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Advancing cancer care through digital access in the USA: a state-of-the-art review of patient portals in oncology

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ABSTRACT

Patient portal use among patients with cancer has increased significantly in recent years. This state-of-the-art review seeks to address and analyse literature involving patient portal use by patients with cancer and their care partners. In this review, we queried articles from PubMed published between January 2018 and April 2024 that describe recent trends and the current presence of portals in cancer care for patients, proxy users and/or care partners. We searched for articles addressing three overarching themes: (1) trends and disparities in portal adoption and use among patients with cancer, (2) use of specific portal components and functions in cancer care and (3) associations between portal use and cancer-related outcomes. Our search identified 278 unique studies, of which 82 were relevant empiric studies that met inclusion criteria and were included in this review. These papers aligned with 12 subthemes, including disparities in patient portal access, growing use of telemedicine via patient portal and patient access to immediately available to electronic health information. Our findings indicate that patient portals play an increasingly important role in helping patients manage their cancer care, despite few disparities that contribute to inequitable use. However, despite consistent growth in use over recent years, there are many areas for improvement in how portals support patients with cancer and a demand for functionality to continually evolve with patient needs.

INTRODUCTION

Patient portals (portals) are web-based and smartphone-based tools that allow patients, proxy users and/or care partners to connect remotely with healthcare organisations and with their electronic health information. These portals are linked to a healthcare organisation's electronic health record (EHR) system and allow patients to access their medical information, message with their healthcare team, review and schedule appointments, pay bills electronically and schedule appointments.[1 2] In the USA, 88% of hospitals offer portal access to their patients, primarily as a result of the Health Information Technology for Economic and Clinical Health Act of 2009.[3 4] This law established the 'Meaningful Use' programme, which set incentives and mandates that promoted the national adoption of EHR technology, including portals, by health systems.[5]

There has been widespread growth in portal adoption in recent years. A 2023 study found that the percentage of patients who access the portal increased from 31% in 2014 to 68% in 2022, including a 46% increase between 2020 and 2022.[6] This growth was partially driven by two recent external catalysts. First, the COVID-19 pandemic caused many healthcare organisations to rely on the portal for telehealth to deliver care remotely and to deliver results from COVID-19 tests online. Through COVID-19, the delivery of healthcare through virtual formats became more widely accepted and healthcare organisations began to standardise telehealth delivery through the portal. Second, the information blocking provisions of the 21st Century Cures Act (Cures Act) came into effect in 2021,[7 8] which mandated that patients have immediate access to their electronic health information, including test results and clinical notes, on request. American healthcare organisations are no longer permitted to delay or withhold the release of most test results, including results considered sensitive such as from cancer diagnostic testing.

While portals have been widely adopted and used across many patient populations, patients with cancer may particularly benefit from portal functionality. The use of patient portals extends to patients of all ages and includes parents and care partners who have portal access. Nearly 40.5% of men and women in the USA likely to be diagnosed with cancer in their lifetimes.[9] People with cancer commonly undergo rapid, intensive, outpatient treatments that can be managed and coordinated through the portal.[10] Patients may also use the portal to support numerous self-management challenges that accompany

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cancer treatment, including symptom management, monitoring treatment progression, appointment scheduling and sharing information across clinical teams.[11] Many portals also help to support care partner engagement by providing shared access to portal delegates who help manage a patient's health and health care.[12–14] However, while the portal aims to be a tool for all patients, disparities in portal adoption hamper equitable access. Studies have highlighted inequities in access and use across diverse demographic and socioeconomic groups, including among black individuals, have limited English proficiency, have limited health literacy or limited access to technology.[15–18]

We conducted a state-of-the-art literature review[19] of portal use among patients with cancer to investigate the ways in which patients use the portal to support cancer treatments and the impacts of portal use on cancer-related health outcomes. This review seeks to capture how recent shifts in the US healthcare environment, due to factors such as COVID-19 and the Cures Act, have affected portal use for patients with cancer and how portal use impacts cancer treatments. We focus our review on three timely, expert-derived topics that impact cancer treatment and care delivery to delineate how patients with cancer stand to benefit from portal use.

METHODS

We performed a state-of-the-art review[19] to collect and evaluate prior research about portal usage by patients with cancer and their care partners. Our literature search was performed in April 2024 and included articles from January 2018 to April 2024. We queried PubMed for articles using the structured search strategy in Box 1. The search was developed iteratively through review of resulting title and abstracts. We restricted our results to articles published since 2018 to ensure relevance to recent events and policy changes that influenced portal use in the United States, including the COVID-19 pandemic and 21st Century Cures Act.

