources to ensure consistency in the application of selection criteria. We observed that some studies used the terms '*EHRs*' or '*PHRs*' instead of '*patient portal*'. Following the theoretical framework previously presented **[1,2,4-7]**, we considered it as a portal if participants had access to their personal health information or data. Subsequently, five reviewers screened all titles and abstracts and independently applied the same selection criteria. At the full-text screening step, the same five reviewers conducted another calibration on 10 full-texts. All titles and abstracts, and full texts, underwent dual screening. Discrepancies regarding the included studies were resolved through consensus among the five reviewers, including the two ‘patient partners’ (SO and CC) and an experienced reviewer, during weekly meetings.

Data Extraction

We used an Excel sheet to manage data extraction. Data from all included studies were extracted once by four reviewers and validated by an experienced reviewer to ensure accuracy and completeness. We developed an extraction form that was pretested by the five reviewers, as recommended **[25].** We extracted the study characteristics (first author, year of publication, country, study type, method, population, sample size, and data source) as well as concept data.

Data Synthesis

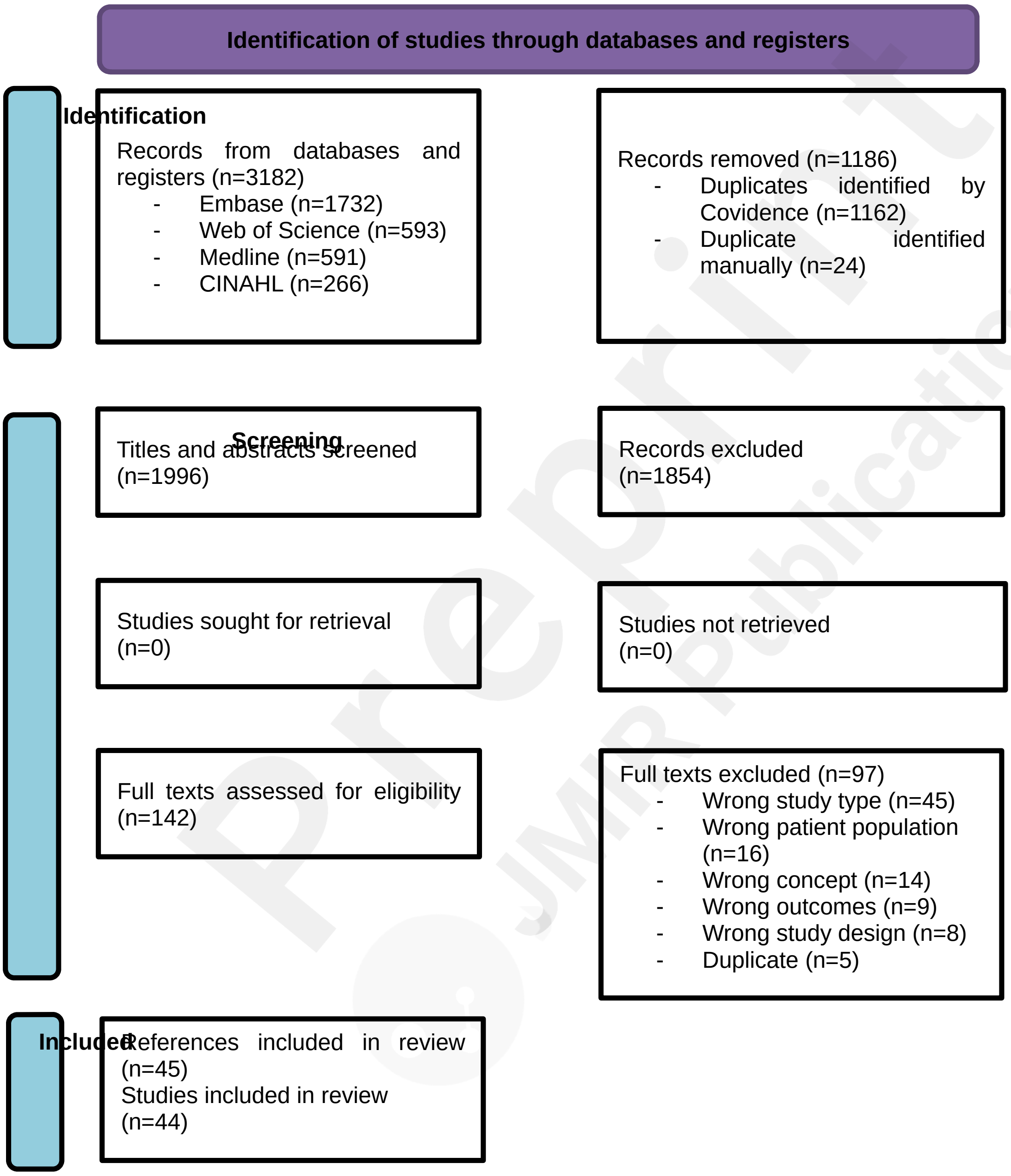
We structured narrative summaries as follows: all retained studies involved portal use, defined as participants having access to their personal health information **[1,2,4-7]**. We synthesized the data using three conceptual frameworks. First, we identified two main categories of functionalities: 1) e-messaging and 2) access to health services **[1,2,7]**. Second, we applied the five outcome categories used in chronic disease interventions: 1) clinical (such as disease progression), 2) behavioral (such as medication adherence), 3) technology experience (such as user satisfaction), 4) biopsychosocial (such as health-related quality of life), and 5) healthcare system outcomes (such as care coordination effectiveness) **[13]**. Third, we used the PROGRESS-Plus framework to characterize individuals based on social determinants of health and dimensions of inequity **[14]**. This framework, widely used in public health research, considers factors such as place of residence, race (or ethnicity), occupation, gender (or sex), religion, education, socioeconomic status, and social capital. The ‘Plus’ encompasses additional factors, including age, disability, and other vulnerabilities that influence health outcomes.

