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Codesign of Lynch Choices™: Using implementation science to create a clinically deliverable patient decision support website to transform cancer genetics care pathways

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Abstract

Background: Resources including Patient Decision Aids (PtDA) are useful and valued by patients and clinicians to provide information and complement shared decision-making. Despite their promise, few PtDA exist for patients with genetic cancer susceptibility facing difficult decisions about risk management. We aimed to fill this gap, partnering with patients to codesign Lynch Choices™, a PtDA website for families with Lynch Syndrome. In addition to a Patient Reference Panel, we purposively invited an international stakeholder panel including charities, public bodies, clinical and academic experts. Implementation strategies and frameworks were employed to optimise translation of research findings to improve care.

Methods: Patient/stakeholder suggestions were incorporated in a transparent Table of Changes and prioritised using the Person-Based Approach throughout planning and codesign of Lynch Choices™. An interactive stakeholder meeting was convened to identify barriers and facilitators to clinical implementation of the PtDA.

Results: Patient and stakeholder partnerships drove the direction of the research throughout codesign, resulting in several iterative refinements to the PtDA prior to roll out including the addition of illustrations/videos, clearer presentation of cancer risks and increased accessibility for lower literacy. Barriers and facilitators identified from stakeholders were used to create an implementation process map.

Conclusions: Creating an effective, engaging PtDA is not enough. Systematic uptake in real world clinical practice, with its resource limitations, is needed to optimise benefit to patients and clinicians. Assessment of speed and breadth of dissemination and usage will be collected to further evidence the benefit of embedding implementation science methods from the outset to translate research findings into clinical practice.

KEYWORDS
cancer genetics, codesign, decision support intervention, implementation science, patient decision aid, psychosocial support, translation of research to clinical practice

1 | BACKGROUND

Decision support interventions including patient decision aids (PtDA) have been shown to help people feel more informed, take into account their personal values and deliberate more about difficult decisions when compared to usual care across a range of medical settings.[1] Although robust evidence has been gathered about usefulness and acceptability of PtDA, successful clinical implementation appears to have been limited, which prevents patients having the chance to benefit from them. The reasons for this are likely multifactorial, including challenges keeping digital interventions up-to-date, securely hosted and accessible to the target population as well as resource limitations for healthcare professionals to train and engage with the PtDA and signpost patients. This is despite national guidance[2,3] and expert recommendations[4–9] supporting the widespread use of shared decision-making between patients and healthcare professionals, including the use of PtDA where appropriate.

Patients face complex decisions regarding genetic testing or making choices about cancer risk management after receiving their genetic test results. A 'good' decision is intricately personal and based on values, priorities, life situation, tolerance for uncertainty and the influence of others.[10] Patient-facing resources for genetic cancer susceptibility are needed to scale-up information provision, due to the ever-increasing amount of genetic testing initiated through universal tumour screening[11–13] 'mainstreaming' beyond the traditional clinical genetics setting to point of care testing in oncology clinics[14–18] and additional findings in cancer susceptibility genes from genetic or genomic (whole genome sequencing) testing initiated for non-cancer related indications.

Despite their potential usefulness and acceptability to patients and clinicians, a recent systematic literature review of decision support resources for genetic testing or cancer risk management did not identify any PtDA for patients with a genetic cancer susceptibility that were suitable for clinical implementation.[19] Most of the published resources were focussed on breast and ovarian cancer susceptibility due to a pathogenic variant (mutation) in the *BRCA1* and *BRCA2* genes with few resources dedicated to other conditions such as Lynch syndrome ('Lynch').

People with Lynch have a genetic predisposition increasing the lifetime risks for certain cancers that vary according to which of the mismatch repair genes *MSH2* (or *EPCAM*), *MLH1*, *MSH6 or PMS2* contains a pathogenic variant (https://www.insight-database.org) as well as the patient's age, sex and surgical/treatment history (www.plsd.eu). Personalised risks and management guidelines are now understood to be significantly different for each of the genes, leading to a recent position statement arguing that there are four gene-specific Lynch syndromes.[20] This suggested change in terminology from Lynch syndrome to Lynch syndromes illustrates one of the key design challenges for a PtDA, to keep up with the rapid advancement of clinically relevant research.

