
Proceedings Paper:

Manni, Simona, Phillips, Bob, Hamzaki, Zulfiya et al. (2024) Negotiating Neutrality: Designing a Responsive Video to Support Fertility Preservation Decision-making by Cancer-diagnosed Young Female Patients. In: Proceedings of the The ACM International Conference on Interactive Media Experiences 2024. ACM International Conference on Interactive Media Experiences 2024, 15-17 May 2024 ACM, SWE.

https://doi.org/10.1145/3639701.3656304

Negotiating Neutrality: Designing a Responsive Video to Support Fertility Preservation Decision-making by Cancer-diagnosed Young Female Patients

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ABSTRACT

This paper explores how novel possibilities for personalisation and interactivity in video media, posed by developments in responsive video technology, can be applied to support patients as they make complex decisions about their health and care. We present the stakeholder-centred design of Exploring Your Options, a narrative-based responsive video developed to support young female patients in understanding and negotiating the fertility preservation options available to them following a cancer diagnosis. By reflecting on findings resulting from the process of designing and analysing Exploring Your Options with the involvement of cancer-experienced young people, health professionals and related stakeholders, we reveal opportunities for designing health information videos leveraging personalisation and interactivity to meet both informational and emotional support needs of patients, and highlight insights and considerations that can guide designers seeking to leverage these opportunities in ways that are sensitive and appropriate to the demands of complex healthcare contexts.

CCS CONCEPTS

• **Human-centered computing → Human computer interaction (HCI)**; • **Applied computing → Health care information systems**.

KEYWORDS

Cancer, decision support, fertility, health, object-based media, personalisation, storytelling, video.

ACM Reference Format:
Simona Manni, Bob Phillips, Zulfiya Hamzaki, Sherzah Jamal, and Jonathan Hook. 2024. Negotiating Neutrality: Designing a Responsive Video to Support Fertility Preservation Decision-making by Cancer-diagnosed Young Female Patients. In *ACM International Conference on Interactive Media Experiences (IMX '24), June 12–14, 2024, Stockholm, Sweden.* ACM, New York, NY, USA, 16 pages. https://doi.org/10.1145/3639701.3656304

1 INTRODUCTION

Patients experiencing health conditions must often make decisions about their care. Some decisions require patients to evaluate complex information about options based on multiple factors ranging from health status to personal preferences [37]. In the case explored in this paper, patients who need to make choices around fertility preservation before starting cancer treatment must consider factors including type of cancer, urgency of treatment, age, facilities availability, finances, and family planning values [22, 38, 48]. Decisions can be made even more challenging when patients are impacted by worrying diagnoses and must act under time pressure. These factors can make decision involvement a considerable burden for patients [34] and result in decisional conflict and regret [5].

Providing appropriate information in combination with conversations with health professionals has been shown to benefit patients during decision-making processes [4, 17]. Decision-aids – media-based resources that inform patients about their options, from an evidence-based perspective, and encourage and scaffold active engagement in decision-making processes [58] – have been shown to positively impact patients' knowledge, decisional conflict and engagement [49]. However, these tools can have limitations, such as the risk of overwhelming patients with excessive information, some of which may vary in relevance depending on individual circumstances, and the necessity for increased emotional support for decision-makers [12, 35].

Our research explores the potential role new forms of responsive video media can play in supporting patients involved in making decisions about their healthcare. Developments in responsive video technology [e.g. 2, 10, 52] make it possible to create videos that

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IMX '24, June 12–14, 2024, Stockholm, Sweden

ACM ISBN 979-8-4007-0503-8/24/06
https://doi.org/10.1145/3639701.3656304

change their content based on viewers' interactions and other information from or about them. Prior work has hypothesised, and begun to explore, whether these forms might offer ways to support patients during decision-making processes – in particular, by combining beneficial qualities of visual narrative media (e.g. the sensitive presentation of emotionally complex topics by relatable human voices) with novel opportunities for personalisation (e.g. tailoring information to account for the circumstances of each viewer) [16, 28]. However, this possibility remains under-explored, with the development of such resources depending on unanswered questions such as: what specific design opportunities do responsive videos offer to support decisions across clinical contexts and patient groups; how will such videos be perceived and used by patients and other stakeholders; and what effects will they have on patients' ability to make decisions, and experiences of making them?

We present a research project that brought together stakeholders from health professional and patient perspectives to investigate the potential role responsive videos can play in supporting young female[1] patients with a cancer diagnosis in making decisions about the preservation of their fertility. Our work contributes: i) the design of Exploring Your Options, a narrative-based responsive video demonstrating how responsive video features can be applied to sensitively address the needs of patients in one specific healthcare context; and ii) key design considerations arising from the process of creating, iterating and analysing Exploring Your Options with the involvement of cancer-experienced young people, health professionals and related stakeholders. Central to the contribution of our findings is understanding how responsive video design can negotiate a trade-off between achieving the neutral, unbiased and complete presentation of information important for effective and safe decision aids [31] while still offering patients potential benefits from personalising content, features, and experiences to their needs and preferences. By developing and presenting design strategies that allowed these two dimensions to co-exist in ways that were satisfactory from both the perspectives of medical professionals and young people with lived experience, we aim to provide practical guidance for leveraging responsive video media across a range of healthcare decision-making contexts.

2 BACKGROUND & RELATED WORK

2.1 Fertility Preservation Decisions

Cancer treatments (e.g. chemotherapy, radiotherapy, surgery) can negatively affect patients' reproductive fitness, but fertility preservation procedures (e.g. egg, embryo or ovarian tissue freezing, ovarian suppression) can mitigate these risks, especially when performed before the start of cancer treatment [15]. Choosing whether to have such procedures, and which option to choose, requires patients to consider a range of complex and interlinked health-related and personal factors [48], including negotiating whether to prioritise urgency of treatments over fertility preservation [6, 33]. Making the most appropriate choice can depend on patients having knowledge of how different cancer treatments may affect their fertility and the benefits and risks of multiple fertility preservation options [36]. It can also depend on patients' self-awareness of their values and future plans for having children, which especially younger patients might have not developed at the point of diagnosis [23]. These decisions are made even more challenging by the urgency within which they must often be made [20] combined with the intense emotional impact of receiving a cancer diagnosis [60]. Together these factors mean patients making fertility preservation decisions can report high levels of decisional conflict [36] and experience increased stress [60]. Such issues can cause low uptake of fertility preservation procedures [22], which in turn can lead to higher prevalence of decisional regret compared to patients who decide to undergo fertility preservation [7].

Appropriate informational and emotional support can improve the experience of making fertility preservation decisions. Lower levels of knowledge about fertility issues and treatments correlates with increased decisional conflict [41]. Having the opportunity to discuss fertility preservation options with a specialist [23, 36] and accessing psychological counselling have been shown to reduce decisional conflict or regret and to have a significant impact on the emotional health of patients [29]. While the positive impacts of engagement with medical professionals are clear, there are also limitations, with some patients left desiring more information and support [20, 60]. Consultation with fertility specialists has been argued to offer the most effective form of support [4, 24, 27], but many patients are not given this opportunity due to resource and time constraints and instead receive information and support primarily from their oncologist [4, 27, 32]. Familiarity with fertility risks and preservation options can vary across oncologists, and this can influence their willingness and ability to have fertility preservation discussions with patients [11, 44]. When consultations can be provided by specialists, these are often limited in length, with much time spent explaining background information on fertility preservation needed to make subsequent discussion effective [4]. Conversations around topics of fertility have also been reported to be uncomfortable for younger patients in the presence of parents and with doctors [43, 44].