We selected studies through an expert-driven review of articles along three overarching topics: (1) trends and disparities in portal adoption and use among patients with cancer, (2) use of specific portal components and functions in cancer care and (3) associations between portal use and cancer-related outcomes. Our inclusion criteria allowed studies that described implemented portals and studies describing feature prototypes and pilot programmes. We excluded editorials, studies in which portals were used only as an approach to data collection (ie, to identify study participants or upload study-related data), studies that were conducted outside of the USA, and studies that were primarily focused on patient-reported outcomes (which might have been collected via the portal). Studies were also excluded if they did not examine patient-facing portal applications or were not primarily focused on the portal or its features. We additionally excluded systematic reviews because of the many recent changes to digitally enabled healthcare delivery and functionality delivered through the patient portal that are not covered in prior reviews. As long as the study focused on portal use, study participants could include patients, care partners and providers. Literature extraction and review were performed using the Covidence systematic review management tool (Covidence.org, Melbourne, Australia).

The initial title and abstract screening was performed by one author (US) to filter studies that were not relevant to our topic of interest. In the second phase, two authors (US and BS) performed full-text review on the remaining studies, applying the inclusion and exclusion criteria to determine a final corpus of the literature. Disagreements between the two authors were resolved through discussion and consensus. Finally, a single author performed full-text review for all included studies to extract details about each study, including study population, methods, relevant results and limitations using a standardised data extraction form. Our extracted studies did not undergo a formal quality assessment, but we did take into consideration the limitations provided in each study, as well as the study type and methods. Included studies were organised into groups using thematic analysis.[20]

Box 1 Structured search strategy for relevant articles

("patient portal"[Title/Abstract] OR "personal health record"[Title/Abstract] OR "EHR"[Title/Abstract] OR "Electronic Health Record"[Title/Abstract] OR "electronic patient record"[Title/Abstract]) AND ("cancer"[Title/Abstract] OR "oncology"[Title/Abstract])

RESULTS

Our literature search identified 1734 unique manuscripts, of which 1454 were excluded during title and abstract screening. After full-text review of the remaining 278 studies, we identified 82 studies that met inclusion criteria and were thematically relevant to our review (figure 1). 59 of these studies were conducted on general populations of patients with cancer and 23 were among patients having 8 distinct cancer types (figure 2). A summary of each study, including sample size and research design, is presented in online supplemental table 1.

We report results in three main sections: (1) rates of portal adoption and use among patients with cancer overall, (2) specific portal components and functions employed in cancer care (including lab results, messaging, and clinician notes) and (3) effects of portal use on health outcomes or healthcare utilisation.

TRENDS AND DISPARITIES IN PORTAL ADOPTION AND USE AMONG PATIENTS WITH CANCER

Portals have become increasingly important for patients with cancer to manage their care. Patients with cancer use the portal at a higher rate than all patients in the USA,

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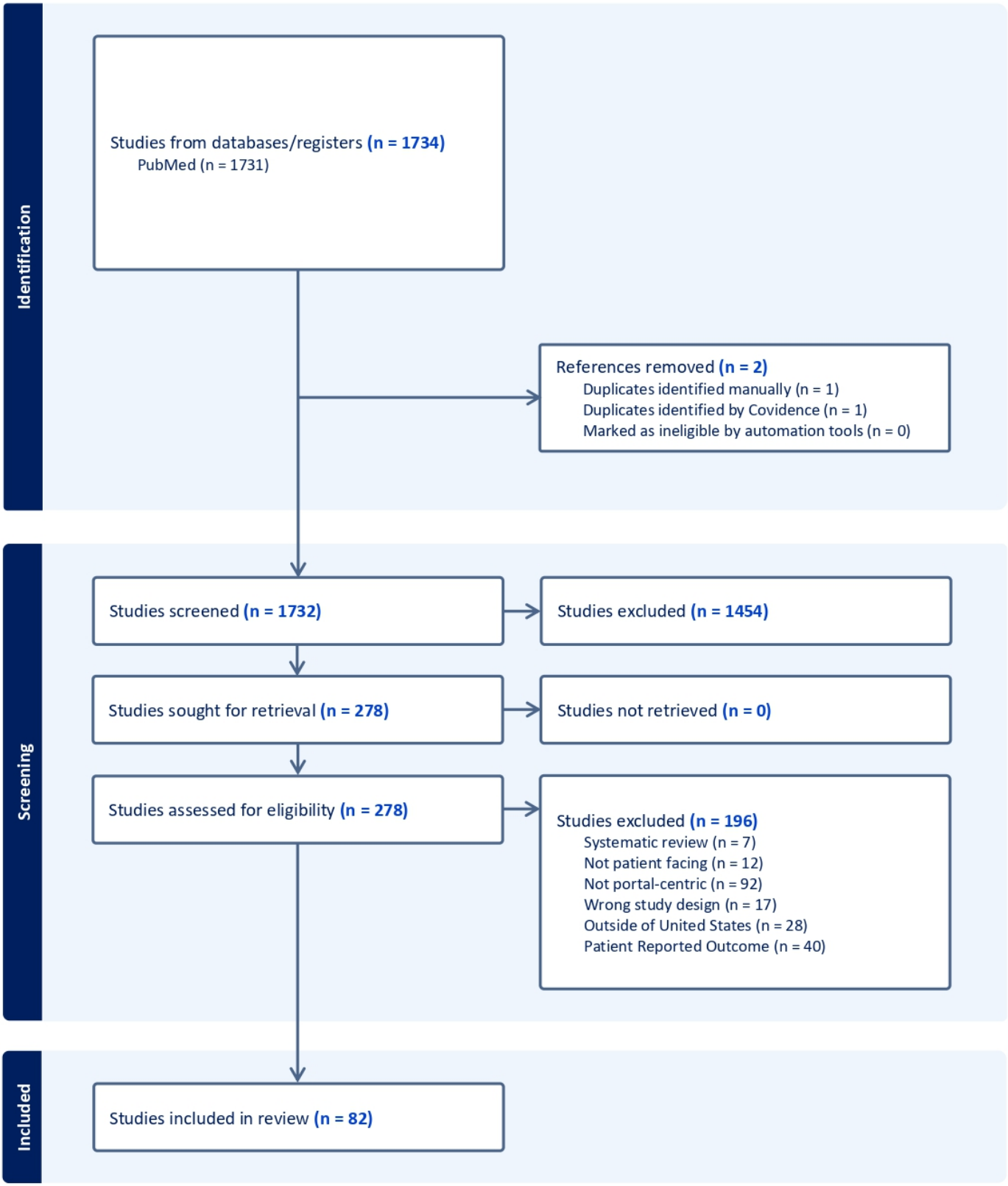

