Prioritising Key Concepts for informed health choices in cancer: An evidence-based online educational programme

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ABSTRACT

Objective: The overabundance of health misinformation has undermined people's capacity to make evidence-based, informed choices about their health. Using the Informed Health Choices (IHC) Key Concepts (KCs), we are developing a two-stage education programme, Informed Health Choices-Cancer (IHC-C), to provide those impacted by cancer with the knowledge and skills necessary to think critically about the reliability of health information and claims and make well-informed choices. Stage 1 seeks to prioritise the most relevant Key Concepts.

Methods: A project group and a patient and carer participation group completed a two-round prioritisation process. The process involved disseminating pre-reading materials, training sessions, and a structured judgement form to evaluate concepts for inclusion. Data from each round were analysed to reach a consensus on the concepts to include.

Results: Fourteen participants were recruited and completed the first-round prioritisation. Fifteen participants undertook the second-round prioritisation. Nine Key Concepts were selected for the programme across five training sessions and two consensus meetings.

Conclusion: The prioritised concepts identified represent the most pertinent aspects of cancer-related information for those impacted by the disease. By incorporating these concepts into educational materials and communication strategies, healthcare providers and organisations can potentially help cancer patients, survivors, and their loved ones to recognise and combat cancer-related misinformation more effectively.

Innovation: This study introduces a participatory prioritisation process, which integrates the expertise of healthcare professionals with the insights of patients and carers, thereby enhancing the programme's relevance and applicability.

1. Introduction

The landscape of health information has changed in recent decades with increased internet access and social media use [1]. As a direct consequence, the dissemination of misinformation has also surged [2-4]. Health-related misinformation concerns all aspects of cancer, including

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the screening [5], treatment and its effectiveness [6,7], prevention [6], and patients' and families' decision-making [8,9].

People impacted by cancer often seek extra health information outside of their healthcare professionals' advice to inform their decisions about treatment options [10,11]. However, there is a considerable risk of encountering harmful misinformation, especially that promoting unproven treatments [12,13]. Despite the unreliability of such misinformation, it reaches and impacts cancer patients worldwide [14]. Research has found that a third of the most popular articles shared on social media on the four most common cancers contained false, inaccurate, or misleading information [15]. The dissemination of misinformation can have deleterious effects, potentially guiding people toward treatment decisions associated with suboptimal health outcomes [13,16]. Evidence suggests that people are more likely to engage with unreliable information than with trustworthy information [17]. Research has found that those who display a lack of trust in healthcare professionals have lower health literacy, limited access to information, and lower educational attainment are most susceptible to cancer misinformation [18-20].

Everyone in society is at risk of harm from misinformation, but people impacted by cancer or other serious conditions may be at greater risk. Contrary to popular belief, the spread and acceptance of misinformation cannot be solely attributed to a lack of access to scientifically supported information [21,22]. Rather, individual beliefs and behaviours in the face of misinformation are shaped by knowledge, cognitive processes, and various social factors [23]. To date, programmes and interventions targeting health misinformation have employed various strategies with mixed success [24]. However, there is limited research specifically addressing cancer-related misinformation. One study focusing on misinformation in a skin cancer population found that exposure to a news literacy video and real-time correction did not effectively 'inoculate' individuals against misinformation regarding sunscreen myths [25,26]. While studies suggest that correction interventions can be beneficial in countering misinformation in cancer [25-28], research suggests that one of the most effective methods of combating misinformation is to foster critical thinking ability [29]. By doing so, people can make better-informed decisions, leading to improved health outcomes. Enhancing one's knowledge and skills is a potentially valuable approach to achieving this. Given the current scenario, where misinformation and misleading content about cancer is rampant, there is an urgent need to assist those impacted by cancer, i.e. current cancer patients, cancer survivors, loved ones, and carers. By improving critical thinking skills people can be empowered to be able to identify misinformation and make better decisions.

In this current project, we aim to take steps to address this need through the creation of an online education programme entitled Informed Health Choices-Cancer (IHC-C), which is based on a set of 49 Informed Health Choices (IHC) Key Concepts (KCs) (see Appendix). The KCs provide principles for recognising the reliability of claims, comparisons, and making health choices [14,30]. They enable individuals to identify the presence of health claims, evaluate the reliability of the evidence behind the claims, and make well-informed choices when considering different options [31-33]. From a practical standpoint, the IHC framework provides a means of enhancing critical thinking when making choices. The KCs have been adapted and used in several previous studies across different disciplines to improve the critical thinking capabilities of both primary school children, adolescents, and adults [34-39]. Acknowledging the unique challenges and information needs of those impacted by cancer, there is a pressing requirement to prioritise and determine which of the 49 IHC KCs are most relevant for individuals impacted by cancer.

In this paper, we report on the prioritisation process of the KCs for those impacted by cancer and detail a two-round prioritisation process to identify the most relevant KCs that enhance critical thinking and decision-making for this specific group.

2. Methods

We conducted two rounds of prioritisation to identify the most relevant KCs for people impacted by cancer. The prioritisation process used a structured, iterative development process [14] adapted from the protocol used by Oxman et al. for lower secondary schools in East Africa [40].

2.1. Ethical approval and consent

Ethical approval for this study was granted by the University of Galway Research Ethics Committee (reference: 2022.03.005). Informed consent was obtained from all participants before their participation in this study.

2.2. Participants

2.2.1. Establishing the project group

To gather a range of perspectives on cancer and misinformation, a project group (PG) was formed by involving multiple stakeholders [14]. The project group was assembled to encompass a diverse range of perspectives, including those of healthcare professionals specialising in cancer care, as well as invaluable patient and public involvement (PPI) inputs. The team comprised individuals directly impacted by cancer, medical oncologists, cancer nurses, cancer researchers, methodology experts, specialists from the IHC Key Concepts initiative, and seasoned educationalists. This multidisciplinary approach ensured that the project benefited from a comprehensive understanding of the challenges faced by those impacted by cancer and the expertise needed to develop effective solutions. The participants of the project group were actively involved in the decision-making process to select the KCs that were ultimately included in the IHC-C programme.

2.2.2. Establishing the patient and carer participation group

A patient and carer participation group was established to capture the perspectives of those impacted by cancer [14], including (1) current cancer patients diagnosed with any type of cancer, (2) survivors of any type of cancer, (3) informal caregivers of people with cancer, and (4) loved ones of people with cancer (family, friends, or others who care about those with cancer [14]. To help achieve diversity among participants in this group, several recruitment drives were undertaken utilising a variety of channels, including social media and oncology outpatient departments. All participants were financially compensated for their participation in line with INVOLVE guidance [41].

2.2.3. Recruitment process

To participate in the study, potential candidates were required to complete three distinct steps before being recruited.

- The first step involved sharing a recruitment information package that included a brief introduction to the study and an online EOI survey (EOI-1). Those who were interested could provide their email addresses and express their interest by filling out the EOI-1 survey.
- Secondly, within a week, a participant information leaflet was shared with those who completed the EOI-1 survey. The leaflet provided detailed explanations of the IHC-C study's background and aim, study procedures, role and tasks of the patient and carer participation group participants, and the compensation offered for participation.
- Thirdly, if participants remained interested after reviewing the information leaflet, they were invited to complete a more detailed online EOI survey (EOI-2). EOI-2 collected additional information, such as gender, age range, education level, types of cancer diagnosis, relationship with individuals diagnosed with cancer, and reasons for their interest in participating in this study.