2.2 Supporting Decision-Making

Such challenges necessitate forms of support for those making fertility preservation decisions that complement discussions with medical professionals. The use of media resources, also defined as decision-aids [58], to inform patients about fertility preservation options is an increasingly common way to achieve this. Decision-aids have been developed using multiple media types – including audio [45], video [13] and even chat-bots [47] – but most often take the form of text and graphic resources on paper or on websites [58]. Decision-aids are typically provided to patients at consultations with medical professionals, either as a resource to access further information on topics discussed in a consultation or to help a patient prepare for subsequent consultations (e.g. to be read between meeting an oncologist and an appointment with a fertility specialist) [1]. The content of decision-aids can include necessary background information (e.g. how the reproductive system works), followed by information about fertility preservation options and their potential benefits and risks, to help the patient in making an informed

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[1] We use the term female to refer to people with ovaries and a uterus, to be consistent with current practice in the healthcare context explored. However, we acknowledge that this definition presents inclusivity challenges and are exploring alternatives as the terminology used in this area develops.

decision [59]. Decision-aids can also include materials aiming to structure and scaffold active engagement in decision-making processes (e.g. exercises to evaluate and compare choices or clarify values) [19, 37, 58] as well as patient experience accounts [51].

Benefits of decision-aids include providing access to specialist and evidence-based information about fertility preservation that can be read in advance of a consultation – expanding on what is possible to cover in time-limited meetings with medical professionals, allowing space for patients to digest information [59] and offering an alternative modality for information provision for those who are uncomfortable in discussing fertility preservation with medical professionals and parents [40]. Studies have shown the application of decision-aids in the context of fertility preservation can offer benefits including satisfying patients' desires for further information, decreased decisional conflict and regret, and greater satisfaction with the decision-making process [e.g. 40, 56, 57]. However, limitations of existing decision-aids have also been reported. These include concerns that providing too much detailed information, some of which may be of varying relevance to patients depending on their individual circumstances, could be overwhelming [12, 35, 46]; decision-aid information presented primarily as text may become a barrier for those with lower-literacy levels [13, 25]; and materials that are the same for all audiences may not present information in culturally appropriate ways to some patients [13, 25]. Moreover, there is a risk that by focusing primarily on addressing informational gaps during decision-making processes, materials are not designed to address equally important gaps in emotional support resulting from variable access to specialist counselling services [29, 54, 59].

2.3 The Potential of Responsive Video

Interactive technology is presenting opportunities to revolutionise healthcare experiences and processes [e.g. 9, 14]. Within this, digital media forms, including interactive storytelling and video, have the potential to address challenges of existing decision support resources. Video, as a richer narrative media form, can be used to present information instead of, or as a complement to, text-based resources [13, 18]. Compared to text, video presents advantages such as better content accessibility and approachability for those with lower literacy levels [13], and opportunities to make materials more emotionally supportive through, e.g., the use of human faces and voices, both in the presentation of medical information and the inclusion of accounts from cancer-experienced people who have previously made fertility preservation decisions [50, 55]. Interactive platforms, such as websites, can provide patients with personalised information of higher relevance to their individual health status and context. This has been explored through automatic personalisation of content based on information provided by patients, or using the input of medical professionals, and through allowing choice-based exploration driven by the interests and needs of patients using simple hyperlinks [35, 39, 42, 53]. Such personalisation has been reported to offer benefits relating to information overload [39, 42], perception of control and willingness to seek social support [42], perceived informativeness and cognitive absorption [39] and reduced decisional conflict [35].

Novel responsive video technologies make it possible to combine the opportunities for personalized presentation of information offered by other interactive digital formats, with the approachability and emotional support potential of video. These forms are able to vary their content (e.g. videos, graphics, sound) and narrative structure depending on who is watching, both automatically based on information collected about the viewer [e.g. 10] or in response to their interactions during viewing [e.g. 52]. We hypothesise there is potential to harness such capabilities to create decision support resources that reduce information overload by adapting information and its presentation to suit the needs of individual patients, while also using engaging and approachable human presentation to increase content relatability and emotional support. Prior research at the turn of the millennium investigated the application of nascent responsive video technologies for patient decision-making, including automated personalisation [16], choice-based navigation while viewing [28] and the combination of such capabilities with human testimonies [16]. While studies of these examples demonstrated impacts on knowledge [16] and satisfaction and confidence in decisions [28], widespread uptake has not been seen. One explanation for this is prior examples were developed using niche laserdisc technology, not widely available to patients in hospitals and at home. Subsequent developments in object-based media now make it possible to deliver responsive video experiences to patients via standard web browsers on personal computers and mobile devices [e.g. 2, 52]. Leveraging these advances to bring the benefits of responsive video resources to patients at scale, will depend on an in-depth understanding of how possible features can be designed to sensitively support patients through highly complex and emotionally challenging decision-making processes. Prior work does not offer this, focusing on clinical effects and offering little documentation or analysis of resource design.

3 METHODOLOGY & PARTICIPANTS

In this paper, we take a first step toward developing a body of in-depth design insight informing the development of responsive videos for supporting patient decision-making, which are both effective and appropriate for the needs of patients in clinical contexts. We describe and reflect upon a case study in which we investigated how a variety of responsive video features might be applied in support of a particular clinical context: fertility preservation decision-making for young female patients. Our work was focused around the stakeholder-centred design, implementation and evaluation of a prototype responsive video called *Exploring Your Options*. This happened over several phases of activity: a preliminary exploration of responsive video design possibilities based on an existing decision-aid; a series of consultations with relevant stakeholders to collect feedback on an initial design concept; the production of a working prototype, Exploring Your Options; and an acceptability evaluation of this prototype.

The project was led by a team assembled to provide expertise from multiple key perspectives, including: three researchers in responsive video, a paediatric oncologist and clinical researcher (HP1), and an external consultant who specialised in using participatory film with young people affected by cancer (TS1). The knowledge

Table 1: Participants involved in various stages of the project, identified using the coding scheme: health professional (HP); decision psychologist (DP); cancer-experienced young person (YP); and third sector professional (TS).

Code	Description	Concept Feedback	Evaluation	Featured in Video
HP1	Consultant Paediatric Oncologist	✓	✓	✓
HP2	Consultant Oncologist	✓		
HP3	Consultant Paediatric Endocrinologist	✓	✓	
HP4	Consultant in Obstetrics & Gynecology		✓	✓
HP5	Assistant Divisional Nurse and Researcher			✓
DP1	Professor of Health Psychology	✓	✓	✓
YP1	Young Cancer Survivor & Mental Health Advocate	✓	✓	✓
YP2	Young Cancer Survivor		✓	
TS1	Filmmaker with Expertise in Young Adult Cancer	✓	✓	
TS2	Founder/CEO of Cancer & Mental Health Charity		✓	

from within this team was augmented with insights from: four further medical professionals (HP2-5), a third-sector professional who runs a charity in support of cancer patients' mental health (TS2), an expert in decision-aid design (DP1); and two cancer-experienced young people (YP1-2). Health professionals were recruited through the professional network of the research team, while the young people were referred by the media consultant who had previously worked with them in participatory projects. Participants and research team members were involved in the project at a variety of different stages and capacities, with some involved in more than one activity. We note HP1 (who is a co-author) and TS1 were involved in a dual capacity straddling roles as research team members and participants, and as such quotes from them are included in the reporting of our findings. DP1 has subsequently joined our research team for future phases of work. Table 1 gives details about participants, their backgrounds and which activities they were involved in. Our work received ethical approval from the University of York.

