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Research Article

Development of a Cancer Pathway Support Guide for Patients and Carers: A Codesign Project

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Background. Cancer diagnosis is a complex and multifaceted process that can be stressful and anxiety-provoking for patients. Evidence-based tools and information aids that can be used for guiding and supporting patients during cancer investigations and after diagnosis are limited. This paper presents a user-centred codesign project that aims to develop a cancer pathway support tool for patients, carers, and healthcare professionals. *Method*. A mixed-method codesign approach was used including prototype development (January–March 2022), three online codesign workshops (April–June 2022), one-to-one feedback, and beta testing informed by the standardised Theoretical Framework of Acceptability (TFA) questionnaire (July–October 2022). Nine individuals with lived experience of cancer contributed to the project and are referred to as codesigners. *Results*. The codesigners valued the potential importance of a tool that can be used by the patients and carers if they want specific information about cancer investigations, diagnosis, and treatment. The ability to select what they need as opposed to long leaflets and generating their own questions for the healthcare providers were highlighted as important aspects of improving patient care. The tool was collectively designed to provide clear definitions of the cancer care pathway and easily accessible links from trusted resources and includes practical information to minimise the burden that can be experienced from preparation for appointments and tests. Beta testing results with a small sample of potential users including patients, carers, and healthcare providers ($n = 23$) showed high acceptability of the guide (range = 7–35, mean = 28.52, and standard deviation = 3.88) based on the TFA questionnaire. *Conclusion*. A cancer pathway support tool called "Your Cancer Pathway Support Guide (YCPSG)" was developed as a result of an iterative codesign process aiming to improve patient experience and outcomes for people referred on a suspected cancer pathway or who have been diagnosed with cancer. The tool provides information and support in both digital and PDF formats. Further studies are needed to evaluate the potential impact of "Your Cancer Pathway Support Guide" on patient outcomes and experience and the wider system.

1. Background

Cancer diagnosis can be a complex and multifaceted process. An average of 2 million individuals in England (a minimum 10% increase since 2015) receives a referral for suspected cancer with 7% subsequently receiving a cancer diagnosis [1]. There are a number of routes to getting a cancer diagnosis in England, from a general practitioner (GP)-suspected cancer referral (almost 40%) to emergency presentations (just under 20%). There is clear guidance on information to be shared with patients, notably that the referral is for suspected cancer [2]. However, the outcomes and patients' experiences vary significantly across the routes to cancer diagnosis. Clear communication and appropriate information from the point of referral can help patients understand the reason for the urgent referral, what to expect during the diagnostic process, and how to navigate the healthcare system.

In England, there is an annual survey—the National Cancer Patient Experience Survey (NCPES) [3], which enables cancer patients to give feedback on the care they received across

the cancer pathway. The NCPES data on patients' communication needs suggest that negative experiences are fuelled by inadequate information, lack of effective follow-ups, and communication barriers between primary and secondary care [4–10]. NCPES and other sources reveal the inequalities in patient experience across protected groups, geography, and sociodemographic characteristics [4, 6]. For instance, patients from ethnic minority groups report lower satisfaction, lower confidence, and low understanding of the consultation contents delivered by healthcare professionals [6]. Patients with dementia need further support such as continuity of care, navigating through the healthcare system, shared decision-making, and support from family members [7]. For caregivers, the unmet needs are for information about the illness and the treatment and care. Furthermore, about 5% of the patients who are referred to the suspected cancer pathway do not attend their urgent referrals. Nonattendance has been associated with the patient's age, male gender, deprivation, suspected cancer site, time of referral, and distance to the hospital [8]. Patients' unmet needs after diagnosis include emotional support, managing the effects of treatment, and fatigue [9, 10]. These findings across the various groups support the need for better and more effective communication between the patient and the healthcare providers across the pathway. This is highly challenging because of the specificity required for different cancer types, the variation in investigations, symptoms, and different providers and hospitals. This information needs to be personalised and tailored to patients' needs.

Evidence-based tools and information aids that can be used for guiding and supporting patients during cancer investigations and after diagnosis in England are limited. To our knowledge, digitally accessible information resources for suspected cancer referral and cancer pathways are mostly developed by patient-centred third-party organisations such as Cancer Research UK [11] or Macmillan [12]. The information often captures only part of the cancer pathway, is not easy to find using web browsers without specific search terms requiring a priori knowledge (e.g., two-week wait, suspected cancer, straight to test, and cancer nurse specialist), and cannot be tailored for personal use. There is also no standardised patient information leaflet for suspected cancer referrals in England and the information is often tailored regionally or locally which could potentially increase variation in the care delivered across the country [13, 14].