Figure 1 Preferred Reporting Items for Systematic Reviews and Meta-Analyses diagram of article screening and inclusion.

as Health Information National Trends Survey data from 2019 to 2020 reported 45.5% of patients with cancer, compared with 38% of all patients, used portals.[21 22] As more patients opt into using the portal, research follows this uptick in adoption. There were 28 articles that described trends around how patients with cancer are adopting the portal and which patients are using the portal (themes are summarised in table 1).

Care partners, who are the family members or close relations to a patient involved in navigating the health system

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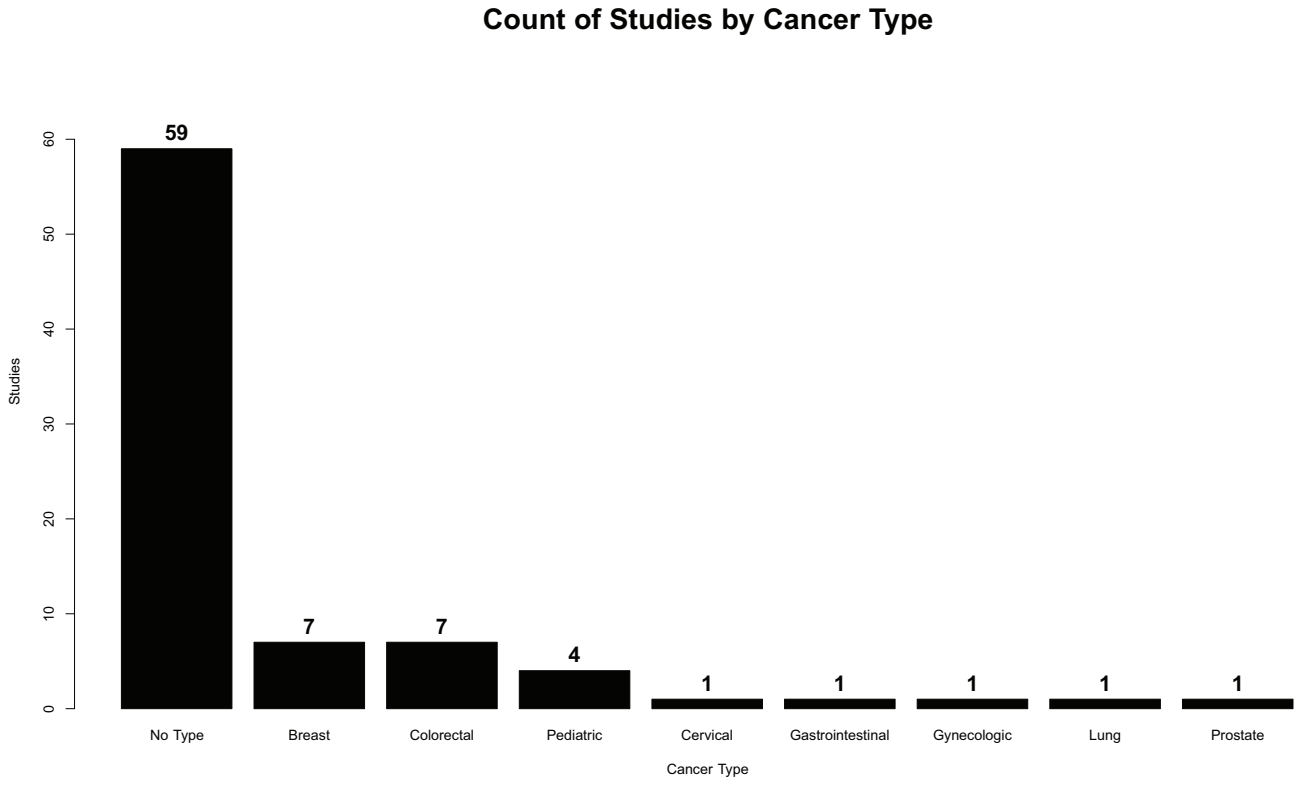

