

Evaluating Implementation Challenges and Features of Virtual Communities in Cancer Care: A NASSS Framework Systematic Review

Jiapei Dong, Yi He, Lili Tang

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Evaluating Implementation Challenges and Features of Virtual Communities in Cancer Care: A NASSS Framework Systematic Review

Jiapei Dong^{1*}; Yi He^{1*}; Lili Tang¹

¹ Peking University Cancer Hospital Beijing CN

*these authors contributed equally

Corresponding Author:

Lili Tang

Peking University Cancer Hospital

No. 52 Fucheng Road, Haidian District, Beijing, 100142, China

Beijing

CN

Abstract

Background: Cancer survivors often face significant psychological challenges, including depression, anxiety, and social isolation, exacerbated by treatment side effects. Traditional psychosocial support systems are usually inaccessible, underfunded, or not tailored to the needs of underserved populations, limiting their effectiveness. Virtual communities have emerged as an alternative, providing emotional support and opportunities for information exchange. However, the implementation and sustainability of these platforms are constrained by technological, organizational, and policy-related barriers.

Objective: This systematic review applies the NASSS (Non-adoption, Abandonment, Scale-up, Spread, and Sustainability) framework to evaluate the characteristics, implementation challenges, and sustainability of virtual communities in cancer care.

Methods: A comprehensive search of six major electronic databases identified 25 relevant studies, published between 2019 and 2024, that met predefined inclusion criteria. Data extraction focused on how virtual community features match the needs of cancer patients and their impact on mental health and quality of life.

Results: Key factors contributing to the success of virtual communities include platform design, user engagement, organizational support, and adaptability to evolving patient needs. While virtual communities provide emotional support, reduce loneliness, and facilitate information sharing, challenges such as privacy concerns, limited scalability, and integration with healthcare systems remain.

Conclusions: Virtual communities offer significant potential for supporting cancer patients, particularly in improving psychological well-being and facilitating access to information. However, challenges regarding technology, privacy, and system integration must be addressed to ensure their long-term success. Future research should focus on adapting these platforms to meet the evolving needs of patients throughout various cancer stages (e.g., diagnosis, treatment, remission) and integrating them into existing healthcare frameworks to enhance effectiveness. Clinical Trial: PROSPERO CRD42025638853; https://www.crd.york.ac.uk/prospERO/display_record.php?RecordID=638853

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Author information: Jiapei Dong^{1,2#}, Yi He^{2#}, Lili Tang^{1,2*}

¹ Inner Mongolia Medical University, Hohhot, China

² Department of Psycho-Oncology, Peking University Cancer Hospital Beijing, China

* Corresponding author:

Dr. Lili Tang, Department of Psycho-Oncology, Peking University Cancer Hospital & Institute. Fu-Cheng Road 52, Hai-Dian District, Beijing 100142, China. Tel:8610-88196648; Fax: 8610-88196648.

E-mail: tanglili_cpos@126.com.

ORCID ID: <https://orcid.org/0000-0003-1524-4617>.

Jiapei Dong and Yi He have equal contributions as co-first authors

All authors' E-mail addresses:

Lili Tang: tanglili_cpos@126.com

Yi He: heyi0962@sina.com

Jiapei Dong: djp0572@gmail.com

ABSTRACT

Background: Cancer survivors often face significant psychological challenges, including depression, anxiety, and social isolation, exacerbated by treatment side effects. Traditional psychosocial support systems are usually inaccessible, underfunded, or not tailored to the needs of underserved populations, limiting their effectiveness. Virtual communities have emerged as an alternative, providing emotional support and opportunities for information exchange. However, the implementation and sustainability of these platforms are constrained by technological, organizational, and policy-related barriers.

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Keywords: Cancer care, virtual community, psychosocial support, NASSS framework, implementation challenges, patient outcomes



INTRODUCTION

Advancements in medical technology, early diagnostic practices, and innovative treatment modalities have significantly improved cancer survival rates [1]. However, long-term cancer survivors often face a heightened risk of mental health issues, including depression and anxiety, with incidence rates up to four times higher than those in the general population [2]. Additionally, the toxic side effects of anticancer drugs, such as pain, fatigue, and nausea, frequently lead to profound psychological, social, and spiritual distress [3, 4]. These challenges undermine patients' social adaptability and self-efficacy, exacerbating psychological and social isolation [5, 6]. This cycle severely diminishes the quality of life, with emotional distress correlated to increased mortality rates [7].

Despite this critical need, existing mental health support systems remain inadequate, with only 10% of cancer patients receiving the formal psychosocial support they require [8]. Resource limitations, unequal distribution, and access barriers disproportionately affect vulnerable populations, such as those with lower education levels, financial constraints, or inadequate social support networks [9-11]. These disparities highlight an urgent need for innovative solutions to address the psychological and social needs of cancer patients, particularly among underserved groups.

The rapid evolution of digital technologies has positioned virtual communities as valuable platforms for cancer patients seeking psychosocial support. These online networks transcend geographical and temporal barriers, enabling individuals to exchange information, share experiences, and offer emotional support [12]. Virtual communities empower patients, foster psychological resilience, and alleviate feelings of loneliness [13, 14], providing a flexible and accessible alternative to traditional support systems. Anonymity further encourages open expression, allowing patients to share sensitive experiences and seek guidance in a safe environment [12].

Despite their potential, virtual communities face substantial challenges in implementation and sustainability [15]. Key barriers include insufficient organizational resources, limited system

interoperability, and gaps in policy frameworks and privacy protections, all of which undermine patient trust and participation [16-19]. Moreover, existing digital health frameworks often use linear evaluation models, which fail to capture the dynamic complexities of virtual communities, including technological evolution, user behavior patterns, and multi-stakeholder collaboration [20, 21]. These limitations call for a more comprehensive framework to guide the design, implementation, and optimization of virtual communities in cancer care.

The NASSS (Non-adoption, Abandonment, Scale-up, Spread, and Sustainability) framework provides a structured methodology to analyze the adoption and implementation of digital health technologies [22]. By addressing key dimensions such as condition characteristics, technology design, value proposition, user attributes, organizational capacity, external context, and dynamic interactions, the NASSS framework enables a holistic evaluation of the opportunities and challenges associated with virtual communities in cancer care [22].

This study is the first to apply the NASSS framework to virtual communities, adapting it to address the specific challenges of these platforms. Focusing on “feature alignment”, this research evaluates whether the characteristics of virtual communities meet the needs of cancer patients and improve access to support and treatment adherence. From an implementation science perspective, the study emphasizes the importance of considering factors such as stakeholder involvement, organizational capacity, and system compatibility in ensuring the successful adoption and sustainability of these digital platforms [23]. By doing so, it provides practical strategies to optimize virtual communities, ensuring they are both effective and sustainable in enhancing patient outcomes and quality of life.

METHOD

This study was conducted in accordance with PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) 2020 guidelines to ensure transparency and precision in the review process [24]. The PRISMA checklist is presented in Multimedia Appendix 1. This systematic

review was prospectively registered in PROSPERO (CRD42025638853), although the protocol was not uploaded.

Search Strategy

A comprehensive search was performed across six major electronic databases: PubMed, EMBASE, SCOPUS, Web of Science (Core Collection), EBSCOhost, and PsycINFO. The search strategy used Boolean logic and Medical Subject Headings (MeSH), with details provided in Multimedia Appendix 2. The search keywords are listed in Table 1.

Table 1. Search Keywords.