4 DEVELOPING AN INITIAL CONCEPT

In the first stage of our project, we created a design concept illustrating possible ways responsive video could address challenges observed with prior decision-aids in the context of female fertility preservation. We did this because previous work involving stakeholders in the development of responsive videos has found participants can struggle to envision a full range of design possibilities due to a lack of familiarity with such forms [30]. We based our design concept on Cancer, Fertility and Me [21], which is a clinically approved text-based decision-aid designed to prepare cancer-diagnosed teenage and young adult women of childbearing age for discussion of fertility preservation options.

We began by analysing the Cancer, Fertility of Me decision aid to identify its main features, so they could be translated into responsive video form. Cancer, Fertility, and Me is a text-based resource available as a paper booklet or set of static web pages. It focuses mostly on fertility preservation decision-making required to take place before the start of cancer treatment, with brief sections on decisions to be taken during and after cancer treatment (Fig. 1). The aid begins by providing information about general female fertility, followed by descriptions of how the most common cancer treatments can disrupt the ability of patients to get pregnant and complete a pregnancy in the future. It then presents a range of preservation options, describing them one by one and answering frequently asked questions about each. This is followed by guidance on sources of support for coming to a decision. At regular intervals the aid offers spaces to note down questions that can later be discussed with a healthcare professional, especially on topics (e.g. diagnosis, type and gravity of cancer, overall health, personal values, family planning intentions) too specific to be addressed by a generic decision-aid.

We developed a design proposal for a resource that would preserve the main features and information from Cancer, Fertility, and Me, while employing responsive video capabilities to address challenges posed by prior decision-aids as documented in the literature and observed in clinical practice by HP1. The concept broached the same high-level topics as the text-based decision-aid in the same order (i.e. background information, cancer treatments' effects on fertility, information on preservation options, guidance on making a decision). However, it had a non-linear structure – in which each patient could view different video content, potentially shown in a different order, depending on their individual needs and preferences. That is to say, while the experience of watching the video would be of viewing a continuous narrative (i.e. as opposed to browsing disparate clips on a video-sharing website), the segments within this would change based on who is watching and their interactions. We describe the key features of this non-linear structure in the following sections, grouping its proposed features around the benefits we hypothesised responsive video could bring to patients.

4.1 Personalisation of Content and Structure to Reduce Information Overload

A principal motivation of the video's non-linear structure was addressing challenges of information overload in decision-aids, by showing patients a reduced or re-arranged set of content most relevant or interesting to them. Three types of personalisation were proposed to achieve this aim, each applied to a different section of the content according to its informational aims. Firstly, a section offering general non-cancer-related background information on

Figure 1: The structure of the the Cancer, Fertility of Me decision aid.

fertility (e.g. the reproductive system) was proposed to provide different, or differently pitched, content depending on each patient's existing knowledge of that subject. We hypothesised this form of personalisation could prevent the viewing experience from beginning with information many patients would already know, but while still providing full information for those patients who might not. Secondly, a section on fertility-related side effects of common cancer treatments was proposed to show only, or predominantly, video segments related to cancer treatments included in a patient's care plan, to avoid them being presented with irrelevant information. Thirdly, it was proposed that a section describing possible fertility preservation options could either filter or highlight particular choices (e.g. as relevant) based on a combination of clinical information about the patient (e.g. in cases where a preservation option may not be recommended for a person with a specific type of cancer or for prepubescent patients) or information about personal values affecting the range of fertility choices available (e.g. future childbearing intentions, partnership status, willingness to use in vitro techniques or sperm donors). The concept proposed the information needed to enable these forms of personalisation could either be input by a patient's medical professional or gathered from their medical records automatically (e.g. clinical information), or entered by the patient either at the start of the video (e.g. prior knowledge of anatomy and fertility, values and circumstances) or through active choices while viewing (e.g. clicking to see the answer to a question).

4.2 Human Presentation of Information to Increase Relatability

We envisaged a key benefit of a video-based resource would be presenting information to patients using human faces and voices, which we hypothesised would be more approachable and emotionally supportive. The concept proposed clinical information would be presented in spoken interviews by medical professionals, and the final stages of the video would include accounts by past patients speaking about their experiences of decision-making. It was also proposed the choice of speakers shown in these sections might be personalised to take into account the patient watching. E.g., patients might be shown experiences from past patients who had chosen the options they were considering or who had similar values, priorities or circumstances to them, or, if resources permitted, medical information could be presented by professionals from the hospital they would be treated at.

4.3 Interactive Note-taking and Information Sharing to Facilitate Future Consultations

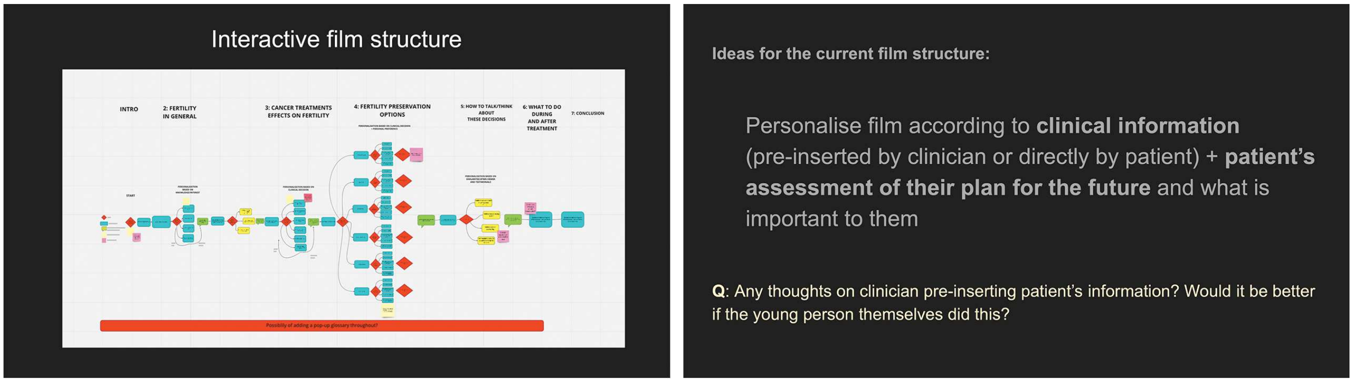
The concept proposed several ways information from and/or about the viewing experience could be collected to support discussions with medical professionals at subsequent consultations. Like the text-based decision-aid, the concept proposed patients would be given the option to write down any questions they had at the end of key sections. This would be achieved through a user interface appearing during pauses in viewing. At the end of viewing, patients would receive a list of these questions for their own record or for sharing with a medical professional at a future consultation. The concept also proposed options for this information to be shared directly with medical professionals in advance of consultations, possibly alongside a visualisation showing which sections had been watched or skipped, and which choices were made during viewing.