Participants were invited to sign an informed consent form indicating their full understanding of the information provided in the leaflet and their willingness to participate. After gathering detailed information from participants, the research team carefully reviewed it to determine the final list of eligible participants for the patient and carer participation group. This was based on the eligibility criteria outlined in the previously published protocol [14].

2.3. Rewrite of the Key Concepts for pre-reading material

The IHC Key Concepts (2022 version) formed the basis for the prioritisation process [30]. To improve readability and simplify the structure, the language was revised with input from patient and public participants and PPI partners before each prioritisation training round. The content was reorganised into different sections, and a glossary table was included to explain complex terms. An experienced health journalist provided further guidance on simplifying the language and content.

2.4. Training for all participants

After recruitment, online training sessions were held using Zoom software [42]. The purpose of the trainings was to give participants a clear explanation of this project and the prioritisation process. Trainings focused on the outline of the IHC-C programme and the purpose of prioritisation. Separate training sessions were held for the project group and patient and carer participants to accommodate their distinct perspectives, while the core content of the training sessions remained consistent [14].

2.5. Prioritisation process

After the training, participants undertook a prioritisation process to determine which of the KCs should be included in this online education programme.

2.5.1. Determining judgement criteria

We established judgement criteria consisting of five multiple-choice questions and two open-ended questions, as shown in Table 1 [14]. The project group and patient and carer participants utilised these criteria to evaluate each of the 49 KCs during the prioritisation process.

2.5.2. Prioritising the Key Concepts

The prioritisation process was conducted in two rounds. In the first round, all project group participants and four patient and carer participants completed the prioritisation. In the second round, the number of KCs was reduced, and only patient and carer participation group participants ($n = 15$) were involved in the prioritisation process. This strategy to include only patient and carer participants in this second round was utilised to solicit a wider range of opinions and perspectives from those impacted by cancer. We felt that doing so would enrich the understanding of the project's impact and relevance from the viewpoint of the target users. Participants had approximately one month to conduct the prioritisation process after they had attended the training session.

2.6. Consensus

Two online consensus meetings were held to discuss the findings of each round of prioritisation and decide on the final KCs after each round of prioritisation. The participants of the consensus meeting were drawn from those who had undertaken either round of prioritisation. Participants were purposefully selected to ensure a diverse range of perspectives, considering factors such as age, gender, and type of cancer impact. This approach aimed to capture a balanced and comprehensive representation of the views of those impacted by cancer. Pre-reading materials were distributed one week before the consensus meetings to

Table 1
Judgement criteria used for prioritisation.

Key Concepts	Criteria					Judgement	Comments
	How easy is it to understand this concept?	How relevant (i.e., of current significance or importance) do you think this concept is?	How likely is it that people are already aware of this concept?	How helpful do you think this concept is in supporting people to assess treatment claims or make well-informed choices?		Do you think this concept should be included in an education programme to help people impacted by cancer think critically about the reliability of a treatment claim or make well-informed choices?	If "Uncertain" or "No", please state why: / Any other comments/ suggestions/thoughts about this KC:
Key Concept 1	☐ Very easy ☐ Easy ☐ Uncertain ☐ Hard ☐ Very hard	☐ Very relevant ☐ Relevant ☐ Uncertain ☐ Irrelevant ☐ Very irrelevant	☐ Very likely ☐ Likely ☐ Uncertain ☐ Unlikely ☐ Very likely	☐ Very helpful ☐ Helpful ☐ Uncertain ☐ Unhelpful ☐ Very unhelpful		☐ Yes ☐ Uncertain ☐ No	
Key Concept 2							
Key Concept 3							

provide participants with the necessary information and an overview of the purpose and schedule. During the consensus meeting, the results of prioritisation were presented and discussed, followed by an open discussion and solicitation of suggestions to reach a consensus on the final KCs to be included. The consensus meetings played a crucial role in determining which KCs should be prioritised. Participants were encouraged to share their thoughts, opinions, and suggestions freely regarding any aspect of the prioritisation process, the prioritised KCs, or the overall programme.

2.7. Data analysis

Eligibility for Key Concepts

We used Microsoft Excel software [43] and SPSS software (version 26.0) [44] to record and analyse prioritisation results. The mean and standard deviation of measurement data and proportions of counting data were used to analyse the responses to the judgement criteria. For each KC, initially, we focused on the participants' responses to the question, *"Do you think this concept should be included in the IHC-C programme"*. Response options for this question included "yes", "uncertain", and "no". We considered the number of "yes" responses as the primary indicator for determining the inclusion of a KC. For example, if 15 participants did a given round of prioritisation, the total number of responses for "yes", "uncertain", and "no" options for each KC would be 15. We iteratively developed cut-off values based on the number of "yes" responses. For example, if the cut-off value for "yes" responses was set at 10, KCs with 10 or more "yes" responses would proceed to the next

round of prioritisation or be ultimately included. However, rather than using '10' as the sole cut-off value, numbers close to 10, such as '8', '9', '11', or '12', were also considered as potential values through an iterative process. The final decisions on which cut-off values to use were based on discussions and considerations from the consensus meetings. KCs that did not meet the cut-off value in each round were not immediately excluded. Instead, we reanalysed those KCs using responses to the other four multiple-choice questions [14]. These questions assessed whether a KC is easy to understand, relevant to the topic, if people are already aware of it or if it is helpful in supporting people to assess treatments or make well-informed choices. The response options for each of the four questions were categorised into three groups "easy", "uncertain", and "hard". We applied the same cut-off value used for the initial question to each of these four questions. For example, if 15 participants were involved in the prioritisation process and the cut-off value for the number of "yes" responses was set at 10, KCs with 10 or more "easy" responses for all four questions would advance to the next round of prioritisation or be ultimately excluded.