Figure 2 Distribution of studies by cancer type.

and coordinating care, also benefit from using the portal because it allows them to better manage care for patients by involving them in the patient journey and providing access to health information. Care partners who use the portal to manage their own care are more likely to use the portal to manage care for someone else.[23 24] Through their interactions with the portal, care partners have also expressed suggestions for improved functionality, including integration of support groups and complementary and complementary medicine education into the portal.[25–29]

Disparities in access and use

Generally, disparities in portal access among patients with cancer are consistent with disparities in portal use among general patient populations. Patients with cancer are less likely to use the portal if they reside in a rural area, have limited access to broadband internet, have limited English proficiency, are from non-white race, are men, are older, are uninsured, and are unmarried.[30–43] Among patients with cancer, those with severe disease were more likely to use portals in the inpatient setting in a retrospective review conducted at Mayo Clinic in Jacksonville, Florida, USA.[42] Notably, some studies also mentioned that they provided the portal in other languages, such as Spanish, or were using interpreter services while they bridged an offering of non-English language functionality.[33 44]

These disparities affect care partners as well. Care partners were less likely to use the portal if they were of Hispanic ethnicity and had an education level lower than a college degree.[34 36–38 44 45] Additionally, non-white patients and their care partners were also less likely to have and use the portal than white patients and their care partners.[33 36 38–41 46 47] Care partners of patients with paediatric cancer were more likely to use the portal if they had a child of younger age, spoke English, lived within closer proximity to the hospital and had a patient with more radiology tests.[38] Patients who have someone use the portal on their behalf, or portal delegates, were also more likely to be men, older and from non-white race.[34] Disparities do not vary based on the type of cancer, but rather by type of portal user.[48]

USE OF SPECIFIC PORTAL COMPONENTS AND FUNCTIONS IN CANCER CARE

There were 38 studies that provided insights into how patients with cancer and their care partners access specific portal components or functions to manage cancer care. Themes from these studies are summarised in table 2.

Secure messaging

Research shows that patients with cancer use portals in different ways than patients with non-cancer.[49] Secure messaging with their healthcare team has emerged as a key function of portal use and a primary way that patients with cancer give and receive information outside of the traditional clinical setting. These exchanges include communication about clinical information over the course of their treatment and information for logistical

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Table 1 Summary of portal adoption trends and disparities in use among patients with cancer

Theme	Description	Key points
Increased access to portals by patients with cancer	Characterising the uptake of portals and the changes in how patients are being offered the portal by clinicians	▲ Portal use continues to rise, with 13% more patients using the portal in 2020 from 2014 and another 46% more from 2020 to 2022[6 21 22] ▲ Portal functionality has expanded to support care partners[23–29]
Disparities in portal access for patients with cancer	Cataloguing the barriers to portal access for patients and care partners	▲ Disparities in portal use among patients with cancer reflect broader portal disparities, including non-white, male, uninsured, older, unmarried patients with cancer, have limited English proficiency, reside in rural areas and have lower broadband access are less likely to use the portal[30–43] ▲ Sociodemographic disparities exist in care partners as well, as Hispanic care partners and care partners with lower than a college education are less likely to use the portal[33 34 36–41 44–47]

coordination, both during their routine care and in palliative circumstances.[50 51] Other categories of use were information-seeking, emotional support and shared decision-making.[50 52] Care partners also used secure messaging, though sometimes without appropriately setting up accounts as portal delegates.[53]