In this paper, we describe the results of a service improvement project conducted by the North Central London Cancer Alliance (NCLCA) to develop a patient information guide that addressed the key stages in the cancer pathway (from referral to discharge) and we present the final product that was produced as an outcome. The guide aims to improve patient experience, confidence, activation, and shared decision-making by improving understanding of what to expect on the pathway and signposting to supportive services/resources. Codesign methodology was used to develop the guide for people referred on a suspected cancer pathway or who have been diagnosed with cancer. Codesigners on the project included people who have lived experience of cancer, family members, carers, and those who have had a suspected cancer referral.

2. Methods

2.1. Project Background. The project was initiated and facilitated by the North Central London Cancer Alliance (NCLCA), with support from a health and social care champion organisation called Healthwatch Barnet and advocacy from Macmillan Cancer Support. NCLCA brings together patients, hospital trusts, GPs, health service commissioners, and local authorities to improve cancer outcomes and care. It covers the London boroughs of Barnet, Camden, Enfield, Haringey, and Islington. NCLCA is one of 21 cancer alliances established by the National Health Service (NHS) England to transform cancer transform the diagnosis, treatment, and care for cancer patients. These partnerships enable care to be more effectively planned across local cancer pathways.

2.2. Ethics Statement. This project was exempt from ethical review and was carried out as part of service improvement and evaluation led by the North Central London Cancer Alliance (NCLCA).

The codesign methodology was used throughout the project to develop and design the cancer pathway support guide with patients and healthcare professionals [15]. A mixed-method approach informed by the Beyond Sticky Notes CoDesign process was used including three online codesign workshops, one-to-one feedback, beta testing, and an online acceptability questionnaire [16]. Here, we will discuss the first five phases of the codesign process, namely, (1) build the conditions, (2) immerse and align, (3) discover, (4) design, and lastly, (5), test and refine. See Table 1 for the objectives to be achieved at each phase of the project. The last stage (6) implement and learn will be addressed in the discussion. Figure 1 demonstrates the flow and the timeline of the project based on the aforementioned codesign process.

2.3. Procedure

2.3.1. Phase 1–3: Build the Conditions, Immerse, Align, and Discover. A case for change was developed as a response to national data (NCPES), local thematic system-wide performance, and patient experience feedback. As part of the exercise, a brief scoping review to identify existing patient and public-facing tools and information for addressing these barriers in the cancer pathways was performed.

The findings showed that there was no existing support that met the needs across the whole pathway. The response to the case for change and the scoping review was to map the main stages of the pathway with key questions and answers users may have. This was the draft prototype. The draft prototype was initially sense-checked and feedback was provided by a patient representative, NCLCA team members, Macmillan, and Healthwatch Barnet stakeholders. The revised draft was shared with the wider user group. The updated prototype was used as the baseline product.

2.4. The Prototype. The initial prototype included 12 touchpoints in the cancer diagnosis pathway where patients may have a different experience with healthcare

Table 1: Your cancer pathway support guide codesign objectives.

Codesign phases	Objectives
Build the connections	Identify partners and stakeholders who are invested and interested in developing a product that will aim to improve patient experience in the cancer diagnosis pathways
Immerse and align	Identify why the aforementioned stakeholders and partners are delivering the project
Discover	What is the gap in the evidence in relation to improving patient communication in the cancer diagnosis pathways? What do we know about the patient experience? Is there an existing tool for improving patient experience across the cancer diagnosis pathway? What information is already being provided at the referral? What is the evidence?
Design	What information is needed by those who have been through the cancer diagnosis pathways? How do we build a resource that can be personalised and used by patients entering the cancer diagnosis pathway from different routes to diagnosis? How can we make sure the resource is accessible, equitable, and easy to understand? What are the psychological consequences of using the tool?
Test and refine	Is the tool working as intended? Do people understand the information provided?
Implement and learn	How can we evaluate the resource? What is the patient benefit? e.g., immediate, medium, and long-term How can we improve the resource? Future research ideas and evaluation