5 STAKEHOLDER CONCEPT FEEDBACK

To investigate the suitability of the concept's proposed features, in the context of both clinical practice and patient experience, we conducted a series of design meetings with stakeholders, including: three health professionals involved in the design of the text-based decision-aid (HP2, HP3, DP1), a young person who had experienced cancer in the past and had to make fertility preservation decisions before the start of their treatment (YP1), and a practitioner who had extensive experience of producing films with cancer-experienced young people (TS1). Each meeting started with a presentation of the concept followed by an open discussion, in which the participant was asked to comment on their general impressions of its approach and main features. The concept was presented to participants using a a set of PowerPoint slides describing and illustrating possible features, and a graph-based diagram illustrating the proposed sections within the non-linear structure and the content available within each (Fig. 2). Meetings were recorded, transcribed and anonymised. We then used thematic analysis [8] to categorise the discussion content by participants' background (medical or patient perspective), type of reactions, opportunities and concerns, and suggestions of design changes, and to then develop a series of key thematic findings described in the following sections.

5.1 Health Professional Perspective

Health professionals perceived multiple advantages of the concept for young patients, especially the potential of video and interactive presentation to suit preferences for consuming content (*"trying to engage (...) young people to learn things, do things, see things, that's exactly what you've got to do and (...) if every so often you're choosing*



Interactive film structure

Ideas for the current film structure:

Personalise film according to **clinical information** (pre-inserted by clinician or directly by patient) + **patient's assessment of their plan for the future** and what is important to them

Q: Any thoughts on clinician pre-inserting patient's information? Would it be better if the young person themselves did this?

Figure 2: Examples of materials used to illustrate the design concept during meetings with stakeholders: structure diagram (left) and PowerPoint slide used to support the discussion of a design feature (right).

a direction then it's almost like it's split up into the separate YouTube videos, which is how they are consuming all their content at the moment anyway" HP3). However, they also raised concerns about possible risks introduced by aspects of the proposed responsive video approach and features.

5.1.1 Risks of Personalisation on Neutrality of Information Presentation. Health professionals were concerned personalisation of information could be conceptually incompatible with key principles of decision-aid design. They discussed how decision-aids are designed to keep a field of options open for patients to explore equally without being directed towards specific outcomes (*"a decision-aid is designed to present choices, not guide people towards them"* (...) *"you shouldn't make assumptions and you shouldn't make suggestions"* HP2; *"if it's going to support patients' decision-making it all has to be neutral"* DP1). The way information is presented in decision-aids can affect how patients come to a decision: *"the way you present some choices is going to influence what information they see (...), if they make choices and those influence the information they are shown, we are ultimately almost pushing them towards an outcome"* HP2. Participants noted re-organising content shown to viewers via personalisation could embed assumptions about their circumstances in the video, with the risk of leading them towards a decision which might not be right for them.

The importance of not making assumptions was attributed by health professionals to the difficulty of assessing each patient's situation, and it was felt this would make personalisation based on clinical information impossible to implement with the required level of precision. While for some patients understanding which fertility preservation option might be more or less relevant is a straightforward process, for others it is more nuanced: *"some of them are no-brainers, almost that you [the patient] are automatically not able to have this or that (...) but there's going to be quite a lot that are sort of in between"* HP3. Participants described how this complexity results from a multiplicity of factors affecting options available to a patient, in terms of resources (including cost, geographical variations, HP2; and what is considered accepted practice in different areas, HP3); and unpredictable modifications to their treatment plans in response to how their bodies react (*"the treatment might change, they might think they have chemotherapy, but maybe they have surgery further down the line [...], so if you tailor it too early in the process is that going to be worse?"* DP1). So, overall, *"it's not always easy to properly categorise people, and there will be some people (...) who are in a certain category which would ordinarily mean that they have x, y and z options available to them, but there's something specific about their case that means they can't have y"* HP3. The concept's proposal to filter or highlight different preservation options by patient relevance was, thus, noted to present risks of directing patients' decision-making prematurely (*"that's pushing them, you've prioritised and made an assumption about which one is going to be more priority to that patient"* DP1).

5.1.2 The Importance of Diversity and Affiliation. Health professionals noted risks around the relationship between presenter diversity and video-based narration. In order to present information neutrally, text-based decision-aids do not feature images of individuals, while video would inevitably present speakers and, with them, the cultural and ethnic background they belong to: *"the reason we don't have any face in our booklet is because it's really hard (...), there's lots of literature at the moment about different ethnic groups distrusting certain groups of medical professionals"* DP1. It was noted this could influence the content patients choose to watch, with the risk of avoiding chunks of content if it is narrated by people patients do not feel they can relate to: *"if [patients] don't identify with the person that they're looking at, they'll be encouraged not to go with them, and I'm thinking in terms of inclusion and diversity, sexuality, trans individuals, different ethnic origins, religious beliefs"* HP3. As a consequence, it was suggested the resource would need to present such a wide array of narrators from diverse backgrounds (*"unless you build inclusivity into this so that everybody can try at some point and identify with the person presenting the information it's going to be really difficult [to fairly represent diversity]"* DP1) that there would be a risk of fragmentation and over-complexity (*"the alternative is just to make it unbelievably complicated, so you have to choose your age, sexual orientation, race, religious beliefs, in order to find your testimony or personalisation that fits perfectly with what you want"* HP3). Conversely, it was observed that while having a narrator a patient cannot relate to could hinder engagement, when a patient is able to feel connected to the person presenting the medical information this could make communication more successful than a neutral delivery: *"something that's personalised and people identify with, I think has a much better influence and impact on [the patients] to enjoy it more, they identify with it more, you potentially get more from it"* HP3.

5.1.3 Proposals to Mitigate the Contrast between Personalisation and Neutrality. Health professionals proposed possible solutions to mitigate risks around personalisation and varying narrator-affiliation. These included only excluding or de-emphasising options absolutely irrelevant to a specific patient, for instance using hormonal strategies on pre-pubescent patients (*"you're not trying to have lots of categories (...), but just to rule out things that are completely irrelevant"* HP3); presenting every option but changing the order they are displayed in (*"they all need to be presented, you might want them all to look the same, but you could change the order so that the most likely ones are at the beginning"* HP2); allowing viewers to choose which content they access rather than automating personalisation using an algorithm (*"the information is presented in a different way and the personalisation asks you which bits they want to see, but that's not predetermined by an algorithm that guides them towards one thing or another"* HP2); warn patients about the fact that treatment plans might change and they should be prepared for every scenario (*"there has to be some kind of disclaimer for all of these things"* HP3); offering a choice of different narrators to support diversity and inclusion (*"you do an exercise at the beginning to choose who you want (...), you choose your therapist that takes you through the journey and they may be a 18 year old white female or they might be a 23 year old trans individual (...) and there's an inclusive group of people that you choose and they go with you through the whole journey"* HP3).

5.2 Patient Perspective

YP1, a cancer-experienced young person, and TS1, who commented based on their experience of working closely with and as an advocate for many cancer-experienced young people, responded positively to the design concept, especially its potential to present information in a relatable way and promote reflection.