Telehealth

There were 10 studies about telehealth for patients with cancer, in which 6 involved telehealth delivered through the portal,[37 41 54–57] 1 that was explicitly telehealth outside of the portal[58] and 3 without mention of how telehealth visits were conducted.[46 59 60] Telehealth to support cancer care delivery was in limited use before the pandemic, and uptake increased significantly in response to the COVID-19 pandemic and distancing guidelines.[57] Since patients with cancer often require many visits to manage their care, telehealth was introduced as an option to save patients time and money when their visits did not involve procedures.[61] During the COVID-19 pandemic, patients with cancer accepted telehealth delivered through the portal as an acceptable substitute for many visits that did not involve a physical examination or procedure.[59] In this way, telehealth can be helpful for patients who live farther from their medical oncologist. Telehealth for cancer care has only recently been delivered through the portal, with some of our studies tracking the course of implementation in their respective health systems.[37 41 54–56] While telehealth can serve as an alternative approach to receiving healthcare, it still carries issues around access to care that exist in traditional care settings. Patients who identify as men, non-white race/ethnicity, Spanish-speaking, uninsured or unmarried were less likely to use telehealth.[41] In this way, telehealth can continue to exacerbate disparities for patients with cancer, since underserved populations are less likely to use and benefit from telehealth.

Open notes

The 21st Century Cures Act mandated that patients have access to encounter notes written by their clinicians.[7] The practice of disclosing notes to patients was originally spearheaded beginning in 2010 by the OpenNotes initiative, based at Beth Israel Deaconess Medical Center in Boston, Massachusetts, USA. Patients with cancer reported emotional benefits, including increased feelings of trust, ownership and control, when they were able to read their notes.[51] Among patients with cancer, 98% reported that they wanted access to their oncology notes.[62] Clinician attitudes towards open notes are mixed. There is some concern among clinicians that open notes may increase documentation and may also cause patients with cancer to worry, particularly among individuals with lower health literacy.[63] However, the readability of notes is improving, as some clinicians are catering the way they write notes to their new audience.[64]

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Table 2 Summary of specific portal components and functions in cancer care

Theme	Description	Key points
Supporting cancer care with portal functionality; secure messaging and more	Highlighting the portal functions that patients with cancer are using to manage their care journey through their screening, cancer care, survivorship and end-of-life decision-making	▲ Patients with cancer use secure messaging in the portal to exchange information with clinicians, as well as to seek information, emotional support and shared decision-making[49–52] ▲ Care partners can also benefit from using portals for managing care via the secure messaging functionality[53]
Trends in recent telehealth adoption	Portal-hosted telehealth use has increased in patients with cancer through COVID-19, but disparities in use persist	▲ Telehealth, delivered through the portal, experienced a surge in adoption through the COVID-19 pandemic[57 59] ▲ Patients reported a similar level of satisfaction between care delivered in-person versus telehealth and acknowledge there are benefits such as eliminating the need to travel for care[61] Male, non-white, Spanish-speaking, uninsured and unmarried patients are less likely to use telehealth[41]
Patients with cancer and open notes	Identifying the effects of having visit notes available to patients in the portal	▲ Patients with cancer expressed benefits from reading the notes that their clinician writes for them after their visit[51 62] ▲ Through this practice of open notes, the notes for patients with cancer are becoming longer but they are also becoming more readable[64]
Test result and other health information access in the portal	Identifying recent changes from 21st Century Cures to immediate test result access and other information access for patients with cancer using the portal	▲ Patients with cancer review results as they become available, and many say that they enjoy doing so[65 66 73] ▲ Many patients report that they would not like to receive a cancer diagnosis through the portal[71 72] ▲ The majority of patients and clinicians alike believe that routine test results should continue to be released immediately through the portal[66 67] ▲ Most patients are interested in receiving results through the portal and feel that it benefits them[73–77] ▲ However, results may be difficult to interpret, and result interpretability is a space for improvement[27 81 82 84]

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Benefits and challenges to receiving test results via portal

With the 21st Century Cures Act, patients with cancer can now access results that are immediately available via the portal and have indicated in surveys that they like having the ability to do so.[65 66] Woolen *et al* found that preferences changed based on the length of follow-up time, such that some patients preferred receiving results through the portal if the alternative method is getting a phone call about them after a 6 or more day wait.[67] The proportion of patients who reviewed their test results prior to their clinician after Cures Act implementation increased by nearly 52% for highly sensitive results, such as anatomical pathology reports for cancer diagnoses, which were previously released after a delay (eg, a 14-day delay at one organisation).[68] In a survey of 8139 patients across four sites, 96% of patients indicated that they prefer to receive their results through the portal the moment they become available, irrespective of result abnormality.[66] Preferences do vary—some patients may prefer to discuss with their clinician before reviewing results; others may prefer to review results, process, research, then discuss with clinician. Still, some patients prefer face-to-face interaction and would prioritise these interactions rather than receiving results via portal.[31] At least one survey found that some patients were not interested in using the portal for viewing health data because of privacy concerns.[69] When interviewed, oncologists expressed mixed opinions around portal use for adolescents and their parents, asserting that while portals can empower patients and support communication, they can also impede on confidentiality for adolescent patients and induce undue worry.[70] This is an area for future research that has not yet been well studied.