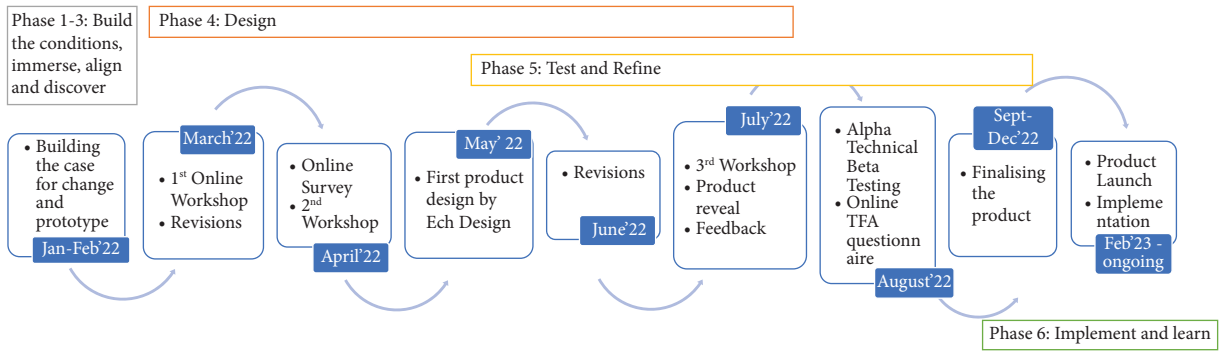

Figure 1: YCPSG codesign project timeline.

professionals depending on how their investigations have been initiated or concluded (see Table 2). See Supplementary Materials 1 Section 1 for the prototype toolkit.

Within the key transition points (based on the literature, existing information aids, and discussions with primary stakeholders), 65 initial questions were identified to support patients at different stages of the diagnosis pathway. The majority of the questions focused on how to navigate the healthcare system and practical issues (e.g., do I need to prepare for the tests?). In addition, there were many questions regarding where to access support (e.g., emotional and financial) and where to find further information (e.g., signposting links from verified and trusted sources). The draft prototype did not include the responses to the queries at this stage, allowing the codesigners to reflect and contribute to the resource rather than a top-down approach.

2.4.1. Phase 4: Design

(1) Setting. All engagement was carried out via Microsoft Teams and recorded using verbal consent in the secure NCLCA drive supported by NHS Digital. The codesign workshops were hosted by the NCL CA delivery team (DT) and Healthwatch Barnet. No identifiable individual data were collected, used, or shared as part of this project and adhered to General Data Protection Regulations (GDPRs) throughout the project.

(2) Codesigners. Individuals were invited through Healthwatch Barnet and social media tools such as Twitter using structured invitations, aiming to recruit those who are interested in improving local NHS cancer services and either/or

Table 2: Key transition points in the generic cancer pathway for patients.

1	At the point of referral into the urgent suspected cancer pathway
2a	At first clinical consultation (healthcare professional led, e.g., doctor/clinical nurse specialist)
2b	If the first appointment is straight to test
3	Investigations
4	If further investigations are needed
5	DIAGNOSIS
	A.1. Negative cancer diagnosis: not cancer: no pathology found
	A.2. Negative cancer diagnosis: not cancer: significant other pathology found
	B. A cancer diagnosis is made
6	Multidisciplinary team discussion
7	Decision to treat
8	Treatment process
9	Intertrust referrals* for further specialised care (if relevant)
10	Intertrust referral* back for continuation of care
11	Treatment review
12	Discharge and community care planning (could be over a series of encounters)

*Intertrust referral, where a patient is referred by one NHS provider to another NHS provider for cancer treatment.

(1) People with lived experience (living with cancer)

(2) People who have been through a cancer pathway (no cancer)

(3) People who currently use healthcare services and pathways and can contribute to improving the experience

(4) Carers/relatives who support patients in the above categories

Nine people with lived experience of cancer as a patient, carer, and service user contacted the NCLCA wanting to contribute to the project. Once individuals agreed to join the workshops, they received an electronic or printed copy of the draft prototype to review. They were asked to look at the content, language, format preferences, and accessibility considerations, as well as implementation planning. Here on, they are referred to as codesigners to reflect the equal contribution made by all individuals who took part in the workshops and provided consent for publishing the anonymous information collected at the workshops. No data were collected about the demographic characteristics of the individuals who took part in the workshops apart from their acknowledgment of lived experience of cancer.