5.2.1 Personalisation and Relatability. YP1 and TS1 told us young people who are newly diagnosed and have to make fertility preservation decisions tend to look for others they can relate to, seeking out accounts from people who have been through similar experiences: *"at any stage through the cancer treatment you're looking for people to relate to, I think just hearing people talk openly about how they're feeling and about their experiences would be really helpful"* YP1. The presence of young people's accounts in the concept was praised from a patient perspective by DP1 as well, who spoke about how young patients in particular requested personal accounts in the development of the Cancer, Fertility and Me decision-aid: *"it was more important for the youngests, they said no actually we really, really want those stories (...), it's just that finding the neutrality in those is difficult"*. This challenge stemmed from the same diversity and inclusion concerns voiced by health professionals, which meant accounts of people's experiences in the decision-aid had to be simplified to not include people's faces or detailed circumstances. While this simplification supported neutrality, according to the young person involved in the design meeting, it undermined their relatability: *"I feel like you maybe need something a bit more concrete than that (...), something that connects it a little bit more to a human experience"* YP1. Moreover, according to TS1, when young people cannot access curated accounts from other young people through dedicated platforms, they tend to look for them online: *"every young person that I've ever worked with do[es] that, they go online they find YouTube videos, they explore the possibilities and then they probably take that back to the consultant"* TS1. This exposes young patients to a wide array of non-validated materials: *"when you're googling something on YouTube or wherever, you get the most random things (...), you'd get random treatments, (...) a real array of things"* TS1. Building on their positive response to the design concept's inclusion of lived-experience accounts, YP1 suggested expanding the presence of cancer-experienced young people throughout all stages of the narrative by having them act as narrators to the content: *"a young person, I think if you can hear yourself in the narrator it would definitely [help]"*.

5.2.2 Video, Question Spaces, and Lived-experience Narration can Support Reflection and Information Absorption. YP1 explained how difficult it can be for newly diagnosed patients to absorb the level of information necessary to make fertility preservation choices: *"when I was going in for these meetings, as soon as I left the office that information had gone out of my head, so I think if it's too much information coming at you then I don't think it will go in (...), because the clinicians, they're in such a rush to get you into treatment, they give you loads of information (...), there was a kind of distance between me and what was happening to me at the time, so I wasn't really connecting to anything, it was a lot of pressure to be present enough, to think about what I needed to be asking"* YP1. Having the space to absorb and understand medical information was argued to be essential for enabling young patients to formulate and ask questions to their health professionals: *"they can only ask certain questions if they know that sphere of what it is they're asking about, if they know absolutely nothing, they're not going to be able to ask the clinicians the questions"* TS1. YP1 suggested presenting information in video form could help in this process, as it could facilitate a slower, more gradual absorption of information compared to going directly into a face-to-face consultation (*"it would be different with the video because it's slowing down and taking the time to explain everything (...), it just gives you a chance to reflect closely at your own pace"*). The proposal to allow viewers to note down questions at regular intervals could also, according to YP1, help them reflect and record their thoughts: *"those sections of reflection on the information is really important, and I think a guided reflection is really helpful"*. This guided reflection would be best provided by people with lived experience of the issue: *"if you've got somebody else with you to reflect on those things it might [help], because I feel like you need somebody to help you process that information at that time"* YP1.

6 PROTOTYPE DESIGN & IMPLEMENTATION

In the next phase, we reviewed the aims of the proposed concept and made alterations to its design in response to stakeholder feedback, in particular the divergence between patient needs for relatable and focused content, and potential trade-offs raised by health professional concerns about loss of neutrality. At this stage, we developed a working prototype, *Exploring Your Options*, with the

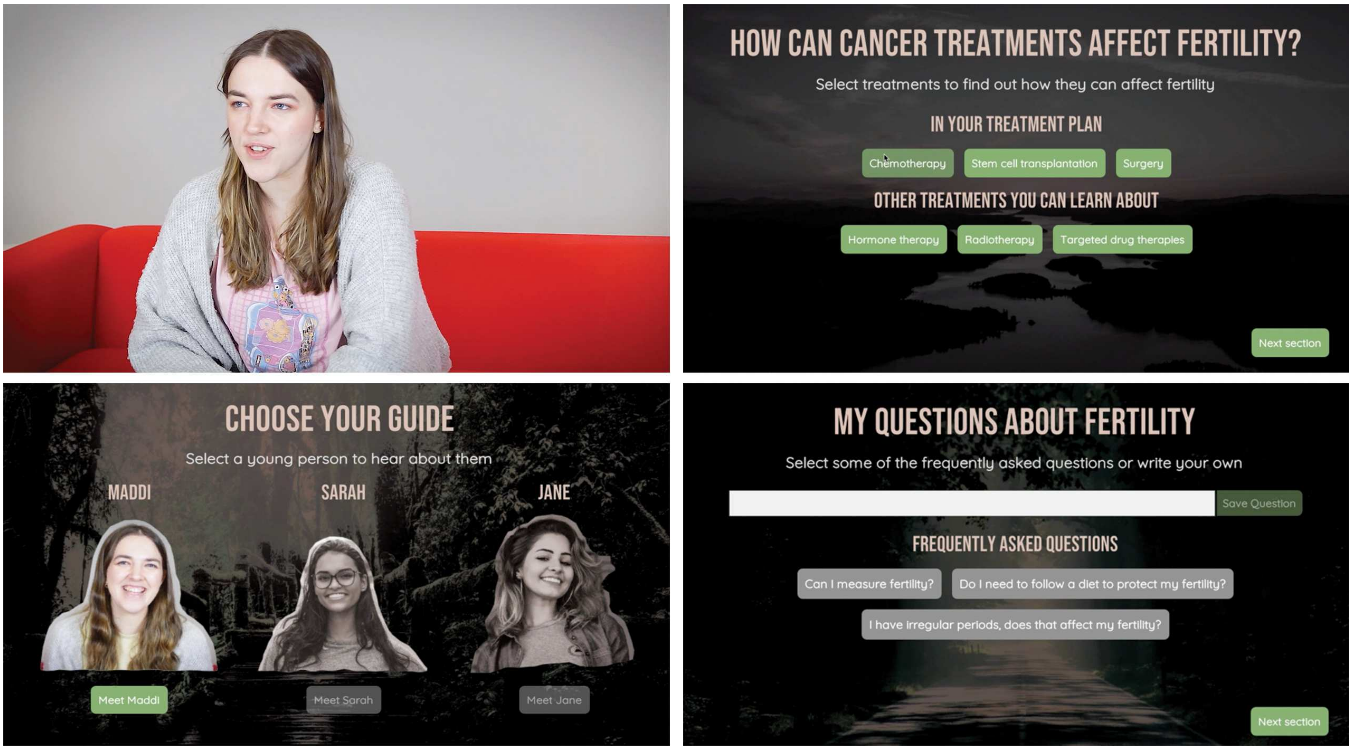


Figure 3: The Exploring Your Options prototype (clockwise): (i) a young-person narrator; (ii) a menu allowing a choice of content, with options categorised by patient treatment plan; (iii) a question space interface; (iv) the menu a selecting the young person narrator.

aim of providing a richer and more concrete illustration of design opportunities to further inform stakeholder feedback. This prototype included video footage shot in collaboration with YP1, who acted as a cancer-experienced narrator in the prototype; HP1, who acted as the main presenter of medical information; and additional medical professionals (DP1, HP2, HP4, HP5) who provided further, specific information at key moments. The research team drafted a preliminary script, which was shared with YP1 for feedback. Subsequently, the script underwent further review and adaptation during filming to align more closely with YP1's communication style and to better reflect their lived experience of diagnosis and fertility preservation decision making. The responsive video was implemented using the object-based media tool Cutting Room[2]. In the following sections, we describe the design of this prototype, highlighting key modifications made in response to stakeholder feedback. A trailer illustrating the approach and main features of the prototype is provided in the paper's video figure.