3. Results

3.1. Participants

The project group comprised a total of 12 participants, of which two were cancer survivors. Eleven of these completed the prioritisation process (see Fig. 1). Among these participants, the majority were female (7, 63.6%), identified as white (10, 90.9%), aged between 33 and 44 (6,
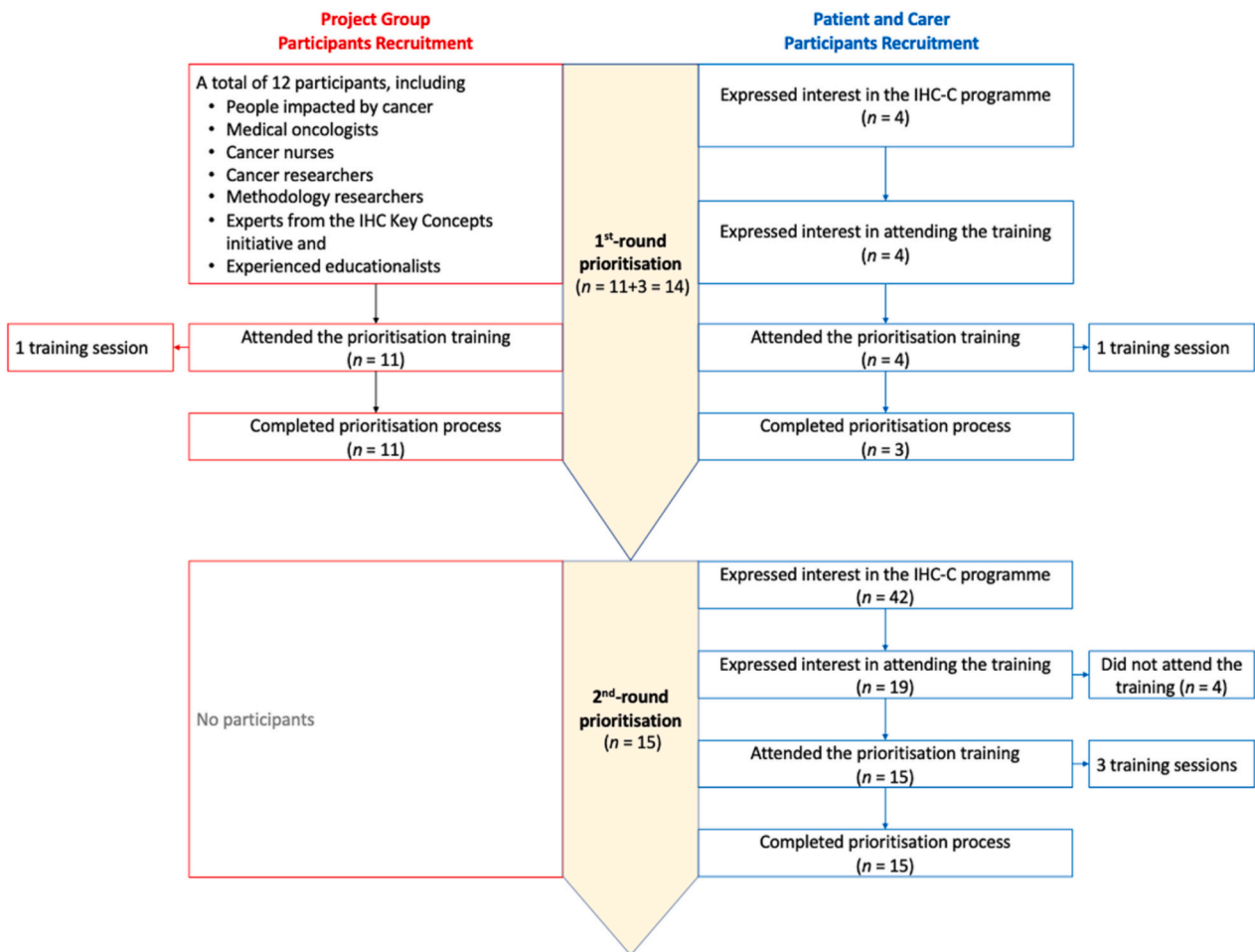

Fig. 1. Recruitment process of both groups.
IHC: informed health choices; IHC-C: informed health choices-cancer.

54.6%), and possessed a third level of education (11, 100.0%) (see Table 2). Additional detail about the characteristics of the project group participants has been outlined in our previously published protocol [14].

The recruitment of the patient and carer participation group took place over five months, from August to December 2022.

Four people impacted by cancer initially expressed their interest in joining this programme. All of them were interested in attending the training and attended a training session, while three participants completed the first round of the prioritisation process (see Fig. 1).

After the first-round prioritisation, 42 people impacted by cancer expressed their interest in participating. Of these, 19 were interested in attending the training sessions, and 15 participants attended training sessions and completed the second round of the prioritisation process (see Fig. 1).

Of the 18 patient and carer participants involved in the prioritisation, most were female (13, 72.2%). Most identified as white (17, 94.4%) and were aged between 35 and 64 (17, 94.4%). Additionally, 10 (55.6%) were cancer survivors, with 7 (38.9%) having a diagnosis of breast cancer, and 15 (83.3%) had achieved a third level of education. Of those impacted by cancer who did not have a diagnosis of cancer, one participant was the mother of a child diagnosed with cancer, one was the daughter of a parent diagnosed with cancer, and one fulfilled both roles. On average, the people diagnosed with cancer (including the children/parents who had cancer of the carers and loved ones) had been living with the condition for approximately 4.10 (0.3, 12) years (see Table 3).

3.2. Rewrite of the Key Concepts document for the general public

The 2022 version of the IHC Key Concepts, which consists of 49 KCs categorised into three sections ("claims", "comparisons", and "choices"), served as the foundation material for our study (see Appendix) [30,31]. We provided participants with a document giving an overview of the Key Concepts for first-round prioritisation training. In this revised document, we re-structured the original content into explanation, examples, and implication sections while retaining the health and treatment-related content for each KC. We included a glossary table, with terms explained in the glossary hyperlinked throughout the document for easy reference.

Following the first-round prioritisation, the project group and three patient and carer participants suggested further simplifying the document's language for the second-round prioritisation, as participants might come from diverse educational backgrounds, especially if the second round were to be conducted solely with those impacted by cancer. In response, we condensed the document into an *overview of Key Concepts for the second-round prioritisation training*. We retained the three

Table 2
Sociodemographic characteristics of the project group participants.

	n = 11 (%)
Gender	
Female	7 (63.6)
Male	4 (36.4)
Age	
35–44	6 (54.6)
45–54	2 (18.2)
55–64	1 (9.1)
Above 64	2 (18.2)
Ethic background	
White	10 (90.9)
Asian	1 (9.1)
Education level	
Third level (postgraduate award)	11 (100.0)

Table 3
Sociodemographic characteristics of the patient and carer participation group.

	n = 18 (%)
Gender	
Female	13 (72.2)
Male	5 (27.8)
Age	
18–24	1 (5.6)
25–34	0 (0)
35–44	4 (22.2)
45–54	3 (16.7)
55–64	6 (33.3)
Above 64	4 (22.2)
Ethic background	
White	17 (94.4)
Asian	1 (5.6)
Education level	
Secondary education	3 (16.7)
Third level (primary degree)	7 (38.9)
Third level (postgraduate award)	8 (44.4)
Type of impacted by cancer	
Current cancer patients	5 (27.8)
Cancer survivors	10 (55.6)
Informal caregivers	2 (11.1)
Loved ones	1 (5.6)
Caregivers & loved ones' relationship with the cancer patient (*n* = 3)	
Mother of a cancer diagnosed child	1 (5.6)
Daughter of a cancer diagnosed parent	1 (5.6)
Mother of a cancer diagnosed child and Daughter of a cancer diagnosed parent	1 (5.6)
How long the people diagnosed with cancer lived with cancer (years)	
	4.10 (0.3, 12)
Cancer diagnosis types (including the children/parents who had cancer of the carers and loved ones)	
Breast cancer	7 (38.9)
Prostate cancer	2 (11.1)
B Cell Lymphoma	1 (5.6)
Basal Cell carcinoma	1 (5.6)
Bowel cancer	1 (5.6)
Cervical cancer	1 (5.6)
Colorectal	1 (5.6)
Invasive ductal carcinoma	1 (5.6)
Leukaemia pancreatic cancer	1 (5.6)
Multiple Myeloma	1 (5.6)
Wilms' Tumour	1 (5.6)

sections, but significantly revised the language used throughout the document. An experienced health journalist was consulted to assist in reviewing and simplifying the language. Additionally, feedback was sought from the patient and carer participants involved in the first-round prioritisation, to gather their insights and recommendations on making the content the content more accessible and suitable for those impacted by cancer.