(3) Workshops (31 March 2022, 5 April 2022, and 5 July 2022). The first two workshops followed a structured focused group process in which the individuals were introduced to the prototype in detail, the aims of the product once it is produced, why it is needed, and why NCLCA as an organisation was well placed to deliver this project demonstrating the first three phases of the codesign process. The workshops then followed with open-ended questions, asking the participants to be critical about what information should be provided to patients across the cancer pathway, what they would expect from a guide if it was produced, how it should look, and how it should be presented to make sure it is accessible for all individuals. The workshops were two hours long and comments from the codesigners were noted for discussion and inclusion in the next iteration of the prototype in workshop 3. A design brief was created for the design agency (Ech Design) that was commissioned to develop the web-based product (see Supplementary Materials 1 Section 2). Additional feedback was received throughout the project using an open online commentary and feedback across system stakeholders (e.g., NHS Trusts, healthcare professionals, and patient representatives).

2.4.2. Phase 5: Test and Refine. Alpha and beta testing were key parts of the testing and refinement of the product and were led by the NCLCA DT and Ech Design. Alpha testing was done prior to and after workshop 3. Beta testing (both technical and focused) was performed to check usability, reliability, accessibility, and quality. Technical beta testing was carried out to improve the product before it was released to actual users. In total, 38 issues were raised, inclusive of changes in the wording of the text, typos, and issues with navigation on the guide. Seven meetings with Ech Design were carried out to address the changes and approve amendments. The last meeting was carried out on 17 October 2022.

Focused beta testing was performed to monitor specific features or components of the software product. In this testing, the software product was released to a group of people and their feedback and suggestions were collected for making improvements. The focused beta testing was carried out using an online questionnaire informed by the standardised Theoretical Framework of Acceptability (TFA) questionnaire [17]. TFA consists of seven constructs that aim to address to what extent an intervention is acceptable to the population who will be receiving or delivering it. TFA has previously been used in the development of interventions using the codesign methodology evaluating how users feel about an intervention, assessing the effort required to complete it, whether it is designed for the users intended, its clarity, the opportunity costs, perceived effectiveness, and the self-efficacy of the individuals [18].

3. Data Analysis

The information about the design of the resource was analysed primarily using content analysis for editing the prototypes after each workshop. The comments and suggestions from codesigners were mapped onto each touchpoint and the relevant stage of the cancer pathway. At each iteration, more details were included. At the end of workshop 1, the themes that emerged from the content analysis were used for understanding different information needs at different stages of a cancer diagnosis. The same process was applied at workshop 2 and informed the development of prototype 3. The changes were then demonstrated with the "you said—we did" approach at subsequent workshops to highlight that the codesigners' contribution to the product had been evaluated, understood, valued, and collaboratively applied where it was feasible.

At the end of the workshops, all the recordings from the workshops were transcribed and analysed using inductive thematic analysis [19]. YH coded each transcript line by line, collated codes into potential themes, and discussed the potential themes with the rest of the authors. The thematic analysis aimed to understand what factors were associated with the acceptability of the guide and explore codesigners' thoughts and feelings relating to the development and implementation of a support guide for individuals going through the cancer pathway.

The final focused beta testing questionnaire was analysed using descriptive statistics and demonstrated in mean values and standard deviations. A general acceptability score was calculated based on the TFA questionnaire data analysis guidelines (range = 7–35) [17]. Low (7–16.33), medium (16.34–25.66), and high score (25.67–35) ranges were identified. Burden and opportunity cost items were reverse scored, indicating a high score would be higher acceptability based on the guidelines provided for the standardised TFA questionnaire. A total mean score of seven TFA items was computed for a single acceptability score. A Pearson correlation coefficient (r) between all items was tested for the direction of the relationships between variables. P values (<0.05) and degrees of freedom were reported. The data analysis was carried out using IBM SPSS statistics version 28. All the free-text comments about potential improvements were noted and addressed before the final web-based product was released.

4. Results

The analysis from the workshops highlighted that improving communication across all pathways is a key factor in improving patient experience for individuals referred on a suspected cancer pathway or who have been diagnosed and/or treated for cancer. The overarching themes across the workshops highlighted that across the whole cancer pathway, the resource should aim to promote autonomy, provide information on how to access the right support at the right time, be tailored for different information needs, and should be made accessible for all individuals. Table 3 demonstrates a summary of the detailed feedback for the revisions that have been made on the prototypes. Additional revisions are described in Supplementary Materials 1 Section 3.