The most common Lynch-related cancers are colorectal, endometrial and ovarian with other associated cancers including small bowel, gastric, pancreatic, brain, skin, prostate and urinary tract.[21] Evidence-based guidelines are available for treatment, surveillance and risk-reducing options[22–26] (https://www.ukcgg.org) but advice continues to evolve[27–30] and decisions can be difficult, especially when considered amongst patients' other priorities and values.[31–34] Traditionally, people with Lynch and other genetic cancer susceptibilities have been tested and supported with multiple in-person clinic appointments involving tailored genetic counselling to provide information, facilitate adjustment to the psychosocial impact of a diagnosis and plan disclosure to family due to the duty to warn at-risk relatives. However, this approach is under pressure as the number of families requiring support grows, without a corresponding increase in the genetics and oncology workforces. Therefore, patient-facing resources, peer groups and charities, as well as streamlined pathways of integrated care in the community, have emerged to fill support needs.

A National Transformation Project by the NHS (National Health Service) in England was introduced to identify the 95% of people with Lynch in the population who do not know they have it.[35] Lynch is no longer considered rare and is likely the most common genetic cancer susceptibility with a population frequency estimated at up to one out of 250 people (https://www.insight-group.org). Our research team (KK, KM, LT, RF, DE, CF) chose to use Lynch as an exemplar condition to codesign an interactive, digital PtDA as part of a 5-year research programme funded by the charity Cancer Research UK, called CanGene-CanVar (https://cangene-canvaruk.org). The decision to focus on Lynch was based on the gap identified through our systematic literature review[19] and feedback from patients,[36] combined with the timely NHS initiative to increase awareness, screening and education. The PtDA template will later be adapted for other genetic cancer susceptibilities[36] and potentially non-cancer related genetic conditions.

The PtDA, called Lynch Choices™ contains sessions focussed on the two main decisions for people with Lynch: taking daily aspirin to lower the chance of developing cancer, and having hysterectomy (+/− removal of the ovaries and fallopian tubes) to prevent endometrial +/− ovarian cancer. The sessions contain interactive, values-based decision-making exercises with a printable summary to bring to clinic. Additional sessions focus on colonoscopy and other surveillance, lifestyle, living with genetic risk, chances and symptoms of cancer (personalised via link to www.plsd.eu), talking to family, and more support. Throughout the website, there are links to other sources of information and support such as charities and patient

groups. Visual presentation of cancer risks using icon arrays, bespoke illustrations and patient stories including videos supplement the text. Figure 1 displays screen shots from the draft PtDA including the home page, aspirin and hysterectomy sessions and an example patient story.

Codesign of Lynch Choices™ and the overall programme of work aimed at translating research findings to realise clinical uptake and patient benefit is underpinned by the following conceptual frameworks and guidelines:

1. The Person-Based Approach[37]: patients and other expert stakeholders were engaged to provide a detailed understanding of their experiences and preferences that directly informed development of a programme theory including core components, guiding principal and a logic model for the PtDA
2. The International Patient Decision Aids Standards[38]: best practice guidelines for evidence-based development were followed and checklists were used to ensure compliance with the recommended systematic process.
3. The Ottawa Decision Support Framework[39]: based on multiple theories and adaptable for any decision. In line with this framework, the PtDA outlines the decisions to be made, the options which include doing nothing, and values-based exercises to consider personal values and priorities.
4. Coulter's framework for decision aid development[40]: throughout the implementation planning and codesign phases, an iterative refinement process was used to incorporate changes and optimise the PtDA in response to feedback
5. The Medical Research Council framework for developing and evaluating complex interventions: guided the methodological and theoretical basis behind how the PtDA will support shared decision-making

High quality decision support interventions underpinned by psychological theory and codesigned with patients may be effective, but if not clinically implemented they will not improve care and support decision-making. Therefore, barriers and facilitators were considered from the earliest stages of the research, using implementation science solutions tailored to current contextual factors, to avoid the 'longstanding and persistent' problem of the 'non-uptake of effective clinical innovations'.[41] Rather than develop an intervention and prove its effectiveness, then pass on to implementation scientists to determine how it should be implemented, our aim was to apply implementation science methods from the outset of the development process to codesign an effective intervention that can be systematically implemented in real-world settings. This paper describes our approach, which involved informing, engaging, collaborating and partnering with a formal Patient Reference Panel throughout the codesign process. We complemented this by partnering with a large group of multidisciplinary, international experts in research and clinical care for genetic cancer susceptibility and other specialist areas such as low literacy, risk communication, art, film, graphic design, and digital behavioural interventions. We also considered the importance of systems, specialist and general services, community, digital regulations and policy.[42,43] We took the objective of gathering this knowledge and experience to create a process map outlining the