6.1 Choice-based Personalisation

The Exploring Your Options prototype presents information mirroring the content of the Cancer, Fertility and Me decision-aid using video clips in a non-linear structure. The initial design concept proposed the choice of clips shown would be in large part automated based on a comprehensive range of medical and personal criteria (e.g. age, type of cancer, urgency of cancer treatment, patient family planning values). The prototype takes an alternative, principally choice-based, approach to content selection. The viewing experience is structured around a series of menus (Fig. 3.ii) allowing viewers to choose which content is watched in each section. Some menus list video clips that can be watched on a topic (e.g. information on the side effects of a treatment) while others present a range of frequently asked questions viewers may wish to find the answer to (e.g. *"Can embryo freezing increase the chances of cancer coming back?"*). We intended this approach would allow patients to access content most relevant to them, or in an order that is, but without introducing identified risks of overly-directive content presentation, potentially based on inaccurate information or assumptions, as highlighted by health professionals in their feedback to the design proposal (section 5.1.1).

6.2 A Moderated Approach to Automated Information Personalisation

Acknowledging the well-documented negative impacts of information overload in the decision-aid literature, as a design team (including health professional HP1) we sought to still include elements of automated information personalisation in the prototype where this could be done appropriately. Two approaches were developed to achieve this, taking into account health professionals' concerns (section 5.1.1). Firstly, a menu allowing viewers to choose

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[2] https://github.com/Digital-Creativity-Labs/CuttingRoom

which treatments they would like to learn the side effects of, groups options according to which are in a patient's treatment plan (Fig. 3.ii). Our aim in adopting this approach was to make the extent of content in this section feel less overwhelming, but without hiding or removing information that may become relevant should a treatment plan change. Secondly, we included the option for a health professional to remove specific fertility preservation options from the video, should they be fully confident they will not be relevant to the patient (e.g. those unavailable to pre-pubescent patients). In this case, the hidden options would not be shown on a menu where the patient chooses which preservation option they would like to hear about. We proposed health professionals would be able to specify these forms of personalisation using a lightweight mobile app, which would generate a link to an individually-configured version of the video that could be shared with the patient. The prototype included a functional mock-up of this app, which could be used to configure the video.

6.3 Encouraging Comprehensive Exploration

In response to health professional concerns that under the prototype's non-linear structure patients might skip content they feel is not relevant to them at the time of watching, but which might become relevant later should circumstances change (section 5.1.1) and to their suggestions of warning patients on the potential impact of skipping key content (section 5.1.3), the prototype includes sections of narration recommending specific segments of content are watched even when they might not seem relevant to the viewer. E.g., at one point the young person narrator explains how their therapy plan changed in the course of treatment from chemotherapy only, to chemotherapy and radiotherapy, and suggests for this reason viewers watch the side effects of all treatments, including those which are not highlighted as being in their current treatment plan. We aimed that explicitly relating aspects of this guidance to the lived experience of a young person narrator would make reasons for viewing information that might not feel presently relevant more meaningful.

6.4 Expanded Role of Cancer-Experienced Young People and Narrator Choice

Our initial design concept proposed most information would be presented by health professionals, with content from cancer-experienced young people limited to experience accounts of decision-making in a final section. In response to feedback about the powerful impact the presence of cancer-experienced young people in the video could have on patients (section 5.2.1), in the prototype a young person (YP1 themselves) acts as a primary narrator throughout, guiding and accompanying the viewer as they engage with all sections (Fig. 3.i). With YP1, we developed a script where the young person introduces the aims and workings of the responsive video, introduces sections of medical content presented by doctors, and reflects on the importance of how this information relates to fertility preservation decision-making. The young person also intersperses personal reflection of her own experience of decision-making throughout the narration. To enable the expanded inclusion of young person narrators who would feel genuinely relatable to a diversity of patients in response to concerns raised by health professionals (section 5.1.2), the prototype introduces the viewer to a range of different young people at the beginning and allows them to select one to *be their guide* (Fig. 3.iv). The chosen young person then remains with the viewer as a primary narrator throughout the remainder of the experience. We also extended this interaction to allow the viewer to select a particular medical professional who would serve as the main presenter of clinical information in the video. We intended this could enhance engagement by enabling patients to choose a medical professional with whom they feel, e.g., comfortable with, who have a preferred presentation style, or, should resources allow it in the future, who work at the unit where they will be treated. We chose to consistently feature a single viewer-selected narrator from each category throughout the main stages of the experience where core medical information is presented, rather than interspersing a diversity of people throughout, in order to avoid concerns expressed earlier in the design process that varying levels of engagement might arise if certain content elements are presented by a range of people the viewer feels a varying level of affiliation with[3].

6.5 Question Spaces as Means of Scaffolding and Capturing Reflection

In line with the initial design concept and in response to the positive feedback on question prompts' ability to assist patients' reflection and information retention (section 5.2.2), the prototype includes interactive *Question Spaces* after each information section (Fig. 3.iii). Viewers can note down their own custom questions using these spaces, or select from a set of suggested *FAQs*. A list of these questions, categorised by section, is provided at the end of the viewing experience. This is intended for use as an aide-memoire at the patient's next medical consultation. Due to a combination of privacy and practical concerns, a proposed feature that would allow sharing of viewing log data with medical professionals was not included in the prototype.

7 PROTOTYPE ACCEPTABILITY EVALUATION

In the final stage of the project reported in this paper, the Exploring Your Options prototype was evaluated with eight participants representing both health professional and patient perspectives. These included participants who had previously been involved in the earlier stages of the research process (HP1, TS1, DP1, HP3, YP1), some of whom were also involved in filming content; a participant who was only involved in filming (HP4); and two participants who were new to the project (YP2 and TS2). We chose these participants to ensure the views of different stakeholders with different levels of familiarity with the prototype could be explored. We considered important to involve participants who had taken part in previous stages of the design development so that they could have the opportunity to reflect on the ideas and contributions provided as they were manifest in the resulting prototype. The evaluation was designed as a preliminary acceptability analysis – providing evidence of the viability of the intervention in support of, and to collect feedback to shape iteration prior to, subsequent patient trials. Therefore, it would not have been ethically appropriate to involve patients

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[3] The prototype evaluated in this paper only contained one narrator per category for demonstration purposes, due to resource constraints. However, additional narrators have been subsequently added.

presently in the process of making fertility preservation decisions who face considerable pressure in decision-making and would have been exposed to risks of having their decisions incorrectly influenced by an experimental prototype that had yet to be validated for safe use in real decision-making. Instead, we gained a patient perspective from two cancer-experienced young people who had previously made fertility preservation decisions following a diagnosis in the past and were in remission at the time of participating in the study. Both reported that when making fertility preservation decisions they did not feel adequately prepared, mostly due to time constraints: *"I didn't feel like I chose"* YP1, and *"I was told that there wasn't enough time and therefore you couldn't go through with it and that was basically what my fertility preservation looked like, (...) there just wasn't time to even contemplate it"* YP2.