• Virtual Community: “virtual community”, “online community” • Cancer Patients: “cancer”, “carcinoma”, “neoplasms”, “cancer survivors”, “oncology patient” • Psychosocial Support: “psychology”, “psychosomatic”, “emotional support”, “mental health”, “quality of life”

The search was restricted to articles published in English within the last five years (2019–2024) and focused on original research. Articles retrieved were imported into *EndNote X9* software, and duplicates were automatically and manually removed. We have developed the following criteria to determine research eligibility in Table 2.

Table 2. Eligibility Criteria.

Criteria Type	
Inclusion Criteria	Exclusion Criteria
• Participants: Cancer patients at any stage (e.g., undergoing treatment, recovery, or survivors) • Interventions: Virtual community platforms (e.g., social media, online support groups, mobile apps) addressing information, skills, social support, or participation • Study designs: Randomized controlled trials (RCTs), quasi-experimental studies, cohort studies, case-control studies, qualitative studies, mixed-methods	• Studies not involving cancer patients • Interventions limited to telephone or text-based communication methods • Reviews, editorials, or opinion pieces without empirical data • Studies with methodological limitations (e.g., small sample size, no control group) • Studies published before 2019 or in languages other than English

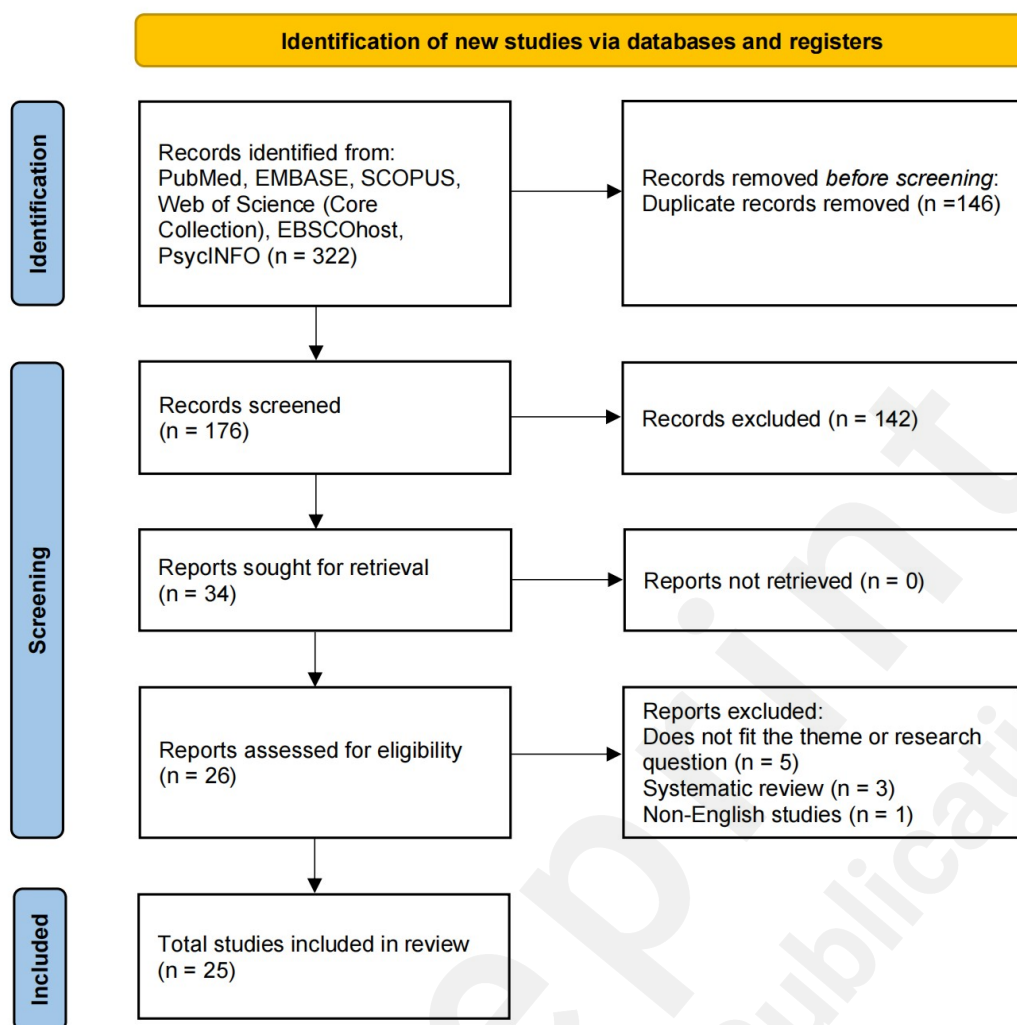
studies

- Data: Quantitative, qualitative, or mixed, including statistical or patient experience data
 - Outcomes: Impact of virtual community on mental health (e.g., depression, anxiety) or quality of life
-

Study Screening and Selection Process

A total of 322 records were retrieved from the database searches. After removing 146 duplicate articles, 176 unique studies remained. Titles and abstracts were screened independently by two reviewers to exclude irrelevant articles. Of these, 34 studies met the inclusion criteria and were selected for full-text review. Following detailed evaluation, 9 additional studies were excluded due to methodological flaws or lack of relevant outcomes, resulting in 25 studies being included in the final review. The article selection process and reasons for exclusion are summarized in the PRISMA flow diagram as Figure 1 shows.

Figure 1. PRISMA flow diagram.



Data Extraction

This study utilized the NASSS framework to guide data extraction and analysis [22]. The focus shifted from broad complexity assessments to analyzing “feature alignment”, which explores how well the core attributes of virtual communities align with their intended objectives and users’ needs. We analyzed the following key dimensions in Table 3.

Table 3. Key Dimensions.

Dimension type	Details
Technological Features	Assessed the compatibility of technological design, including user interface friendliness, operational simplicity, and the ability of functional modules to address cancer patients’ needs for emotional support and psychological counseling

User Experience	Evaluated the alignment of virtual communities with the psychological states, social preferences, and usage habits of cancer patients, emphasizing factors influencing patient satisfaction and long-term engagement
Organizational Support	Examined resource allocation and management capabilities, focusing on content quality assurance, user privacy protection, and the sustainability of resource investment
Implementation and Scalability	Investigated the scalability and long-term applicability of virtual communities, analyzing the optimization of content modules, user support mechanisms, and sustainable development pathways

Process and Tools

A total of 25 studies were analyzed using a standardized data extraction process. A predefined form was used to ensure consistency, capturing key elements such as NASSS subdomains, implementation outcomes, and critical issues (see Multimedia Appendix 3). The data extraction methodology was referenced from Melissa M et al. 2022 with necessary adjustments [25]. Data extraction was performed manually using Excel for organization, with necessary transcription or translation to preserve clarity (see Multimedia Appendix 4), and was completed independently by JPD and confirmed by YH.

To capture the diversity of interventions and technological applications, additional data were extracted based on the Digital Health Intervention Taxonomy [26], including the sequence of content delivery and potential benefits of peer interactions.

The methodological validity of each study was assessed using the Mixed Methods Appraisal Tool (MMAT) [27], evaluating participant selection, study design, data collection, analysis, and interpretation. Studies with significant flaws were excluded, ensuring reliable and high-quality evidence for the review.

RESULTS

Research Distribution and Trends

This review includes 25 articles published between 2019 and 2024, from nine countries (see Figure 2 for publication year distribution). Sixteen percent of these involved international collaborations, all of which included the United States. Research activity peaked in 2020, with seven studies published that year, likely driven by the COVID-19 pandemic, which led to increased interest in virtual communities for healthcare delivery. A total of five studies specifically addressed the impact of COVID-19 [28-32]. Geographically, North America accounted for the majority of studies (n=14), followed by Europe (n=6), Australia (n=5), and Asia (n=2), with detailed regional distributions visualized in Figure 3. This concentration highlights the technological and funding disparities between regions.