4.1. Promoting Autonomy for Patients. Providing individuals with the right information at the right time promotes autonomy, a sense of control, collaboration with the healthcare team, and better shared decision-making as individuals have the confidence and knowledge to actively participate in their healthcare. This was highlighted as an important aspect of navigating the uncertainty in cancer care. All codesigners agreed that the tool could have been useful at different stages through their engagement with the cancer pathway. While some information might not have been useful for them, all designers found the guide to be potentially useful rather than being provided with printed documents at appointments.

> *"I'm thinking that maybe . . .. . .specific signposting at the earliest stage give(s) the control back to the patient. Yeah. So they're not just waiting to hear back for an urgent referral or the letter saying what they should be doing next. So it's . . .. sort of . . .. giving them control." (Co-designer 1)*

> *"There's a lot of information, but it's all spread out in really diverse places. And so, you know, again, one of the, I suppose key things about this tool is kind of bring that back together, but at the right time for the you know, the right place for linking it to that person as they're journeying through as they're travelling through this." (Co-designer 3)*

> *"For me, it's really important to think about how we can empower patients asked me to be thinking about asking the right questions. And I think one of the things that strikes me again and again, is having the possibility of having a key person that you can link with, and because much of our care become so fragmented." (Co-designer 9)*

4.2. Right Support. A particular focus has been given to making sure individuals who are going through the pathway know who best to contact at different stages when support is needed. Codesigners advised that signposting should be made available from trusted sources to facilitate access to appropriate support. All agreed that the resources should be monitored regularly and updated where necessary.

> *"Any dealing with any large organisation, and the NHS, other commercial organisations, something I always do is say, what is the next stage? When is it going to happen? Give me a deadline. When am I going to get response back or something? Who do I contact if I don't get results or has not delivered in two weeks? So I think throughout the process, you've always got to say, here's the next stage. When's it going to happen by? If it doesn't happen by then, who do I call?" (Co-designer 1)*

A few designers suggested that signposting to emotional support was missing in the guide and recommended that this be prioritised for inclusion as not all organisations would have the appropriate training and knowledge to deliver the right care.

> *"But you know, if you're, you're trying to get through to your GP, you can't get through, you can't get an appointment, or whatever, that just raises anxiety, even more. I think that having a key person where possible, or even if whether it's in the primary and community or secondary care sector is so important. If I need emotional support here, you know, who can I contact? I think that is really important. And I just think that if I if I just been given that diagnosis, and then who could I talk to for emotional support to see Samaritans by the side of it wouldn't necessarily be the most appropriate thing for me to say. Because that has, I think, a certain perception as an implication of seeing Samaritans there. So I think it you know, maybe it's a local support group or Macmillan or whoever." (Co-designer 5)*

Table 3: Summary of the feedback from the codesigners for each touchpoint in the cancer pathway to be included in the prototype.

	Referral and investigation	Diagnosis	Treatment and decision	Treatment	Posttreatment
Communication	(i) Contact telephone number of someone empathetic (ii) Consider language used—do patients understand 2 ww pathway? urgent referral? (iii) Change "pathway" to "journey"? or other (iv) Cancer pathway support (v) Cancer referral route support tool (vi) Language needs to be more personal/ softer—"you," "I," "your," etc.	(i) Should a more senior health professional be delivering news—diagnosis?	(i) Better communication needed between people and services	(i) Make sure patient knows who to contact in between appointments	(i) Helpline telephone number—easy access (ii) Who can I contact after for follow-up care? (iii) Opportunity to discuss other illnesses
Info/signposting practical	(i) What do I do if I cannot speak English? (ii) Key contact numbers (iii) Add practical prompts (iv) Local services (v) Who do I contact if I am on a 2 ww referral if I have questions		(i) Signpost where to get help with state benefits (ii) Signpost to additional resources—nutrition, dietician, physical activity (iii) Where can I get practical advice? Financial, transport, support groups	(i) Financial, benefits, employment, housing advice (ii) Physical exercise guidance—prehab (iii) Info personal care—hair colouring, etc.	(i) Short-term and long-term effects of treatment
Emotional support info and signposting	(i) Local support groups (ii) Where can my family get support?	(i) Professionals giving feedback on diagnosis should be able to answer follow-up questions if they are delivering diagnosis news	(i) Signpost to local Macmillan information and support centre and support groups (ii) How do I tell my family? (iii) My cancer is genetic—where can I get support to discuss with family?		(i) Signpost to services for after care (ii) Faith groups?

Table 3: Continued.