Results

Overview

Out of a total of 1996 titles and abstracts, along with 142 full-text articles that underwent dual screening, 44 studies reported across 45 articles (one study was reported in two separate articles) met the eligibility criteria **[26-70]**. (**Figure 1)**.

Figure 1. The PRISMA 2020 flow diagram



Main Objective: Portal Functionalities and Assessed Outcomes

All the 44 included studies involved participants with access to their personal information or data through a digital portal. However, the availability of e-messaging or access to health services was not a prerequisite for inclusion. To address the main objective of this review—identifying the main functionalities of portals used by individuals with cancer and the outcomes assessed—the characteristics of the 44 studies are presented in **Table 2**.

Table 2. Characteristics of Included Studies

First author, year, country	**Study type, method or data source**	**Possibility to E-messaging**	**Access to health services**	**Number of participants**	**Outcomes assessed or measured**
Alpert, 2019, USA [26]	Qualitative. Interviews.	Yes	Yes	35 patients, 13 oncologists, and 12 informaticists.	Communicative behaviors with physicians, personal health knowledge, and patients' communication preferences.
Baun, 2020, Denmark [27]	Mixed methods. Questionnaires and interviews.	Not mentioned or related to the objective	Not mentioned or related to the objective	Questionnaires: 46 patients. Interviews: 4 patients.	The patients' use and their attitudes toward the health portal and access to scan results.
Cahill, 2014 USA [28]	Quantitative descriptive. Data from different sources.	Yes	Yes	186 patients.	Portal use predictors and access-related factors.
Colussi, 2024, Argentina [29]	Qualitative descriptive. Free text field in a survey.	Not yet (to be implemented)	Yes	422 survey responses. Patients may have responded more than once.	User needs and expectations regarding patient-oriented information systems, aimed at planning and prioritizing improvements to an existing patient portal.
Conroy, 2023, USA [30]	Quantitative descriptive. Data from the EMRs.	Yes	Yes (not the aim of this study)	4069 patients.	Patient technology experience with e-messaging: Comparison of '*MyChart*' users

					and non-users, and demographic factors associated with the use of the messaging function.
Coquet, 2020, USA [31]	Quantitative descriptive. Data from the EHRs.	Yes	Yes (not the aim of this study)	9900 cancer patients (6446 patients after propensity score matching).	Two-year survival rate (comparing patients who initiated emails to non-email users), healthcare utilization, chemotherapy-related inpatient admissions, and timely responses from the healthcare team.
Daly, 2020, USA [32]	Mixed methods. Single-arm pilot study. Questionnaire and interviews.	Yes	Yes	100 patients.	Feasibility and acceptability of an intervention for capturing symptoms, integrated into the patient portal, evaluated through enrollment and response rates, symptom alerts, perceived value by patients and providers, and likelihood of using acute care.
DeRegge, 2020, Belgium [33]	Mixed methods. Survey, interviews, and logged data.	Yes	Yes	23 patients.	Patient engagement, caregiver feedback, general practitioners' interest, and

					suggestions for improvement.
Ector, 2020, Netherlands [34]	Qualitative. Pilot study. Interviews.	Yes	Yes	8 patients.	Patient preferences for features in their portal.
Elkefi, 2021, USA [35]	Quantitative descriptive. Survey.	Not mentioned or related to the objective	Not mentioned or related to the objective	4328 patients. 693 patients with cancer.	Likelihood of cancer patients to use portals compared to others.
Emamekhoo, 2023, USA [36]	Quantitative. Questionnaire.	Yes	Yes	2076 patients.	Portal login frequency, impact of oncology visits, use of portal functionalities, and demographic associations.
Fridriksdottir, 2023, Iceland [37]	Mixed methods. Questionnaire and interviews.	Yes	Yes	69 patients.	Portal adoption and engagement, usability and acceptability, patient-reported outcomes, and healthcare professional feedback.
Geerts, 2019, Netherlands [38]	Mixed methods. Questionnaire and interviews.	Not yet (to be implemented)	Not yet (to be implemented)	204 patients.	Patient interest, physician concerns, customization needs, and engagement by involving both patients and healthcare providers in the development.
Geerts, 2023, Netherlands [39]	Mixed methods. Questionnaire and	Yes	Yes	18 patients.	Usability, usage, recommendations, and implementation