Not all clinicians agreed that sensitive test results, such as those related to cancer diagnosis, should be released immediately to patients—citing it might upset patients to receive abnormal test results without counsel.[71] Some clinicians preferred to delay or withhold release of test results that are highly sensitive, and some patients agreed, saying that they would not want to be diagnosed with cancer through the portal.[71 72] However, studies have indicated that both clinicians and patients agree that routine test results, such as complete blood count tests and metabolic panels, should be released via the portal.[66 67]

Many patients with cancer were interested in receiving their test results through the portal.[73] In surveys, patients with cancer indicated that they are interested in having results delivered to them through the portal and are even seeking more data, such as genetic data and educational materials).[74 75] Patients also asserted that receiving their information digitally helps to improve their confidence with portal use.[76 77] Studies are yet to substantially differentiate which results patients would prefer receiving via the portal, and if patients have differing preferences between new and existing disease management.

Despite the perceived usefulness of receiving results through the portal, there are some concerns, from both clinicians and patients, that results received through the portal without counsel can be misinterpreted. Some patients found radiology reports specifically confusing,[78] and some care partners of patients with paediatric cancer said that results were easy to misinterpret.[27] Although portals have evolved in their design, there remains opportunity for improvement and patients cited some challenges in use.[79 80] Research focused on improving result interpretability have proposed solutions including expanding patient education, increasing oncologist involvement in the portal to make them more available to answer questions and shifting billing incentives to pay oncologists for their time answering questions from patients.[81 82]

ASSOCIATIONS BETWEEN PORTAL USE AND CANCER-RELATED OUTCOMES

This section encompasses research from 22 studies that describe associations between portal use and outcomes in cancer care (themes are summarised in table 3).

Associations with cancer screening

In intervention studies, portal-based secure messaging reminders to screening-eligible patient populations were associated with a 45% increase in appropriate screening for cervical cancer.[83] Results for similar messaging interventions for colorectal cancer screening were mixed, with Hahn *et al*, Goshgarian *et al* and Vachon *et al* finding increases of 8%, 32% and 24%, while Elston Lafata *et al* finding no significant effect.[84–87]

In observational studies, overall use of the portal was positively associated with the likelihood of cancer screening. Patients at risk for breast cancer increased mammogram screening rates when they are provided with self-scheduling features through the portal versus patients who schedule through staff members using the phone.[88] Similarly, as patients used the portal more, registered more interactions within the portal and used various functions, their odds of getting screened for cancer increases.[89 90]

Associations with patient perceptions, preferences and health behaviours

Patients with higher portal utilisation also reported better experiences when making medical decisions.[91] They reported feeling that they have better access to high-quality information.[92] Using the portal was also associated with patients with cancer feeling more in agreement with their care plans.[93]

Associations with treatment adherence

One study found that patients with cancer who sent messages asking for professional opinions, giving thanks, and seeking medications to treat side effects were more likely to adhere to their treatment.[94] Conversely, patients who increased their rate of messaging, discussed medication side effects without asking for treatment for them and brought up topics related to surgery were more likely to discontinue treatment.[94]

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Table 3 Summary of associations between portal use and cancer-related outcomes

Theme	Description	Key points
Health-related and treatment-related outcomes associated with cancer screening	The portal can serve as a useful mechanism for driving cancer screening	▲ Portal-delivered reminders for cancer screening increased uptake[83–87] ▲ Portal use was associated with an increased likelihood of cancer screening[88–90]
Health-related and treatment-related outcomes associated with patient perception and patient reported outcomes	Use of the portal may help patients feel more connected to the delivery of their care	▲ Portal use improved how patients felt about making medical decisions, having access to quality medical information, and their self-efficacy[91 92] ▲ Portal use increased patient concordance with care plan[93]
Health-related and treatment-related outcomes associated with adherence to treatment	The portal serves as a place for patients to express themselves in ways that capture their potential for treatment adherence	▲ Portal use and content of secure messages were associated with likelihood of continuation or discontinuation of treatment[94]
Health-related and treatment-related outcomes associated with healthcare utilisation	Use of the portal is connected with use of the healthcare system	▲ Portal use decreased health system utilisation[95]
Health-related and treatment-related outcomes associated with healthcare outcomes	Health outcomes may be downstream of patient activity in the portal	▲ Portal use may be associated with increased survivorship[96]
Health-related and treatment-related outcomes associated with portal use	Portal use can yield healthcare delivery and process-related outcomes in patients with cancer	▲ Portal use benefitted patients with cancer by increasing their adeptness with navigating the healthcare system and advocating for their care[97–102]