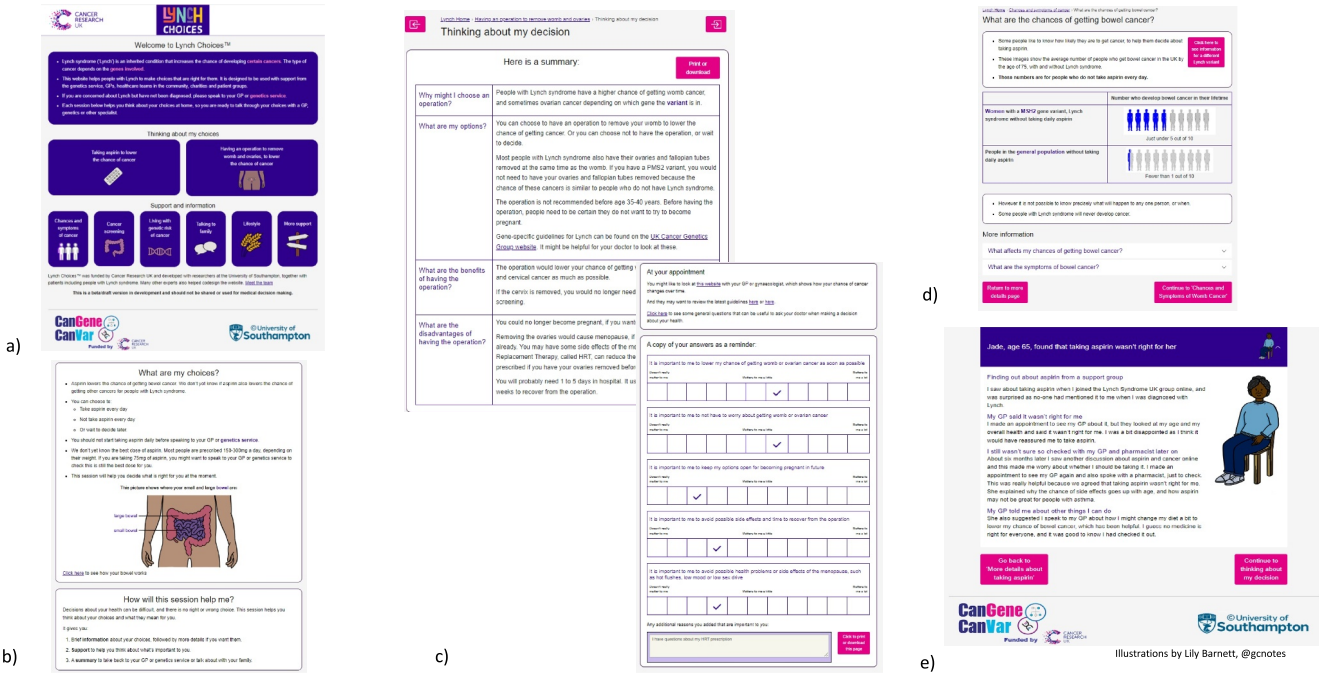

FIGURE 1 Screenshots from the draft version of Lynch Choices™, showing (A) landing page, (B) part of the aspirin decision aid, (C) printable summary and checklist from values-based decision support exercise from hysterectomy session, (D) visual presentation of cancer risks using icon arrays, (E) example patient story.

finer details about how the PtDA could be widely adopted into clinical practice, to guide uptake in the real-world setting.

2 | METHODS

A Patient Reference Panel (chaired by LT) was engaged from conception of the CanGene-CanVar programme. We also obtained valuable input from diverse patient groups in the community through patient engagement workshops, including those with or without cancer and/or a genetic cancer susceptibility, from minority ethnic groups, younger (<30 years) or older (>70 years), neurodiverse, LGBTQ+, lower literacy or any other underserved groups. Patient codesign was the central ethos for our research using the Person-Based Approach,[37] since patients are the experts in their own care and will not use the PtDA unless it is engaging, accessible and meaningful. A large group of international experts in clinical care, research and behavioural interventions was purposively sampled and invited to the International Lynch Decision Aid Stakeholder Panel (see consortium author list), to complement patient contributions and provide depth and breadth of experience and perspectives from wide-ranging medical and academic systems. Patients were offered remuneration for their time in line with the National Institute for Health and Care Research 'Payment guidance for researchers and professionals' (https://www.nihr.ac.uk). Other stakeholders were not offered remuneration, but attendance at meetings and level of engagement was voluntary to accommodate the many clinical and/or academic commitments. Terms of reference (Supplementary Files 1–2) were agreed for both groups and members were free to leave at any point. A publication policy was agreed (Supplementary File 3). Patients and other stakeholders were either invited to be named authors on presentations or publications, according to level of involvement, or included in a consortium author list under acknowledgements.