	interviews.				through the initiation of an RCT to study the effects of an e-health application.
Gerber, 2014, USA [40]	Quantitative. Data from the patient portal.	Yes	Not mentioned or related to the objective	6495 patients.	Retrospective analysis of enrollment in and use of 'MyChart,' a patient portal.
Greenberg-Worisek, 2020, USA [41]	Quantitative descriptive. Secondary analysis of survey data.	Yes	Yes	3031 cancer patients or survivors.	Cancer patients' current use of health information technology tools by residential location.
Griffin, 2023, USA [42]	Quantitative descriptive. Data from the patient portal.	Yes	Yes	28942 patients.	Portal access, use, number of clinical encounters, and disparities (structural and patient factors affecting portal access and usage).
Groen, 2017, Netherlands [43]	Mixed methods. Questionnaires, a focus group, and analysis of user log data.	Yes	Not mentioned or related to the objective	37 patients.	Feasibility, usability, impact on patient activation, quality of life (QoL), physical activity, and participation rate.
Haggstrom, 2022, USA [44]	Qualitative. Interviews	Yes	No	6 patients and 4 caregivers.	Access and communication, self-management, implementation, and relational impact for

					patients and providers.
Kayastha, 2018, USA [45]	Qualitative. Interviews.	Yes	Not mentioned or related to the objective	20 patients.	Patients' experience reading their care notes: comprehension, anxiety, control, and trust.
Kuijpers, 2016, Netherlands [46]	Mixed methods. Questionnaire and focus group.	Not mentioned or related to the objective	Yes	92 patients.	User satisfaction, quality of life (QoL), physical activity, and professional impact.
Leader, 2021, USA [47]	Quantitative. Survey of patients and caregivers.	Yes	Yes	346 patients and 13 caregivers.	Assessing digital literacy and technology use among a diverse sample of patients with cancer and caregivers.
Liu, 2022, USA [48]	Quantitative. Survey.	Yes	Yes	626 patients.	Considering patient-centered communication and self-efficacy as mediators in the effects of portal use on psychological and physical health.
Longacre, 2023, USA [49]	Mixed methods. Data from the portals, surveys, and interviews.	Yes	Not mentioned or related to the objective	20 patients and 19 caregivers.	Patients' and caregivers' satisfaction with a system designed to engage family caregivers by integrating them into the patient's existing portal system,

					caregiver strain, clinician perception, and system usability.
Luo, 2022, USA [50]	Quantitative descriptive. Survey.	Yes	Yes	207 patients	Portal usage among older cancer survivors, social support, confidence in data security safeguards, and health-related internet use.
Luoh, 2021, USA [51]	Quantitative. A retrospective analysis of portal usage data.	Yes	Not mentioned or related to the objective	5950 patients.	Portal usage patterns (likelihood of sending and viewing oncologist-specific messages and results compared to non-oncologist-specific ones), geographic and demographic factors, and the impact of cancer stage on portal use.
McCleary, 2018, USA [52]	Mixed methods. Survey and focus groups	Yes	Yes	Survey: 1019 patients. Focus groups: (staff n=20; patients, n=5).	Usability of the portal, barriers to portal usage, and portal accessibility.
Nahm, 2019, USA [53]	Quantitative. Questionnaire.	Yes	Yes	30 patients.	QoL, symptom management, patient feedback, and engagement.
Ngo, 2020, USA [54]	Qualitative. Interviews.	Yes	Not mentioned or related to the objective	27 patients.	Impact on nurse care coordinators, access to health information,

					usability issues, and the integration of an application.
O’Connor, 2022, UK [55]	Mixed methods. Service utilization data, surveys, and interviews.	Yes	Yes	518 patients participated in the online survey.	Portal user satisfaction, non-user feedback, and impact on self-management (eg, attending appointments at the hospital, being able to contact clinical team).
Pho, 2019, USA [56]	Quantitative. Data from the 'MyChart' portal login records.	Yes	Yes	2524 patients.	Mobile access, usage among underserved groups, overall portal usage, and impact on patient experience.
Rexhepi, 2018, and Rexhepi, 2021, Sweden [57,58]	Qualitative. Interviews.	Not mentioned or related to the objective	Not mentioned or related to the objective	30 patients.	Cancer patients' information-seeking behavior related to portals, understanding and control of their health conditions, anxiety, preparation for physician visits, and impact on healthcare providers.
Rexhepi, 2020, Sweden [59]	Quantitative. Survey.	Not mentioned or related to the objective	Not mentioned or related to the objective	347 out of 2587 respondents.	Differences in attitudes toward, effects of, and experiences with portals among cancer patients and other patient groups.