Participants were shown Exploring Your Options in one-to-one in person and online meetings, in which they could interact with the prototype on a laptop or online using their devices. Participants were prompted to share any spontaneous thoughts or comments as they viewed, using a think-aloud approach. Following this, participants took part in a semi-structured interview based on a protocol developed by the research team. The protocol included questions on the film's overall approach, on specific design elements, and included tailored questions for medical, patient, and third-sector participants. Visual prompts were used to aid recall of different film segments. Conversations and interviews were transcribed and anonymised. Transcripts were then analysed using thematic analysis to identify key themes around participants' spontaneous reactions to the film, elements viewed as positive, elements viewed as concerning, suggestions for improvement, reflections on personalisation and neutrality, and suggestions for practical application.

7.1 Participants Responded Positively and Identified Qualities that Could Encourage Patient Engagement

The general response from participants was enthusiastic (*"I love it (...) I think it ought to be really useful, really helpful"* HP4; *"It's absolutely brilliant (...) "* DP1; *"I absolutely loved it"* HP3; *"it's lovely, it's really nice"* TS2). Combining video and interactivity was noted to give depth to information delivery: *"[the film] has really brought the book alive"* DP1; *"it just seemed to get it in to me in a very different way than reading and writing"* HP1; *"it's really nice and inviting to watch, it's not cold like the leaflets"* YP1; *"I think it's much nicer than getting (...) another leaflet to sit and read through"* YP2. Both health professionals and cancer-experienced young people made an effort to imagine how current patients might receive the video and expected a positive response: *"I would imagine most people, if they had a vested interest in it, if they're a patient or a or a clinician (...) would actually enjoy watching it"* HP3; *"they're more likely to engage with that than they are a booklet that's been handed out (...) it's more actually information for them"* HP1; *"they are probably more likely to do it [engage with resource] than if you gave them necessarily a big book of information (...), this is how they want to do things, they want it to be electronic, they want it to be interactive, they want it to be short, sharp bursts of information"* HP3. YP2 envisioned benefits the prototype could have had on their experience of decision-making: *"this gives those right tools in an explanation of every step so that the person can make a decision because I think, like [the young person narrator] said, I wouldn't have considered my fertility right at the beginning and it wasn't my big focus either, especially when the doctors were like, oh no there isn't time, I then just was like, oh okay fine of course, rather than understanding why there wasn't time, understanding what impacts that might have had on my future fertility"*.

In the following sections, we unpack how participants responded to different aspects of the narrative structure of the prototype, including use of supportive language, interactivity, choice-based structure, inclusion of diverse and relatable narrators, and space for reflection.

7.1.1 Use of Supportive language and Dialog-based Style. Participants noted the narration and use of images combined to create an inviting tone: *"the images and the way that things are flowing in and out of each other, I think feels really nice, it feels comfortable, it feels safe, it feels like I can trust it"* HP4; *"the language that's used is really kind (...) and I think that's so important because essentially young people are going to be watching this at that moment where they've just got that diagnosis"* (TS2). They also commented on how the video's stylistic traits enhanced the personable and intimate feeling of the viewing experience. In particular, they expressed a preference for shots where narrators were speaking to camera, as they strengthen the impression narrators are addressing the viewers directly (*"when the frontal view is coming to me, I feel like she's talking to me"* HP4; *"I feel much more engaged when she's looking me in the eye that when she's talking off camera"* TS1).

7.1.2 Choice-based Interaction. The choice-based, interactive structure of the prototype was described as capable of increasing agency and preventing information overload. Interacting *"does the opposite of overloading, that gives you choice"* HP1, and can help viewers engage with the content: (*"if it was just one long film I would skip through (...), this helps keep the viewer engaged"* YP1). TS2 thought a more active modality of content presentation could feel empowering to viewers in this particular circumstance: *"I love the fact that there's a sense of empowering them to try and find information at a time when they probably feel like they have no control over anything"*. For YP1, interactivity offered an enhanced sense of exchange with the narrators in the film: *"obviously it's an interactive film but if it feels like you're interacting with the people on there"*.

7.1.3 Combination of Medical and Lived-experience Narrators. A strength of the prototype identified by participants was the presence of both medical professionals and cancer-experienced young people as narrators. Participants stressed the importance of including narration by people with lived experience of the issue discussed: *"it's more powerful when [the young person narrator]'s saying to them, and I think the health professionals are great, but bear in mind not all the young people are going to click on all the health professionals films, because they just won't, they will be listening more to the young person"* TS2. HP4 stated: *"you have professionals with the required expertise, that's the strength (...), I think that to have it led by a cancer survivor is absolutely the way to go, people need to be able to be immediately engaged by someone's who been through this, that's me, that could be me, I think that's really good"*. Having the medical and lived-experience perspectives intertwined in the video was thought to help fulfil two key needs of young patients in this situation, a need for accessing clear medical information and a need for relatability: *"medical information they wanted from professionals, psychological support and experiences they wanted from young people, they don't want medical information from peers, they want that from somebody in a white coat that knows what they're talking about, so they do want that mix"* TS1. The narration provided by the young person, who mixes explanations of why certain information is necessary, recaps information presented by the health professionals, and personal experiences, was praised for its genuinity: *"she's very genuine and open"* HP3. For YP2 some of the young person's experiences embedded in the narration can help viewers reflect on important issues, like the fact that treatments plans can change over time according to how the patient responds to them: *"I loved how [the young person narrator] explained about how the treatment option (...) can change because I know that this is the case for many of my friends that have gone through it"* YP2.

7.1.4 *Offering a Diverse Choice of Narrators.*

Participants appreciated the offer of a diverse range of narrators to choose from: *"I appreciate the diversity of folks you have here, that's really nice to me, the tonal difference (...) I like the idea of being able to choose (...), having the variability of experience is key"* HP1). This aspect will be further enhanced in future iterations of the prototype, where viewers will be able to choose from a larger pool of narrators (*"there'll be a range of different people's journeys they can follow"* DP1). Health professionals suggested ways to ensure wider representation: *"if you had some gender representation and you had ethnicity representation, then you know if you've covered that in terms of the types of people"* HP3. In terms of choosing a young person narrator from a pool of different options, YP1 commented that the use of a clip showing the young narrator in their own environment with a brief presentation of their life outside of cancer would be a good way to understand whether the viewer can relate to them: *"it makes them a little bit more human doesn't it, I think it's a nice touch to have, to show a little bit about a person's life outside of cancer"*. On the other hand, YP1 and YP2 stated they would choose a medical narrator based on their job title and expertise (*"the job title (...) would sway my decision in who I choose"* YP1) and on how they feel they would connect with their information delivery style (*"that's what my decision would come down to, it's who am I going to tune into and how am I going to zone out from"* YP2), while relating personally to health professionals is much less important than it is for choosing a young person narrator (*"I don't think there's any sort of need to relate to those doctors, you just need the information from them"* YP1).