Research Design and Methods

Qualitative studies dominate the field, comprising 52% (13/25) of the studies, followed by mixed-methods (20%) and quantitative studies (16%). Thematic analysis is the most common approach (14 instances), often combined with semi-structured or qualitative interviews (7 and 3 instances, respectively). Quantitative studies primarily use surveys (6 instances), particularly in psychological research, with tools like the Hospital Anxiety and Depression Scale (HADS) to assess mental states. Emerging methodologies, such as open coding, content analysis, netnography, and text mining, reflect a growing integration of technology-driven approaches with traditional qualitative methods, highlighting a focus on user experiences in the digital context of virtual communities.

Data Sources and Research Diversity

The studies use diverse data sources, mostly from publicly available social media and online forums. Some employed existing virtual community platforms for surveys or interviews, while a few created independent communities for research or interventions. This methodological diversity—ranging from secondary data analysis to direct interventions—highlights the flexibility of virtual community research and its adaptability to different contexts and patient needs.

Risk of bias assessment

The MMAT assessment indicated a moderate to high risk of bias in qualitative studies, mainly due to sample selection, reporting, and information biases (see Multimedia Appendix 5). These studies often rely on self-reported data from voluntary online communities, which may exclude inactive participants and introduce bias. Quantitative studies generally met MMAT standards but were subject to similar biases, limiting their generalizability. Despite these limitations, valuable insights into cancer patients' emotional support and self-management were gained.

Figure 2. Publication year included in the study.

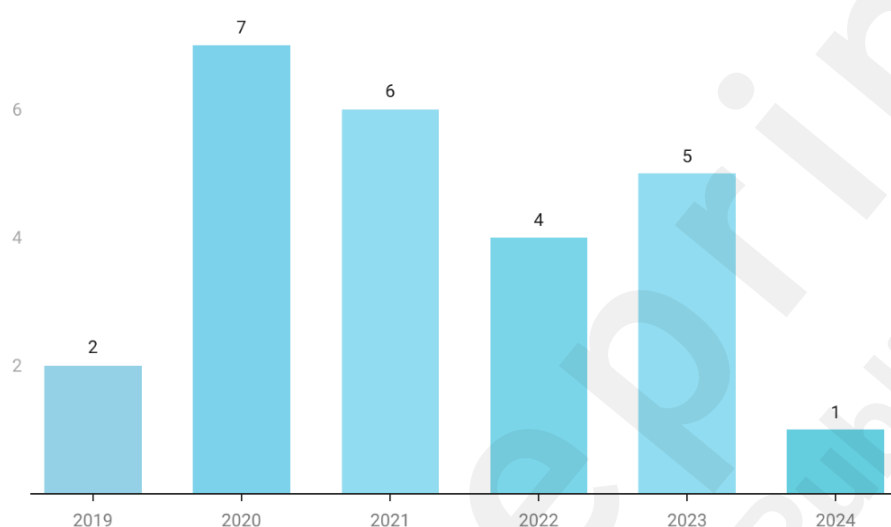
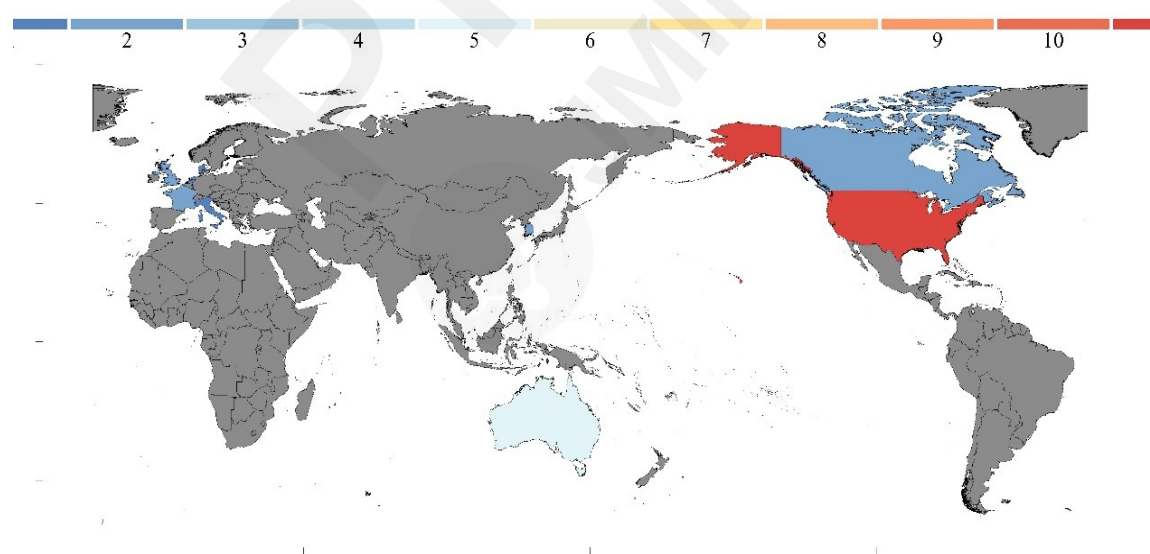


Figure 3. Source countries included in the study.



Domain 1: Condition

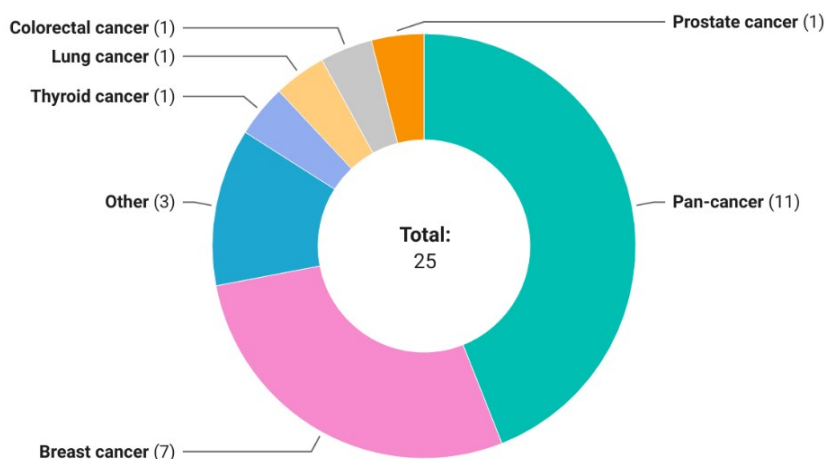
Breast cancer is the most commonly studied cancer type, reflecting its significance in research [28, 33-38]. Pan-cancer studies, which cover various cancer types, are also prevalent [29, 32, 39-46]. Nevertheless, several clinically significant cancer types—including brain, lung, soft tissue sarcomas, acute myeloid leukemia, thyroid, and colorectal cancers—remain comparatively understudied in current research paradigms [31, 47-51], as evidenced by the research gap analysis presented in Figure 4. Research on specific populations, including disabled survivors [33] and adolescent and young adult (AYA) cancer patients [29], is emerging.

Studies cover all stages of cancer, from early diagnosis to advanced treatment. Breast cancer research addresses stages 0-III and advanced disease [28, 38], while lung cancer research primarily focuses on stage IV [31]. Thyroid cancer studies often involve preoperative patients with comorbid anxiety and depression [50], and young colorectal cancer studies typically examine patients in later stages after treatment [51]. Some studies focus on recurrence or postoperative management [32, 35].

Most research focuses on patients aged 30-49 years [28, 30, 33, 35, 36, 50], while limited attention is given to older patients. Survival analyses are limited, mainly focusing on long-term survivors in postoperative or recurrence stages [35]. Although studies mention comorbidities like anxiety and depression, particularly in thyroid cancer patients [50], the analysis of psychological comorbidities remains limited.