Santos, 2021, Canada [60]	Qualitative. Interviews.	Not mentioned or related to the objective	Not mentioned or related to the objective	10 patients and 1 family caregiver.	The experiences of oncology patients and their family caregivers using portals to support their healthcare needs.
Schultz, 2018, USA [61]	Qualitative. Interviews.	Not mentioned or related to the objective	Not mentioned or related to the objective	19 caregivers of children.	Caregivers' preferences for receiving test results and their views on using an online patient portal.
Schultz, 2021, USA [62]	Quantitative descriptive. Data from a hospital database.	Yes	Yes	390 caregivers of children.	Portal activation by caregivers, sociodemographic disparities, clinical variables (treatment length and number of radiology tests), and equity concerns.
Shaverdian, 2019, USA [63]	Quantitative. Survey.	Not mentioned or related to the objective	Not mentioned or related to the objective	136 patients (baseline survey completed).	From open access to physician notes: understanding of diagnosis and treatment side effects, reassurance, communication with family and others, and potential negative effects (worry, confusion, or regret).
Strekalova, 2019, USA [64]	Quantitative. Survey.	Yes	Yes	542 patients.	Frequency of portal access by patients and predictors of

					portal use.
Tarver, 2019, USA [65]	Quantitative. Survey.	Yes	Not mentioned or related to the objective	22 patients.	Perceptions of the ease of use and satisfaction with the portal.
Vachon, 2022, USA [66]	Quantitative. Survey.	Yes	Not mentioned or related to the objective	22 patients.	Adherence to colonoscopy and tests, patient beliefs, and the feasibility of using a portal to increase surveillance adherence among colorectal cancer survivors.
Weis, 2020, Germany [67]	Qualitative. Interviews.	Not mentioned or related to the objective	Not mentioned or related to the objective	22 patients and 9 caregivers.	Caregivers' role, access rights (whether caregivers should have full or graduated access to the portal), and the patient-caregiver relationship.
Wickersham, 2019, USA [68]	Quantitative. Survey.	Yes	Yes	85 patients.	Patients' use of the Internet and portals in an outpatient cancer clinic.
Williamson, 2017, USA [69]	Quantitative descriptive. Data from the medical charts.	Not mentioned or related to the objective	Not mentioned or related to the objective	624 cancer survivors.	Registration and usage, transition to adult care, annual survivor care follow-up, and demographic factors.
Wolff, 2019, USA [70]	Quantitative pilot randomized controlled	Not mentioned or related to the	Yes	132 patient and family caregiver dyads.	Intervention acceptability, 'MyChart' portal registration, and

trial. Surveys.	objective	usage over time.

All these studies met the inclusion criteria of individuals with cancer already using portals with an access to personal health information and at least one outcome assessed. Most studies were conducted in the United States (31/44, 70%), 11% in the Netherlands (5/44), 5% in Sweden (2/44) and 6 in other individual countries. Most studies used quantitative methods (23/44, 52%), while 25% used mixed methods (11/44), and 23% used qualitative approaches (10/44).

E-messaging and Access to Health Services Functionalities

E-messaging functionalities were identified in 73% (32/44) of studies, not identified or unrelated to the objective in 23% (10/44) of studies and planned for implementation in 5% (2/44) of studies. Access to health services, such as appointment booking or medication renewal, was identified in 59% (26/44) of studies, not mentioned or unrelated to the objective in 39% (17/44) studies, and planned for implementation in one study. In 23% (10/44) of the studies, neither of the functionalities was mentioned or was unrelated to their objectives.

Categories of Assessed Health or Healthcare Outcomes

Based on a previously developed outcome categorization used in chronic disease interventions **[13]**, we identified 23 studies assessing technology experience outcomes **[26-30,32-34,37-40,46,49,52,54-56,59-61,65,70]**, 16 assessing behavioral outcomes **[26,33,37,43-46,48,50,51,53,55,57,58,63,66,69]**, five assessing healthcare system outcomes **[31,36,42,55,62]**, four assessing biopsychosocial outcomes **[43,46,48,53]**, and two assessing clinical outcomes **[31,32]**. The outcomes grouped into the five categories are presented in **Table 3**.

