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A rapid systematic review on developing web-based interventions to support people affected by cancer.

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ABSTRACT

Objective: To systematically identify and explore the existing evidence to inform the development of web-based interventions to support people affected by cancer (PABC).

Design: A rapid review design was employed in accordance with the guidance produced by the Cochrane Rapid Reviews Methods Group and reported using the PRISMA checklist. A rapid review was chosen as there was a need for a timely evidence synthesis to underpin the subsequent development of an online digital resource (Shared Lives: Cancer) as part of an ongoing funded project.

Methods and outcomes: Keyword searches were performed in MEDLINE to identify peer-reviewed literature that reported primary data on the development of web-based interventions designed to support PABC. The review included peer reviewed studies published in the English language with no limits set on publication date or geography. Key outcomes included any primary data that reported on the design, usability, feasibility, acceptability, functionality, and user experience of web-based resource development.

Results: Ten studies were identified that met the pre-specified eligibility criteria. All studies employed an iterative, co-design approach underpinned by either quantitative, qualitative, or mixed methods. The findings from the ten articles were grouped into the following overarching themes (1) exploring current evidence, guidelines, and theory, (2) identifying user needs and preferences, and (3) evaluating the usability, feasibility, and acceptability of resources.

Conclusion: The findings of this rapid review provide novel methodological insights into the approaches used to design web-based interventions to support PABC. Our findings have the potential to inform and guide researchers when considering the development of future digital health resources.

Trial registration: The review protocol was registered on the Open Science Framework (osf.io/ucvsz).

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STRENGTHS AND LIMITATIONS OF THIS STUDY

- This rapid review provides original and important insights into the methodological approaches used to design and develop web-based resources to support PABC.
- This review provides a rapid, yet comprehensive synthesis of the current evidence to support the time-sensitive decision making for the development and implementation of a novel digital resource (Shared Lives: Cancer) to help support PABC.
- This rapid review, whilst streamlined, was conducted using a systematic methodology, following rigorous reporting guidelines to ensure transparency and reproducibility.
- Whilst considered a key part of the knowledge synthesis 'family', rapid review methods are not subject to the same robustness as a full systematic review and are more vulnerable to bias and error.
- Due to time constraints, database searches were restricted to one database only and no formal quality assessment was performed on the included studies.

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INTRODUCTION

Improvements in cancer screening, early detection, diagnostic methods, and treatment are resulting in an increasing number of people living with and beyond cancer.[1-4] Globally, there were an estimated 18.1 million new diagnoses in 2018.[5] In the UK, it is estimated that 4 million people will be living with and beyond cancer by 2030.[6] As services have expanded to support the continuing rise in cancer incidence, so too have the complexities in delivering care.[7-9] This is epitomised by the changes in the way cancer care has been implemented over recent decades, which in the UK for example, now involves a multitude of bodies responsible for purchasing, commissioning, delivering, and regulating services.[8,10]

To ensure the provision of future cancer services adapts to changes in health needs, medical advances, and societal developments, NHS England implemented a long-term plan in which digital health technologies are central.[11] Digital health technologies have become an important tool in cancer care with the potential to revolutionise patient data, transform patient experiences, improve patient recovery, and improve the access, integration, and personalisation of care.[9-12] Evidence suggests that individuals living with and beyond cancer are engaging with digital health technologies now more than ever[13-16] and are using them to frequently access online health information as well as virtual support groups and forums.[17,18]

The rapid growth of internet use has led to a substantial increase in the number of web-based interventions to support PABC, including a wide range of educational and psychosocial platforms,[19-21] social media sites,[22] mobile applications,[22,23] and digital health interventions that focus on specific health behaviours e.g. physical activity and diet.[24] Whilst previous reviews have focused predominantly on the evaluation of web-based interventions, there remains little evidence documenting the developmental (design, usability, feasibility, acceptability, functionality, and user experience) processes of web-based interventions in cancer populations. This review assumes a novel approach by exploring and synthesising the academic literature that reports on the development of web-based tools in cancer.

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The findings will be used to directly inform the development of a novel web-based resource called (Shared Lives: Cancer),[25,26] that aims to support PABC through making qualitative research data on lived cancer experience publicly available and freely accessible.

This rapid review aims to:

- Identify and map the peer-reviewed academic evidence that reports primary data concerning the development of web-based interventions for supporting PABC.
- Collate and report on the academic evidence with a view to informing web-based interventions for supporting PABC.

METHODS

This study used a rapid review approach adhering to the recently published guidance from the Cochrane Rapid Reviews Methods Group and for reporting used the Preferred Reporting Item for Systematic Reviews and Meta-Analyses (PRISMA) checklist, see supplementary material (S1). Rapid reviews are now considered a key component of the knowledge synthesis family alongside systematic reviews, scoping reviews and realist reviews. They provide a streamlined, efficient, and pragmatic approach to evidence synthesis.[27] In summary, rapid reviews are a form of evidence synthesis in which components of the systematic review process are simplified, with a view to producing findings in a timely manner.[28,29] Still, rapid reviews must remain systematic in their approach and have a duty to report their methods in a transparent manner making sure they are clear about deviations or omissions from the PRISMA criteria. This review was conducted over a 4-month period (July 2021 – October 2021). The study protocol has been registered on the Open Science Framework (osf.io/ucvsz) to promote reproducibility and facilitate methodological transparency, see supplementary material (S2).

Ethics Approval

Not applicable/No human participants included.

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Patient and Public Involvement

No patient involvement.

Search Strategy

Keyword searches together with Boolean operators (OR and AND) and truncation (*) were used to locate relevant peer-reviewed literature on the development of web-based support that is delivered to PABC. Due to the need to produce findings in a timely manner, database searches were limited to one database which is considered acceptable for a rapid systematic review. MEDLINE was searched as it is the leading full-text database of biomedical and health journals. The primary search strategy and syntax was developed and refined by three members of the review team (SC, DN, HG). All database searches were supplemented by Google Scholar searches in addition to forward and backward citation tracking on all relevant articles. Database searches were continually updated to identify and incorporate the most up to date evidence where appropriate.

To identify PABC the following keywords were used: "cancer surviv*" or "living with cancer" or "living with and beyond cancer" or "cancer patient*" or "patients with cancer" "people affected by cancer" or "oncology patient" or "cancer experience*" or "cancer management" or "cancer support" or "cancer care*". To identify web-based support and interventions the following keywords were used: "web*" or "internet*" or "online*" or "digital*". To search literature on user experience the following keywords were used: "user experience*" or "usability" or "functionality" or "design" or "interaction" or "development" or "user testing". The search strategy for MEDLINE can be found in supplementary material (S2).

All retrieved records were collated and stored using Endnote referencing software (EndNote X9, Clarivate Analytics, Philadelphia, USA). The titles and abstracts were screened against the eligibility criteria by one reviewer (SC). Identified discrepancies were resolved via discussion. Following title and abstract screening, the remaining articles were independently screened by full text, for inclusion by two reviewers (SC and DN), with any disagreements again resolved through discussion.

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Eligibility Criteria

Inclusion criteria

Peer-reviewed publications were selected for inclusion in this review if they met the following pre-defined eligibility based on the PICOT approach. **Population:** Adults (aged 18+), all genders, people living with cancer or affected by cancer, caregivers, any geographical location. **Intervention:** Website-based cancer support resources. **Comparator:** Not applicable. **Outcomes:** Reports primary data on the design, usability, feasibility, acceptability functionality, or user and developer experience of web-based support for PABC. **Type:** Reports empirical research data using either quantitative, qualitative, or mixed methods design. Only publications written in English language were included.

Exclusion criteria

Peer-reviewed publications were excluded based on the following exclusion criteria. **Population:** Non-adult population (under the age of 18). **Intervention:** Support programmes that focus solely on mobile and digital apps, E-learning programmes or interventions (self-directed and practitioner/professionally led), social media or networking sites. **Comparator:** Not applicable. **Outcomes:** No primary data reported on the design, usability, feasibility, acceptability, functionality, or user experiences of web-based support for PABC. **Type**: Systematic reviews or literature reviews, editorials, commentaries, opinion pieces, case series, or reports. Any publications that were not written in the English language were excluded from this review.

Data abstraction

Data were extracted using an adapted Cochrane Data Extraction Template, see supplementary (S3). One reviewer (SC) undertook data extraction for each full text article with cross checking taking place by a second reviewer (DN). Study characteristics were extracted from each study based upon (1) study methods (e.g. aims/objectives, study design, participants, outcomes) (2) details on the web-based intervention/support and (3) study findings (details of all relevant data concerning user experience, needs, preferences, usability, acceptability ,feasibility, functionality, and design).

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Quality assessment

The focus of this rapid review is on identifying and exploring the literature on the development of web-based support that is delivered to PABC therefore, a quality assessment of included articles was not deemed appropriate.

Data synthesis and analysis

The review included a wide range of study designs that utilised quantitative, qualitative, and mixed methodologies. To identify and map the evidence on the development of web-based interventions for supporting PABC we tabulated the results. This was then accompanied by a narrative summary where comments on the similarities and dissimilarities within data were made. Due to the wide heterogeneity of the design and outcomes of included studies, as well as the considerable amount of qualitative data, a formal statistical meta-analysis was not conducted; however, the findings were synthesised narratively.

RESULTS

Search results

The search of MEDLINE database provided a total of 2,446 distinct citations with an additional 6 identified through secondary sources, see Figure 1. After reviewing for title and abstract, 2,439 did not meet the pre-specified eligibility criteria. The remaining 13 citations were reviewed for full text and examined in detail for inclusion in this review. Three did not meet the pre-specified inclusion criteria for various reasons, see Figure 1. Overall, 10 studies met the pre-defined eligibility criteria that focused on the development of web-based tools to support PABC.

Study Characteristics

The ten articles were published between 2012-2020 and were undertaken in Australia,[31] Belgium,[32] Vietnam,[33] United Kingdom,[34-37] and the United States of America.[38-40] Five studies focused on people with specific cancer types including survivors of Hodgkin Lymphoma,[38] patients with experience of gynaecological cancers,[34] survivors of oral cancer,[39] and patients and survivors of

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breast cancer,[32,40] whilst four studies,[31,35,36] included patients with experience of a range of cancer types. Some studies also included family caregivers,[39] intimate partners,[32] healthcare professionals,[33,34,36,38] and researchers[34] alongside people with lived cancer experience. One of the included studies collected data with carers of people with cancer and health professionals only.[37]

All studies employed an iterative, co-designed methodological approach for the development of web-resources to support PABC. Two of the studies employed a mixed methods research design,[38,40] six utilised both quantitative and qualitative methods,[31,32,35-37,39] and two articles used solely qualitative methods.[33,34] Four studies explored user needs and preferences using focus groups,[32,38] discussion workshops,[33,34] semi-structured interviews,[33,39] and questionnaires.[32] Three articles explored preferences around the design of the web-based resources using discussion workshops,[34,37] and interviews.[31] Seven studies evaluated the usability and/or acceptability of web resources using 'think aloud' cognitive interviews,[36,38-40] focus groups,[35,36] semi-structured interviews,[40] structured interviews,[35] acceptability E-scales,[38] readiness scales,[31] website tracking,[31,37] and online surveys.[31,40] One study evaluated the feasibility of web-resources using a combination of surveys, questionnaires, and structured interviews,[35] and another carried out user testing (separate to usability testing) via interviews and evaluation surveys.[39] See Table 1 for further details of the characteristics of included studies.