Female participation in virtual communities is significantly higher than male participation, especially in breast cancer communities, where female involvement ranges from 66.7% to 82% [28, 34-37, 44]. Male participation is lower, possibly due to cultural and societal gender roles [35]. Participants are typically highly educated, middle-income urban residents, with lower participation from rural or remote patients [29, 36, 50].

Figure 4. Cancer type included in the study.



Domain 2: Technology

Current Applications of Technology in Virtual Communities

Virtual communities offer diverse engagement for cancer patients and their support networks through forums, Q&A boards, interactive panels, and social media platforms. Forums facilitate in-depth discussions for treatment experiences and psychological support [38, 46, 47]. Q&A boards address specific issues quickly, providing precise information [37, 50]. Interactive panels enable real-time interaction and immediate responses [28, 32]. Social media platforms like *Facebook*, *Twitter*, and *Reddit* offer closed groups [31, 51], public interactions [42, 48], and hybrid models [34, 44], enhancing communication dynamics. Custom apps with private messaging and personalization features ensure privacy while improving user experience [32, 43].

Many virtual communities utilize public social media platforms, leveraging their frameworks and user bases for easy access [38, 42-44]. These platforms combine closed groups for privacy with public interactions for support and information exchange. Hybrid models integrate resources, reducing costs and enhancing engagement. Familiar smartphone interfaces and cross-platform access improve adaptability [28, 32, 47, 49].

Technological integration across platforms creates a comprehensive support experience. Thematic posts in forums can generate valuable responses in Q&A boards, and real-time discussions in interactive panels can be archived for long-term knowledge [34, 43]. This synergistic model

ensures immediate support and lasting value for cancer patients and their support networks.

Technological Features

Virtual community platforms are characterized by user-friendly interfaces, diverse functionality, and cross-platform compatibility. These aspects apply to both customized applications (e.g., *WeCanManage*, *WalkON*, *Kræftværket*) and broader health communities (e.g., *Mayo Clinic Connect*, *breastcancer.org*, *Kanker.nl*) [38, 46].

1. User-Friendly Interfaces

Intuitive and simple interfaces enhance user experience, particularly for patients with limited technical skills. Platforms like *Kanker.nl* and *breastcancer.org* are well-designed for ease of use [38, 46], while others, such as *Cancer Survivor Network (CSN)* and *Cancer Council Online Community (CCOC)*, have less optimized designs, make navigation difficult for older users [34, 41]. *Mayo Clinic Connect* exemplifies an excellent interface design for community engagement [36].

2. Diverse Functionality

Platforms must balance feature richness with simplicity to meet diverse user needs. For example, *Thyroid Family* [50] and *Les Impatientes* [37] offer disease-specific forums, while *Kanker.nl* combines peer support, emotional assistance, and information sharing [46]. Proper integration of these features is crucial to avoid operational challenges.

3. Cross-Platform Compatibility

Cross-platform compatibility ensures consistent user experience across devices. *Mayo Clinic Connect* and *Kanker.nl* achieve this with optimized web interfaces [36, 46], while platforms like *CCOC* are web-only, limiting flexibility [45]. Social media platforms such as *Facebook* and *Reddit* enhance accessibility by facilitating seamless device transitions.

Anonymization Design

Anonymization mechanisms are essential in virtual communities, ensuring privacy and

encouraging open self-expression, while influencing user engagement and community dynamics.

On social media platforms, anonymity offers significant benefits for cancer patients. *Reddit*, with its pseudonymity model, allows users to discuss sensitive topics freely, fostering open dialogue [40, 44, 48]. Platforms like *Twitter* and *Instagram* use hashtags and visual content to build supportive community for health stories and social support, attracting a diverse group of participants [42, 49]. *Facebook* private groups, such as *COLONTOWN®*, balance privacy and trust by allowing pseudonymous accounts while maintaining credibility through real-name systems [31, 51].

For customized applications, platforms like *WalkON* and *Kræftværket* offer support but differ in anonymization. *WalkON* encourages user interaction through step-sharing and leaderboards without anonymization [28], while *Kræftværket* permits anonymity, though this may limit deeper connections [29]. *iaya* strikes a balance, offering users the option between anonymity and real-name usage, which helps maintain both privacy and trust [32].

Some platforms prioritize anonymization to create safe spaces for sensitive discussions. *CCOC* uses anonymization to provide emotional support, combining open forums and private groups for a balance of broad participation and privacy [39, 45, 52]. *Thyroid Family* and *Les Impatientes* also emphasize anonymity, enabling users to share personal experiences openly [37, 50].

While anonymization protects privacy and facilitates emotional support, it can weaken community bonds and reduce the depth of interactions [29, 37, 43]. Platforms address these issues with different approaches, such as full anonymity, pseudonymity, and hybrid models. *Reddit* fosters open discussion with pseudonymity [44, 48], while *Facebook* uses real-name systems for enhanced trust [51], and *iaya* offers flexibility for users to choose their level of anonymity [32].

Intervention Design

Customized applications like *WalkON* and *Kræftværket* offer tailored interventions, including health monitoring, educational modules, and automated data collection [28, 29]. In contrast, social media platforms and online forums lack specialized intervention modules and depend on user

participation for efficacy.

Personalized design and data collection methods still require improvement. Many studies rely on outdated tools, like paper questionnaires, instead of leveraging mobile apps with real-time data collection features [28, 29]. Behavioral analytics platforms could enhance data tracking while maintaining privacy [32].

Privacy and Data Management

Platforms like *Kræftværket* in Denmark adhere to national cybersecurity regulations, including the General Data Protection Regulation (GDPR), to ensure user privacy [29]. Similarly, *iaya* in the U.S. emphasizes data security with encrypted transmission and storage, complying with the Health Insurance Portability and Accountability Act (HIPAA) [32].

Domain 3: Value Proposition

Virtual communities are crucial for the psychosocial rehabilitation of cancer patients, addressing unmet needs in informational support, emotional comfort, psychological empowerment, and social interaction. Online platforms like *Mayo Clinic Connect*, *CSN*, and *Reddit* provide structured information, emotional support, and peer reassurance, reducing loneliness and anxiety, particularly during diagnosis and treatment. These platforms help enhance self-management, psychological resilience, and confidence in disease management [34-38]. For AYAs, *Kræftværket* reduces isolation and promotes resilience [29, 32], offering targeted support for marginalized groups like women facing reproductive challenges [44].

Tailored approaches address the specific needs of different cancer types. For example, prostate cancer survivors share management advice [30], soft tissue sarcoma patients benefit from medical and personal insights [47], and lung cancer patients receive personalized guidance in closed groups [31]. Brain cancer patients value privacy and prefer anonymous platforms [48]. Mobile apps like *WeCanManage* integrate mindfulness exercises with community interaction, improving symptom management and quality of life [33].

On the supply side, virtual communities help reduce healthcare costs through simple designs, volunteer-based operations, and mobile apps, all of which improve peer support and management efficiency [28]. Many platforms operate on low-cost, scalable models, making them more accessible [37, 51]. These communities enhance emotional care, disease management, and patient involvement in medical decisions, promoting better provider-patient interactions [31, 36, 43]. They also facilitate efficient data collection through surveys, health monitoring tools, and personalized support, improving patient care and healthcare system efficiency [40, 50].

Domain 4: Adopters

Patient Needs and Expectations

Patients in virtual communities take on diverse roles, such as newcomers seeking information, altruists offering emotional support, and autonomous users answering others' inquiries [45, 51]. Tailoring community features to these roles can enhance engagement. Patients' needs evolve as their illness progresses; early-stage patients prioritize authoritative information, while advanced-stage patients need psychological support to manage disease progression and existential anxiety [44, 50]. Rare disease patients often require more specialized services due to isolation [43].