Associations with healthcare utilisation

A small pilot programme at a health system that prioritises portal use and technology integration indicated that patients who used the portal are more likely to have decreased acute care usage, such as emergency department visits, compared with patients who do not use the portal.[95]

Associations with health outcomes

We collected only one study that provided an association between health outcomes and portal use. In this study, with a propensity score-matched cohort and large sample size, patients who initiated messages through the portal were observed to have increased survival while receiving chemotherapy.[96]

Associations with portal use

Though interventions delivered through the portal may or may not affect a desired health outcome, some portal-based interventions have led to increasing portal use. In breast cancer care, even the possibility of offering an intervention through the portal encouraged patients to register accounts and log in more frequently.[97–99] Additionally, patients with lung and breast cancer were observed to have more interactions with clinicians in the portal when following a portal-based intervention.[99–102]

DISCUSSION

This review of the state of the art of the empirical literature surfaced themes and findings that point to the ongoing development of portals as a part of the digital cancer experience for patients in the USA. We found literature supporting themes around (1) the trends of portal adoption and use for patients with cancer, (2) portal functionality used by patients with cancer and (3) any associations between portal use and health outcomes or healthcare utilisation.

Research in patient portal adoption and use among patients with cancer highlighted both the uptake of portals and the road ahead in adoption. Approximately 57% of American patients reported using patient portals in 2022, and an estimated 40.5% of adults will be diagnosed with cancer in their lifetime.[9 21] Patients with cancer use the portal differently from patients with non-cancer in the specific ways that they review their radiology results, use notes to manage their treatment, message clinicians about treatment-related side effects and inquire about new research and clinical trials.[10 11] As portal capability increases, future research could address integration with clinical trials and introduce mechanisms for trial monitoring and enrolment. However, adoption trends also show socioeconomic disparities that can negatively impact access to care for marginalised groups, both with and without cancer.[15–18 30–47] It should be further noted that intersecting disparities may cause some subgroups to experience compounded inequities in portal access and use. Overall, there is relatively little interventional

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research on how to reduce disparities in portal use. A 2019 review of 18 studies found that approaches based on behavioural economics and investment into usability showed promise.[103] Research on best practices to reduce disparities in portal access and usage is an important direction for future work.

Examining the specific portal functions that patients with cancer use highlights how messaging, telehealth and immediate access to test results and clinic notes have expanded the role of portals in oncology-specific contexts. Patient preferences are important. Researchers have been historically slow to explore how patients prefer to receive information in the portal. Additionally, recent trends in telemedicine and test result release policies are providing new avenues for patients with cancer to interact with the portal in ways that are of interest to portal researchers. These new behaviours, such as an uptick in patient messaging, may have consequences for clinicians as they take on the burden of addressing patient concerns and information needs asynchronously.[104] Healthcare systems now expect clinicians to spend additional time corresponding with patients and managing information, for which they are not explicitly reimbursed. Despite growing reliance on portals to support patients with cancer, portal use associations with health outcomes have mixed results.[83–102] There is a clear need for more research in how portals relate to health outcomes. Future investigations may determine how patients and care partners can best use the portal to improve health outcomes.

There is a growing expectation among patients for seamless online access to their health information—and this is especially true for people facing cancer. This expectation mirrors the transformation seen in online banking, which has fundamentally altered the accessibility and management of secure financial accounts. Beyond cancer, patients are becoming more accustomed to accessing their health information during various stages of care, such as young adulthood and routine health screenings. Consequently, when a patient in the USA receives a cancer diagnosis—whether through a test result or during a primary or specialty care visit—they will anticipate immediate and easy access to their health information. This shift towards digital access to health data may become as ingrained in US healthcare culture as it is in some European countries.[8]

The complexity of cancer is escalating,[105] not only for haematologists and oncologists but also for patient communities. With the advancement of precision medicine, newly diagnosed patients might quickly learn a new lexicon, including staging, grading and the array of biomarkers that distinguish their specific cancer from others in the same anatomical location. Online patient support groups, often facilitated through social media platforms, are increasingly sophisticated and self-correcting, with longer-term survivors identifying themselves not by the location of their cancer (eg, lung) but by their specific biomarkers (eg, ROS1+).[106] Evidence-based patient-facing information could be integrated into patient portals. Until such time, patients are not waiting for academics to bridge these knowledge gaps; they are frequently crowdsourcing answers to their questions.[107 108] While patients may benefit from this timely information seeking, there could also be disadvantages to reviewing some information without counsel from a clinician, such as reports that are medically complicated or easily misinterpreted. Additionally, while seeking additional details about their health information, some patients may encounter medically incorrect or explicit misinformation.