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Table 1. Characteristics of included studies

Study (Country)	Population	Methods/Design	Key Outcomes
Amweg et al. (2020)[38] (USA)	Hodgkin Lymphoma Survivors n=10 Healthcare professionals n=9	Mixed methods, user-centred design Two phases: **1)** Focus groups **2)** Usability testing (cognitive interviews and acceptability E-scale)	**User needs and preferences** (Phase 1) Feedback on participants' specification preferences of website **Usability** (Phase 2) Feedback of preferences and experience of using website Acceptability of website
Ashmore et al. (2020)[34] (UK)	Gynaecological cancer patients n=5 Healthcare professionals n=5 Researchers n=3	Qualitative, multi-disciplinary co-creation approach Four discussion workshops **1)** Establish understanding of available support and treatment **2)** Establish key areas for support **3)** Website design and requirements **4)** Review of initial resource	**User needs and preferences** (Workshop 1 & 2) Establish understanding of available support and treatment Establish key areas of support **Website development** (Workshop 3 & 4) Development of initial resource through creation of a design brief 'wish list' Review of the design of initial resource and identification of recommendations for design team
Badr et al. (2016)[39] (USA)	Oral cancer survivors **n=13** Family caregiver **n=12**	Quantitative and qualitative user-centred design Three phases: **1**) Qualitative needs assessment (semi-structured interviews) **2)** Prototype development **3)** Formative evaluation (usability testing - 'think aloud' interviews and user testing – interviews and survey)	**Preferences** (Phase 1) Feedback on the unmet needs and preferences for website **Website development** (Phase 2) Development of website prototype **Usability/User testing** (Phase 3) Identify navigational difficulties of website Identify participants' experiences of using website Evaluation survey (attractiveness, controllability, efficiency, intuitiveness, learnability)
Bartlett et al. (2012)[35] (UK)	Cancer patients n=259 (Breast, Colorectal, Germ cell, Gynaecology, Haematology, Kidney, Prostate, Sarcoma, Upper gastrointestinal)	Quantitative and qualitative user-centred design Three phases: **1)** Website design (focus groups and interviews) **2)** Computer and internet survey usage **3)** Crossover study (questionnaires and structured interviews)	**Usability** (Phase 1) Patient feedback on initial web resource **Feasibility** (Phase 2) Socio-demographics Computer and internet usage **Usability/Feasibility/Acceptability** (Phase 2) Web resource activity tracking Usability and acceptability feedback
Bradbury et al. (2019)[36] (UK)	Cancer patients n=32 (Breast, colorectal, and prostate cancer patients) Supporters of cancer survivors (nurses, GPs, care assistants, cancer charities) n=31	Quantitative and qualitative evidence, theory, and user-centred approach Seven phases: **1)** Scoping review **2)** Guiding principles **3)** Behavioural analysis **4)** Logic model **5)** Prototype of website **6)** Qualitative optimisation study 1 **7)** Qualitative optimisation study 2	**Usability/Acceptability** (Phase 6 and 7) Feedback of participants experience of exploring website, includes participants' likes, dislikes and recommendations for change
Fennell et al. (2017)[31] (Australia)	Cancer patients n=122 (Bones, breast, cervix, colorectal/bowel, lymphoma, lung, melanoma, ovaries, prostate, testicular, brain)	Quantitative and qualitative user-centred approach Two phases: 1) Website development (interviews) 2) Acceptability testing (website tracking activity, readiness scale, online survey)	**Design** (Phase 1) Feedback on initial website content and design **Usability/Acceptability** (Phase 2) Website usage Website acceptability and perceived impact

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Table 1. Continued

Study (Country)	Population	Methods/Design	Key Outcomes
Kapoor et al (2018)[40] (USA)	Breast cancer patient or survivor n=15	Mixed methods, evidence, theory, and user-centred approach Seven phases: **1)** Literature review and expert panel **2)** Review of current breast cancer survivorship guidelines and plans **3)** Development of decisions **4)** Curation of decisions **5)** Prototype design and development **6)** User feedback (semi-structured interviews) **7)** Usability testing ('think aloud' and semi-structured interviews and online surveys)	**Perceived usefulness** (Phase 6) Identify participants' perception and perceived usefulness of the website **Usability** (Phase 7) Identify the overall usability of the website
Pauwels et al (2012)[32] (Belgium)	Breast cancer survivors n=57 Intimate partners n=28	Quantitative and qualitative user-centred design Pre and post design (post-questionnaire, website tracking, care needs questionnaire)	**User needs** Assessment of participants' needs for information and support **Design** Evaluation of the content and lay-out of the website. Concepts evaluated include user friendly, well-built, interesting, informative, understandable, new, incomplete, irrelevant, unreliable, too extensive, or confusing **Usability** Information gathered about participants' use of the website
Santin et al (2019)[37] (UK)	Cancer carers n=12	Quantitative and qualitative co-design approach Two phases: **1)** Co-design model -Design of website (workshops and meetings) -Development of prototype 1 -User testing phase 1 (unstructured feedback sessions) -Refining prototype **2)** User testing -User testing and refinement (semi-structured interviews, web survey, website tracking) -Final development	**Design** (Phase 1) Evaluation and refinement of website design **Usability** (Phase 1 & 2) To gather views and experiences of users' interactions with the web-resource. Evaluate website use through tracking website activity
Santin et al (2020)[33] (Vietnam)	Informal cancer carers n=20 Healthcare professionals n=23	Qualitative co-design approach Two phases: 1) Identification of needs (interviews and focus groups) 2) Stakeholder verification and refinements (co-design workshops)	**User needs and perspectives** (Phase 1 & 2) Identifying and understanding the needs of informal cancer carers to underpin resource content Learn and agree upon shared priorities and resource components between informal cancer carers and healthcare professionals

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Overarching themes

The findings from the ten articles were grouped under the following three areas (1) exploring current evidence, guidelines, and theory (2) identifying user needs and preferences, and (3) evaluating the usability, feasibility, and acceptability of resources.

Exploring current evidence, guidelines, and theory

Bradbury et al.[36] conducted a rapid scoping review to identify the barriers and facilitators to intervention success including the participants needs and attributes and intervention components. Synthesised evidence from the review informed key design objectives including employing an approach that promotes well-being, ensuring the appropriate promotion of behaviour change, providing easy, timely and tailored information, and ensuring an efficient design. These findings were used to establish intervention guiding principles and inform the behavioural analysis and logic model that would underpin resource development. Similarly, Kapoor et al.[40] conducted a literature review to identify the needs of breast cancer survivors to assist in informing web-resource development. The findings, combined with input from an expert panel, helped to identify core functions to be incorporated into the design of a prototype resource including recording and tracking of quality life indicators, recording user-reported treatment-related symptoms, viewing breast cancer related medical history, viewing scheduled follow-up visits, and generating and displaying customised alerts related to symptoms and quality of life issues. Other studies also reported reviewing patient websites and performing literature reviews but were not explicit on how findings informed web-resource development.[31,37]

In addition to reviewing the available literature, studies also reviewed existing guidelines and theory to inform web-resource development. Kapoor et al.[40] conducted a comprehensive review of current breast cancer survivorship guidelines and existing survivorship plans which were used to inform the inclusion of key support information within the web-resource. Badr et al.[39] explored the best practices underpinning the management for oral and swallowing complications following radiotherapy, whilst also reviewing national healthy lifestyle guidelines for cancer survivors and evidence surrounding the self-determination theory. The findings were used to develop a prototype web-resource that specifically focused on promoting survivor and caregiver autonomy, competence, and relatedness; by providing

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tailored information, skill-building education, and support services. Other studies also reported reviewing clinical practice guidelines alongside reviewing the academic literature.[31]

Identifying the needs and preferences for resources

Participants of the included studies emphasised the need for resources that provide comprehensive information on cancer management and survivorship.[32-34,39] The need for clear information on survivorship care with a specific focus on physical, psychosocial, psychosexual, and emotional well-being was identified;[32,34,38] in addition to information on adjusting to 'new normal', returning to work, financial management, and lifestyle advice.[32,34,39] The inclusion of practical advice and information on the side effects of cancer treatments was viewed as essential[34,39] and participants expressed the need to learn from other survivors and carers through shared experiences and self-care strategies.[33,34,39] Concerns were raised by survivors regarding the risk of secondary cancers and how to communicate with family about experiences of cancer survivorship.[34] The inclusion of a 'Frequently Asked Questions' page was also proposed to ensure a safe space for users to search for specific information.[33,34]

Reported discussions between healthcare professionals focused on the need to ensure resources can be integrated easily into existing digital systems and are accessible across clinical specialities.[38] It was also considered important that participants did not view resources as a substitute for clinical care[38] and that information on family/carer support be included.[34] Caregivers expressed the need for emotional and supportive information on how to cope with cancer in addition to information on cancer side effects and lifestyle advice.[32,33,39] Concerns were also raised regarding the fear of reoccurrence and the need for specific self-care information and better family communication for carers.[39] Caregivers also discussed the inclusion of information regarding cancer causes and treatment, pain management, hospital administration and treatment processes, hospital daily living, and signposting to skills training.[33,39]

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Evaluating the usability, feasibility, and acceptability of resources

Studies explored the usability, feasibility, and acceptability of resources by qualitatively drawing upon the users' positive and negative experiences of web-resource interaction. Users viewed web-resources positively and valued their use in providing centralised, easily accessible information to support and facilitate survivorship care.[36-38,40] The content included within web-resources were regarded as useful in managing the consequences of cancer and was viewed as a credible source of information due to its development by trusted experts.[36,37,40] Accessing information through web-resources and video formats was perceived as less burdensome than written information and allowed users to easily access advice.[37] Resource features including providing useful website links, being able to access medical history, and tracking quality life indicators was also perceived as valuable components of web-resources.[40]

Whilst web-resources did provide easy access to information, the content of web-resources was considered impersonal with users expressing the need for more customised and prioritised information[35,37,38,40] that was representative of all genders.[37] Web-resources were found to be too complex with users experiencing difficulties in navigating and understanding the purpose of certain web-features highlighting the importance in developing simple and user-friendly web-resources.[35,38,39] Issues with web-resource design were also experienced with users emphasising the need for more appealing web-designs that use appropriate colour and size of both fonts and paragraphs, include greater cross-links, and incorporate much clearer navigational features.[31,38,39]

Studies also evaluated the usability, feasibility and acceptability of web-resources using a range of quantitative methods. A common approach identified was the use of Likert scale style questionnaires and surveys.[32,39,40] For example, Badr et al.[39] reported an overall resource usability score of 80/100 with individual areas rates as attractiveness (4.0/5), controllability (4.2/5), efficiency (4.1/5), intuitiveness (3.9/5), and learnability (3.8/5). Amweg et al.[38] employed an acceptability E-scale to objectively identify web-resource acceptability reporting an overall score of 29.8 (a score of <24 was considered an indicator of web-resource acceptability). Other studies also used descriptive

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questionnaires and surveys with users rating web-resources as easy to use, useful, relevant, necessary, and likely to return and recommend.[35,37] Studies were also shown to objectively explore website usability using website analytics.[31,32,35,37] For example, Santin et al.[37] reported 2769 unique visits between November 2017 and May 2018 of which 743 were returning visitors. Visitors were shown to access multiple website components including the 'getting through treatment', 'caring for you', 'financial', and 'employment' elements. Peer-led videos were the most frequently accessed content whilst professional led material, supporting children, and the emotional aspects of caring were the least visited.

DISCUSSION

This rapid review has systematically identified and mapped the peer reviewed academic evidence that reported on primary data concerning the development of web-based interventions for supporting PABC. Our findings highlight the use of user-centred, co-designed methodological approaches that are underpinned by iterative, but not necessarily sequential, development processes. A common approach used to develop web-based resources involved the initial exploration of the current evidence, guidelines, and theory followed by an assessment of user needs and preferences to ensure that web-resources were designed to meet the needs of its users. This was typically proceeded by the evaluation of resources involving usability, feasibility, or acceptability testing using a wide range of quantitative, qualitative, and mixed methods that often fed back into further resource refinement. Whilst previous reviews focus predominantly on evaluating the effectiveness of web-based resources, this rapid review differs in that it provides important and novel insights into the methodological approaches that underpin the development and implementation of web-based resources to support PABC. Our findings have the potential to assist other researchers who are developing digital resources and will be used by the current research team to inform the development of a web-based support platform (Shared Lives: Cancer)[25,26] that aims to make qualitative research data on lived cancer experiences publicly available via an open access searchable website.

Ensuring the appropriate design of web-based resources is a critical component of website development[41] in which the use of iterative, co-designed methods is strongly advocated,[42,43]

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especially with respect to cancer care.[44] This is supported by previous evidence that demonstrated the engagement of stakeholders throughout the developmental process ensures that digital tools are firmly grounded within the user's needs, which consequently improves usability and increases user engagement.[45-47] However, there must be an appreciation that users will have varying levels of digital literacy and this needs to be considered when designing and delivering digital resources. Existing research has shown that poor digital literacy is linked with computer anxiety and barriers to internet use amongst PABC.[48,49] Therefore, resources should be accessible and lay friendly to encourage engagement with people who have lower levels of digital literacy. At the same time, there will and continues to be PABC who prefer non-digital support for a variety of reasons. Therefore it is important that face-to-face support is maintained as digital services continue to be widely rolled out as a consequence of both the Covid-19 pandemic and global healthcare policies.

The findings from this review also emphasises the importance of collecting data on usability, feasibility, and acceptability, which are widely considered as important elements when developing web-based resources. An important decision future researchers may face during the ongoing development of digital resources is deciding how these areas will be measure. In line with evidence concerning usability and acceptability testing,[50,51] our findings point towards employing the use of a wide range of quantitative and qualitative methods and where possible should consider a combination of methodologies.[52] Whilst we identify key assessment methods including website analytics, E-scales, questionnaires, 'think aloud' interviews, semi-structured interviews, focus groups and workshops, future research should also consider other methods including more objective and automated methods, especially in the context of usability testing.[50,52]

The development and implementation of digital tools has enormous potential in supporting future healthcare services through transforming the way individuals engage with services and professionals, advancing efficient care coordination, and allowing individuals to better manage one's health and well-being.[53-55] The use of digital technology is now considered a fundamental element that will underpin many of the proposed changes as part of the NHS long-term plan,[11] including desires to facilitate better care and support for individuals at home through the use of digital health tools. As the NHS looks

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to transform and adapt over the next decade, it is important to consider digital health technologies as a potential solution to improve and strengthen aspects or cancer care.[44] The findings of the current review provide important methodological insight that should be used to develop emerging digital health technologies that may help transform and support future healthcare services.