Implementation science strategies and frameworks aimed at supporting systematic uptake of the PtDA were reviewed and considered through a scoping review of the literature and online resources along with meetings with experts in implementation science. Importantly, these strategies were employed early in the project rather than waiting until the PtDA was completed. A meeting focussed on potential implementation barriers, facilitators and strategies was completed. Stakeholders were invited to join virtually or give feedback separately via email or a private meeting. Padlet (https://padlet.com) was used as a collaborative visual message board tool to capture ideas and suggestions in real time. Padlet message boards were created to request feedback, ideas and suggestions from the perspective of patients and other experts regarding the following questions about the PtDA:

1. What will be the key barriers to implementation?
2. How will clinicians know the decision aid is available to offer patients?
3. How can people find the decision aid themselves at home?

Additional patient/stakeholder meetings were held virtually, every three to six months during the prototype codesign process for the PtDA. Breakout rooms were used for small group discussions, with chat and message board functions used to capture feedback, along with short digital surveys. Email communication and meetings were arranged with individual stakeholders in response to need for expert advice and guidance related to specific content for the PtDA, for example, aspirin chemoprevention, gynaecological cancer surveillance and risk-reducing surgery, psychological theory underpinning behavioural interventions, risk communication, low literacy adaptations, uncertainty management and implementation science strategy. Feedback about the PtDA from patients and stakeholders was recorded line-by-line in a Table of Changes using the Person-Based Approach.[37] Suggested changes to the PtDA were reviewed and prioritised using the **MoSCoW** method of prioritisation to identify refinements that **M**ust be, **S**hould be, **C**ould be, or **W**on't be made this time, but would be made if there is enough time and resource in future.[44] This enabled transparent reporting back to stakeholders regarding how conflicting input was resolved, which changes were applied, how, why and when. Stakeholders who were national experts in specific content were consulted where needed, such as the lead of the aspirin prevention trial or a surgeon leading risk-reducing hysterectomy outcome studies.

2.1 | Ethical approval statement

Ethical approval was not required for patient and stakeholder engagement activities. Ethical approval was obtained from the UK Health Departments National Research Ethics Service and Health Research Authority (REC reference 22/NI/010, IRAS Project 312473) for a nested study involving in-depth patient interviews by KK to identify support needs, understanding of personalised cancer risks and decision support needs (paper in preparation).

2.2 | Consent statement

The CanGene-CanVar Patient Reference Panel and International Lynch Decision Aid Stakeholder Panel were not required to provide written consent but agreed Terms of Reference and were free to leave at any time. Written consent was obtained for specific activities such as recording videos of patient stories to be included on the website.

3 | RESULTS

The CanGene-CanVar Patient Reference Panel comprised 13 members with varied backgrounds and lived experiences with cancer or a family history of cancer. Some had genetic testing, and a few had a known genetic cancer susceptibility. Members included nine females and four males, ranging in age from 20 to 60s with personal/

professional backgrounds including lawyer, business owner, teacher, journalist, boat builder and student. Some were members from the beginning of the project and others joined at various times, after being invited by their clinician or another member. Interactions were respectful, with dissenting opinions valued, debated and resolved through discussion. Members made key recommendations to improve the validity, acceptability and relevance of the research approach (for example, asking demographic questions at the end of the interview after rapport was established) and PtDA content (for example, choosing the logo and changing the font to make it easier to read).

The International Lynch Decision Aid Stakeholder Panel evolved during the PtDA codesign process and comprised a multidisciplinary mix of patient groups, charities, public bodies, clinicians from multiple disciplines as well as researchers with expertise including behavioural science, shared decision making, psychology, risk communication, low literacy resources, implementation science and public policy. A summary of the roles and geographical location of stakeholders can be viewed in Supplementary File 4 and an acknowledgement slide presenting a visual overview of the diversity and geographical spread is shown in Figure 2.