Gender influences participation, with women more likely to seek emotional support online, while men often rely on offline networks [29]. Male patients, particularly those with prostate cancer, may feel embarrassed about certain side effects, highlighting the need for privacy-focused support [30]. Age also affects virtual communities usage, with younger, tech-savvy patients preferring platforms like *WhatsApp* and *Instagram*, while older patients prefer simpler, healthcare provider-endorsed resources [36, 43].

Some patients disengage due to unmet deeper needs or a desire to avoid focusing on their "sick role" [41, 45]. Younger patients prefer interactive platforms like *Instagram*, while older patients lean toward more information-focused platforms like *Facebook* [36, 49].

User Experience and Satisfaction

Interface design is crucial for user satisfaction and engagement. Patients prefer clean layouts and intuitive navigation that facilitate quick access to information [32]. Features such as small fonts, unclear icons, and overly complex hierarchical structures can reduce usability [33, 52]. Improvements such as larger fonts, simplified layouts, and better navigation can significantly enhance user experience [33]. Younger users, particularly adolescents, prefer interactive designs that foster a sense of belonging and community integration [29].

Functionality is central to the patient experience. Older patients and those in remote areas may face barriers due to limited digital literacy or lack of device access. Features like community filters and resource searches can exacerbate these challenges [30, 52]. Simplifying functionality, adding help options, and refining navigation can improve usability, though mobile optimization remains a key area for improvement [52].

Personalized support is essential for user satisfaction. Patients value connecting with peers who share similar diagnoses or treatment experiences [29, 32]. Closed groups with real names and photos encourage engagement, while open communities may lack focus and anonymity, reducing their supportive impact [49]. Younger patients seek immediate feedback and social interaction, while older patients prioritize ease of use and credible information [29, 36]. Adolescents emphasize belonging and peer support, while patients with rare diseases require expert guidance [32, 43]. Inclusive community designs are critical for addressing the barriers faced by users in remote areas or with limited digital skills [30].

Interaction quality greatly influences the patient experience. Peer exchanges alleviate loneliness and provide practical advice [32]. However, low engagement, such as unresponsive posts, can undermine the community's value. Mechanisms like pinned posts for new users or AI-driven comment prompts can boost participation and create a more active environment [45].

Negative content in virtual communities can impact patients' mental well-being. Exposure to discouraging experiences can increase psychological distress [32]. To mitigate this, platforms should

employ text recognition to flag or minimize negative content, while reinforcing psychological support features like counseling and positive interactions [42, 43].

Role of Healthcare Providers

Healthcare providers play a key role in enhancing virtual communities by offering evidence-based medical information, addressing misconceptions, and supporting symptom management and counseling. Some cancer centers use clinician-led forums to build trust and improve access to information [34, 43, 47]. Despite the potential of virtual communities, concerns about content accuracy persist, especially in open forums. Anonymity may promote emotional safety but weaken trust and interaction quality [43, 50].

To maximize the benefits of virtual communities, improving digital literacy, implementing robust verification systems, and optimizing governance are essential. This will help virtual communities function as valuable extensions of healthcare, providing personalized support and fostering innovation in medical services.

Role of Technology Developers

Technology developers are vital in improving virtual communities by enhancing accessibility, functionality, and real-time support. Usability testing and user feedback help address challenges like small font sizes and complex navigation. Customizable features like audio and text adjustments are important for users with cognitive impairments [33]. Collaboration between developers, clinicians, and patients can help optimize designs and increase engagement [32].

Developers should focus on accessible design, data security, and privacy protection. Features like identity verification and content moderation are recommended to ensure credibility while simplifying operations for older patients [40, 43].

Domain 5: Organization (Internal Factors)

Many organizations face gaps in technological infrastructure, staffing, and cross-departmental collaboration. Few studies mention the employment of sufficient technical professionals or training

support [33], and while some mention collaboration between IT and mental health departments, detailed accounts are lacking. Organizational flexibility in addressing user feedback and operational issues, along with the capacity for continuous improvement, is rarely demonstrated. For example, the *WeCanManage* and *iaya* studies showed improvements in user experience and technical challenges through iterative updates [32, 33], but most studies fail to elaborate on these efforts, indicating a lack of organizational preparedness and adaptability.

To address these gaps, better allocation and training of skilled professionals, strengthened cross-departmental collaboration, and efficient feedback mechanisms are needed. Successful examples from *WeCanManage* and *iaya* highlight how continuous improvement and technological advancements can significantly enhance user experience and service quality.

Domain 6: Wider System (External Factors)

Many studies overlook privacy and data protection, as virtual communities often operate under local legal regulations, with less emphasis on compliance. While social media platforms have robust privacy mechanisms, app-based platforms must adhere to stricter regulations—such as the GDPR in Europe [28], especially regarding sensitive health data.

Sociocultural contexts and language adaptability also influence the effectiveness of virtual communities, yet these factors are rarely addressed in research. Cultural and linguistic barriers hinder information access, particularly in multicultural settings, and some platforms lack cultural adaptability by mandating English-language interfaces [28]. Denise Pyle et al., and Nataly R. Espinoza Suarez et al., both mentioned that culture and language may form obstacles, and adaptive adjustments should be made to these problems [53, 54].

Supportive technological environments, such as smartphone usage and free activity-tracking apps, have been underexplored. Interoperability issues remain common, with discrepancies between computer simulations and actual operations, highlighting the need for better adaptability to diverse technological environments.

While community engagement designs are critical, they remain underdeveloped. Examples like modular learning and integrating virtual communities with offline support networks show potential [33, 47], but these practices are not widespread, indicating a gap in the importance of engagement in community design.

Domain 7: Embedding and Adaptation Over Time

Long-Term Usage and Evolving User Needs

The needs of cancer patients evolve throughout disease progression, with virtual communities playing pivotal roles at each stage. During diagnosis, patients seek information about the disease and treatment options, such as those provided by *WeCanManage* [33]. In the treatment phase, demands for emotional support, side effect management, and lifestyle adaptation grow, addressed by apps like *WalkON* offering psychological counseling and social support [28]. During rehabilitation, patients continue to need psychological assistance and peer interaction, which *Kræftværket* supports through long-term aid and experience sharing [29]. In advanced stages, emotional comfort and end-of-life care become primary priorities for patients and their families [31].

Different patient groups exhibit distinct needs. AYAs patients prefer peer interactions and rely heavily on peer support [29], while breast cancer patients experience five psychological processes: mirroring, monitoring, modeling, belonging, and distancing [35]. New users often focus on information acquisition with minimal engagement, whereas long-term active users gradually take on guiding and supportive roles within the community. Research on *CSN* indicates that 62.5% of registered users do not return after their initial login, while long-term active users provide emotional support to newcomers [38, 41].

Technological Updates and Continuous Optimization

Most virtual communities struggle to adapt to evolving patient needs, limiting their ability to meet varying requirements across different disease stages. Yao et al. observed that many virtual communities fail to provide tailored support for specific stages of illness, emphasizing the need for

enhanced designs that address stage-specific needs [41]. This highlights the lack of dynamic adaptability in current virtual community designs.

Additionally, many virtual communities have not effectively integrated with healthcare management systems. Tripathi et al. noted that in palliative care, healthcare providers could integrate social media platforms or anonymous forums (e.g., *Reddit*) into personalized care plans as therapeutic tools [48]. This highlights the inadequacies of virtual communities in integrating healthcare resources and technological tools, preventing them from reaching their full potential.