A strength of this review is that it allowed for a rapid synthesis of the current evidence needed to provide timely information to inform the decision-making process surrounding the development and implementation of a novel digital support resource (Shared Lives: Cancer)[25,26] as part of an externally funded project. It provides important insight into the methodological approaches used to develop web-based resources which may be used to guide and inform the design of future digital resources. A limitation of the current review was the lack of consistency and uniformity across outcome measurement tools of included studies, making it challenging to compare and interpret findings. Whilst rapid reviews are key in synthesising timely and informative evidence, it is recognised that the accelerated review process is not subject to the same robustness as a full systematic review. The current rapid review used a streamlined review process that restricted literature searches to one database only and omitted the inclusion of assessing risk of bias. It is therefore acknowledged that the methodology of the current study is less comprehensive and as a consequence the results may be more susceptible to bias and error.

CONCLUSION

This research adopted a rapid review approach as there is a timely need for an evidence synthesis to support and inform the development of an ongoing project to design an online web-based platform (Shared Lives: Cancer).[25,26] The findings of this rapid review provide an important insight into the methodological approaches used to underpin the development of web-based interventions to support PABC. The evidence generated from this review has the potential to inform and guide future research endeavours when considering the development and implementation of digital resources.

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AUTHOR CONTRIBUTIONS

SC, DN, HG and RK conceptualised and designed the review. SC reviewed titles, abstracts, full-text articles and extracted data with all data extraction verified by DN. SC and DN prepared the initial manuscript. HG, RK, KM, and MG reviewed and edited the final manuscript.

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COMPETING INTERESTS

The authors declare no competing interests.

PATIENT CONSENT FOR PUBLICATION

Not applicable.

DATA SHARING

All data are included within the manuscript and supplementary material.

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Figure legends

Figure 1. Study flowchart[30]

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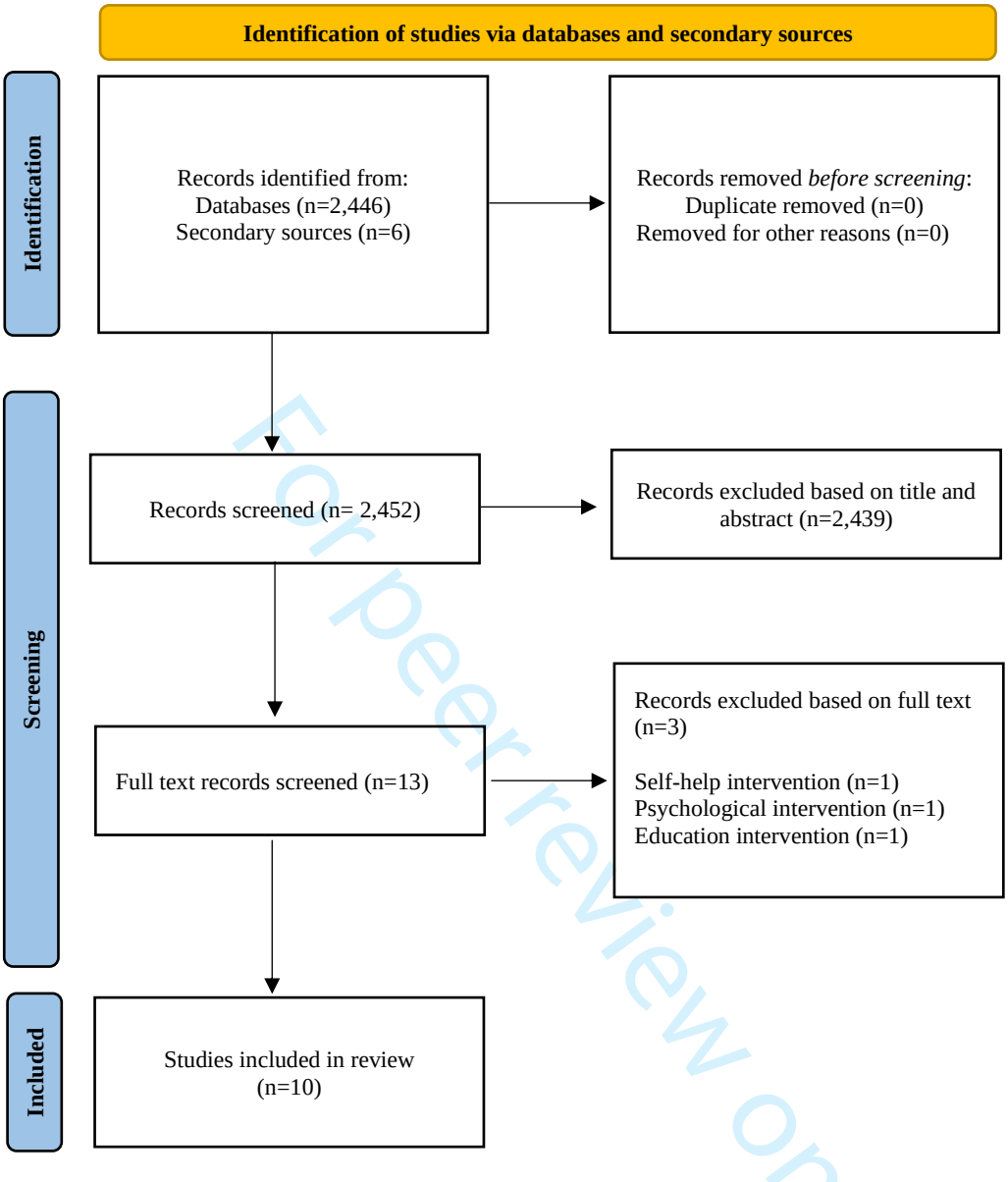

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PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 4/5
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 2/5
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 7
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 6
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary material (S2)
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 6/7
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 7
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 7
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	N/A
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 7
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 7
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 7
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A

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Section and Topic	Item #	Checklist item	Location where item is reported
assessment			
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 8 and Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1
Study characteristics	17	Cite each included study and present its characteristics.	Page 8/9/10/11 (Table 1)
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	N/A
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	N/A
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 15/16/17
	23b	Discuss any limitations of the evidence included in the review.	Page 17
	23c	Discuss any limitations of the review processes used.	Page 16/17
	23d	Discuss implications of the results for practice, policy, and future research.	Page 15/16/17
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 5
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 5
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 18
Competing interests	26	Declare any competing interests of review authors.	Page 18
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Page 7/18

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Developing web-based interventions to support people living with and affected by cancer: a protocol for a rapid review

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Abstract

Introduction: More people are living with and beyond cancer and digital interventions are increasingly being used to support them at all stages through their journey. This rapid review aims to systematically identify and explore the existing evidence that reports on primary data concerning the development of web-based interventions used to support people living with and affected by cancer.

Methods and analysis: Keyword searches were performed in MEDLINE to identify peer-reviewed literature on web-based interventions that are designed to support people living with and affected by cancer. The review will include studies published in the English language and will not have any restrictions on publication date or geography. Screening and data extraction will be completed independently by two reviewers. The included studies will be tabulated and the results synthesised narratively.

Discussion: This rapid review aims to identify and synthesise the peer-reviewed academic literature that reports on primary data concerning the development of web-based interventions to support people living with and affected by cancer. This methodology was chosen to rapidly synthesise the existing peer-reviewed evidence to support the development and design of an online web-based platform that the team are working on to make qualitative research data on lived cancer experience publicly available and accessible.

Ethics and dissemination: The review was registered and given a favourable ethical opinion on the 19/07/21 by a committee at the University of Lincoln (Review ref: 2021_6976). The findings from this rapid review will be presented at appropriate conferences and published in a peer reviewed academic journal as well as a report for the National Institute for Health Research Clinical Research Network.

Systematic review registration: The protocol was registered on the Open Science Framework [insert link here].

Keywords: cancer survivorship; web-based support; user experience; rapid review; protocol

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Introduction

Globally, cancer incidence is increasing with an estimated 18.1 million new diagnoses in 2018.[1] This can be attributed to advances in screening, earlier detection, diagnostic methods and improved treatments. Consequently, more and more people are now surviving cancer, and in the UK it is predicted that there will be four million people living with and beyond cancer by 2030.[2] Cancer raises a wide range of specific issues pertaining to information provision and emotional support [3] and there are now an increasing number of online health communities for people affected by cancer, each with their own specific aims.[4-6] Existing research has shown that people living with and affected by cancer use the internet for (1) content (online health information) (2) communication (e-mail and instant messaging) (3) communities (virtual support groups and forums) and (4) e-commerce (selling or buying products). [7]

The ongoing Covid-19 pandemic poses several challenges to oncology services and people living with and affected by cancer may now rely more heavily on digital and remote support.[8] [9] Consequently, some psychosocial and supportive cancer care has now shifted from face-to-face to virtual delivery.[10] Digital health technologies have the potential to reduce health inequalities in cancer care and can improve access, integration and personalisation of care.[6] They can be particularly beneficial to those in rural and remote settings where access has long been acknowledged as a barrier to care.[11] However, the benefits of digital health technology depend partly on digital health literacy (capabilities and resources required by people to use and benefit from it).[6]

Existing reviews have previously explored the use of web-based interventions for supporting people living with and beyond cancer. These include identifying and evaluating the effectiveness of a wide range of web-based resources such as educational and psychosocial platforms[5 12 13], social media sites[14], mobile applications[14 15], and digital health interventions that focus on specific health behaviours e.g. physical activity and diet.[16] The current review will differ to previous reviews by exploring the academic evidence that reports on user and developer experience/perception for building and developing web-based tools. The evidence synthesised from the review will be used to directly inform the development of a novel web-based resource that will support those living with and beyond cancer through making qualitative research data on lived cancer experience publicly available and accessible.

This rapid review will aim to achieve the following:

- Identify and map the peer reviewed academic evidence that reports on primary data concerning the development and utilisation of web-based tools for supporting people living with and affected by cancer.

- Collate and analyse primary data with a view to informing evidence-based recommendations for the development of a novel and accessible web-based tool that meets the needs of people living with and affected by cancer.

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Methods

The team will utilise a rapid review approach which is now considered a key component of the knowledge synthesis family alongside systematic reviews, scoping reviews and realist reviews.[17] Despite the increase in popularity of rapid review methods there is still no universal agreement within the extant literature as to how a rapid review should be conducted or defined.[18-20] In sum, rapid reviews are a form of evidence synthesis in which components of the systematic review process are omitted or simplified with a view to producing findings in a timely manner. [18 19] Still, rapid reviews must remain systematic in their approach and have a duty to report the methods in a transparent manner making sure that they are clear about deviations or omissions from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria.[21] This review will be conducted in line with the recently published guidance from the Cochrane Rapid Reviews Methods Group[22] and reported using the PRISMA checklist.[23]

Protocol and Ethics

The protocol has been registered on the Open Science Framework [insert link here]. This rapid review will be conducted over a 3-4 month period (July 2021 – October 2021).

The review was given a favourable ethical opinion by a committee at the University of Lincoln (Review ref: 2021_6976) on 19/07/21.

Search Strategy

We used keyword searches together with Boolean operators (OR and AND) and truncation (*) to locate relevant peer-reviewed literature on the user experience of web-based support that is delivered to people living with and affected by cancer. We searched MEDLINE (20/07/21) which is the leading full-text database of biomedical and health journals. The primary search strategy and syntax was developed and refined by three members of the review team (DN, SC, HG). The search strategy for MEDLINE can be found at Appendix 1. Due to time constraints, limited sources and the need to produce findings in a timely manner, we are limiting our search to one database which is considered acceptable for a rapid systematic review.[18 19] All database searches were supplemented with google scholar searches in addition with forward and backward citation searchers of relevant articles. Database searches will continually be updated to identify and incorporate the most up to date evidence where appropriate.

To identify people living with and affected by cancer we will use the following keywords: “cancer surviv*” or “living with cancer” or “living with and beyond cancer” or “cancer patient*” or “patients with cancer” “people affected by cancer” or “oncology patient” or “cancer experience*” or “cancer management” or “cancer support” or “cancer care*”

The following keywords will be used to identify web-based support and interventions: “web*” or “internet*” or “online*” or “digital*”

To search literature on user experience we will use the following keywords: “user experience*” or “usability” or “functionality” or “design” or “interaction” or “development” or “user testing”

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Inclusion and Exclusion Criteria

Peer-reviewed publications will be selected for inclusion in the review utilising the pre-defined eligibility criteria outlined in Table 1 below.

Table 1 Inclusion and Exclusion Criteria

Criterion	Include	Exclude
Population	Adults (18+) All genders People living with cancer/caregivers/people affected by cancer Any geography.	Non-adult populations (under 18).
Intervention	Website based/internet-based cancer support resources.	Support programmes that focus solely on mobile and digital apps. E-learning programmes or interventions (self-directed and practitioner/professionally lead). Social media/networking sites
Comparator	Not applicable.	Not applicable.
Outcomes	Reports primary data on user and developer experience/usability/functionality/design on web/internet-based support for people living with and affected by cancer.	There are no primary data reported on user experience/usability/functionality/design on web/internet-based support for people living with and affected by cancer.
Study design	Reports empirical research data using the following designs: • Quantitative • Qualitative • Mixed Methods	• Systematic and literature reviews • Editorials • Commentaries • Opinion pieces • Case series or reports
Language	Published in the English language.	Not published in the English language.