Patient Reference Panel and Stakeholder engagement was complemented by in-depth, semi-structured patient think-aloud interviews (paper in preparation) plus additional public engagement workshops facilitated through community groups (paper in preparation) which led to refinement of the PtDA to make it more accessible, engaging and useful to wide-ranging groups of people. Changes included correction to the wording to be more inclusive to trans and non-binary patients, addition of more 'real' patient stories and videos, illustrations that displayed ethnic and body type diversity and improvements to the navigation and patient experience by adding more clear menus with 'breadcrumbs' showing which parts of the website people had visited.

Expert implementation science advice from the National Institute for Health and Care Research Applied Research Collaboration Wessex (https://www.arc-wx.nihr.ac.uk) resulted in the implementation toolkit and checklist being chosen to guide the translation of research findings from conception of the project through codesign to clinical implementation (Figure 3). This included use of an implementation wheel to map the project outputs, buy-in and engagement, fit with systems, alignment with healthcare priorities, outcomes and adoption. Failure to plan for any of these domains could result in lack of clinical uptake and limited benefit to patients and clinicians.

The six implementation wheel domains from the National Institute for Health and Care Research Applied Research Collaboration Wessex (https://www.arc-wx.nihr.ac.uk) implementation toolkit and checklist were considered from before the start of the project, throughout the duration and beyond the point of clinical implementation (Figure 3).

The stakeholder meeting focussed on barriers, facilitators and strategies produced crucial insights to consider before clinical implementation of the PtDA (see Supplementary File 5 for results, with a summary in Figure 4). Key barriers identified included inadequate current resources, such as lack of training and understanding

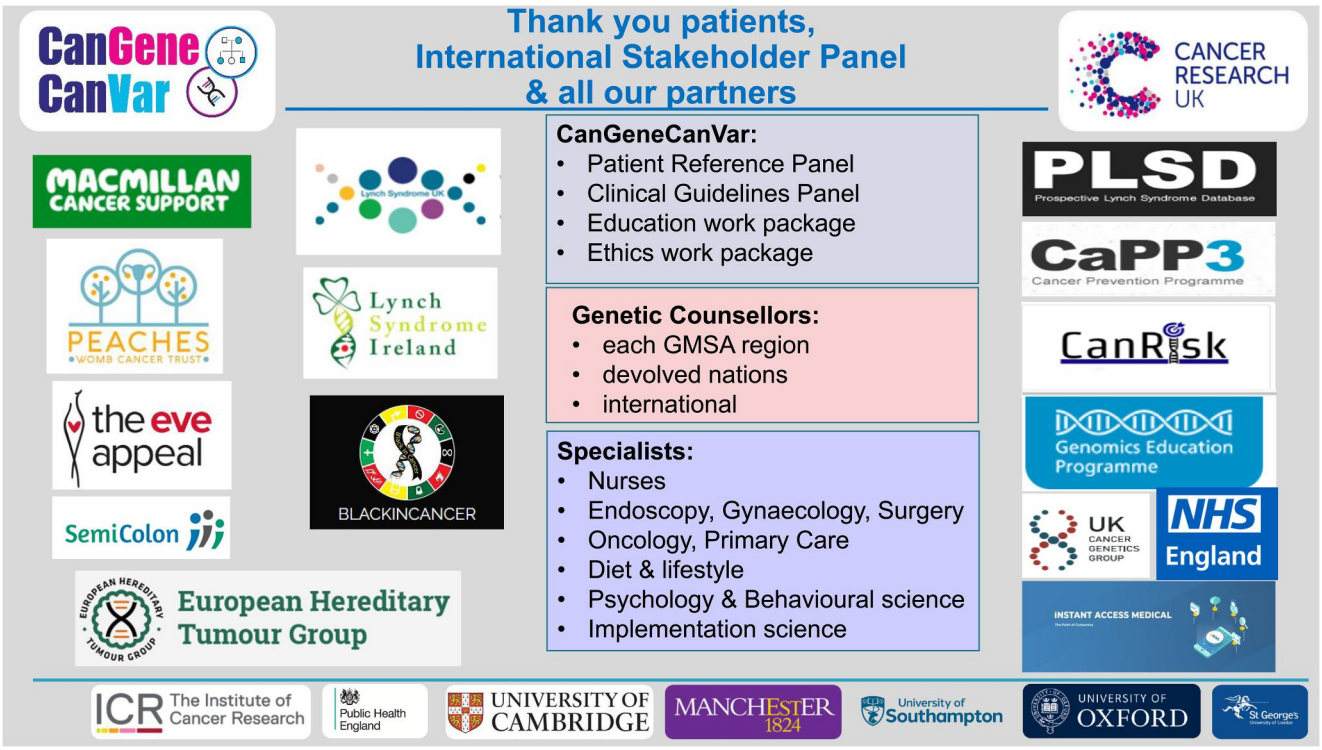

FIGURE 2 Acknowledgement slide shown in presentations displaying the diverse group of stakeholders engaged in codesign of Lynch Choices™, covering a wide geography and areas of expertise.