3.3. Training

To optimise the participants' time, we arranged small-group training sessions with fewer than ten participants based on their time preferences. Before each training session, participants were provided with pre-reading materials to facilitate their understanding and preparation for the training. These pre-reading materials included a training manual that contained information on the programme background, training

content and the planned schedule of the session. Additionally, participants received an overview document that presented the rewritten KCs document. As the number of KCs was reduced after the first round of prioritisation, the pre-reading materials for each of the two rounds differed. During each training session, we used presentation slides and online surveys to explain (1) the background and aim of the IHC-C programme, (2) what the IHC KCs are, (3) why prioritisation is needed, (4) the prioritisation process, (5) participants' expected tasks in the prioritisation process, and (6) the test-runs of the prioritisation survey. The training aimed to equip participants with the necessary knowledge and skills to complete the prioritisation judgement form after training independently. All participants were informed that they were free to contact the researchers after the training sessions to clarify any aspect.

3.4. Prioritisation results

3.4.1. First round of prioritisation and first consensus

A total of 14 participants were involved in prioritising the 49 KCs (see Fig. 1), with 11 from the project group and three from the patient and carer participation group. The result of the number of 'yes' responses to the question "*Do you think this KC should be included in this programme or not*" is presented in Fig. 2. In the initial consensus meeting, the project group participants prioritised including a limited number of KCs considered high priority. A threshold was established where a KC would be prioritised if it received at least nine "yes" responses. This approach resulted in 19 KCs being identified as priorities.

For the 30 KCs not meeting the cut-off value for this question, all four other judgement questions were examined to assess if any met the cut-off value of nine. Consequently, two additional KCs were included, as shown in Table 4. Thus, a total of 21 KCs were deemed appropriate to proceed to the second round of prioritisation.

The qualitative results from the open-ended questions were not considered to merit the inclusion of any other potential KCs in this round, as the participants in the first consensus meeting indicated that 21 KCs already constituted a substantial number moving to further prioritisation.

3.4.2. Second-round prioritisation and final consensus

Fifteen patient and carer participation group participants completed the second round of prioritisation of the 21 KCs. The results of the "yes" responses to the question "*Do you think this KC should be included in this programme or not*" is shown in Fig. 3.

A consensus meeting was held after the second round of prioritisation attended by both the project group and three patient and carer participation group participants who undertook this round of prioritisation. The qualitative discussion among participants from both groups during the consensus meeting, drawing on their experience, highlighted the importance of including a narrower and smaller number of KCs in the programme to ensure it remained manageable size for learners. Therefore, to prioritise the KCs further, participants reached a consensus to set a cut-off value of 12 "yes" responses to the question "*Do you think this concept should be included in the IHC-C programme*" in order for a KC to be included. This resulted in the inclusion of eight KCs: six KCs from the "claims" section and two from the "choices" section of the original KCs lists. No additional KCs were identified based on the result of the other four questions (as shown in Table 5). Initially, all KCs from the "comparison" section were considered for exclusion. However, during the consensus meeting, it was decided to include the KC with the most "yes" responses from the "comparison" section. Two KCs had an equal number of "yes" responses; therefore, qualitative results were used to identify the most suitable one. Based on participants' thoughts and discussions, which emphasised the need for the course to present a comprehensive perspective of the initial IHC KCs, the focus was on
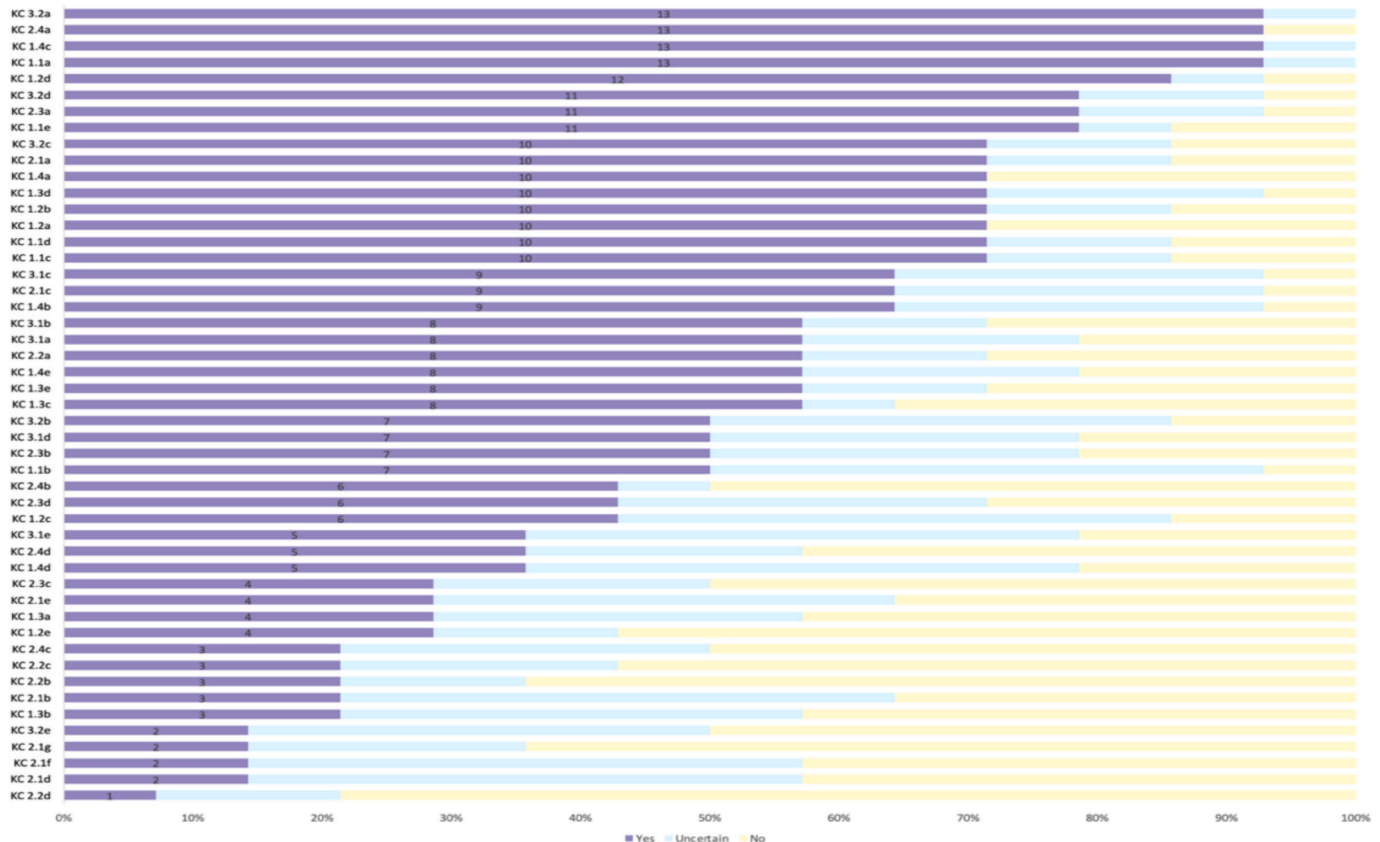

Fig. 2. Prioritisation results of 49 KCs after first-round prioritisation.