Data and Analysis

Record Selection

References identified via the search were exported and managed using Endnote Version X9. The final search identified 2,452 articles for screening, see Appendix 1. The titles and abstracts will be independently screened against the eligibility criteria by two reviewers (DN and SC). Where discrepancies exist, the team will aim to resolve via discussion or through a third reviewer (HG). Following title and abstract screening, the remaining articles will be independently screened by full text, for inclusion by two reviewers (DN and SC), with any disagreements resolved through discussion or a third reviewer (RK). The results will be presented in a PRISMA flow diagram.

Data Extraction

Data will be extracted using an adapted Cochrane Data Extraction Template and this can be found at Appendix 2. This will be piloted with a subset ($n=5$) of full text studies that meet our eligibility criteria to determine whether any further changes are needed to the data extraction

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template. After piloting the tool, two reviewers (DN and SC) will undertake data extraction for each full text article with cross checking for data quality taking place by a third reviewer (HG). Study characteristics will be extracted from each study based upon (1) study methods (e.g. aims/objectives, study design, participants, outcomes) (2) details on the web-based intervention/support and (3) study findings (details of all relevant data concerning user experience, usability, functionality, and design). All discrepancies will be resolved through further discussion, or where required, a fourth reviewer (RK).

Data synthesis and analysis

It is likely that the review will include a wide range of study designs that make use of both quantitative and qualitative methodologies. Following data extraction, the results of the full text articles will be tabulated. Quantitative data will be described using basic descriptive statistics as well as being written up narratively. We do not plan to conduct a formal statistical meta-analysis. Qualitative findings on user experience will be analysed using thematic synthesis.[24] Where possible we will group and comment on similarities and dissimilarities within the user experience data.

Quality assessment

The focus of this rapid review is on identifying and exploring the literature on user experience of web-based support that is delivered to people living with and beyond cancer, therefore, a quality assessment of included articles was not deemed appropriate.

Discussion

The aim of this research is to identify and map the peer reviewed academic evidence that reports on primary data concerning the development of web-based tools that support people living with and affected by cancer. It will also aim to collate and analyse data with a view to informing evidence-based recommendations for the development of a novel and accessible web-based tool that meets the needs of people living with and affected by cancer. It has been acknowledged that digital interventions have the potential to provide an excellent source of support for people living with and affected by cancer.[5 25] Specifically, they can help people to cope better with the disease and with side effects as well as improving self-management and wellbeing.[5]

A rapid review methodology was chosen to support and inform the timely need for the development and implementation of an innovative online web-based platform that is informed by peer-reviewed academic evidence. Rapid reviews are useful in adapting to and overcoming time and resource constraints that genuinely prevent the development and execution of a high-quality systematic review.[22] Nevertheless, researchers must endeavour to optimise the methodological rigour, clarity, and reproducibility of a rapid review, starting with the implementation of a rigorous and systematic protocol.[22]

Systematic reviews and meta-analyses are often intensive[26], especially when considering the large number of included studies, which is likely to be the case for evidence concerning user experience for developing web-based interventions in cancer. Whilst conducting a rapid review may accelerate the development process, it will enable a timely evidence appraisal that will address priority research questions as well as allowing for the rapid dissemination of findings.

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Dissemination

This rapid review and wider work (development of a web-based platform to support people living with and affected by cancer) benefits from the establishment of a study steering group with representation from academic researchers, cancer professionals and people with lived cancer experience. The review team will draw on their expertise and the findings will be disseminated in accordance with an ongoing dissemination strategy that will be developed collaboratively by the review team and steering group. This will involve presenting at appropriate local and national conferences, as well as, publishing in a peer reviewed academic journal. A summary of the findings will also be written up as a report for the National Institute for Health Research (NIHR) Clinical Research Network (CRN) who are funding this work. The team will disseminate the results in lay and accessible formats including using social media and press releases via the University of Lincoln and Macmillan Cancer Support.

Funding

This review was funded by the National Institute for Health Research (NIHR) Clinical Research Network (CRN).

Acknowledgements

We would like to acknowledge the Steering Group for their support in directing this review as well as the wider project. Acknowledgments must also go to Macmillan Cancer Support and the East Midlands Cancer Alliance for previous funding and their continued support throughout the early development of the Shared Lives Cancer project.

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Appendix 1 Search Strategy for MEDLINE

Key search terms	Date	Hits (*n*=)	Parameters
S1: "Cancer surviv*"	20/07/21	27,751	Medline only
S2: "Living with cancer"	20/07/21	865	Medline only
S3: "Living with and beyond cancer"	20/07/21	103	Medline only
S4: "Cancer patient*"	20/07/21	203,503	Medline only
S5: "Patients with cancer"	20/07/21	31,724	Medline only
S6: "People affected by cancer"	20/07/21	146	Medline only
S7: "Oncology patient*"	20/07/21	6,036	Medline only
S8: "Cancer experience*"	20/07/21	2,911	Medline only
S9: "Cancer management"	20/07/21	4,928	Medline only
S10: "Cancer support"	20/07/21	1,350	Medline only
S11: "Cancer care*"	20/07/21	26,976	Medline only
S12: S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11	**20/07/21**	**280,235**	**Medline only**
S13: "Web*"	20/07/21	287,832	Medline only
S14: "Internet*"	20/07/21	113,871	Medline only
S15: "Online*"	20/07/21	150,659	Medline only
S16: "Digital*"	20/07/21	182,713	Medline only
S17: S13 OR S14 OR S15 OR S16	**20/07/21**	**650,510**	**Medline only**
S18: "User experience*"	20/07/21	2,428	Medline only
S19: "Usability"	20/07/21	15,671	Medline only
S20: "Functionality"	20/07/21	66,353	Medline only
S21: "Design"	20/07/21	1,135,342	Medline only
S22: "Interaction"	20/07/21	876,907	Medline only
S23: "Development"	20/07/21	3,148,188	Medline only
S24: "User testing"	20/07/21	350	Medline only
S25: S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24	**20/07/21**	**4,858,310**	**Medline only**
S26: S12 AND S17 AND S25	**02/08/21**	**2,452**	**Medline only**

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Appendix 2 Adapted Data Extraction Form

Review title or ID	
Study ID *(surname of first author and year first full report of study was published e.g. Smith 2001)*	
Report ID	
Report ID of other reports of this study including errata or retractions	
Notes	

General Information

Date form completed *(dd/mm/yyyy)*	
Name/ID of person extracting data	
Reference citation	
Study author contact details	
Publication type *(e.g. full report, abstract, letter)*	
Notes:	

Study eligibility

Study Characteristics	**Eligibility criteria** *(Insert inclusion criteria for each characteristic as defined in the Protocol)*	**Eligibility criteria met?** **Yes**	**No**	**Unclear**	**Location in text or source** *(pg & ¶/fig/table/other)*
Type of study	Quantitative design	☐	☐	☐	
	Qualitative design	☐	☐	☐	
	Mixed methods design	☐	☐	☐	
	Other (Please specify)				
Participants	Cancer (Specify what type)	☐	☐	☐	
	Caregiver	☐	☐	☐	
	Friends/family	☐	☐	☐	
Types of intervention	Website/Internet-based cancer support programme	☐	☐	☐	

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Type of data (quant and/or qual) (Reports primary data on any of the following)	User experience	☐ ☐ ☐	
	Usability	☐ ☐ ☐	
	Functionality	☐ ☐ ☐	
	Design on web	☐ ☐ ☐	
	Internet-based support living with and affected by cancer.	☐ ☐ ☐	
INCLUDE ☐		EXCLUDE ☐	
Reason for exclusion			
Notes:			

DO NOT PROCEED IF STUDY EXCLUDED FROM REVIEW

Characteristics of included studies

Methods

	Descriptions as stated in report/paper	**Location in text or source** *(pg & ¶/fig/table/other)*
Aim of study *(e.g. efficacy, equivalence, pragmatic)*		
Participants *(e.g. Type of cancer, caregiver role, family and friend's role)*		
Design *(e.g. parallel, crossover, non-RCT, exploratory)*		

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Outcomes *(details of primary data e.g. user experience, usability, functionality, design etc)*			
Start/End date			
Ethical approval needed/ obtained for study	☐ Yes ☐ No ☐ Unclear		
Notes:			

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Review title or ID	Hodgkin lymphoma survivor wellness: Development of a web-based intervention.
Study ID *(surname of first author and year first full report of study was published e.g. Smith 2001)*	Amweg et al. (2020)
Report ID	10.1188/20.CJON.284-289
Report ID of other reports of this study including errata or retractions	N/A
Notes: N/A	

General Information

Date form completed *(dd/mm/yyyy)*	12/10/2021
Name/ID of person extracting data	SC
Reference citation	Amweg LN, McReynolds J, Lansang K, Jones T, Snow C, Berry DL, Partridge AH, Underhill-Blazey ML. Hodgkin Lymphoma Survivor Wellness: Development of a Web-Based Intervention. Clin J Oncol Nurs. 2020 Jun 1;24(3):284-289. doi: 10.1188/20.CJON.284-289. PMID: 32441674.
Study author contact details	Could not access
Publication type *(e.g. full report, abstract, letter)*	Full report
Notes: N/A	

Study eligibility

Study Characteristics	**Eligibility criteria** *(Insert inclusion criteria for each characteristic as defined in the Protocol)*	**Eligibility criteria met?** **Yes** **No** **Unclear**	**Location in text or source** *(pg & ¶/fig/table/other)*
Type of study	Quantitative design	☐ ☐ ☐	
	Qualitative design	☐ ☐ ☐	
	Mixed methods design	☒ ☐ ☐	Page 1 – Abstract Page 2 – methods – Focus groups – Development and usability testing
	Other (Please specify)		

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Participants	Cancer (Specify what type)	☒ ☐ ☐	Page 2 – Participant identification and recruitment
	Caregiver	☐ ☐ ☐	
	Friends/family	☐ ☐ ☐	
Types of intervention	Website/Internet-based cancer support programme	☒ ☐ ☐	Page 2 – Design and setting

Type of data (quant and/or qual) (Reports primary data on any of the following)	User experience/Needs/Preferences	☒ ☐ ☐	Page 2 – Focus groups
	Usability/Acceptability/Feasibility	☒ ☐ ☐	Page 2 – Development and individual usability testing
	Functionality	☐ ☐ ☐	
	Design on web	☐ ☐ ☐	
	Internet-based support living with and affected by cancer.	☐ ☐ ☐	
INCLUDE ☒		EXCLUDE ☐	
Reason for exclusion			

Notes:

The aim of this article was to adapt and evaluate a previously developed survivorship care website for Hodgkin Lymphoma survivors.

A mixed methods design broken down into phases

1) Focus group interviews – user needs
2) Web design and user testing – usability

DO NOT PROCEED IF STUDY EXCLUDED FROM REVIEW

For peer review only

Characteristics of included studies

Methods

	Descriptions as stated in report/paper		Location in text or source *(pg & ¶/fig/table/other)*
Aim of study *(e.g. efficacy, equivalence, pragmatic)*	The aim of this article was to adapt and evaluate a previously developed survivorship care website for Hodgkin Lymphoma survivors.		Page 1 – Abstract Page 2 – Introduction – paragraph 2
Participants *(e.g. Type of cancer, caregiver role, family and friend's role)*	Hodgekins Lymphoma survivors		Page 2 – Methods – Participant identification and recruitment
Design *(e.g. parallel, crossover, non-RCT, exploratory)*	Mixed methods user centred design – two phases 1) Focus groups 2) Development and individual usability testing		Page 2 – Methods – Focus groups – Development and usability testing
Outcomes *(details of primary data e.g. user experience, usability, functionality, design etc)*	User needs/preferences and usability of web-resource		Page 2 – Methods – Focus groups – Development and usability testing
Start/End date			
Ethical approval needed/ obtained for study	☒ Yes ☐ No ☐ Unclear	The Dana-Farber/Harvard Cancer Centre Institutional Review Board approved all study procedures. The study was conducted from April 2017 through December 2018.	Page 2 – Methods – Design and setting.

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Notes:

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BMJ Open

A rapid systematic review on developing web-based interventions to support people affected by cancer.

Journal:	*BMJ Open*
Manuscript ID	bmjopen-2022-062026.R1
Article Type:	Original research
Date Submitted by the Author:	16-Jun-2022
Complete List of Authors:	Cooke, Samuel; University of Lincoln, School of Health and Social Care Nelson, David; University of Lincoln, Lincoln International Institute for Rural Health; Macmillan Cancer Support Green, Heidi; University of Lincoln, School of Health and Social Care McPeake, Kathie; Macmillan Cancer Support; NHS Lincolnshire Clinical Commissioning Group Gussy , Mark ; University of Lincoln, Lincoln International Institute for Rural Health Kane, R; University of Lincoln, School of Health and Social Care
Primary Subject Heading:	Oncology
Secondary Subject Heading:	Health informatics, Public health
Keywords:	PUBLIC HEALTH, ONCOLOGY, Health informatics < BIOTECHNOLOGY & BIOINFORMATICS, World Wide Web technology < BIOTECHNOLOGY & BIOINFORMATICS

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A rapid systematic review on developing web-based interventions to support people affected by cancer.