	Referral and investigation	Diagnosis	Treatment and decision	Treatment	Posttreatment
Patient/carer/ relative-centred care	(i) What can I expect to happen at the appointment? (ii) How do I make sure I get answers? (iii) Can I bring a friend with me? (iv) Specific signposting to give patient back control (v) Practical guideline/ timeline—if you have not heard back by this time, call this number (vi) Family support	(i) Diagnosis will be given by consultant and cancer nurse specialist	(i) Are clinical trials available? Pros and cons?	(i) How might treatment affect other conditions?	(i) What type of care will I get from my GP—how will I make sure this happens? (ii) How long will hospital follow-ups last? (iii) Late onset side effects? (iv) What is next?
Supporting navigation	(i) Are the appointments currently happening within 2 ww? (ii) Do you triage a delay? (iii) Tailor info around different patient journeys—e.g., A&E/GP route (iv) A short flowchart at the beginning of the checklist would be helpful outlining why you are being referred, who you should contact with questions, a contact number	(i) Clear info about all possible side effects			
Info exchange	(i) Add positive messaging	(i) If cancer diagnosis—consider signposting to wider support, i.e., not just emotional. Charities, prehabilitation and support with exercise, healthy eating, nutrition, online forums, etc.	(i) Provide videos		(i) Short version and detailed version of tool

4.3. Tailored Information. It was highlighted that information available in the guide should be delivered in different ways enabling it to be tailored to the preferences of the individual accessing it. For example, it was recognised that some individuals are more interested in cancer statistics and some would prefer patient narratives.

"Throughout my treatment, I always discussed statistics with my consultant. As I had good statistics that's why I'm in favour of them. I can equally see that some patients won't want to know statistics. And in my case, I was told the standard remission rate is 60, to 70%. But I was told in my case, that was much, much higher. So I took that to be

85 90% chance of recovery. And I would say that gave me tremendous confidence, to get through the system. To get through the process." (co-designer 1)

"I was actually sort of looking at the format and the sort of language and I was thinking the first column where you discuss the key steps in the cancer journey. It feels very impersonal. From my point of view, what while I'm reading it, if I'm sort of trying to think of it, if I were the patient, I don't know whether that could be made a bit more like a story for the patient." (Co-designer 4)

4.4. Accessibility. Codesigners made the point that whilst having relevant information in one place is great, "I was thinking how do people actually find the right information?." The ability to search and find the right information was considered a barrier to using the guide effectively and this was discussed in detail in workshop 3. Potential solutions were also discussed and they included having a clear structuring of the guide, definitions under each category, and signposts to different organisations. Future solutions such as chatbots and artificial intelligence were suggested. Not being able to tailor for each cancer type was considered a potential limitation of the tool.

"Is there useful information? Actually, if people use it? That's, that's very important. There is no question on that. But I'm thinking also because this will be mainly available. Maybe online? No, you know, websites and everything. But I'm thinking those who don't have access to in a mobile, so don't have knowledge about we know, this social media who don't connect, especially those people, those patients from minority ethnic group. I don't know if there is any other alternative to reach them as well." (Co-designer 7)

Whilst the designers felt that the guide was valuable, making it accessible for different populations was discussed as an important design priority. The codesigners agreed that the guide should be available in different formats and accessible to healthcare professionals, patients, and carers. It was noted that the guide should allow people to make notes so that they could use them in the future.

4.5. Focused Beta Testing Results. In total, 23 individuals provided feedback and completed the brief questionnaire based on TFA. The participants' characteristics are demonstrated in Table 4.

The mean total acceptability score (item range 7–35) for the final product, i.e., YCPSG, was 28.52 (SD = 3.88) indicating high acceptability. The mean results for each item were as follows: general acceptability (range: 1–5, $M = 4.35$, and SD = 0.76), intervention coherence (range: 1–5, $M = 4.22$, and SD = 0.90), perceived effectiveness (range: 1–5, $M = 3.96$, and SD = 0.96), ethicality (range: 1–5, $M = 4.22$, and SD = 0.79), self-efficacy (range: 1–5, $M = 3.87$, and SD = 1.21), burden (range: 1–5, $M = 4.39$, and SD = 0.72), and opportunity costs (range: 1–5, $M = 3.52$, and SD = 1.20).

Table 4: Participants' characteristics ($n = 23$).