Table 4
Assessment for 30 KCs against four additional judgement criteria.

|	How easy is it to understand this concept?			How relevant (i.e., of current significance or importance) do you think this concept is?			How likely is it that people are already aware of this concept?			How helpful do you think this concept is in supporting people to assess treatment claims or make well-informed choices?		
	Very easy/ Easy	Uncertain	hard/very hard	Very relevant/ relevant	Uncertain	irrelevant/ very irrelevant	very likely/ likely	Uncertain	unlikely/very unlikely	Very helpful/ helpful	Uncertain	unhelpful/very unhelpful
	n = 14 (%)			n = 14 (%)			n = 14 (%)			n = 14 (%)		
KC 1.1b	**9 (64.29%)**	2 (14.29%)	3 (21.43%)	**10 (71.43%)**	4 (28.57%)	0 (0)	3 (21.43%)	6 (42.86%)	5 (35.71%)	**9 (64.29%)**	5 (35.71%)	0 (0)
KC 1.2c	7 (50.00%)	4 (28.57%)	3 (21.43%)	**9 (64.29%)**	4 (28.57%)	1 (7.14%)	1 (7.14%)	4 (28.57%)	**9 (64.29%)**	7 (50.00%)	6 (42.86%)	1 (7.14%)
KC 1.2e	2 (14.29%)	3 (21.43%)	9 (64.29%)	4 (28.57%)	9 (64.29%)	1 (7.14%)	1 (7.14%)	4 (28.57%)	**9 (64.29%)**	6 (42.86%)	3 (21.43%)	5 (35.71%)
KC 1.3a	**12 (85.71%)**	1 (7.14%)	1 (7.14%)	8 (57.14%)	4 (28.57%)	2 (14.29%)	9 (64.29%)	2 (14.29%)	3 (21.43%)	5 (35.71%)	8 (57.14%)	1 (7.14%)
KC 1.3b	**12 (85.71%)**	0 (0)	2 (14.29%)	7 (50.00%)	5 (35.71%)	2 (14.29%)	6 (42.86%)	7 (50.00%)	1 (7.14%)	4 (28.57%)	7 (50.00%)	3 (21.43%)
KC 1.3c	**11 (78.57%)**	2 (14.29%)	1 (7.14%)	**9 (64.29%)**	3 (21.43%)	2 (14.29%)	6 (42.86%)	4 (28.57%)	4 (28.57%)	**9 (64.29%)**	2 (14.29%)	3 (21.43%)
KC 1.3e	**9 (64.29%)**	1 (7.14%)	4 (28.57%)	**10 (71.43%)**	2 (14.29%)	2 (14.29%)	2 (14.29%)	2 (14.29%)	**10 (71.43%)**	**9 (64.29%)**	2 (14.29%)	3 (21.43%)
KC 1.4d	**10 (71.43%)**	1 (7.14%)	3 (21.43%)	**12 (85.71%)**	0 (0)	2 (14.29%)	1 (7.14%)	4 (28.57%)	**9 (64.29%)**	**10 (71.43%)**	3 (21.43%)	1 (7.14%)
KC 1.4e	**10 (71.43%)**	2 (14.29%)	2 (14.29%)	**11 (78.57%)**	2 (14.29%)	1 (7.14%)	8 (57.14%)	2 (14.29%)	4 (28.57%)	**10 (71.43%)**	2 (14.29%)	2 (14.29%)
KC 2.1b	7 (50.00%)	2 (14.29%)	5 (35.71%)	**9 (64.29%)**	3 (21.43%)	2 (14.29%)	2 (14.29%)	5 (35.71%)	7 (50.00%)	**9 (64.29%)**	4 (28.57%)	1 (7.14%)
KC 2.1d	6 (42.86%	2 (14.29%)	6 (42.86%)	8 (57.14%)	5 (35.71%)	1 (7.14%)	3 (21.43%)	2 (14.29%)	**9 (64.29%)**	6 (42.86%)	7 (50.00%)	1 (7.14%)
KC 2.1e	6 (42.86%)	4 (28.57%)	4 (28.57%)	**10 (71.43%)**	3 (21.43%)	1 (7.14%)	2 (14.29%)	6 (42.86%)	6 (42.86%)	6 (42.86%)	5 (35.71%)	3 (21.43%)
KC 2.1f	8 (57.14%)	3 (21.43%)	3 (21.43%)	8 (57.14%)	6 (42.86%)	0 (0)	2 (14.29%)	2 (14.29%)	**10 (71.43%)**	6 (42.86%)	6 (42.86%)	2 (14.29%)
KC 2.2a	5 (35.71%)	7 (50.00%)	2 (14.29%)	**12 (85.71%)**	1 (7.14%)	1 (7.14%)	1 (7.14%)	10 (71.43%)	1 (7.14%)	**12 (85.71%)**	1 (7.14%)	1 (7.14%)
KC 2.2c	6 (42.86%)	0 (0)	8 (57.14%)	7 (50.00%)	5 (35.71%)	2 (14.29%)	0 (0)	3 (21.43%)	**11 (78.57%)**	4 (28.57%)	6 (42.86%)	4 (28.57%)
KC 2.3b	4 (28.57%)	0 (0)	10 (71.43%)	**11 (78.57%)**	1 (7.14%)	2 (14.29%)	0 (0)	1 (7.14%)	**13 (92.86%)**	**10 (71.43%)**	1 (7.14%)	3 (21.43%)
KC 2.3c	4 (28.57%)	1 (7.14%)	9 (64.29%)	7 (50.00%)	4 (28.57%)	3 (21.43%)	1 (7.14%)	1 (7.14%)	**12 (85.71%)**	6 (42.86%)	5 (35.71%)	2 (14.29%)
KC 2.3d	4 (28.57%)	3 (21.43%)	7 (50.00%)	**10 (71.43%)**	4 (28.57%)	0 (0)	0 (0)	3 (21.43%)	**11 (78.57%)**	8 (57.14%)	4 (28.57%)	2 (14.29%)
KC 2.4b	7 (50.00%)	2 (14.29%)	5 (35.71%)	**9 (64.29%)**	2 (14.29%)	3 (21.43%)	1 (7.14%)	1 (7.14%)	**12 (85.71%)**	7 (50.00%)	4 (28.57%)	3 (21.43%)
KC 2.4c	3 (21.43%)	2 (14.29%)	9 (64.29%)	7 (50.00%)	4 (28.57%)	3 (21.43%)	0 (0)	2 (14.29%)	**12 (85.71%)**	5 (35.71%)	4 (28.57%)	5 (35.71%)
KC 2.4d	3 (21.43%)	3 (21.43%)	8 (57.14%)	**11 (78.57%)**	2 (14.29%)	1 (7.14%)	1 (7.14%)	3 (21.43%)	**10 (71.43%)**	**9 (64.29%)**	3 (21.43%)	2 (14.29%)
KC 3.1a	**11 (78.57%)**	1 (7.14%)	2 (14.29%)	**13 (92.86%)**	0 (0)	1 (7.14%)	12 (85.71%)	0 (0)	2 (14.29%)	**9 (64.29%)**	2 (14.29%)	3 (21.43%)
KC 3.1b	**10 (71.43%)**	0 (0)	4 (28.57%)	**11 (78.57%)**	2 (14.29%)	1 (7.14%)	4 (28.57%)	3 (21.43%)	7 (50.00%)	**11 (78.57%)**	1 (7.14%)	2 (14.29%)
KC 3.1d	7 (50.00%)	3 (21.43%)	4 (28.57%)	**10 (71.43%)**	2 (14.29%)	2 (14.29%)	3 (21.43%)	3 (21.43%)	8 (57.14%)	7 (50.00%)	4 (28.57%)	3 (21.43%)
KC 3.1e	7 (50.00%)	2 (14.29%)	5 (35.71%)	8 (57.14%)	5 (35.71%)	1 (7.14%)	2 (14.29%)	0 (0)	**12 (85.71%)**	7 (50.00%)	3 (21.43%)	4 (28.57%)
KC 3.2b	8 (57.14%)	0 (0)	6 (42.86%)	**10 (71.43%)**	3 (21.43%)	1 (7.14%)	3 (21.43%)	3 (21.43%)	8 (57.14%)	8 (57.14%)	5 (35.71%)	1 (7.14%)
KC 3.2e	8 (57.14%)	1 (7.14%)	5 (35.71%)	5 (35.71%)	5 (35.71%)	4 (28.57%)	2 (14.29%)	5 (35.71%)	7 (50.00%)	3 (21.43%)	7 (50.00%)	4 (28.57%)
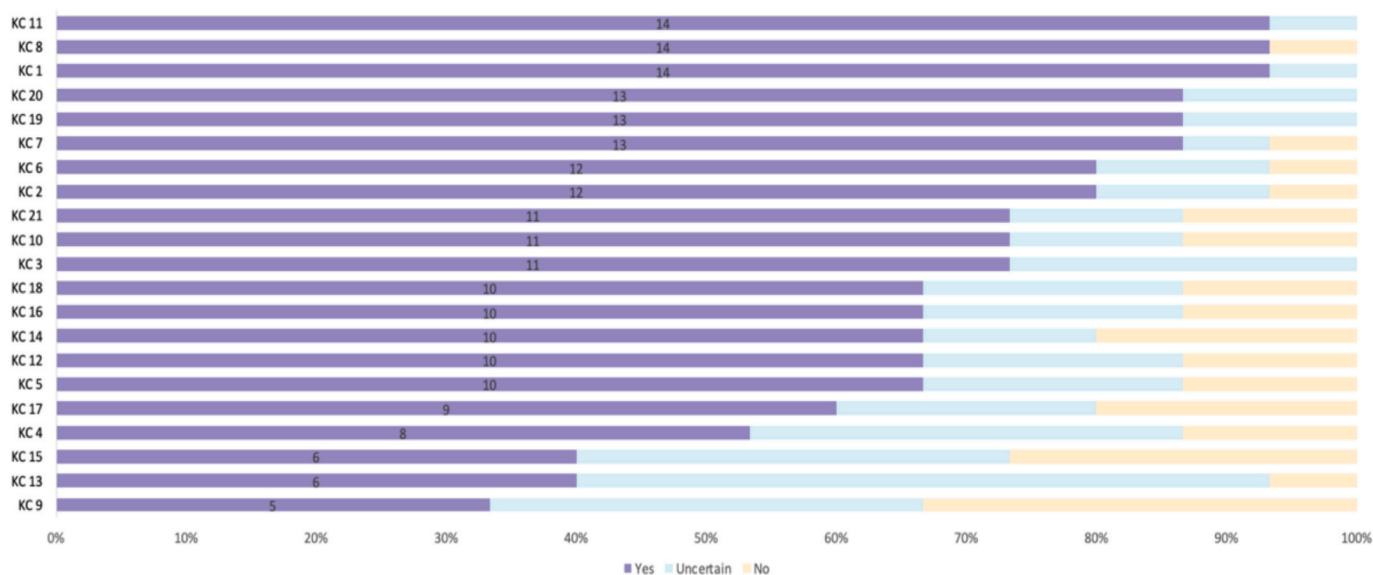
Fig. 3. Prioritisation results of 21 KCs after second-round prioritisation.