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ABSTRACT

Objective: To systematically identify and explore the existing evidence to inform the development of web-based interventions to support people affected by cancer (PABC).

Design: A rapid review design was employed in accordance with the guidance produced by the Cochrane Rapid Reviews Methods Group and reported using the PRISMA checklist. A rapid review was chosen due to the need for a timely evidence synthesis to underpin the subsequent development of a digital resource (Shared Lives: Cancer) as part of an ongoing funded project.

Methods and outcomes: Keyword searches were performed in MEDLINE to identify peer-reviewed literature that reported primary data on the development of web-based interventions designed to support PABC. The review included peer reviewed studies published in English with no limits set on publication date or geography. Key outcomes included any primary data that reported on the design, usability, feasibility, acceptability, functionality, and user experience of web-based resource development.

Results: Ten studies were identified that met the pre-specified eligibility criteria. All studies employed an iterative, co-design approach underpinned by either quantitative, qualitative, or mixed methods. The findings were grouped into the following overarching themes (1) exploring current evidence, guidelines, and theory, (2) identifying user needs and preferences, and (3) evaluating the usability, feasibility, and acceptability of resources. Resources should be informed by the experiences of a wide range of end-users taking into consideration current guidelines and theory early in the design process. Resource design and content should be developed around the user's needs and preferences and evaluated through usability, feasibility, or acceptability testing using quantitative, qualitative, or mixed methods.

Conclusion: The findings of this rapid review provide novel methodological insights into the approaches used to design web-based interventions to support PABC. Our findings have the potential to inform and guide researchers when considering the development of future digital health resources.

Trial registration: The review protocol was registered on the Open Science Framework (osf.io/ucvsz).

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STRENGTHS AND LIMITATIONS OF THIS STUDY

- This review provides a rapid, yet comprehensive synthesis of the current evidence to support the time-sensitive decision making for the development and implementation of a novel digital resource (Shared Lives: Cancer) to help support PABC.

- This rapid review, whilst streamlined, was conducted using a systematic methodology, following rigorous reporting guidelines to ensure transparency and reproducibility.

- Whilst considered a key part of the knowledge synthesis 'family', rapid review methods are not subject to the same robustness as a full systematic review and are more vulnerable to bias and error.

- Due to time constraints, database searches were restricted to one database only and no formal quality assessment was performed on the included studies.

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INTRODUCTION

Improvements in cancer screening, early detection, diagnostic methods, and treatment are resulting in an increasing number of people living with and beyond cancer.[1-4] Globally, there were an estimated 18.1 million new diagnoses in 2018.[5] In the UK, it is estimated that 4 million people will be living with and beyond cancer by 2030.[6] As services have expanded to support the continuing rise in cancer incidence, so too have the complexities in delivering care.[7-9] This is epitomised by the changes in the way cancer care has been implemented over recent decades, which in the UK for example, now involves a multitude of bodies responsible for purchasing, commissioning, delivering, and regulating services.[8,10]

To ensure the provision of future cancer services adapts to changes in health needs, medical advances, and societal developments, NHS England implemented a long-term plan in which digital health technologies are central.[11] Digital health technologies have become an important tool in cancer care with the potential to revolutionise patient data, transform patient experiences, improve patient recovery, and improve the access, integration, and personalisation of care.[9-12] Evidence suggests that individuals living with and beyond cancer are engaging with digital health technologies now more than ever[13-16] and are using them to frequently access online health information as well as virtual support groups and forums.[17,18]

The rapid growth of internet use has led to a substantial increase in the number of web-based interventions to support PABC, including a wide range of educational and psychosocial platforms,[19-21] social media sites,[22] mobile applications,[22,23] and digital health interventions that focus on specific health behaviours e.g. physical activity and diet.[24] Whilst previous reviews have focused predominantly on the evaluation of web-based interventions, there remains little evidence documenting the developmental (design, usability, feasibility, acceptability, functionality, and user experience) processes of web-based interventions in cancer populations. This review assumes a novel approach by exploring and synthesising the academic literature that reports on the development of web-based resources that support PABC. This will explicitly include resources designed to support the physical, mental, and social consequences of cancer.

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The findings will be used to directly inform the development of a novel web-based resource called (Shared Lives: Cancer),[25,26] that aims to support PABC through making qualitative research data on lived cancer experience publicly available and freely accessible.

This rapid review aims to:

- Identify and map the peer-reviewed academic evidence that reports primary data concerning the development of web-based interventions for supporting PABC.
- Collate and report on the academic evidence with a view to informing web-based interventions for supporting PABC.

METHODS

This study used a rapid review approach adhering to the recently published guidance from the Cochrane Rapid Reviews Methods Group and for reporting used the Preferred Reporting Item for Systematic Reviews and Meta-Analyses (PRISMA) checklist, see supplementary material (S1). Rapid reviews are now considered a key component of the knowledge synthesis family alongside systematic reviews, scoping reviews and realist reviews. They provide a streamlined, efficient, and pragmatic approach to evidence synthesis.[27] In summary, rapid reviews are a form of evidence synthesis in which components of the systematic review process are simplified, with a view to producing findings in a timely manner.[28,29] Still, rapid reviews must remain systematic in their approach and have a duty to report their methods in a transparent manner making sure they are clear about deviations or omissions from the PRISMA criteria. This review was conducted over a 4-month period (July 2021 – October 2021). The study protocol has been registered on the Open Science Framework (osf.io/ucvsz) to promote reproducibility and facilitate methodological transparency, see supplementary material (S2).

Ethics Approval

Not applicable/No human participants included.

Patient and Public Involvement

No patient involvement.

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Search Strategy

Keyword searches together with Boolean operators (OR and AND) and truncation (*) were used to locate relevant peer-reviewed literature on the development of web-based support that is delivered to PABC. Due to the need to produce findings in a timely manner, database searches were limited to one database which is considered acceptable for a rapid systematic review. MEDLINE was searched as it is the leading full-text database of biomedical and health journals. The primary search strategy and syntax was developed and refined by three members of the review team (SC, DN, HG). All database searches were supplemented by Google Scholar searches in addition to forward and backward citation tracking on all relevant articles. Database searches were continually updated to identify and incorporate the most up to date evidence where appropriate.

To identify PABC the following keywords were used: "cancer surviv*" or "living with cancer" or "living with and beyond cancer" or "cancer patient*" or "patients with cancer" "people affected by cancer" or "oncology patient" or "cancer experience*" or "cancer management" or "cancer support" or "cancer care*". To identify web-based support and interventions the following keywords were used: "web*" or "internet*" or "online*" or "digital*". To search literature on user experience the following keywords were used: "user experience*" or "usability" or "functionality" or "design" or "interaction" or "development" or "user testing". The search strategy for MEDLINE can be found in supplementary material (S2).

All retrieved records were collated and stored using Endnote referencing software (EndNote X9, Clarivate Analytics, Philadelphia, USA). The titles and abstracts were screened against the eligibility criteria by one reviewer (SC). Where there was uncertainty about the inclusion of an article after title and abstract screening the first author (SC) discussed this with the second author (DN) to reach a final decision. Following title and abstract screening, the remaining articles were independently screened by full text, for inclusion by two reviewers (SC and DN), with any disagreements again resolved through discussion.

Eligibility Criteria

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Inclusion criteria

Peer-reviewed publications were selected for inclusion in this review if they met the following pre-defined eligibility based on the PICOT approach. **Population:** Adults (aged 18+), all genders, people living with cancer or affected by cancer, caregivers, any geographical location. **Intervention:** Website-based cancer support resources. **Comparator:** Not applicable. **Outcomes:** Reports primary data on the design, usability, feasibility, acceptability functionality, or user and developer experience of web-based support for PABC. **Type:** Reports empirical research data using either quantitative, qualitative, or mixed methods design. Only publications written in English language were included.

Exclusion criteria

Peer-reviewed publications were excluded based on the following exclusion criteria. **Population:** Non-adult population (under the age of 18). **Intervention:** Support programmes that focus solely on mobile and digital apps, E-learning programmes or interventions (self-directed and practitioner/professionally led), social media or networking sites. **Comparator:** Not applicable. **Outcomes:** No primary data reported on the design, usability, feasibility, acceptability, functionality, or user experiences of web-based support for PABC. **Type**: Systematic reviews or literature reviews, editorials, commentaries, opinion pieces, case series, or reports.

Data abstraction

Data were extracted using an adapted Cochrane Data Extraction Template, see supplementary (S3). One reviewer (SC) undertook data extraction for each full text article with cross checking taking place by a second reviewer (DN). Study characteristics were extracted from each study based upon (1) study methods (e.g. aims/objectives, study design, participants, outcomes) (2) details on the web-based intervention/support and (3) study findings (details of all relevant data concerning user experience, needs, preferences, usability, acceptability ,feasibility, functionality, and design).

Quality assessment

The focus of this rapid review is on identifying and exploring the literature on the development of web-based support that is delivered to PABC therefore, a quality assessment of included

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articles was not deemed appropriate. The omission of a quality assessment was in line with the methodological approach taken by other rapid systematic reviews where the focus is on producing evidence quickly.[30]

Data synthesis and analysis

The review included a wide range of study designs that utilised quantitative, qualitative, and mixed methodologies. To identify and map the evidence on the development of web-based interventions for supporting PABC we tabulated the results. This was then accompanied by a narrative summary where comments on the similarities and dissimilarities within data were made. Due to the wide heterogeneity of the design and outcomes of included studies, as well as the considerable amount of qualitative data, a formal statistical meta-analysis was not conducted; however, the findings were synthesised narratively.

RESULTS

Search results

The search of MEDLINE database provided a total of 2,446 distinct citations with an additional 6 identified through secondary sources, see Figure 1. After reviewing for title and abstract, 2,439 did not meet the pre-specified eligibility criteria. The remaining 13 citations were reviewed for full text and examined in detail for inclusion in this review. Three did not meet the pre-specified inclusion criteria as these were self-help, psychological, and educational supportive interventions. The resource the team are creating (Shared Lives: Cancer) cannot be classified as a self-help, psychological, or educational intervention, it exists primarily as a stand-alone website that the public can browse and interact with at their convenience. Therefore, we needed evidence directly in line with this approach to inform our own work and so consequently these articles were excluded. Overall, 10 studies met the pre-defined eligibility criteria that focused on the development of web-based tools to support PABC.

Study Characteristics

The ten articles were published between 2012-2020 and were undertaken in Australia,[31] Belgium,[32] Vietnam,[33] United Kingdom,[34-37] and the United States of America.[38-40] Five studies focused

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on people with specific cancer types including survivors of Hodgkin Lymphoma,[38] patients with experience of gynaecological cancers,[34] survivors of oral cancer,[39] and patients and survivors of breast cancer,[32,40] whilst four studies,[31,35,36] included patients with experience of a range of cancer types. Some studies also included family caregivers,[39] intimate partners,[32] healthcare professionals,[33,34,36,38] and researchers[34] alongside people with lived cancer experience. One of the included studies collected data with carers of people with cancer and health professionals only.[37]

All studies employed an iterative, co-designed methodological approach for the development of web-resources to support PABC. Two of the studies employed a mixed methods research design,[38,40] six utilised both quantitative and qualitative methods,[31,32,35-37,39] and two articles used solely qualitative methods.[33,34] Four studies explored user needs and preferences using focus groups,[32,38] discussion workshops,[33,34] semi-structured interviews,[33,39] and questionnaires.[32] Three articles explored preferences around the design of the web-based resources using discussion workshops,[34,37] and interviews.[31] Seven studies evaluated the usability and/or acceptability of web resources using 'think aloud' cognitive interviews,[36,38-40] focus groups,[35,36] semi-structured interviews,[40] structured interviews,[35] acceptability E-scales,[38] readiness scales,[31] website tracking,[31,37] and online surveys.[31,40] One study evaluated the feasibility of web-resources using a combination of surveys, questionnaires, and structured interviews,[35] and another carried out user testing (separate to usability testing) via interviews and evaluation surveys.[39] See Table 1 for further details of the characteristics of included studies.