	N (%)
Sex	
Male	9 (39.1%)
Female	14 (60.9%)
English as first language	
Yes	19 (82.6%)
No	4 (17.4%)
Stakeholder role	
Patient/former patient	7 (30.4%)
Healthcare professional	11 (47.8%)
Third sector	2 (8.7%)
Others (not specified)	3 (13.0%)

The total acceptability score was strongly and positively correlated with general acceptability, $r\ (21) = 0.74$, $p < 0.001$, intervention coherence, $r\ (21) = 0.78$, $p < 0.001$, perceived effectiveness $r\ (21) = 0.67$, $p < 0.001$, ethicality $r\ (21) = 0.79$, $p < 0.001$, and self-efficacy, $r\ (21) = 0.53$, $p = 0.01$. It was not correlated with burden $r\ (21) = 0.33$, $p = 0.13$, and opportunity costs, $r\ (21) = 0.41$, $p = 0.06$. Between-item correlations in Table 5 indicated that perceived effectiveness is also positively correlated with perceived ethicality of the guide and self-efficacy. Ethicality was also positively correlated with intervention coherence and the general acceptability item.

5. Discussion

This paper describes a user-centred design project that aimed to develop a cancer pathway support guide for patients to be used as soon as a patient enters the suspected cancer referral pathway. The final product is called "Your Cancer Pathway Support Guide" (YCPSG). The final product was launched in February 2023 and is available via the NCL CA website and on the websites of trusts in North Central London [21]. A summary of the final prototype (Supplementary Materials 2) and the web-based tool is included in the supplementary materials (see Supplementary Materials 1 Section 4). Our results demonstrate the role of communication, information, and navigation in the cancer diagnosis pathway from nine codesigners points of view with lived experience of cancer and how this was then translated into solutions in a digital (with PDF option) information resource using codesign techniques. Furthermore, we highlight the importance of focused beta testing in monitoring specific features or components of the software product and further evaluation ahead of product launch. Overall, the paper provides insights into the development of a tool that can be used for improving patient experience and as a resource for healthcare professionals who support people affected by cancer.

5.1. Comparison with the Existing Literature. To our knowledge, there are no other codesigned support guides developed in the literature to improve patient experience and reduce the patient burden navigating the complete cancer pathway. YCPSG aims to reduce the variation in the cancer pathway as a codesigned product that captures key points of

Table 5: Means, standard deviations, and correlations between TFA items.

	M	SD	1	2	3	4	5	6	7
1. Total acceptance score (range = 7–35)	28.52	3.88							
2. Opportunity costs (range = 1–5)	3.52	1.20	0.329	—					
3. Burden (range = 1–5)	4.39	0.72	0.410	0.173	—				
4. Self-efficacy (range = 1–5)	3.87	1.21	0.525*	−0.138	−0.146	—			
5. Perceived effectiveness (range = 1–5)	3.96	0.96	0.666**	−0.135	0.025	0.645**	—		
6. Ethicality (range = 1–5)	4.22	0.79	0.786**	0.161	0.399	0.171	0.423*	—	
7. Intervention coherence (range = 1–5)	4.22	0.90	0.783**	0.058	0.352	0.234	0.373	0.691**	—
8. General acceptability (range = 1–5)	4.35	0.76	0.737**	0.089	0.233	0.147	0.381	0.683**	0.797**

* $p < 0.05$; ** $p < 0.01$.

patient engagement with primary and secondary care and pools relevant, up-to-date, and trusted links for individuals without going through multiple websites for finding information regarding what matters to them. For instance, the guide aims to address potential inequalities that might arise from support at consultations and encourages patients to contact the Trusts to organise interpreters or translators. It also highlights different pathways for entering suspected cancer investigations via primary care, cancer screening, emergency care or secondary care, and the relevant information to be considered once they are referred for investigations. The variation in patient experience as a result of entering the pathway from different routes to cancer diagnosis suggests that patients need further support to navigate what will happen next [10]. It aims to reduce patients' concerns about the intensity and the speed of the tests [9] with advice provided about when and who to contact if no feedback is received. It also provides rationale for why some tests may be offered without a consultation and where some require a decision-making process with the doctors.

There are a limited number of research studies using the TFA questionnaire to address the acceptability of patient-facing interventions in cancer research and they have yet to test its usefulness to be able to provide an interpretation of our results using this questionnaire [20, 22]. TFA has also been used in a variety of research as a theoretical framework guiding research design such as assessing the acceptability of interventions for improving cancer screening uptake [23] and digital patient decision-making and support tools postdiagnosis [24] using qualitative approaches. The mixed-method and theory-based approach to codesign in cancer research is still in its infancy, and we need more research providing detailed methods for researchers and healthcare service providers to develop robust evidence and recommendations, limitations, implications, and next steps.