A significant portion of the US population does not reside within the catchment area of a National Cancer Institute-designated comprehensive cancer centre.[109] As a result, telehealth access is crucial for patients seeking second opinions or managing the frequent visits required during active treatment. While many studies focus on portal functions for individuals actively managing their care, survivorship, and screening, it is essential to recognise that not all patients with cancer transition to a stage of survivorship. According to the American Cancer Society, over 600 000 cancer deaths occurred in the USA in 2023.[110] There is a critical need to better understand the portal needs of patients and families in the final 6 months of life, when family care partners may become the primary portal user.[111 112] These care partners may act as official portal delegates, although most are not formally documented in this role through the EHR.[13 14 113] During this period, as patients and care partners choose to cease active cancer treatment and transition to hospice care, their use of portal features to communicate with the oncology team may abruptly cease. Developing accommodating portal functionality to address this shift in care is vital to improving the end-of-life experience for people with cancer.

Findings from this review may not generalise outside of the USA. In the USA, a series of health information laws have shaped the creation and use of portals for patients. In 1996, the Health Insurance Portability and Accountability Act stated that patients must be able to access their health information and control how it was used for anything beyond clinical care and billing.[114] In 2009, the Health Information Technology for Economic and Clinical Health Act (HITECH Act) incentivised adoption of EHRs,[4] resulting in near-universal adoption over the subsequent decade[115]; HITECH Act implementation included requirements to ensure timely patient access to their electronic health information. Finally, the 21st Century Cures Act of 2016 defined and prohibited 'information blocking', meaning that healthcare organisations were no longer permitted to delay patients' ability to access their information or withhold selected information from the portal.[7] Since the 'information blocking' provision took effect in 2021, it has resulted in faster patient access to testing results and other health information in most states, often before their clinicians have reviewed or interpreted it for them.[65] Notably, California and Kentucky block the immediate release of cancer-related test results.[116]

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The American health information laws were passed in the context of a largely private and highly fragmented healthcare system, with a wide array of for-profit and not-for-profit healthcare organisations, and multiple private and public payers with different policies about which clinicians and healthcare services a patient can access. In addition, a persistent percentage of uninsured individuals (currently around 12.2% of people aged 18–64[117]) have much more limited access to healthcare. In addition, American health information laws have permitted many different private vendors to create certified EHR products, generally accompanied by portals. Many patients have multiple portal accounts—each providing access to information from one healthcare organisation—however it is impossible to quantify the number of unique accounts across the country. The lack of a single solution for health information system interoperability means that patients are often responsible for transferring their own medical information between clinicians and clinical teams. This is not necessarily the case outside of the USA, as patient accessible EHRs are implemented differently in other countries. Countries such as France and Finland, with nationalised health systems, were able to set up distinct logins for each patient.[118] These system-level differences in how patients manage their health data may have the potential to greatly impact the extent to which patients use these systems.

Limitations

This review was not systematic in nature and instead focuses on key expert-derived topics about cancer portal use in the USA. We excluded existing reviews and focused on studies that were published since 2018 to ensure relevance about recent policy and practice changes that influenced portal use. The studies in this review are not standardised by type of study or compared across institutions. This means that the conclusions drawn from each study are mostly specific to an institution and hard to compare from one study to another, as this is a state-of-the-art review instead of a standardised review. Of these studies, just 23 focused on cancer type; there may be different experiences for people with rare diseases not captured in these data. In addition, those with cancers affecting cognitive capacities (eg, metastatic cancers, malignant brain tumours) may use portals differently from those without cognitive challenges. Of these studies, 67 were observational and 15 were experimental. This imbalance highlights the lack of interventional research in this space. Additionally, it is not always clear whether the portal is offered in non-English languages, making it difficult to compare portals between sites. We are limited in our ability to draw causal conclusions from these observational studies.

CONCLUSION

The portal continues to grow as a tool for patients with cancer and their care partners. Adoption continues to tick upwards, especially in the wake of the COVID-19 pandemic, and patients report satisfaction with the functionality that has been built out in portal systems thus far. Our review surfaced several important priorities for future research. The linkage between portal use and health outcomes still needs to be studied to determine if portal users enjoy some operational benefits around healthcare system navigation, as well as to make a more direct connection between portal use and cancer outcomes. The future of patients with cancer portal use will ideally build on portal functionality that is codesigned in partnership with patients and care partners (the end users of these tools), including telehealth, secure messaging and immediate result review capabilities. Future research should also develop strategies that advance portal use among marginalised groups, identify best practices for incorporating nuanced patient preference towards receiving clinical information through the portal, and study how telehealth and messaging portal functionality must develop to better engage care partners. Patient portals have played a critical role in helping patients to manage and engage in their cancer care, but it is important that portals continue to develop and support evolving patient needs.

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