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Table 1. Characteristics of included studies

Study (Country)	Population	Methods/Design	Key Outcomes
Amweg et al. (2020)[38] (USA)	Hodgkin Lymphoma Survivors n=10 Healthcare professionals n=9	Mixed methods, user-centred design Two phases: **1)** Focus groups **2)** Usability testing (cognitive interviews and acceptability E-scale)	**User needs and preferences** (Phase 1) Feedback on participants' specification preferences of website **Usability** (Phase 2) Feedback of preferences and experience of using website Acceptability of website
Ashmore et al. (2020)[34] (UK)	Gynaecological cancer patients n=5 Healthcare professionals n=5 Researchers n=3	Qualitative, multi-disciplinary co-creation approach Four discussion workshops **1)** Establish understanding of available support and treatment **2)** Establish key areas for support **3)** Website design and requirements **4)** Review of initial resource	**User needs and preferences** (Workshop 1 & 2) Establish understanding of available support and treatment Establish key areas of support **Website development** (Workshop 3 & 4) Development of initial resource through creation of a design brief 'wish list' Review of the design of initial resource and identification of recommendations for design team
Badr et al. (2016)[39] (USA)	Oral cancer survivors n=16 Family caregiver n=12	Quantitative and qualitative user-centred design Three phases: **1)** Qualitative needs assessment (semi-structured interviews) **2)** Prototype development **3)** Formative evaluation (usability testing - 'think aloud' interviews and user testing – interviews and survey)	**Preferences** (Phase 1) Feedback on the unmet needs and preferences for website **Website development** (Phase 2) Development of website prototype **Usability/User testing** (Phase 3) Identify navigational difficulties of website Identify participants' experiences of using website Evaluation survey (attractiveness, controllability, efficiency, intuitiveness, learnability)
Bartlett et al. (2012)[35] (UK)	Cancer patients n=259 (Breast, Colorectal, Germ cell, Gynaecology, Haematology, Kidney, Prostate, Sarcoma, Upper gastrointestinal)	Quantitative and qualitative user-centred design Three phases: **1)** Website design (focus groups and interviews) **2)** Computer and internet survey usage **3)** Crossover study (questionnaires and structured interviews)	**Usability** (Phase 1) Patient feedback on initial web resource **Feasibility** (Phase 2) Socio-demographics Computer and internet usage **Usability/Feasibility/Acceptability** (Phase 2) Web resource activity tracking Usability and acceptability feedback
Bradbury et al. (2019)[36] (UK)	Cancer patients n=32 (Breast, colorectal, and prostate cancer patients) Supporters of cancer survivors (nurses, GPs, care assistants, cancer charities) n=31	Quantitative and qualitative evidence, theory, and user-centred approach Seven phases: **1)** Scoping review **2)** Guiding principles **3)** Behavioural analysis **4)** Logic model **5)** Prototype of website **6)** Qualitative optimisation study 1 **7)** Qualitative optimisation study 2	**Usability/Acceptability** (Phase 6 and 7) Feedback of participants experience of exploring website, includes participants' likes, dislikes and recommendations for change
Fennell et al. (2017)[31] (Australia)	Cancer patients n=122 (Bones, breast, cervix, colorectal/bowel, lymphoma, lung, melanoma, ovaries, prostate, testicular, brain)	Quantitative and qualitative user-centred approach Two phases: 1) Website development (interviews) 2) Acceptability testing (website tracking activity, readiness scale, online survey)	**Design** (Phase 1) Feedback on initial website content and design **Usability/Acceptability** (Phase 2) Website usage Website acceptability and perceived impact

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Table 1. Continued

Study (Country)	Population	Methods/Design	Key Outcomes
Kapoor et al (2018)[40] (USA)	Breast cancer patient or survivor n=15	Mixed methods, evidence, theory, and user-centred approach Seven phases: **1)** Literature review and expert panel **2)** Review of current breast cancer survivorship guidelines and plans **3)** Development of decisions **4)** Curation of decisions **5)** Prototype design and development **6)** User feedback (semi-structured interviews) **7)** Usability testing ('think aloud' and semi-structured interviews and online surveys)	**Perceived usefulness** (Phase 6) Identify participants' perception and perceived usefulness of the website **Usability** (Phase 7) Identify the overall usability of the website
Pauwels et al (2012)[32] (Belgium)	Breast cancer survivors n=57 Intimate partners n=28	Quantitative and qualitative user-centred design Pre and post design (post-questionnaire, website tracking, care needs questionnaire)	**User needs** Assessment of participants' needs for information and support **Design** Evaluation of the content and lay-out of the website. Concepts evaluated include user friendly, well-built, interesting, informative, understandable, new, incomplete, irrelevant, unreliable, too extensive, or confusing **Usability** Information gathered about participants' use of the website
Santin et al (2019)[37] (UK)	Cancer carers n=12	Quantitative and qualitative co-design approach Two phases: **1)** Co-design model -Design of website (workshops and meetings) -Development of prototype 1 -User testing phase 1 (unstructured feedback sessions) -Refining prototype **2)** User testing -User testing and refinement (semi-structured interviews, web survey, website tracking) -Final development	**Design** (Phase 1) Evaluation and refinement of website design **Usability** (Phase 1 & 2) To gather views and experiences of users' interactions with the web-resource. Evaluate website use through tracking website activity
Santin et al (2020)[33] (Vietnam)	Informal cancer carers n=20 Healthcare professionals n=23	Qualitative co-design approach Two phases: 1) Identification of needs (interviews and focus groups) 2) Stakeholder verification and refinements (co-design workshops)	**User needs and perspectives** (Phase 1 & 2) Identifying and understanding the needs of informal cancer carers to underpin resource content Learn and agree upon shared priorities and resource components between informal cancer carers and healthcare professionals

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Overarching themes

The findings from the ten articles were grouped under the following three areas (1) exploring current evidence, guidelines, and theory (2) identifying user needs and preferences, and (3) evaluating the usability, feasibility, and acceptability of resources.

Exploring current evidence, guidelines, and theory

Bradbury et al.[36] conducted a rapid scoping review to identify the barriers and facilitators to intervention success including the participants needs and attributes and intervention components. Synthesised evidence from the review informed key design objectives including employing an approach that promotes well-being, ensuring the appropriate promotion of behaviour change, providing easy, timely and tailored information, and ensuring an efficient design. These findings were used to establish intervention guiding principles and inform the behavioural analysis and logic model that would underpin resource development. Similarly, Kapoor et al.[40] conducted a literature review to identify the needs of breast cancer survivors to assist in informing web-resource development. The findings, combined with input from an expert panel, helped to identify core functions to be incorporated into the design of a prototype resource including recording and tracking of quality life indicators, recording user-reported treatment-related symptoms, viewing breast cancer related medical history, viewing scheduled follow-up visits, and generating and displaying customised alerts related to symptoms and quality of life issues. Other studies also reported reviewing patient websites and performing literature reviews but were not explicit on how findings informed web-resource development.[31,37]

In addition to reviewing the available literature, studies also reviewed existing guidelines and theory to inform web-resource development. Kapoor et al.[40] conducted a comprehensive review of current breast cancer survivorship guidelines and existing survivorship plans which were used to inform the inclusion of key support information within the web-resource. Badr et al.[39] explored the best practices underpinning the management for oral and swallowing complications following radiotherapy, whilst also reviewing national healthy lifestyle guidelines for cancer survivors and evidence surrounding the self-determination theory. The findings were used to develop a prototype web-resource that specifically focused on promoting survivor and caregiver autonomy, competence, and relatedness; by providing

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tailored information, skill-building education, and support services. Other studies also reported reviewing clinical practice guidelines alongside reviewing the academic literature.[31]

Identifying the needs and preferences for resources

Participants of the included studies emphasised the need for resources that provide comprehensive information on cancer management and survivorship.[32-34,39] The need for clear information on survivorship care with a specific focus on physical, psychosocial, psychosexual, and emotional well-being was identified;[32,34,38] in addition to information on adjusting to 'new normal', returning to work, financial management, and lifestyle advice.[32,34,39] The inclusion of practical advice and information on the side effects of cancer treatments was viewed as essential[34,39] and participants expressed the need to learn from other survivors and carers through shared experiences and self-care strategies.[33,34,39] Concerns were raised by survivors regarding the risk of secondary cancers and how to communicate with family about experiences of cancer survivorship.[34] The inclusion of a 'Frequently Asked Questions' page was also proposed to ensure a safe space for users to search for specific information.[33,34]

Reported discussions between healthcare professionals focused on the need to ensure resources can be integrated easily into existing digital systems and are accessible across clinical specialities.[38] It was also considered important that participants did not view resources as a substitute for clinical care[38] and that information on family/carer support be included.[34] Caregivers expressed the need for emotional and supportive information on how to cope with cancer in addition to information on cancer side effects and lifestyle advice.[32,33,39] Concerns were also raised regarding the fear of reoccurrence and the need for specific self-care information and better family communication for carers.[39] Caregivers also discussed the inclusion of information regarding cancer causes and treatment, pain management, hospital administration and treatment processes, hospital daily living, and signposting to skills training.[33,39]

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Evaluating the usability, feasibility, and acceptability of resources

Studies explored the usability, feasibility, and acceptability of resources by qualitatively drawing upon the users' positive and negative experiences of web-resource interaction. Users viewed web-resources positively and valued their use in providing centralised, easily accessible information to support and facilitate survivorship care.[36-38,40] The content included within web-resources were regarded as useful in managing the consequences of cancer and was viewed as a credible source of information due to its development by trusted experts.[36,37,40] Accessing information through web-resources and video formats was perceived as less burdensome than written information and allowed users to easily access advice.[37] Resource features including providing useful website links, being able to access medical history, and tracking quality life indicators was also perceived as valuable components of web-resources.[40]

Whilst web-resources did provide easy access to information, the content of web-resources was considered impersonal with users expressing the need for more customised and prioritised information[35,37,38,40] that was representative of all genders.[37] Web-resources were found to be too complex with users experiencing difficulties in navigating and understanding the purpose of certain web-features highlighting the importance in developing simple and user-friendly web-resources.[35,38,39] Issues with web-resource design were also experienced with users emphasising the need for more appealing web-designs that use appropriate colour and size of both fonts and paragraphs, include greater cross-links, and incorporate much clearer navigational features.[31,38,39]

Studies also evaluated the usability, feasibility and acceptability of web-resources using a range of quantitative methods. A common approach identified was the use of Likert scale style questionnaires and surveys.[32,39,40] For example, Badr et al.[39] reported an overall resource usability score of 80/100 with individual areas rates as attractiveness (4.0/5), controllability (4.2/5), efficiency (4.1/5), intuitiveness (3.9/5), and learnability (3.8/5). Amweg et al.[38] employed an acceptability E-scale to objectively identify web-resource acceptability reporting an overall score of 29.8 (a score of <24 was considered an indicator of web-resource acceptability). Other studies also used descriptive

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questionnaires and surveys with users rating web-resources as easy to use, useful, relevant, necessary, and likely to return and recommend.[35,37] Studies were also shown to objectively explore website usability using website analytics.[31,32,35,37] For example, Santin et al.[37] reported 2769 unique visits between November 2017 and May 2018 of which 743 were returning visitors. Visitors were shown to access multiple website components including the 'getting through treatment', 'caring for you', 'financial', and 'employment' elements. Peer-led videos were the most frequently accessed content whilst professional led material, supporting children, and the emotional aspects of caring were the least visited.

DISCUSSION

This rapid review has systematically identified and mapped the peer reviewed academic evidence that reported on primary data concerning the development of web-based interventions for supporting PABC. Our findings highlight the use of user-centred, co-designed methodological approaches that are underpinned by iterative, but not necessarily sequential, development processes. A common approach used to develop web-based resources involved the initial exploration of the current evidence, guidelines, and theory followed by an assessment of user needs and preferences to ensure that web-resources were designed to meet the needs of its users. This was typically proceeded by the evaluation of resources involving usability, feasibility, or acceptability testing using a wide range of quantitative, qualitative, and mixed methods that often fed back into further resource refinement. Whilst previous reviews focus predominantly on evaluating the effectiveness of web-based resources, this rapid review differs in that it provides important and novel insights into the methodological approaches that underpin the development and implementation of web-based resources to support PABC. Our findings have the potential to assist other researchers who are developing digital resources and will be used by the current research team to inform the development of a web-based support platform (Shared Lives: Cancer)[25,26] that aims to make qualitative research data on lived cancer experiences publicly available via an open access searchable website. Specifically, the findings have made the team aware that the development of digital resources should be informed by the experiences of a wide range of end-users and co-developed where possible and appropriate. The design and content of resources should be

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centred around the user's needs and preferences and include resource evaluation as part of an iterative approach through usability, feasibility, or acceptability testing using a range of different methods. Following the launch of Shared Lives: Cancer, the team will continue to collect data on user experience to ensure its design and content is grounded within the needs of its intended audience.

Ensuring the appropriate design of web-based resources is a critical component of website development[41] in which the use of iterative, co-designed methods is strongly advocated,[42,43] especially with respect to cancer care.[44] This is supported by previous evidence that demonstrated the engagement of stakeholders throughout the developmental process ensures that digital tools are firmly grounded within the user's needs, which consequently improves usability and increases user engagement.[45-47] However, there must be an appreciation that users will have varying levels of digital literacy and this needs to be considered when designing and delivering digital resources. Existing research has shown that poor digital literacy is linked with computer anxiety and barriers to internet use amongst PABC.[48,49] Therefore, resources should be accessible and lay friendly to encourage engagement with people who have lower levels of digital literacy. At the same time, there will and continues to be PABC who prefer non-digital support for a variety of reasons. Therefore it is important that face-to-face support is maintained as digital services continue to be widely rolled out as a consequence of both the Covid-19 pandemic and global healthcare policies.