comparing both these KCs in terms of their similarity, difficulty, and relevance to the programme. After deliberation, it was finally determined to include one of the KCs.

Ultimately, a total of nine KCs were selected as the final prioritised set after two rounds of prioritisation (see Table 6). Among these, six KCs were from the "claims" section, one from the "comparisons" section and two from the "choices" section.

During the prioritisation process, a concern about the term "Key Concept" being difficult to comprehend was raised. To address this, we engaged in discussions during the second consensus meeting, and it was decided to replace the term "Key Concept" with "Guiding Principle". This new term will be used to develop the online education programme.

3.5. Ordering the prioritised Key Concepts

Initially, we proposed that the order of the prioritised KCs would be ranked once the final set of prioritised KCs was agreed on [14]. However, as the prioritisation process proceeded, it became apparent that ordering the KCs without adding cancer-related content was inappropriate. Therefore, it was decided at the consensus meeting that the ordering of the prioritised KCs would take place later in the programme development.

4. Discussion and conclusion

4.1. Discussion

In this study, the 49 IHC KCs were prioritised to include 9 KCs in the education programme using a two-round prioritisation process with people impacted by cancer. The prioritisation process was carried out collaboratively, involving a project group comprising professional stakeholders and PPIs, and a patient and carer participation group comprising people impacted by cancer. Through the utilisation of five training sessions, two rounds of prioritisation and two consensus meetings, nine KCs that represent all three sections of the original IHC KCs initiative emerged as priorities for people impacted by cancer.

In this study, the prioritisation process and consensus meetings involved both the project group, PPIs, and patient and carer participants, ensuring that the perspectives of those impacted by cancer were considered.

Recruitment primarily focused on engaging patient and carer participation group participants. However, we encountered challenges

in retaining participant engagement, as half of the participants demonstrated a decline in interest upon reading information leaflet. This may be attributed to several factors. Firstly, the extensive time commitment, spanning approximately six hours on different dates for various sessions and reading material, may have posed a burden, particularly for people impacted by cancer, and the effect on those going through treatments would be even higher. This may potentially explain why the majority of recruited patient and carer participants were cancer survivors with higher levels of education who may have been more adept at managing longer training sessions and textual material. This is consistent with the findings of Pii et al. [45] and Green et al. [46], which noted that female cancer survivors who participated in patient and carer participation groups tend to be well-educated. Through discussions with the patient and carer participants, we also found that many of those impacted by cancer still relied heavily on their healthcare professionals for information and decision-making. However, because those impacted by cancer often search for cancer-related information, they may be exposed to unreliable information. While they may trust health care professionals, most people, when using health advice or treatments obtained from non-health care professionals, such as using alternative treatments, tend to make choices based solely on their own experiences or those of the people around them, rather than taking the time to consult with health care professionals [47,48]. This suggests a need for relevant educational programmes to help people improve awareness and knowledge about thinking critically.