DISCUSSION

Principal Findings

This study, based on the NASSS framework, evaluates virtual communities in cancer patients' psychosocial rehabilitation over the past five years. Virtual communities play a significant role in emotional management, self-empowerment, and alleviating loneliness. Emotional support helps reduce loneliness while sharing experiences boosts confidence and positivity [41, 47]. Forums and social media platforms provide informational support, enhancing patients' sense of belonging and purpose while offering a safe space to express negative emotions and reduce psychological stress [34, 42]. Female participants are more engaged, potentially influenced by gender socialization theory [55].

The application of the NASSS framework highlights the dynamics of technology design, policy support, and evolving user needs. From an implementation science perspective, these findings underscore the importance of aligning the technological and social elements to effectively integrate virtual communities into the healthcare system. This study not only examines current applications but also explores how virtual communities can meet personalized patient needs, offer long-term support, and sustain development, providing valuable insights for future research and practice in ensuring these systems can be effectively scaled and sustained over time.

Challenges and Recommendations

Adapting to Patients' Dynamic Needs

The needs of cancer patients evolve at different stages of their journey (diagnosis, treatment, rehabilitation) [56]. During diagnosis phase, patients prioritize authoritative information and psychological reassurance, whereas rehabilitation patients seek long-term psychological support and experience sharing [29, 35]. However, current virtual community designs often lack mechanisms to adapt to these changing needs (Domain 7).

A “Phased Needs Model” could be implemented, incorporating dynamic adjustments. Features such as real-time interactions during treatment and experience repositories during rehabilitation could be introduced. AI algorithms analyzing user behavior (e.g., browsing history, content engagement) can recommend stage-appropriate content tailored to individual needs [57, 58]. Modular designs should also allow communities to automatically adjust support content and interaction methods, ensuring tailored support throughout the patient’s journey. To ensure that such dynamic adjustments are not only technologically feasible but also scalable, health systems and organizational structures must be equipped to integrate these features in a sustainable way [23]. This requires ongoing coordination between healthcare providers, platform developers, and other stakeholders to meet patients’ needs across different stages [23].

Integrating Technology with Psychological Support

While anonymity and real-time interaction are common features in virtual communities, their direct impact on psychological well-being remains underexplored. Anonymity alleviates expression pressure but may undermine trust and belonging within the community [43]. Cultural differences further influence preferences for anonymity and support mechanisms, reflecting distinctions between collectivist and individualist orientations [59, 60].

To address these challenges, a “Layered Anonymity Mechanism” could be implemented to enhance trust while maintaining privacy. New users could participate anonymously and gradually

reveal identity elements as engagement increases [61]. Culturally sensitive designs, such as group-based support for collectivist cultures and personalized recommendations for individualist ones, could better accommodate diverse user needs. Moreover, incorporating multilingual support and localized content can enhance cross-cultural functionality.

Addressing Long-Term Impact and User Retention

There is a scarcity of longitudinal research on the psychological and behavioral effects of virtual communities, with many platforms facing low engagement and retention rates. The “lurker” phenomenon, where users passively consume content without contributing, hinders community vibrancy [36, 38, 39, 43, 46, 52]. Although initial engagement is often driven by novelty or immediate needs, the lack of sustained incentives can lead to diminished activity over time [62].

Introducing reward systems, such as contribution leaderboards or shareable badges, could motivate long-term participation [41, 62]. Regular content updates and user surveys would further foster a sense of belonging. Longitudinal frameworks should be established to track psychological states, quality of life, and engagement patterns, enabling continuous optimization of community features. AI-driven behavioral analysis can personalize content recommendations to sustain interest and engagement [58, 63].

Policy and Organizational Support

Inadequate data privacy measures and regulatory frameworks hinder the scalability and sustainability of virtual communities. Strict adherence to regulations like GDPR and HIPAA is crucial, yet technological advancements often outpace policy adaptations [64].

Integrating blockchain technology and differential privacy models can ensure user data security while maintaining transparency and enabling research. Blockchain guarantees data integrity, while differential privacy balances confidentiality with data analysis [61, 65]. Additionally, fostering collaboration between healthcare institutions and technology companies will enhance the credibility and professionalism of virtual communities. Establishing cross-departmental task forces can

facilitate resource sharing and ensure responsiveness to user needs and policy changes.

Future Direction

Virtual communities play an essential role in patient empowerment, health management, psychological support, and policy optimization. These platforms significantly enhance patients' sense of empowerment and health management by offering personalized health information, emotional support, and interactive platforms, particularly important for managing chronic conditions like cancer [66-68]. However, it is important to note that the study focused mainly on North America, which may affect the generalizability of the results. It is recommended that additional studies be conducted in other regions to increase the diversity and representativeness of the sample. Future research should focus on investigating empowerment mechanisms and their long-term impact on treatment adherence and health outcomes. Furthermore, culturally sensitive support programs tailored to diverse groups, such as LGBTQ+ individuals, low-income populations, and ethnic minorities, are crucial for promoting equity and inclusivity in healthcare [69, 70].

Virtual communities also offer substantial potential for mental health interventions. By utilizing natural language processing (NLP) and machine learning technologies, these communities can identify users' emotional states in real-time and provide targeted psychological support, especially during public health crises like COVID-19 [68, 71]. However, the risk of misinformation must be addressed. Future developments should incorporate health information verification and credibility scoring systems while improving users' health literacy to help them discern accurate scientific information [68, 72].

Technological innovation and data-driven personalized support will be key research directions. Integrating community data to develop intelligent recommendation systems and health-assistive tools can predict user needs and optimize health management [13, 73]. Additionally, large-scale data analysis can uncover patients' real needs and policy gaps, providing insights for optimizing health policies [74]. These advancements, however, must ensure strict data privacy and ethical governance,

including anonymization and encryption techniques to safeguard user privacy and establish comprehensive data-sharing frameworks [68].

Study limitations

This review has several limitations. First, the variability in study methodologies, including differences in data collection methods, sample sizes, and designs, may impact the generalizability of the findings. Many studies were qualitative, introducing biases such as sample selection, reporting, and information biases. These studies relied on self-reported data from voluntary participants in online communities, potentially excluding inactive patients and introducing bias from emotional or social influences. In quantitative studies, although most met MMAT standards, sample selection, and self-report biases still limited the generalizability of results. The search was limited to English-language studies published in the last five years, potentially excluding relevant research in other languages or older studies. Lastly, the lack of longitudinal data makes it difficult to assess the long-term effects of virtual communities on patient outcomes and sustained engagement.

CONCLUSION

This study uses the NASSS framework to explore the application, challenges, and optimization of virtual communities in the psychosocial rehabilitation of cancer patients. The findings highlight the important role of virtual communities in providing psychological support, facilitating information sharing, and reducing loneliness, leading to improvements in emotional regulation and self-empowerment. However, challenges remain in addressing the dynamic needs of patients, integrating technological and psychological support, and ensuring long-term outcomes and policy backing.

To address these challenges, strategies such as dynamic closed-loop mechanisms, fostering technological innovation, diversified designs, and ensuring cultural adaptation are essential. Future research should focus on longitudinal studies, cross-cultural comparisons, and the integration of emerging technologies to enhance the sustainability and impact of virtual communities in cancer rehabilitation. With continued research and improvements, virtual communities can significantly

enhance cancer patients' quality of life and rehabilitation outcomes.

Acknowledgments

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Conflicts of Interest

The authors declare that they have no competing interests.

Abbreviations

AYA: Adolescent and Young Adult

MeSH: Medical Subject Headings

RCT: Randomized Controlled Trial

GDPR: General Data Protection Regulation

HIPAA: Health Insurance Portability and Accountability Act

NASSS: Non-Adoption, Abandonment, Scale-Up, Spread, And Sustainability

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analyses

Multimedia Appendix of supplementary files

Multimedia Appendix 1. PRISMA checklist.