Table 3. Outcomes grouped into the five categories

Categories of outcomes	**Specific outcomes investigated**
Technology experience **[26-30,32-34,37-40,46,49,52,54-56,59-61,65,70]**	- Patients' communication preferences [26] - Patients’ use and their attitudes toward the health portal [27] - Portal use [28] - User needs and expectations [29] - Patient technology experience with e-messaging [30] - Acceptability of an intervention [32] - Suggestions for improvement [33] - Patient preferences for features in their portal [34] - Usability and acceptability [37] - Customization needs [38] - Usability, usage, and recommendations [39] - Use of 'MyChart', a patient portal [40] - User satisfaction [46] - Satisfaction with a system [49] - Usability of the portal [52] - Usability issues [54] - User satisfaction [55] - Overall portal usage, and impact on experience [56] - Experiences with portals [59] - Experiences using portals [60] - Caregivers' preferences [61] - Satisfaction with the portal [65] - Portal registration, acceptability, and usage over time [70]
Behavioral **[26,33,37,43-46,48,50,51,53,55,57,58,63,66,69]**	- Communicative behaviors and health knowledge [26] - Patient engagement [33] - Portal adoption and engagement [37] - Impact on patient activation and physical activity [43] - Self-management [44] - Comprehension, anxiety, control, and trust [45] - Physical activity [46] - Self-efficacy [48] - Confidence in data security safeguards, and health-related internet use [50] - Portal usage patterns [51] - Symptom management and engagement [53] - Self-management [55] - Information-seeking behavior, understanding and control of their health conditions, and preparation for physician visits [57,58] - Understanding of diagnosis and treatment side effects, reassurance, communication with family and others [63] - Adherence to colonoscopy and tests, and patient beliefs [66] - Annual survivor care follow-up [69]

Healthcare system **[31,36,42,55,62]**	- Healthcare utilization, chemotherapy-related inpatient admissions, and timely responses from the healthcare team [31] - Impact of oncology visits [36] - Number of clinical encounters [42] - Attending appointments at the hospital, and being able to contact clinical team [55] - Treatment length and number of radiology tests [62]
Biopsychosocial **[43,46,48,53]**	- Quality of life (QoL) [43] - QoL [46] - Psychological and physical health [48] - QoL [53]
Clinical **[31,32]**	- Two-year survival rate [31] - Likelihood of using acute care [32]

Secondary Objective 1) Representation of Cancer Types and Diverse Groups

Complete details on the types of cancer among participants and their individual characteristics across the 44 included studies can be found in **[Appendix 2]**.

Types of Cancer among Participants

Among the participants, breast cancer was the most frequently identified type in 36% (16/44) of studies, followed by various hematologic cancers such as leukemia, lymphoma, and multiple myeloma in 27% (12/44) of studies. Gastrointestinal cancers, including colorectal and stomach cancers, were also commonly reported in 18% (8/44) of studies. Lung (8/44; 18%) and prostate cancers (7/44; 16%) were identified, along with rarer cancers such as sarcomas (5/44, 11%) brain tumors (2/44, 5%), and kidney cancer (2/44, 5%). We identified the involvement of family or non clinicians' caregivers in 18% (8/44) of studies. Metastasis was a recurring feature across several cancer types identified in 25% (11/44) of studies, with many patients being in advanced stages, particularly stage IV.

Diverse Groups Represented

We extracted participant characteristics from all 44 included studies to identify the PROGRESS-Plus factors, even though these factors were not necessarily examined in each study. Age was the most reported in 95% (42/44) of studies, and gender (or sex) being also frequently identified (39/44, 89%). Race or ethnicity (23/44, 52%) was also reported, with most participants generally being non-Hispanic White, followed by smaller proportions of Black, Hispanic, and other racial groups. Education levels (20/44, 45%), and income levels (8/44, 18%) were also reported. Place of residence, particularly urban versus rural, was reported less frequently (4/44, 9%), as well as language (3/44, 7%), and access to the internet (2/44, 5%). Overall, most studies focused on age, gender (or sex), and race (or ethnicity), with less attention to other factors such as social capital, occupation, and disability. No study reported on the religion factor.

Secondary Objective 2) Individual Characteristics and Use of Portals

We identified the PROGRESS-Plus factors **[14]** associated with the portal use: 43% of included studies (19/44) examined this aspect. The PROGRESS-Plus factors associated with portal use are presented in **Table 4**.

Table 4. The authors' interpretation of PROGRESS-Plus factors associated with the portal use.