The findings from this review also emphasises the importance of collecting data on usability, feasibility, and acceptability, which are widely considered as important elements when developing web-based resources. An important decision future researchers may face during the ongoing development of digital resources is deciding how these areas will be measure. In line with evidence concerning usability and acceptability testing,[50,51] our findings point towards employing the use of a wide range of quantitative and qualitative methods and where possible should consider a combination of methodologies.[52] Whilst we identify key assessment methods including website analytics, E-scales, questionnaires, 'think aloud' interviews, semi-structured interviews, focus groups and workshops, future research should also consider other methods including more objective and automated methods, especially in the context of usability testing.[50,52]

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The development and implementation of digital tools has enormous potential in supporting future healthcare services through transforming the way individuals engage with services and professionals, advancing efficient care coordination, and allowing individuals to better manage one's health and well-being.[53-55] The use of digital technology is now considered a fundamental element that will underpin many of the proposed changes as part of the NHS long-term plan,[11] including desires to facilitate better care and support for individuals at home through the use of digital health tools. As the NHS looks to transform and adapt over the next decade, it is important to consider digital health technologies as a potential solution to improve and strengthen aspects or cancer care.[44] The findings of the current review provide important methodological insight that should be used to develop emerging digital health technologies that may help transform and support future healthcare services.

A strength of this review is that it allowed for a rapid synthesis of the current evidence needed to provide timely information to inform the decision-making process surrounding the development and implementation of a novel digital support resource (Shared Lives: Cancer)[25,26] as part of an externally funded project. It provides important insight into the methodological approaches used to develop web-based resources which may be used to guide and inform the design of future digital resources. A limitation of the current review was the lack of consistency and uniformity across outcome measurement tools of included studies, making it challenging to compare and interpret findings. Whilst rapid reviews are key in synthesising timely and informative evidence, it is recognised that the accelerated review process is not subject to the same robustness as a full systematic review. The current rapid review used a streamlined review process that restricted literature searches to one database only and omitted the inclusion of assessing risk of bias. We would encourage other researchers who are developing this work further to conduct a full systematic review that also includes a quality assessment of the academic literature. It is therefore acknowledged that the methodology of the current study is less comprehensive and as a consequence the results may be more susceptible to bias and error.

CONCLUSION

This research adopted a rapid review approach as there is a timely need for an evidence synthesis to support and inform the development of an ongoing project to design an online web-based platform

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(Shared Lives: Cancer).[25,26] The findings of this rapid review provide an important insight into the methodological approaches used to underpin the development of web-based interventions to support PABC. The evidence generated from this review has the potential to inform and guide future research endeavours when considering the development and implementation of digital resources.

AUTHOR CONTRIBUTIONS

SC, DN, HG and RK conceptualised and designed the review. SC reviewed titles, abstracts, full-text articles and extracted data with all data extraction verified by DN. SC and DN prepared the initial manuscript. HG, RK, KM, and MG reviewed and edited the final manuscript.

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COMPETING INTERESTS

The authors declare no competing interests.

PATIENT CONSENT FOR PUBLICATION

Not applicable.

DATA SHARING

All data are included within the manuscript and supplementary material.

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Figure legends

Figure 1. Study flowchart[56]

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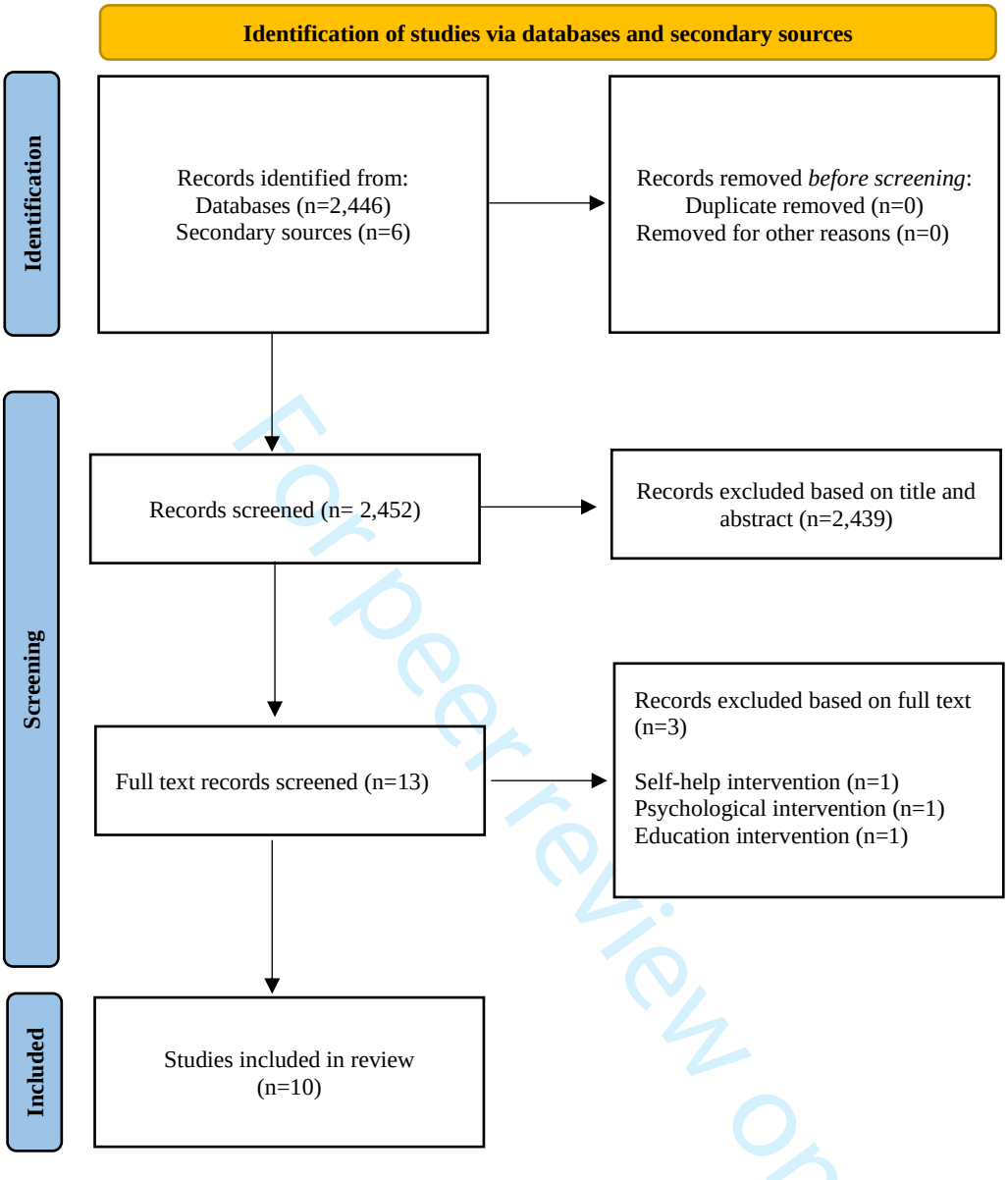

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PRISMA 2020 Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	Page 1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	Page 2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	Page 4/5
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	Page 2/5
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	Page 7
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	Page 6
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	Supplementary material (S2)
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	Page 6/7
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	Page 7
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	Page 7
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	Page 7
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	N/A
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	Page 7
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	N/A
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	Page 7
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	Page 7
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	N/A
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	N/A
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	N/A
Certainty	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	N/A

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Section and Topic	Item #	Checklist item	Location where item is reported
assessment			
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	Page 8 and Figure 1
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	Figure 1
Study characteristics	17	Cite each included study and present its characteristics.	Page 8/9/10/11 (Table 1)
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	N/A
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	N/A
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	N/A
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	N/A
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	N/A
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	N/A
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	N/A
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	Page 15/16/17
	23b	Discuss any limitations of the evidence included in the review.	Page 17
	23c	Discuss any limitations of the review processes used.	Page 16/17
	23d	Discuss implications of the results for practice, policy, and future research.	Page 15/16/17
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Page 5
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	Page 5
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	N/A
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	Page 18
Competing interests	26	Declare any competing interests of review authors.	Page 18
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	Page 7/18

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Developing web-based interventions to support people living with and affected by cancer: a protocol for a rapid review

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Abstract

Introduction: More people are living with and beyond cancer and digital interventions are increasingly being used to support them at all stages through their journey. This rapid review aims to systematically identify and explore the existing evidence that reports on primary data concerning the development of web-based interventions used to support people living with and affected by cancer.

Methods and analysis: Keyword searches were performed in MEDLINE to identify peer-reviewed literature on web-based interventions that are designed to support people living with and affected by cancer. The review will include studies published in the English language and will not have any restrictions on publication date or geography. Screening and data extraction will be completed independently by two reviewers. The included studies will be tabulated and the results synthesised narratively.

Discussion: This rapid review aims to identify and synthesise the peer-reviewed academic literature that reports on primary data concerning the development of web-based interventions to support people living with and affected by cancer. This methodology was chosen to rapidly synthesise the existing peer-reviewed evidence to support the development and design of an online web-based platform that the team are working on to make qualitative research data on lived cancer experience publicly available and accessible.

Ethics and dissemination: The review was registered and given a favourable ethical opinion on the 19/07/21 by a committee at the University of Lincoln (Review ref: 2021_6976). The findings from this rapid review will be presented at appropriate conferences and published in a peer reviewed academic journal as well as a report for the National Institute for Health Research Clinical Research Network.

Systematic review registration: The protocol was registered on the Open Science Framework [insert link here].

Keywords: cancer survivorship; web-based support; user experience; rapid review; protocol

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Introduction

Globally, cancer incidence is increasing with an estimated 18.1 million new diagnoses in 2018.[1] This can be attributed to advances in screening, earlier detection, diagnostic methods and improved treatments. Consequently, more and more people are now surviving cancer, and in the UK it is predicted that there will be four million people living with and beyond cancer by 2030.[2] Cancer raises a wide range of specific issues pertaining to information provision and emotional support [3] and there are now an increasing number of online health communities for people affected by cancer, each with their own specific aims.[4-6] Existing research has shown that people living with and affected by cancer use the internet for (1) content (online health information) (2) communication (e-mail and instant messaging) (3) communities (virtual support groups and forums) and (4) e-commerce (selling or buying products). [7]

The ongoing Covid-19 pandemic poses several challenges to oncology services and people living with and affected by cancer may now rely more heavily on digital and remote support.[8] [9] Consequently, some psychosocial and supportive cancer care has now shifted from face-to-face to virtual delivery.[10] Digital health technologies have the potential to reduce health inequalities in cancer care and can improve access, integration and personalisation of care.[6] They can be particularly beneficial to those in rural and remote settings where access has long been acknowledged as a barrier to care.[11] However, the benefits of digital health technology depend partly on digital health literacy (capabilities and resources required by people to use and benefit from it).[6]

Existing reviews have previously explored the use of web-based interventions for supporting people living with and beyond cancer. These include identifying and evaluating the effectiveness of a wide range of web-based resources such as educational and psychosocial platforms[5 12 13], social media sites[14], mobile applications[14 15], and digital health interventions that focus on specific health behaviours e.g. physical activity and diet.[16] The current review will differ to previous reviews by exploring the academic evidence that reports on user and developer experience/perception for building and developing web-based tools. The evidence synthesised from the review will be used to directly inform the development of a novel web-based resource that will support those living with and beyond cancer through making qualitative research data on lived cancer experience publicly available and accessible.

This rapid review will aim to achieve the following:

- Identify and map the peer reviewed academic evidence that reports on primary data concerning the development and utilisation of web-based tools for supporting people living with and affected by cancer.

- Collate and analyse primary data with a view to informing evidence-based recommendations for the development of a novel and accessible web-based tool that meets the needs of people living with and affected by cancer.

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Methods

The team will utilise a rapid review approach which is now considered a key component of the knowledge synthesis family alongside systematic reviews, scoping reviews and realist reviews.[17] Despite the increase in popularity of rapid review methods there is still no universal agreement within the extant literature as to how a rapid review should be conducted or defined.[18-20] In sum, rapid reviews are a form of evidence synthesis in which components of the systematic review process are omitted or simplified with a view to producing findings in a timely manner. [18 19] Still, rapid reviews must remain systematic in their approach and have a duty to report the methods in a transparent manner making sure that they are clear about deviations or omissions from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria.[21] This review will be conducted in line with the recently published guidance from the Cochrane Rapid Reviews Methods Group[22] and reported using the PRISMA checklist.[23]

Protocol and Ethics

The protocol has been registered on the Open Science Framework [insert link here]. This rapid review will be conducted over a 3-4 month period (July 2021 – October 2021).

The review was given a favourable ethical opinion by a committee at the University of Lincoln (Review ref: 2021_6976) on 19/07/21.

Search Strategy

We used keyword searches together with Boolean operators (OR and AND) and truncation (*) to locate relevant peer-reviewed literature on the user experience of web-based support that is delivered to people living with and affected by cancer. We searched MEDLINE (20/07/21) which is the leading full-text database of biomedical and health journals. The primary search strategy and syntax was developed and refined by three members of the review team (DN, SC, HG). The search strategy for MEDLINE can be found at Appendix 1. Due to time constraints, limited sources and the need to produce findings in a timely manner, we are limiting our search to one database which is considered acceptable for a rapid systematic review.[18 19] All database searches were supplemented with google scholar searches in addition with forward and backward citation searchers of relevant articles. Database searches will continually be updated to identify and incorporate the most up to date evidence where appropriate.