Multimedia Appendix 2. Search strategy.

Multimedia Appendix 3. Data Collection Extraction Entries.

Multimedia Appendix 4. Data Extraction Scale.

Multimedia Appendix 5. MMAT assessment results.

Data Availability

All data generated or analyzed during this study are included in this published article and its supplementary information files.

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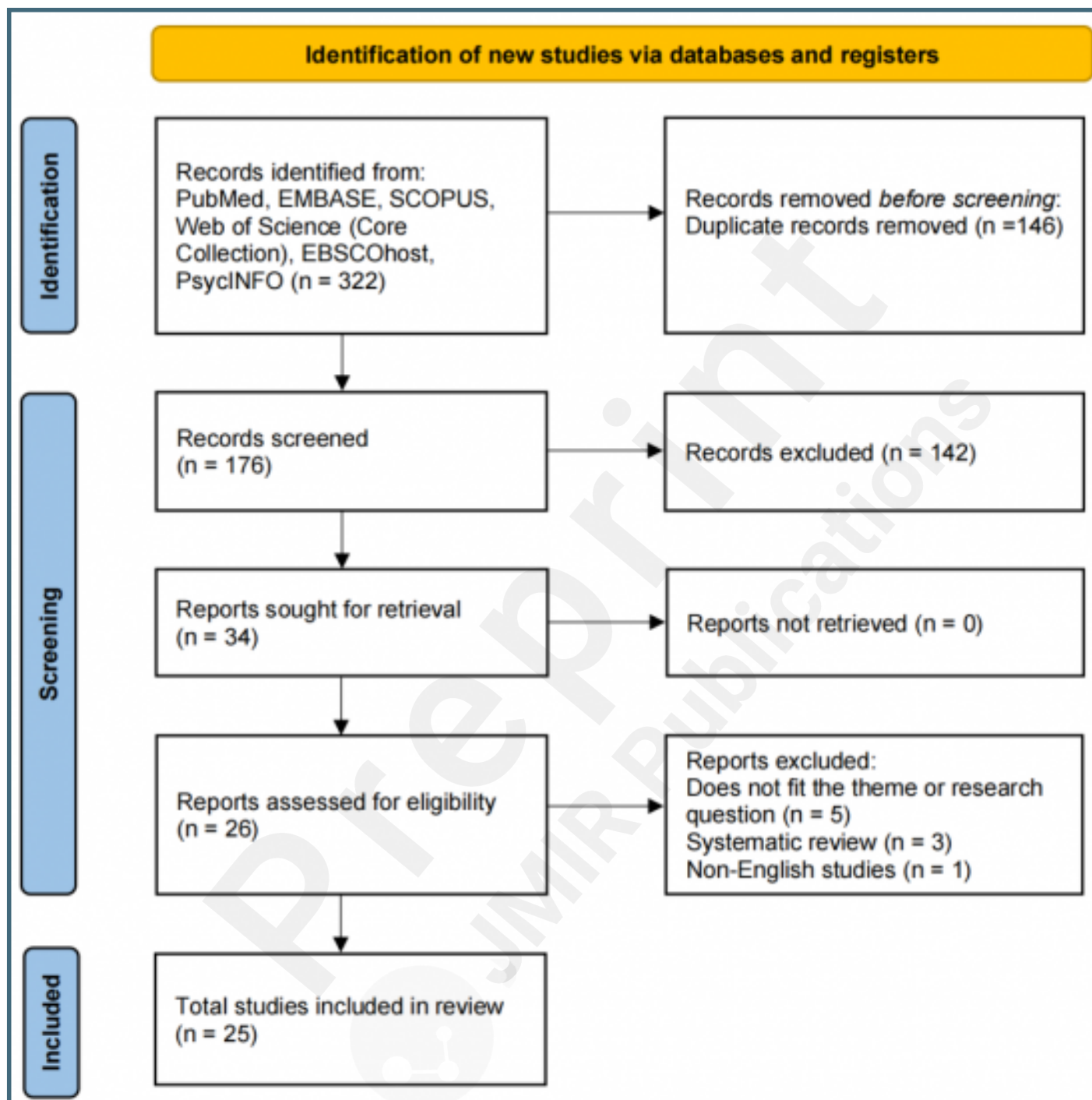
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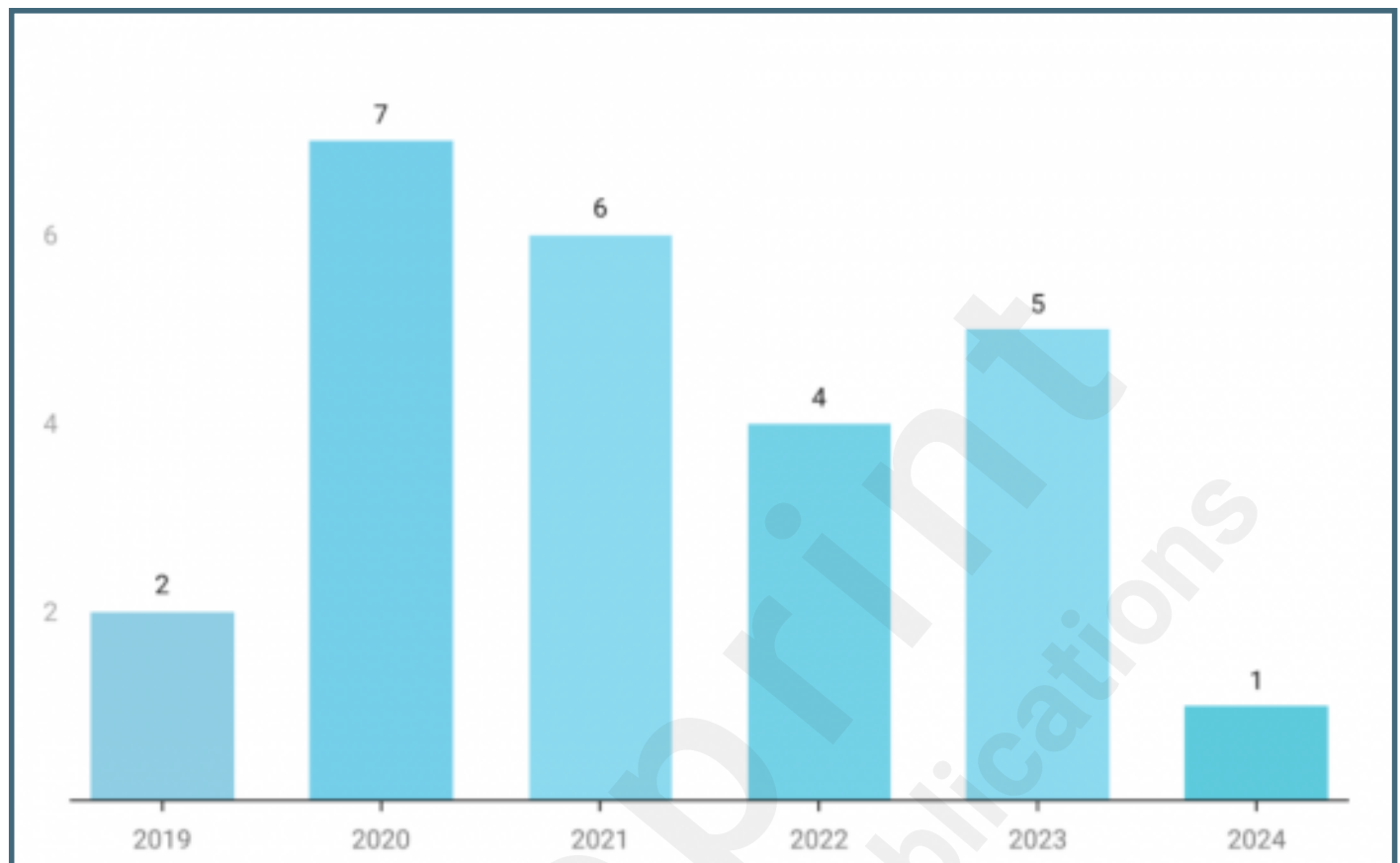
Supplementary Files