A strength of this is study is that in contrast to other studies [49], the patient and carer participants in this study exhibited a broad age distribution, including a substantial number of older people. Moreover, the patient and carer participants who attended training sessions in this demonstrated a high level of commitment, with the majority remaining engaged throughout the study, with the exception of one who had to withdraw due to illness. This could be attributed to our efforts to reward the patient and carer participants and our commitment to providing detailed explanations during the prioritisation process.

The study's social media recruitment was through Instagram, Twitter, and Facebook, with a particular emphasis on Twitter. Given that Twitter is frequently employed by professionals for scholarly exchanges suggested by Schnitzler et al. [50], this may account for the high education level observed within our patient and carer participation group. As recruitment progressed, we observed a continuous increase in the number of followers on our Instagram account, with active user engagement. If additional resources were allocated to recruitment

Table 5
Assessment for 13 KCs against four additional judgements criteria.

	How easy is it to understand this concept?			How relevant (i.e., of current significance or importance) do you think this concept is?			How likely is it that people are already aware of this concept?			How helpful do you think this concept is in supporting people to assess treatment claims or make well-informed choices?		
	Very easy/ Easy	Uncertain	hard/very hard	Very relevant/ relevant	Uncertain	irrelevant/ very irrelevant	very likely/ likely	Uncertain	unlikely/very unlikely	Very helpful/ helpful	Uncertain	unhelpful/very unhelpful
	n = 15 (%)			*n* = 15 (%)			*n* = 15 (%)			*n* = 15 (%)		
KC 3	11 (73.33%)	1 (6.67%)	3 (20.00%)	**13 (86.67%)**	2 (13.33%)	0 (0)	2 (13.33%)	3 (20.00%)	10 (66.67%)	**12 (80.00%)**	2 (13.33%)	1 (6.67%)
KC 4	11 (73.33%)	1 (6.67%)	3 (20.00%)	11 (73.33%)	4 (26.67%)	0 (0)	2 (13.33%)	6 (40.00%)	7 (46.67%)	10 (66.67%)	5 (33.33%)	0 (0)
KC 5	**12 (80.00%)**	1 (6.67%)	2 (13.33%)	**12 (80.00%)**	1 (6.67%)	2 (13.33%)	4 (26.67%)	3 (20.00%)	8 (53.33%)	**13 (86.67%)**	1 (6.67%)	1 (6.67%)
KC 9	8 (53.34%)	2 (13.33%)	5 (33.33%)	7 (46.67%)	6 (40.00%)	2 (13.33%)	2 (13.33%)	1 (6.67%)	**12 (80.00%)**	6 (40.00%)	5 (33.33%)	4 (26.67%)
KC 10	**12 (80.00%)**	0 (0)	3 (20.00%)	11 (73.33%)	2 (13.33%)	2 (13.33%)	5 (33.33%)	6 (40.00%)	4 (26.67%)	**12 (80.00%)**	1 (6.67%)	2 (13.33%)
KC 12	10 (66.67%)	2 (13.33%)	3 (20.00%)	11 (73.33%)	3 (20.00%)	1 (6.67%)	3 (20.00%)	5 (33.33%)	7 (46.67%)	10 (66.67%)	4 (26.67%)	1 (6.67%)
KC 13	11 (73.33%)	0 (0)	4 (26.67%)	**12 (80.00%)**	3 (20.00%)	0 (0)	4 (26.67%)	1 (6.67%)	10 (66.67%)	10 (66.67%)	4 (26.67%)	1 (6.67%)
KC 14	11 (73.33%)	0 (0)	4 (26.67%)	11 (73.33%)	4 (26.67%)	0 (0)	2 (13.33%)	3 (20.00%)	10 (66.67%)	10 (66.67%)	2 (13.33%)	3 (20.00%)
KC 15	**13 (86.67%)**	1 (6.67%)	1 (6.67%)	9 (60.00%)	2 (13.33%)	4 (26.67%)	2 (13.33%)	4 (26.67%)	9 (60.00%)	8 (53.33%)	1 (6.67%)	6 (40.00%)
KC 16	9 (60.00%)	3 (20.00%)	3 (20.00%)	**12 (80.00%)**	1 (6.67%)	2 (13.33%)	2 (13.33%)	4 (26.67%)	9 (60.00%)	11 (73.33%)	2 (13.33%)	2 (13.33%)
KC 17	**13 (86.67%)**	0 (0)	2 (13.33%)	**13 (86.67%)**	2 (13.33%)	0 (0)	3 (20.00%)	5 (33.33%)	7 (46.67%)	11 (73.33%)	2 (13.33%)	2 (13.33%)
KC 18	**13 (86.67%)**	1 (6.67%)	1 (6.67%)	**12 (80.00%)**	2 (13.33%)	1 (6.67%)	4 (26.67%)	5 (33.33%)	6 (40.00%)	**12 (80.00%)**	1 (6.67%)	2 (13.33%)
KC 21	**12 (80.00%)**	1 (6.67%)	2 (13.33%)	11 (73.33%)	4 (26.67%)	0 (0)	6 (40.00%)	2 (13.33%)	7 (46.67%)	11 (73.33%)	3 (20.00%)	1 (6.67%)

Table 6
Prioritised Key Concepts.

Sections	Key Concepts (KCs)	Topic
	KC 1	Not all health treatments that work are 100% safe.
	KC 2	We can rarely be 100% sure that a treatment works or is safe.
Claims	KC 6	Just because a health treatment is linked with people getting better or worse, that doesn't mean it was the cause of people getting better or worse.
	KC 7	The results of single studies can be misleading.
	KC 8	Not all 'new' treatments are better.
	KC 11	Don't let what you believe lead you down the wrong path about a health treatment.
Comparisons	KC 14	Consider whether the people being compared in a study were similar.
	KC 19	Does a health treatment have more advantages than disadvantages for you?
Choices	KC 20	When you are making a choice about a health treatment, think about how important each advantage and disadvantage is.

through Instagram, it may have resulted in more efficient recruitment. Therefore, in future studies, understanding the social media habits and preferences of the targeted population is crucial for recruitment purposes [51]. Additionally, exploring effective online recruitment strategies for patient and carer participation group related to cancer should be investigated in future research.

We rewrote two versions of the overview of KCs documents and utilised them during all training sessions. For the second rewrite, the support of a journalist experienced in writing cancer-related articles and a patient and carer participation group participant was enlisted to assist in simplifying the content. This collaborative approach yielded valuable insights, highlighting the importance of using plain language and avoiding overly technical or uncommon terms when developing materials for the public. It also underscored the significance of early-stage patient and carer participation group involvement in the research and material development [52]. We recommend that future research involve patients and carers in the early stage of development, evaluation, and revision of materials to ensure their relevance and accessibility.