PROGRESS-Plus Factors	Authors' interpretation
Place of residence	- Patients residing in Texas were more likely to use the portal than those living out-of-state [28] - Rural cancer patients were significantly less likely to email health care providers compared to urban patients [41] - Patients living in areas with higher broadband access were more likely to use the portal persistently [42] - Urban residents used the portal more frequently than those in rural areas [51] - Those living in higher Child Opportunity Index (COI) areas were more likely to use the portal [60]
Race (or ethnicity)	- Non-Hispanic Black and Hispanic patients were significantly less likely to use e-messaging compared to non-Hispanic White patients [30] - Non-Hispanic White patients were more likely to use portals than Hispanic or non-Hispanic Black patients [35] - Patients “of color” logged into the portal less frequently [36] - White patients had higher odds of accessing the portal compared to Black, African American, or Hispanic patients [42] - Non-White patients were significantly less likely to use the portal [47] - White patients were more likely to use the portal [51] - White and Asian survivors were more likely to register for the portal, while Black survivors were less likely to use it meaningfully [69]
Occupation	- Employed patients were more likely to use the portal persistently [42]
Gender (or sex)	- Females were more likely to use the portal [26] - More males were active users [33] - Female patients were more likely to use online portals than male patients [35] - A higher percentage of regular portal users were women [36] - Women were more likely to access the portal than men

	[42] - Not significantly linked to portal use [50] - Male patients were more likely to use the portal [51]
Religion	- None
Education	- Higher education levels and better internet access were more likely to use the portal [26] - Higher educational levels were more likely to use the portal [27] - A college education or higher were more likely to use the portal [28] - Active users had a higher proportion of high school education, while non-active users had further education [33] - Higher education levels were associated with increased use of portal [41] - Patients with higher education levels were more likely to use the portal [47]
Socioeconomic status	- Higher household incomes were more engaged with the portal [26] - No significant impact of household status on the portal use [27] - Middle-income earners ($30,000–$99,999) were more frequent users compared to higher-income earners [28] - The patients with Managed care were more likely to use e-messaging compared to those with Medicare or Medicaid [30] - Higher income levels were linked to more frequent use of portal [41] - Income not significantly linked to portal use [50] - Patients with private insurance had higher usage rates [51] - Those with higher socioeconomic status were more likely to use the portal [55] - Those with private health insurance were more likely to use the portal [60] - Those with higher income levels were more likely to use portals frequently [64]
Social capital	- All active users lived with someone, while non-active users included those living alone [33] - Participants with more social support experienced lower odds of using portals [50]
Age	- Older patients were more likely to use the portal [26] - No significant age difference between users and nonusers [27]

	- Younger patients were more likely to use e-messaging [30] - Active users were slightly younger on average (44.3 years) compared to non-active users (49.2 years) [33] - Older patients (≥65 years) were less likely to use portals compared to younger patients [35] - Younger patients logged into the portal less frequently [36] - Older patients were less likely to use email to communicate with their health care providers [41] - Younger patients (under 40) were more likely to access the portal compared to older patients (over 65) [42] - Younger patients were more likely to use the portal [47,51] - Older patients were less likely to enroll in the portal [52] - Older prostate cancer patients were less likely to register and use the portal [55] - Younger children had higher odds of their caregivers activating the portal [60]
Disability	- Greater physical impairment was associated with higher portal use [28]
Other vulnerabilities	Health literacy: - Higher health literacy felt more comfortable navigating and understanding the portal [26] Language: - English-speaking patients were more likely to use e-messaging, and those requiring an interpreter were less likely to use it [30] - Caregivers who spoke English were significantly more likely to activate the portal [60] Technical proficiency: - Active users generally had better computer and internet skills [33] Computer access: - Patients without computer access were less likely to enroll in the portal [52] Information technology skills: - Lack of computer skills and access to computing facilities were common reasons for non-use [55]

In addition to the PROGRESS-Plus factors, we identified five individual, cancer-related characteristics associated with the portal use **(Textbox 1)**.

Textbox 1. Individual, cancer-related characteristics associated with portal use

- Individuals with bone cancer and those in the active treatment phase were more likely to use the portal [33]

- Each additional oncology office visit in a month increased the frequency of portal logins [36]
- Individuals with metastatic cancer were more frequent users compared to those with non-metastatic cancer [51]
- Caregivers of children undergoing longer treatments, and more radiology tests were more likely to activate the portal [60]
- Those who transitioned from pediatric to adult care used the portal more consistently and frequently [69]

Discussion

Principal Findings

While patient technology experience and behavioral outcomes are frequently studied, healthcare system, biopsychosocial, and clinical outcomes remain underexplored, suggesting a need for further research on how portal use directly impacts healthcare efficiency and patient health outcomes. Few studies systematically assess equity-related aspects such as social capital, disability, occupation, or religion. Instead, most focus on age, socioeconomic status, gender (or sex), and race (or ethnicity), leaving gaps in understanding how different populations engage with portals. Additionally, some studies include both patients and caregivers, highlighting an emerging interest in caregiver access and roles within patient portals, though this remains a less common focus.

Comparison with Other Reviews

We identified three reviews focusing on patient portals, but with participants having diverse diseases or health conditions [**1,5,7**]. We also identified three reviews involving participants with cancer but focusing on a variety of digital technologies [**3,8,16**]. Our review enhances this body of work by focusing on participants with cancer using portals, defined as an access to personal health information or data **[1,2,4-7]**.