Figures

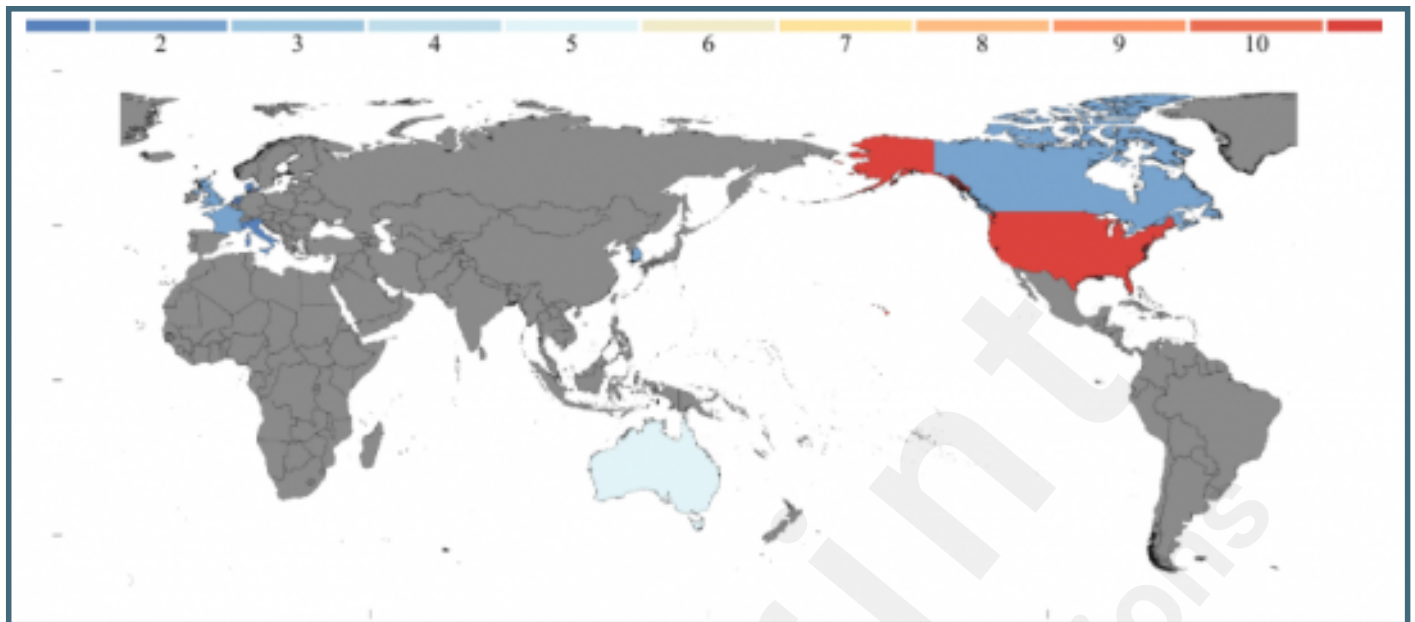
PRISMA flow diagram.



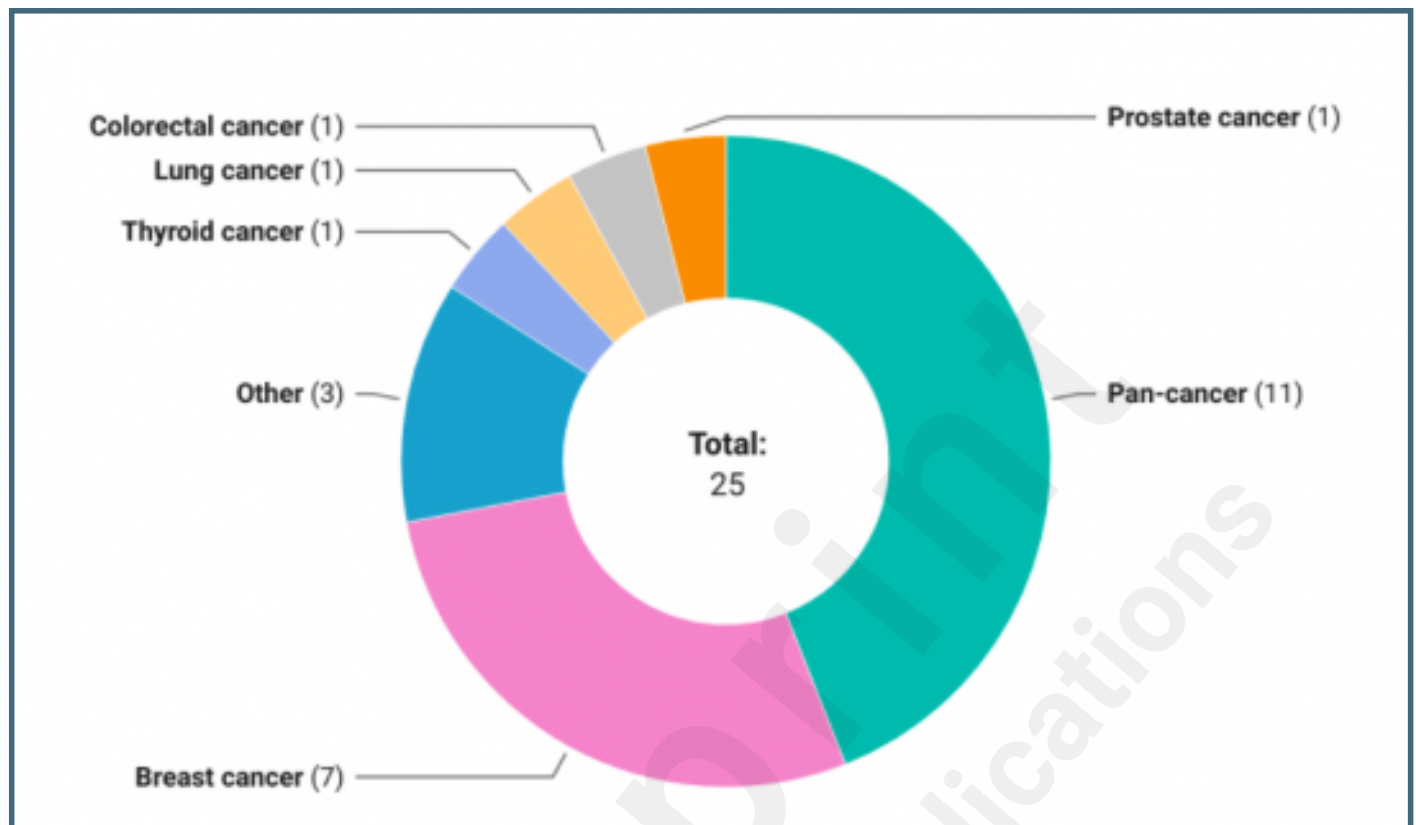
Publication year included in the study.



Source countries included in the study.



Cancer type included in the study.



Multimedia Appendixes

PRISMA checklist.

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Search strategy.

URL: <http://asset.jmir.pub/assets/e73df1b2de4efeec01cc9a294c610722.pdf>

Data collection extraction entries.

URL: <http://asset.jmir.pub/assets/5f0511e4f1cbca9b133ae90429de289e.pdf>

Data extraction scale.

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MMAT assessment results.

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