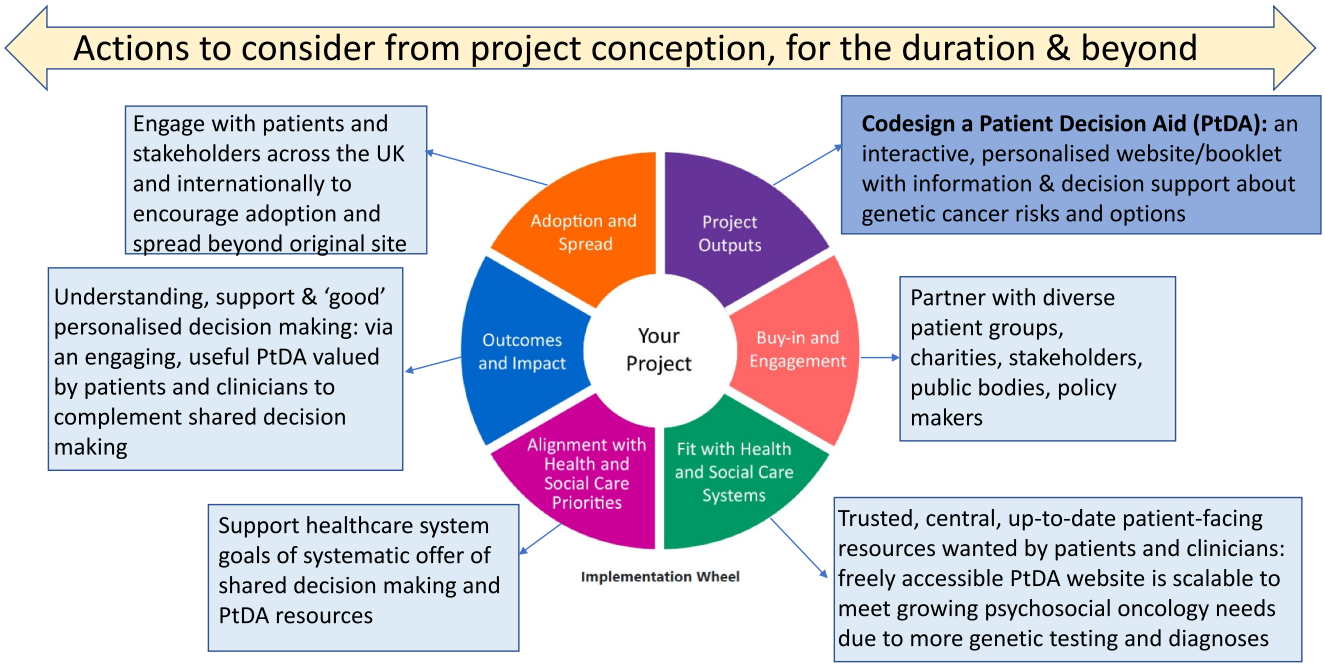

FIGURE 3 Implementation wheel showing the six domains considered from the conception of a project, throughout codesign and beyond the implementation of a Patient Decision Aid (PtDA) website/booklet. Adapted from NIHR ARC Wessex (https://www.arc-wx.nihr.ac.uk/other-resources).