We identified only one review, published in 2018, that involved participants with cancer and focused on portal use **[4]**. It shows that portals seem to play a significant role in enhancing self-management (a behavioral outcome) among cancer survivors. Consistent with our findings, younger age, ‘White race’, and higher socioeconomic status were associated with increased portal use. As it emphasized the need for more studies on factors influencing portal use, our review provides an updated portrait of advancements on this topic by considering all the PROGRESS-Plus factors, and by identifying diverse categories of outcomes assessed.

Another review of portal functionalities for individuals with diabetes found that 50% of studies (6/12) included e-messaging, and 17% (2/12) included access to health services **[1]**, which is less than our findings. Some associations of portal use with clinical outcomes were identified, such as improved glycemic control **[1]**. This contrasts with our findings in cancer-focused studies, where clinical outcomes assessed were limited to proxies such as two-year survival rates **[31]** and the likelihood of using acute care **[32]**.

Another review on portals outcomes across all populations reported improvements in behavioral outcomes, but inconsistent effects on clinical outcomes suggesting that confounding factors exist **[5]**. In another review of educational materials within portals dedicated to any populations, their increasing use was reported, expressing satisfaction and improved behavioral outcomes **[7]**. This supports our findings in which behavioral and technology experience outcomes received greater attention than other categories. As well as the review of portal functionalities for individuals with diabetes, biopsychosocial and healthcare system outcomes were scarcely investigated **[1].**

In a breast cancer population, a review of eHealth tools, including portals, showed inconsistent effects on symptoms and lifestyle-related outcomes, although participants were generally satisfied with these technologies **[8]**. Another review examined the impact of various digital technologies on clinician-patient communication, finding that effective use of these tools improved behavioral outcomes and technology-related experiences **[3]**. A further review on cancer-specific patient-centered technologies for underrepresented populations, including African Americans, rural populations, and Hispanics, reported significant improvements in behavioral outcomes such as screening adherence and knowledge **[16]**.

Findings from other reviews are complementary to ours and lay the foundations for future research. Barriers to the implementation of patient-centered technologies were identified, such as unfamiliarity with complex tools and the need for additional support, highlighting areas for improvement **[16]**. In another review focusing on portals, most individuals with cancer accessed their own health information or data but struggled to interpret it accurately **[4]**. These findings suggest a need for initiatives to enhance portal use among diverse groups, considering the PROGRESS-Plus factors identified in our review.

Strengths and Limitations

The strengths of this review include the application of three conceptual frameworks to focus our criteria: one to identify two main categories of functionalities—e-messaging and access to health services **[1,2,7]**; one for the outcomes structure in chronic disease interventions **[13]**; and another for participants' characteristics (PROGRESS-Plus) **[14]**. Using these theoretical foundations helped us identify empirical research gaps in portal implementation for individuals with cancer.

We acknowledge some limitations. First, we restricted our search strategy to the last 10 years prior to March 2024 and to four databases. However, the selected timeframe and databases were carefully chosen to align with the emergence of digital portals and health-related research, making it unlikely that significant relevant studies were overlooked. Second, our search strategy was not peer-reviewed by another librarian. To facilitate replication, detailed documentation is provided in **[Appendix 1]**. Third, data from the included studies were extracted once by four novice reviewers. However, an experienced reviewer, with advanced expertise in methodology and digital health technologies, validated the extracted data.

Conclusions

This review offers a comprehensive overview of digital portal use among individuals with a cancer diagnosis. It highlights disparities in the availability of functionalities, the categories of outcomes assessed, and the PROGRESS-Plus factors associated with portal use. The findings provide insights for researchers and stakeholders, including patient advocacy groups, health policymakers, healthcare providers, and health information technology developers. This review highlights the predominant focus on e-messaging and access to health services functionalities in oncology patient portals, with patient technology experience and behavioral outcomes being the most frequently assessed. Despite some attention to diverse patient characteristics, key equity-related factors remain underexplored, emphasizing the need for more inclusive research to optimize portal accessibility and impact in oncology care.

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Data Availability

The database search strategies are available in **[Appendix 1]**. The PRISMA Extension for Scoping Reviews (PRISMA-ScR) checklist is available in **[Appendix 3]**. All data generated or analyzed during this study are included in this published article and its supplementary information files.

Authors’ Presentation and Contributions

SO, a person living with chronic brain cancer, proposed the research question to the SPOR Evidence Alliance to obtain the funding for this study. SO, MS, SD, MPG, and AL designed the study, while MS and SO developed with MCL the search strategy. SO wrote the first draft of this manuscript. SO, WS, CC, FN, and MS participated in the screening and data extraction processes. CC, a person living with a chronic disease, is the second ‘patient partner’ in this project. All authors have reviewed and approved the final draft of this manuscript.