In this study, we conducted five small-group training sessions for the two rounds of prioritisation. The small group sessions allowed us to consider each participant's input and ensure they had ample time for questions and discussion. While the patient and carer participants did not suggest or modify the content of the pre-readings or training slides, we recognised the importance of carefully considering the text content when conducting a programme involving patient and carer participation group participants. Ensuring that all text is explained in simple language, and avoiding vagueness, excessive length, difficult terminology, or academic language is crucial [18,49,53]. The language used should be tailored to the thought processes of the public. For example, percentages should be employed instead of using specific numbers to make the information more relatable and easier to understand. Previous work has shown that a significant portion of patient information materials may be perceived as hard to read [18,49]. Seeking involvement from professionals, like a health journalist, could be used in future studies as a guide for developing patient and carer participation group-oriented textual content. Researchers should critically evaluate whether the content is necessary and if the wording is simple and concise enough to align with the reading habits of the public.

Previous projects using the IHC KCs also prioritised them to reach a more manageable number for inclusion in an education programme. However, some involved prioritisation judgements by the research team [34]. While the number of KCs from the "comparisons" were less than those prioritised in other studies [34,54], this may be explained in part by the fact that the KCs in this section are related more to science researches and may be perceived as more difficult [55], this may suggest that additional training are needed before the general public [55] to

fully understand the importance of these KCs. In addition, although we did not assume the number of KCs that would be prioritised before obtaining the results of each round, the final number of prioritised KCs was consistently approximately half of the total after each round, aligning with the results of previous [34,35,37,56].

We have engaged the thoughts and perspectives of many stakeholders into the consensus and decision-making process. From study design to each round of the prioritisation and setting the cut-off values, we presented ideas, speculation and made final decisions together with those people. Involving both groups in the consensus process not only facilitated the identification of KCs, but also streamlined the steps compared to a previous iteration of IHC prioritisation [56]. This may be attributed to our involvement of patient and carer participants in every decision-making step, allowing us to incorporate additional input from individuals impacted by cancer, resulting in outcomes that truly represent those impacted by cancer.

The results of this study identified nine KCs critical to addressing cancer-related misinformation. These KCs are distributed across all three sections of the IHC initiative: six on recognising unreliable claims, one on recognising reliable evidence, and two on making well-informed choices. Firstly, the six KCs on recognising unreliable claims help individuals discern the reliability of cancer claims. This skill is essential given the abundance of available information and the need to avoid being misled. Secondly, the KC on recognising reliable evidence helps participants recognise information based on good science. It is crucial for any claim to be supported by solid and relevant evidence. However, the quality of evidence can vary significantly. At times, scientific findings may be misrepresented or selectively reported to favour a particular claim. Additionally, different studies can sometimes yield conflicting results. To ensure credibility, studies must be designed to allow fair comparisons and to reduce the likelihood of systematic errors (bias) and random variations (chance). Finally, the two Key Concepts on making informed decisions guide individuals in applying critical evaluation and research understanding to their personal health choices. Making informed decisions requires evaluating the nature of the problem, assessing the relevance of the available evidence, and balancing the potential benefits, harms, and costs.

We will develop each into a learning unit that includes cancer-specific exemplars and then incorporate them into an online learning management system to create an online educational programme. These KC units will be expanded upon in the context of cancer and cancer treatments, using real-life examples from diverse sources such as social media and newspaper articles to make the content relatable and understandable. Each unit will conclude with summaries that highlight the application of critical thinking and informed decision-making. By focusing on both the process and the content of informed decision-making, we aim to provide people impacted by cancer with the skills and knowledge necessary to think critically about the reliability of health information and claims and make informed health choices through the learning resource.

A significant strength of this study lies in our inclusion of various stakeholders in the whole study process, including the planning and decision-making processes from the early stage of the study. This approach ensured that the perspectives and needs of those impacted by cancer were considered in a meaningful and purposeful way. In addition, the provision of two rewritten KCs documents, tailored to the understanding levels of the participants, appeared to help them engage with the pre-reading materials effectively. Furthermore, the detailed training content and small-group training sessions ensured that participants completed the prioritisation process with a generalised understanding of the entire IHC-C study.

One of the limitations to our study is that despite our intention to recruit a diverse patient and carer participation group, it would have been preferable if the participants had increased diversity in particular in terms of ethnic and education backgrounds. Furthermore, the patient and carer group was not particularly large. This may have influenced the

inclusion of certain KCs. The 49 KCs were initially explained and listed in their original order within three sections i.e., claims, comparisons, and choices. The original KCs were organised in three main groups and ten subgroups [30,31]. Using this order may have resulted in the KCs in those which appeared first in our reading materials being prioritised as participants may have been more engaged at the start of the process. We acknowledge that randomly disordering the three groups or all the KCs in each round of prioritisation may lead to different KCs being prioritised. However, reordering the KCs may also result in several KCs of varying complexity appearing consecutively, which could be challenging for participants. Additionally, a potential limitation is that while we are confident that our training was comprehensive, we did not assess participants' understanding of the KCs before prioritisation. Therefore, further research should assess at how difficult the concepts were perceived by those impacted by cancer.

4.2. Innovation

The methodological approach of this study represents a paradigm shift in collaborative healthcare research. By meticulously orchestrating a two-round prioritisation process with diverse stakeholder engagement, the study transcends traditional top-down approaches. Our innovative methodology, characterised by a synergistic blend of professional expertise and real-world insights from patient and carers, ensures a more comprehensive and empathetic understanding of the complexities surrounding health literacy in cancer care. This approach not only builds consensus but also fosters a collaborative environment where diverse perspectives are harmonised to identify the most relevant KCs for the IHC-C programme.

The outcome of this project is a carefully curated list of nine KCs, demonstrating the efficacy of our innovative approach. This outcome extends beyond academic exercise, reflecting tangible benefits arising when experiential knowledge from patients and carers is valued equally with professional expertise. The selected KCs, informed by the latest research and the lived experiences and realities of those directly impacted by cancer, mark a significant advancement in developing health literacy programmes, especially in oncology. This integration paves the way for more nuanced, empathetic, and patient-centric health interventions. The prioritised KCs hold significant potential to guide health professionals and healthcare institutions in designing and implementing targeted cancer education programmes. It is imperative for practitioners and institutions to consider these prioritised concepts to enhance the effectiveness and relevance of educational initiatives for this population.

4.3. Conclusion

This study prioritised nine KCs through a two-round prioritisation process and two consensus meetings that involved multiple stakeholders Our work provides a roadmap for a variety of stakeholders in cancer care and education to develop materials for education and counselling. By focusing on the most relevant KCs, the findings provide valuable insights to assist in developing the IHC-C programme which will aim to improve critical thinking and decision-making skills for individuals impacted by cancer.

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CRediT authorship contribution statement

Mengqi Li: Writing – original draft, Resources, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Declan Devane:** Writing – review & editing, Validation, Supervision, Project administration, Methodology, Investigation, Funding acquisition, Conceptualization. **Claire Beecher:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Maura Dowling:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Austin G. Duffy:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Caitriona Duggan:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **David Robert Grimes:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Avril Kennan:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Claire Kilty:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Allen Nsangi:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Andrew D. Oxman:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Derek C. Stewart:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Elaine Toomey:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization. **Marie Tierney:** Writing – review & editing, Validation, Supervision, Resources, Project administration, Methodology, Investigation, Data curation, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.pecinn.2024.100311.

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