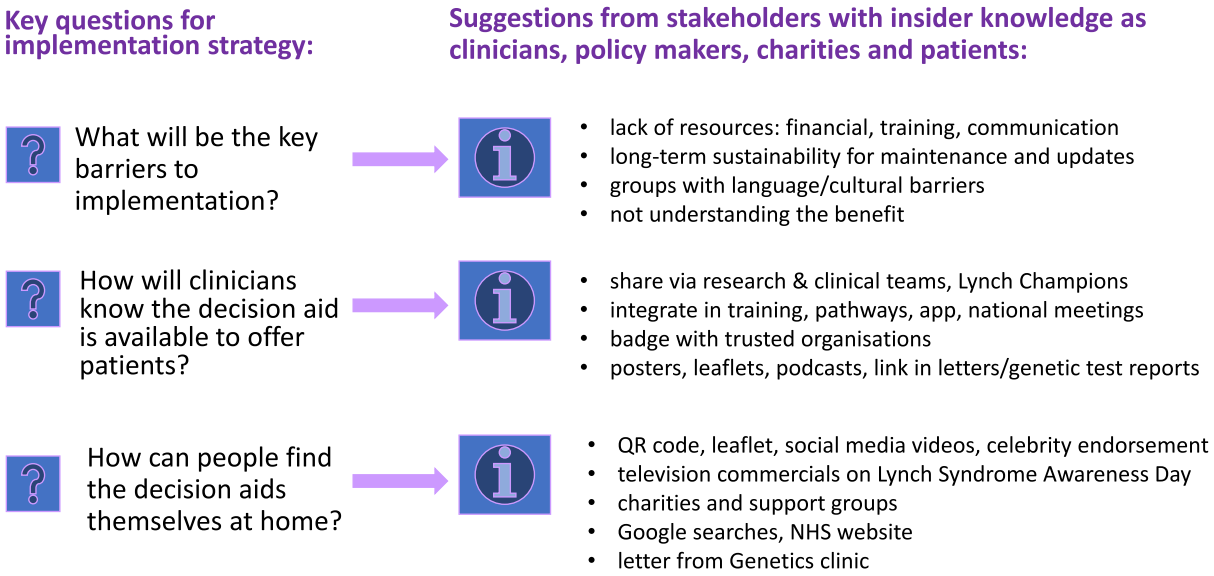

FIGURE 4 Summary of results from stakeholder meeting focussed on implementation barriers, facilitators and strategies held early in the PtDA prototype codesign process.

of the benefits of decision support interventions and future resources including long-term, sustainable funding to host and update the PtDA. Ideas about how clinicians could know the PtDA was available to offer patients included having QR codes for ease of access, links with charities, MDT champions and integration into trusted websites and systems. Regarding how patients could find the PtDA themselves, suggestions included leaflets, blogs, social media and endorsement from trusted professional groups along with celebrity champions. Enough administrative support in clinics to produce leaflets with QR codes to signpost to the website and possible partners to host and signpost to the PtDA.

Feedback from patients and stakeholders combined with personal 'on the ground' knowledge from experience as a cancer genetic counsellor was used by KK to create a process map for implementation (Supplementary File 6). This considered in detail the real world resources, systems and processes to highlight potential

implementation barriers and facilitators to address during PtDA codesign and before roll out. Stakeholders and patients have expressed enthusiasm about using the PtDA and confidence that their contributions have been instrumental in codesign of the website and preparedness for to achieve systemic uptake and allow for robust outcome reporting. Iterative optimisations to the PtDA were completed based on stakeholder and patient feedback recorded in the Table of Changes and prioritised using MoSCoW. A web developer was contracted to build and refine the PtDA website (draft viewable at https://canchoose.org). This will continue in future based on evolving evidence and clinical guidelines.

3.1 | Future work

Digital feedback surveys are being advertised in the community via stakeholders inviting patients in the target population and healthcare professionals to evaluate the PtDA in terms of aspects including usefulness and ease of understanding using Likert scales. The survey results will inform any final PtDA refinements and will be reported in a separate paper. Finally, roll out of the PtDA is planned in 2024. Incorporation into routine clinical practice is anticipated based on positive feedback and indication of readiness for use by patients and stakeholders with robust coverage of geographies and relevant specialty clinics. Usage will be tracked, and users invited to provide evaluative feedback to inform further optimisation of the PtDA. This will allow assessment of the number and type of clinical settings that adopt the PtDA and make it available for patients and their relatives as well as any gaps to target education of healthcare professionals in these areas. Primary outcomes that will be measured include time spent, decisional conflict and acceptability.

4 | DISCUSSION

Patient decision support interventions including PtDA show great promise to help people make difficult decisions in line with their priorities and values, feel more informed, and minimise decision regret. PtDA are not designed to replace shared decision-making with healthcare professionals but can complement this process by providing an informative and supportive patient-facing resource that can be accessed outside of clinic and shared with relatives. There is a longstanding and growing evidence base for the effectiveness of PtDA,[1,39,45] as well as confirmation from patients that they want a central, trusted resource[31,32] and recommendations from national healthcare services[3] and government bodies[2,46,47] to make shared decision making and use of PtDA routine clinical practice. However, there is little evidence of successful clinical implementation of PtDA.[6,48]