Conflicts of Interest

None declared.

Appendix 1

The search strategies for each database (PDF File)

Appendix 2

Types of cancer and diverse groups represented in studies on patient portal use in oncology (PDF File)

Appendix 3

PRISMA-ScR checklist (PDF File)

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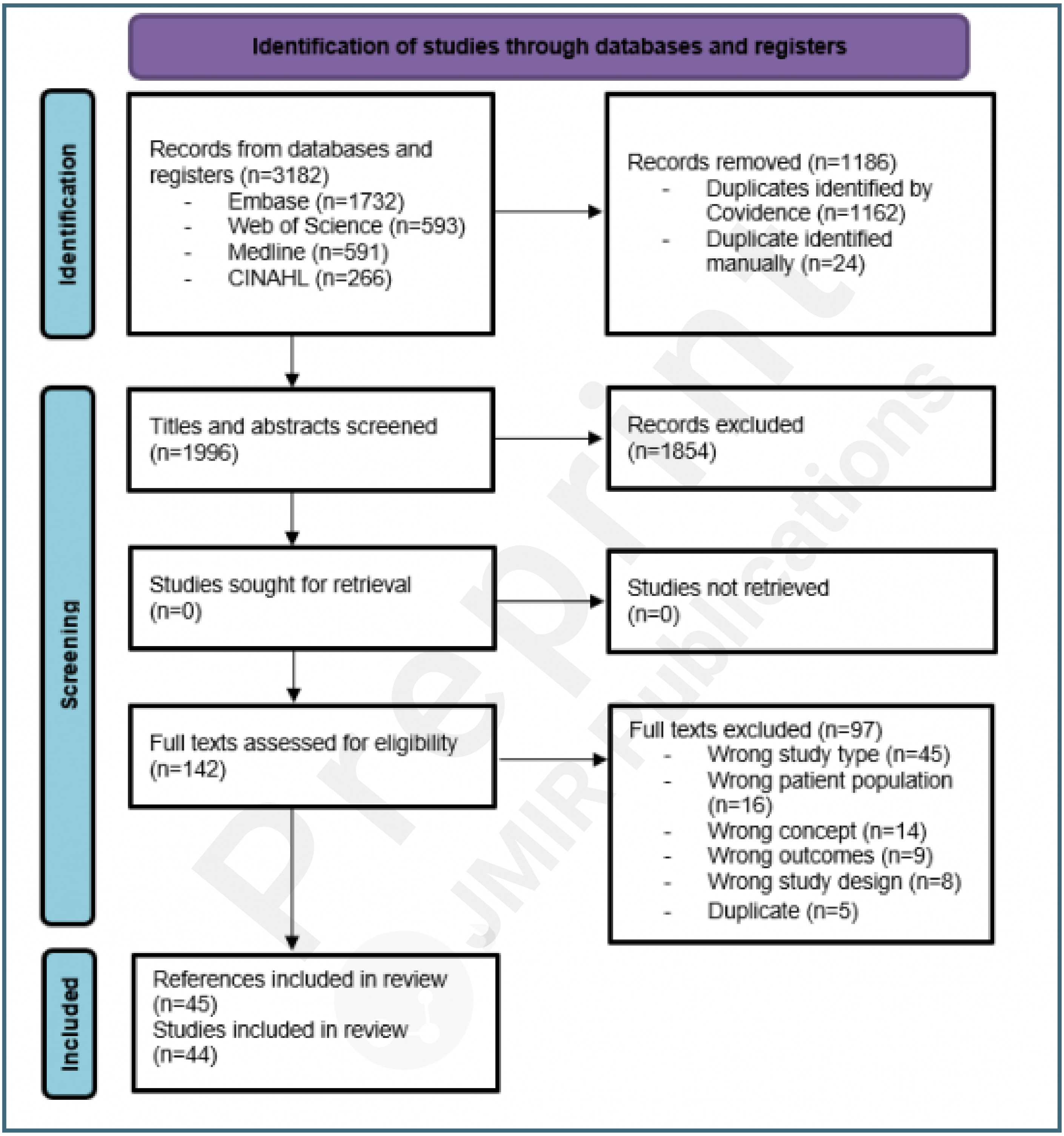
Supplementary Files

Figures

The PRISMA 2020 flow diagram.



Multimedia Appendixes

The search strategies for each database.
URL: http://asset.jmir.pub/assets/19537944726fb3db10201b4d7c03efd0.pdf

Types of cancer and diverse groups represented in studies on patient portal use in oncology.
URL: http://asset.jmir.pub/assets/3de6bec68e5e8856952391408975b536.pdf

PRISMA-ScR checklist.
URL: http://asset.jmir.pub/assets/617e1bf3a246a7b0873455c34b49b8bf.pdf