To identify people living with and affected by cancer we will use the following keywords: “cancer surviv*” or “living with cancer” or “living with and beyond cancer” or “cancer patient*” or “patients with cancer” “people affected by cancer” or “oncology patient” or “cancer experience*” or “cancer management” or “cancer support” or “cancer care*”

The following keywords will be used to identify web-based support and interventions: “web*” or “internet*” or “online*” or “digital*”

To search literature on user experience we will use the following keywords: “user experience*” or “usability” or “functionality” or “design” or “interaction” or “development” or “user testing”

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Inclusion and Exclusion Criteria

Peer-reviewed publications will be selected for inclusion in the review utilising the pre-defined eligibility criteria outlined in Table 1 below.

Table 1 Inclusion and Exclusion Criteria

Criterion	Include	Exclude
Population	Adults (18+) All genders People living with cancer/caregivers/people affected by cancer Any geography.	Non-adult populations (under 18).
Intervention	Website based/internet-based cancer support resources.	Support programmes that focus solely on mobile and digital apps. E-learning programmes or interventions (self-directed and practitioner/professionally lead). Social media/networking sites
Comparator	Not applicable.	Not applicable.
Outcomes	Reports primary data on user and developer experience/usability/functionality/design on web/internet-based support for people living with and affected by cancer.	There are no primary data reported on user experience/usability/functionality/design on web/internet-based support for people living with and affected by cancer.
Study design	Reports empirical research data using the following designs: • Quantitative • Qualitative • Mixed Methods	• Systematic and literature reviews • Editorials • Commentaries • Opinion pieces • Case series or reports
Language	Published in the English language.	Not published in the English language.

Data and Analysis

Record Selection

References identified via the search were exported and managed using Endnote Version X9. The final search identified 2,452 articles for screening, see Appendix 1. The titles and abstracts will be independently screened against the eligibility criteria by two reviewers (DN and SC). Where discrepancies exist, the team will aim to resolve via discussion or through a third reviewer (HG). Following title and abstract screening, the remaining articles will be independently screened by full text, for inclusion by two reviewers (DN and SC), with any disagreements resolved through discussion or a third reviewer (RK). The results will be presented in a PRISMA flow diagram.

Data Extraction

Data will be extracted using an adapted Cochrane Data Extraction Template and this can be found at Appendix 2. This will be piloted with a subset ($n=5$) of full text studies that meet our eligibility criteria to determine whether any further changes are needed to the data extraction

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template. After piloting the tool, two reviewers (DN and SC) will undertake data extraction for each full text article with cross checking for data quality taking place by a third reviewer (HG). Study characteristics will be extracted from each study based upon (1) study methods (e.g. aims/objectives, study design, participants, outcomes) (2) details on the web-based intervention/support and (3) study findings (details of all relevant data concerning user experience, usability, functionality, and design). All discrepancies will be resolved through further discussion, or where required, a fourth reviewer (RK).

Data synthesis and analysis

It is likely that the review will include a wide range of study designs that make use of both quantitative and qualitative methodologies. Following data extraction, the results of the full text articles will be tabulated. Quantitative data will be described using basic descriptive statistics as well as being written up narratively. We do not plan to conduct a formal statistical meta-analysis. Qualitative findings on user experience will be analysed using thematic synthesis.[24] Where possible we will group and comment on similarities and dissimilarities within the user experience data.

Quality assessment

The focus of this rapid review is on identifying and exploring the literature on user experience of web-based support that is delivered to people living with and beyond cancer, therefore, a quality assessment of included articles was not deemed appropriate.

Discussion

The aim of this research is to identify and map the peer reviewed academic evidence that reports on primary data concerning the development of web-based tools that support people living with and affected by cancer. It will also aim to collate and analyse data with a view to informing evidence-based recommendations for the development of a novel and accessible web-based tool that meets the needs of people living with and affected by cancer. It has been acknowledged that digital interventions have the potential to provide an excellent source of support for people living with and affected by cancer.[5 25] Specifically, they can help people to cope better with the disease and with side effects as well as improving self-management and wellbeing.[5]

A rapid review methodology was chosen to support and inform the timely need for the development and implementation of an innovative online web-based platform that is informed by peer-reviewed academic evidence. Rapid reviews are useful in adapting to and overcoming time and resource constraints that genuinely prevent the development and execution of a high-quality systematic review.[22] Nevertheless, researchers must endeavour to optimise the methodological rigour, clarity, and reproducibility of a rapid review, starting with the implementation of a rigorous and systematic protocol.[22]

Systematic reviews and meta-analyses are often intensive[26], especially when considering the large number of included studies, which is likely to be the case for evidence concerning user experience for developing web-based interventions in cancer. Whilst conducting a rapid review may accelerate the development process, it will enable a timely evidence appraisal that will address priority research questions as well as allowing for the rapid dissemination of findings.

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Dissemination

This rapid review and wider work (development of a web-based platform to support people living with and affected by cancer) benefits from the establishment of a study steering group with representation from academic researchers, cancer professionals and people with lived cancer experience. The review team will draw on their expertise and the findings will be disseminated in accordance with an ongoing dissemination strategy that will be developed collaboratively by the review team and steering group. This will involve presenting at appropriate local and national conferences, as well as, publishing in a peer reviewed academic journal. A summary of the findings will also be written up as a report for the National Institute for Health Research (NIHR) Clinical Research Network (CRN) who are funding this work. The team will disseminate the results in lay and accessible formats including using social media and press releases via the University of Lincoln and Macmillan Cancer Support.

Funding

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Acknowledgements

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Appendix 1 Search Strategy for MEDLINE

Key search terms	Date	Hits (*n*=)	Parameters
S1: "Cancer surviv*"	20/07/21	27,751	Medline only
S2: "Living with cancer"	20/07/21	865	Medline only
S3: "Living with and beyond cancer"	20/07/21	103	Medline only
S4: "Cancer patient*"	20/07/21	203,503	Medline only
S5: "Patients with cancer"	20/07/21	31,724	Medline only
S6: "People affected by cancer"	20/07/21	146	Medline only
S7: "Oncology patient*"	20/07/21	6,036	Medline only
S8: "Cancer experience*"	20/07/21	2,911	Medline only
S9: "Cancer management"	20/07/21	4,928	Medline only
S10: "Cancer support"	20/07/21	1,350	Medline only
S11: "Cancer care*"	20/07/21	26,976	Medline only
S12: S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11	**20/07/21**	**280,235**	**Medline only**
S13: "Web*"	20/07/21	287,832	Medline only
S14: "Internet*"	20/07/21	113,871	Medline only
S15: "Online*"	20/07/21	150,659	Medline only
S16: "Digital*"	20/07/21	182,713	Medline only
S17: S13 OR S14 OR S15 OR S16	**20/07/21**	**650,510**	**Medline only**
S18: "User experience*"	20/07/21	2,428	Medline only
S19: "Usability"	20/07/21	15,671	Medline only
S20: "Functionality"	20/07/21	66,353	Medline only
S21: "Design"	20/07/21	1,135,342	Medline only
S22: "Interaction"	20/07/21	876,907	Medline only
S23: "Development"	20/07/21	3,148,188	Medline only
S24: "User testing"	20/07/21	350	Medline only
S25: S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24	**20/07/21**	**4,858,310**	**Medline only**
S26: S12 AND S17 AND S25	**02/08/21**	**2,452**	**Medline only**

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Appendix 2 Adapted Data Extraction Form

Review title or ID	
Study ID *(surname of first author and year first full report of study was published e.g. Smith 2001)*	
Report ID	
Report ID of other reports of this study including errata or retractions	
Notes	

General Information

Date form completed *(dd/mm/yyyy)*	
Name/ID of person extracting data	
Reference citation	
Study author contact details	
Publication type *(e.g. full report, abstract, letter)*	
Notes:	

Study eligibility

Study Characteristics	**Eligibility criteria** *(Insert inclusion criteria for each characteristic as defined in the Protocol)*	**Eligibility criteria met?** **Yes**	**No**	**Unclear**	**Location in text or source** *(pg & ¶/fig/table/other)*
Type of study	Quantitative design	☐	☐	☐	
	Qualitative design	☐	☐	☐	
	Mixed methods design	☐	☐	☐	
	Other (Please specify)				
Participants	Cancer (Specify what type)	☐	☐	☐	
	Caregiver	☐	☐	☐	
	Friends/family	☐	☐	☐	
Types of intervention	Website/Internet-based cancer support programme	☐	☐	☐	

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Type of data (quant and/or qual) (Reports primary data on any of the following)	User experience	☐ ☐ ☐	
	Usability	☐ ☐ ☐	
	Functionality	☐ ☐ ☐	
	Design on web	☐ ☐ ☐	
	Internet-based support living with and affected by cancer.	☐ ☐ ☐	
INCLUDE ☐		EXCLUDE ☐	
Reason for exclusion			
Notes:			

DO NOT PROCEED IF STUDY EXCLUDED FROM REVIEW

Characteristics of included studies

Methods

	Descriptions as stated in report/paper	**Location in text or source** *(pg & ¶/fig/table/other)*
Aim of study *(e.g. efficacy, equivalence, pragmatic)*		
Participants *(e.g. Type of cancer, caregiver role, family and friend's role)*		
Design *(e.g. parallel, crossover, non-RCT, exploratory)*		

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Outcomes *(details of primary data e.g. user experience, usability, functionality, design etc)*			
Start/End date			
Ethical approval needed/ obtained for study	☐ Yes ☐ No ☐ Unclear		
Notes:			

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Review title or ID	Hodgkin lymphoma survivor wellness: Development of a web-based intervention.
Study ID *(surname of first author and year first full report of study was published e.g. Smith 2001)*	Amweg et al. (2020)
Report ID	10.1188/20.CJON.284-289
Report ID of other reports of this study including errata or retractions	N/A
Notes: N/A	

General Information

Date form completed *(dd/mm/yyyy)*	12/10/2021
Name/ID of person extracting data	SC
Reference citation	Amweg LN, McReynolds J, Lansang K, Jones T, Snow C, Berry DL, Partridge AH, Underhill-Blazey ML. Hodgkin Lymphoma Survivor Wellness: Development of a Web-Based Intervention. Clin J Oncol Nurs. 2020 Jun 1;24(3):284-289. doi: 10.1188/20.CJON.284-289. PMID: 32441674.
Study author contact details	Could not access
Publication type *(e.g. full report, abstract, letter)*	Full report
Notes: N/A	

Study eligibility

Study Characteristics	**Eligibility criteria** *(Insert inclusion criteria for each characteristic as defined in the Protocol)*	**Eligibility criteria met?** **Yes** **No** **Unclear**	**Location in text or source** *(pg & ¶/fig/table/other)*
Type of study	Quantitative design	☐ ☐ ☐	
	Qualitative design	☐ ☐ ☐	
	Mixed methods design	☒ ☐ ☐	Page 1 – Abstract Page 2 – methods – Focus groups – Development and usability testing
	Other (Please specify)		

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Participants	Cancer (Specify what type)	☒ ☐ ☐	Page 2 – Participant identification and recruitment
	Caregiver	☐ ☐ ☐	
	Friends/family	☐ ☐ ☐	
Types of intervention	Website/Internet-based cancer support programme	☒ ☐ ☐	Page 2 – Design and setting

Type of data (quant and/or qual) (Reports primary data on any of the following)	User experience/Needs/Preferences	☒ ☐ ☐	Page 2 – Focus groups
	Usability/Acceptability/Feasibility	☒ ☐ ☐	Page 2 – Development and individual usability testing
	Functionality	☐ ☐ ☐	
	Design on web	☐ ☐ ☐	
	Internet-based support living with and affected by cancer.	☐ ☐ ☐	
INCLUDE ☒		EXCLUDE ☐	
Reason for exclusion			

Notes:

The aim of this article was to adapt and evaluate a previously developed survivorship care website for Hodgkin Lymphoma survivors.

A mixed methods design broken down into phases

1) Focus group interviews – user needs
2) Web design and user testing – usability

DO NOT PROCEED IF STUDY EXCLUDED FROM REVIEW

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Characteristics of included studies

Methods

	Descriptions as stated in report/paper		Location in text or source *(pg & ¶/fig/table/other)*
Aim of study *(e.g. efficacy, equivalence, pragmatic)*	The aim of this article was to adapt and evaluate a previously developed survivorship care website for Hodgkin Lymphoma survivors.		Page 1 – Abstract Page 2 – Introduction – paragraph 2
Participants *(e.g. Type of cancer, caregiver role, family and friend's role)*	Hodgekins Lymphoma survivors		Page 2 – Methods – Participant identification and recruitment
Design *(e.g. parallel, crossover, non-RCT, exploratory)*	Mixed methods user centred design – two phases 1) Focus groups 2) Development and individual usability testing		Page 2 – Methods – Focus groups – Development and usability testing
Outcomes *(details of primary data e.g. user experience, usability, functionality, design etc)*	User needs/preferences and usability of web-resource		Page 2 – Methods – Focus groups – Development and usability testing
Start/End date			
Ethical approval needed/ obtained for study	☒ Yes ☐ No ☐ Unclear	The Dana-Farber/Harvard Cancer Centre Institutional Review Board approved all study procedures. The study was conducted from April 2017 through December 2018.	Page 2 – Methods – Design and setting.

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Notes:

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