A group of expert clinicians and/or researchers could create an effective PtDA on their own. However, this is not enough; even a PtDA that 'works' by producing the intended outcomes and minimal harm will not benefit patients if it is not used.[41,42] We employed implementation science strategies throughout the codesign of a PtDA which allowed us to engage with and listen to the people who will use it (patients) as well as the healthcare professionals who will decide whether to signpost it in clinic. Elements included to plan for successful implementation are in line with the PARIHS (Promoting Action on Research Implementation in Health Services)[43] conceptual framework: evidence-based information endorsed by experts is included in the PtDA; local, 'real life' context of the delivery setting has been considered, and translating research evidence into clinical uptake has been prioritised in partnership with patients and other experts. Our strategy of assembling multidisciplinary collaborations has been recommended to address the 'global challenge' of successfully implementing psycho-oncology interventions into routine practice.[49]

Aims and objectives were achieved in the planning and codesign phases of Lynch Choices™ PtDA codevelopment, including engagement of a patient panel, community patient groups and other expert stakeholders. This informed a realistic process map to guide implementation and adherence to implementation science and intervention development guidelines and conceptual frameworks. The international stakeholder panel made significant contributions to iterative optimisation of the PtDA prototype codesign through provision of expert advice and guidance about content and implementation facilitators/barriers.

4.1 | Study limitations

Reimbursement for patient time, travel and accommodation was costed in the CanGene-CanVar programme grant, which provided good coverage for activities during PtDA prototype codesign. The research team recognised that to increase equality, diversity and inclusion, there was a need to invite more patient partners from different communities. This was achieved, but required additional, dedicated grant funding and small pilot projects working with trusted leaders and patient charities/groups. Funding was not available for other expert stakeholders' time, which limited their availability.

4.2 | Clinical implications

Increased genetic testing means more people with cancer and their relatives are told they have a higher chance of developing cancers than the general population due to predispositions such as Lynch. Lynch is no longer considered rare; although the number of diagnoses is growing, this has not been matched by a proportionate increase in the genetics and oncology workforces. Patients want trusted, up-to-date resources that are engaging and helpful to support decisions about managing genetic cancer risks. Using implementation science strategies and frameworks, we engaged extensive partnership networks with diverse patient groups and international stakeholders to codesign an interactive, personalised patient website for Lynch that will later be adapted for other genes. We are poised for systematic

uptake in clinical practice of a PtDA, despite significant resource limitations. Future publications will report on this, along with outcome measurements to evaluate the benefit to patients.

5 | CONCLUSIONS

Clinicians and patients have a shared goal of good communication and understanding to support high-quality decision-making and outcomes. Working together, with the support of a suite of resources including PtDA, shared decision-making between healthcare professionals and patients can help to support a 'good decision', which is always individual and the one that a patient feels 'is right for me'.[10] More research is needed to discover whether people follow through on intended decisions and whether use of PtDA improves patient care and health outcomes. However, none of this will be possible unless high quality, effective PtDA are used in the real-world setting, in the context of the resource limitations and time pressure that make systematic uptake challenging even when recommended by healthcare systems and government guidance. Developers of PtDA should take a codesign approach from conception of their projects, partnering with the patients who will use the resource and the healthcare professionals who will be asked to recommend it. Strategies and methods from implementation science should be considered, to bridge the gap between evidence-based research and clinical practice. This should maximise the uptake of PtDA so the potential benefit to patients and clinicians can be realised. Further research is needed to assess the speed and breadth of dissemination and usage, to evidence the benefit of embedding implementation science methods from conception of PtDA codesign projects.

AUTHOR CONTRIBUTIONS

Conception and design of the manuscript: Kelly Kohut; involved in drafting the manuscript or revising it critically for intellectual content: Kelly Kohut, Kate Morton, Lesley Turner, Rebecca Foster, Diana Eccles, Claire Foster; giving final approval of the manuscript: Kelly Kohut, Kate Morton, Lesley Turner, Rebecca Foster, Diana Eccles, Claire Foster, consortium authors CanGene-CanVar Patient Reference Panel, International Lynch Decision Aid Stakeholder Panel (see lists of names in acknowledgements); agreed to be accountable for all aspects of the work: Kelly Kohut, Kate Morton, Lesley Turner, Rebecca Foster, Diana Eccles, Claire Foster.

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CONFLICT OF INTEREST STATEMENT

The authors have no conflict of interest to declare.

DATA AVAILABILITY STATEMENT

The data that supports the findings of this study are available in the supplementary material of this article.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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