Here, we discuss the final phase of the codesign process, namely, "implement and learn." While YCPSG offers relevant information for navigating the cancer pathways otherwise not available in a single resource, its limitations and strengths should be considered for future research and clinical practice. First, the guide was developed to be accessed through the Internet which could potentially exclude those who do not seek health-related information online and those who do not have access to the Internet. We aimed to reduce this barrier by making it open access and promoting its use by healthcare providers. It was also designed to be a printable document which was also reviewed by codesigners and patient representatives. The user's adoption of different versions should be evaluated for accessibility of the toolkit. Furthermore, YCPSG has been developed locally in North Central London; however, it is a tool that can be used across England due to the nonlocation-specific nature of the content.

Second, it was developed as part of a codesign process. Coproduction and codesign in the NHS have been recommended as default for the improvement of services and patient experience to gain insights, receive feedback, and inform change in clinical practice [25]. The codesign methodology has been increasingly used in healthcare, but it has also been criticised for its lack of evaluations and reporting standards [26]. Thus, we aimed to provide a detailed methodology to ensure the rationale of the project, the design of the prototype, and the final product are clear. However, it should be noted that this project was not carried out as a research study; therefore, scientific rigour may have been limited. For instance, it employed an opportunistic sample of individuals with lived experience of cancer and did not record their sociodemographic characteristics. This is an important limitation to be considered in terms of the representativeness of the codesigners and the participants to be included in future evaluations to ensure the guide is not unintentionally widening inequalities. While an evidence-based approach was embedded throughout, thorough research processes are needed to test, retest, and further design the toolkit. Nevertheless, the implementation and evaluation of YCPSG aim to demonstrate the potential impact of this guide on patients and healthcare professionals. For instance, a recent experimental study suggests that tailoring information for patients could improve patient experience and reduce information burden [27]. In the current version, the use of this guide could help in identifying the right information at the right stage of the investigations to be delivered to the patients and carers, which could help reduce the amount of information provided to patients. It could allow patients to be more involved in the decision-making process after diagnosis and during treatment, in line with the developments in personalised cancer care [28]. However, it should be also noted that the current version of YSPSG does not include cancer type specific information and this was discussed as part of the codesign workshops as an important limitation for the individual use and user experience to be considered. This has been part of the discussions for developing the guide further (e.g., chatbots and artificial

intelligence); however, more evidence is needed to identify which information would be beneficial and important and will improve patient experience.

Furthermore, it will be important to measure patient experience among those who have been provided with the YCPSG at referral to cancer investigations, compared to those who did not access it, and to evaluate if using the guide reduces health inequalities arising from access to information, translation, travel, and other wider social and psychological determinants of health. Furthermore, it would be important to evaluate if it improves patients' and carers' confidence in being on cancer pathways. Both qualitative and quantitative research methods will be important to ensure the guide can be further improved, tailored, and scalable across England to provide standardised information about what to expect at different stages of the cancer pathway.

6. Conclusion

Overall, the paper provides valuable insights into the codevelopment of a resource that aims to improve patient experience and outcomes for people referred on a suspected cancer pathway or who have been diagnosed with cancer and the healthcare professionals who support these individuals from the point of referral onward. The findings of this study can be useful for researchers, healthcare professionals, and policymakers who are interested in improving the cancer pathway and indeed other healthcare pathways.

Data Availability

The data used to support the findings of this study are available from the corresponding author upon request.

Disclosure

All codesigners were offered to review the final draft of the manuscript and consented for their quotes to be published in the manuscript anonymously. The project was delivered as part of service improvement and evaluation led by the North Central London Cancer Alliance (NCLCA).

Conflicts of Interest

The authors declare that they have no conflicts of interest.

Authors' Contributions

AB conceived the project and developed with SC and CN. AB, SC, and CN delivered the workshops. YH carried out the data analysis and drafted the manuscript. AB and CVW reviewed the initial draft. MF and IA carried out evaluations and supported the revisions. All authors have reviewed and commented on the final manuscript.

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Supplementary Materials

Supplementary 1: YCPSG Supplementary Materials 1 includes four sections, namely, (1) prototype toolkit, (2) design brief, (3) changes to the prototype, and (4) final product summary. Supplementary 2: YCPSG Supplementary Materials 2 includes the final prototype with revisions that have been made throughout the project. (*Supplementary Materials*)

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