7.1.5 *Accounts of Decision-making Experiences.*

Lived-experience narration is a key part of the final section of the video, dedicated to emotional support, where the young person narrator is joined by health professionals and other young people in discussing the emotional side of the decision-making process and how to get support. TS2, whose professional practice revolves around mental health experiences of cancer-diagnosed young people, commented on the importance of this section as it is responsive to the emotional state of many young patients, who might to go *"into survival mode"* and *"park [their] emotions and then all of a sudden they're having to be forced to think about their future"*. Receiving reassurance from a lived-experience narrator that *"your emotions will change and that's okay, you can get angry about this, you can get upset about this, you can take control of this (...) or you might not really care about this and that's okay and it's okay for those feelings to change"* can be particularly comforting for newly-diagnosed young patients, according to TS2. Discussion with participants around this section highlighted the need to focus on dynamics related to the decision-making process over the factual fertility preservation decisions taken by cancer survivors, as to avoid raising expectations and directing viewers towards specific fertility preservation options based on narrators' individual experiences: *"we shouldn't be letting people know about the decision (...), but how would they make those decisions, I think that is more important because this is about supporting you in making a decision, not telling you to come to a decision"* HP1. YP1 noted the importance of stressing the individuality and uniqueness of each narrator's personal experience by *"making it clear that this is this person's specific experience and it's not necessarily going to be [the same for everyone]"*.

7.1.6 *Space for reflection.*

For YP2, a merit of the prototype was its ability to make space for information processing and reflection, removing the pressure of having to make decisions on the spot: *"if I was to have been given the film it would have allowed me the space to not have to ask the questions straight out but understand some of it first and then go for the questions, it just gives you a bit more ownership in it rather than it being a decision you have to make in the there and then"* YP2. Question spaces were perceived as particularly useful to foster reflection and record thoughts as they arise: *"it's good because there is just so much information going around that it's giving you questions to ask instead of just leaving you to think of questions, and I know that people would say do you have any questions about this, and I'd go no, and then later I'd say, oh I wish I'd asked this"* YP1. Question spaces were also expected to provide a sense of increased agency: *"being able to write your own questions as well, it does feel like you've got a bit more control over your options, like it's really consulting the person"* YP1.

7.2 Participants Did Not Think the Proposed Personalisation Would be Detrimental

Health professionals previously expressed concerns that personalised elements of responsive videos could detract from neutrality of content presentation, to the point of inappropriately directing patients to specific options. Interacting with the prototype during the evaluation seemed to ease some of these concerns, and the way the prototype gently personalises some aspects of content presentation was not considered directive enough to prematurely influence decisions. According to HP4, the prototype's approach to personalising content *"is really good because there's such a lot to take on board anyway, you don't want people to be bombarded with stuff they don't need or to get confused and think, well why are they telling me this?"* However, the prototype still provides *"people, the patient and their parents and anyone else near to them the overall picture"* to prepare them for future conversations: *"they are then going to have a personalised conversation aren't they, so this is not the end of it"* HP4. For HP3, the level of personalisation provided in the prototype would still be operating over a foundation of general information which is relevant to most patients, and so would not close off options for them: *"you just provide generic information that* *covers everything (...), I think this [personalisation] is fine because (...) it makes sense to have emphasis on the things that are relevant, with a background of information on other things that could become relevant at some point but aren't yet".*

Health professionals, YP1, and YP2 stressed the benefits of exploring options even when patients might not necessarily be able to choose them because of time constraints, health constraints, or regional availability. According to HP3, *"people would be more upset to find out about options that were never discussed with them or that never came up than to see all the options that are out there, know what's available, be informed about and then (...) being able to go to discuss them and make decisions with the clinicians"*, even when they might then discover in conversations with clinicians that specific options are not available to them. YP2 confirmed that *"understanding how it affects fertility, understanding how chemotherapy affects hormones and all of that information was really useful and would have been useful regardless of then having an option or not having any"*. HP1 stressed the importance of not ruling out any options from those the patient can explore in the video, because doctors might not get the full picture of a patient's circumstances during initial consultations: *"what if she told me she didn't have a boyfriend [which would possibly rule out embryo freezing as an options for her] but that actually was because her mum was in the room and maybe they wouldn't mind having a baby together? (...); I initially thought that taking things out would be a good idea, so that it didn't get overload but having been in a couple of situations where it's clear that different clinicians receive different levels of personal information (...), I think it's probably sensible to have [all options visible]"*.

Finally, some participants suggested age as an additional criterion to further personalise the content: the resource is aimed at patients roughly within the age range of 16 to 25 and YP1 recognised needs might be different between the youngest and oldest patients, and this should be reflected in the choice of narrators offered in the video: *"if somebody's started going through treatment when they were 25, and their narrator, like me, said when I started getting through treatment I hadn't even thought about children yet, maybe somebody when they were 25 might already have children or be thinking about it, so they wouldn't relate as much"* YP1. Choosing a doctor narrator could also be based on their patients' age range: *"being able to pick based on the age group they work with will help some young people click into it"* YP2.

7.3 Participants Proposed ways in which the Prototype Could be Incorporated in Practice

TS1 encouraged greater consideration of how the prototype would sit within a patient's journey of care: *"who's presenting this to them, for them to be able to go through this process (...) it might be a Macmillan nurse, it might be a teenage cancer trust worker, it might be an activities coordinator, it might be a youth worker?"*. HP3 and HP4 agreed providing the video to patients would depend on the care team around them being aware of fertility preservation issues and willing to share resources. This is not always the case, depending on facilities available and the medical predisposition of the oncologist: *"the break point is the cancer specialist (...), there are a lot of places where the oncologists have purely got their eye on the cancer and the objective is to save the life of that cancer sufferer and there will be some consequences, there'll be some fallout but this is the priority"* HP4, while on the other hand, *"I think it's fair to say there are some centres that are really heavily focused on fertility preservation (...) and I think there are also some clinicians who are very switched on to this and know all the options"*, but this is *"variable"* HP3. According to these participants, the uptake of the prototype and ability to reach individual patients would depend on how much a care team endorses discussions on fertility preservation.

Other conversations centred around some specific aspects of the prototype. When asked about configuring elements of automated personalisation in the video, and whether this should be done by a clinician or by the patient themselves, YP1 expressed a preference for the first option, to avoid demanding an additional cognitive ask to the patient: *"for a lot of people the information that's given to them just goes straight over their head so they might forget what treatment they've been told that they're going to have"*. Some discussion addressed what should happen to the report of questions generated at the end of the viewing experience. The report was considered useful both by young participants and the health professionals as a way to have a tangible reference to take to consultations (*"I love the fact that you can then save these questions for talking to your doctor"* YP2; *"I think it's quite a good prompt to come to a consultation with a list of things that weren't clear"* HP4). Sending the reports directly to clinicians at the end of the viewing experience in advance of a consultation was not deemed realistic by most participants (*"would the doctors even have the time to review if because they're so busy?"* YP1) and might even damage the trust between patient and clinician: *"it's better just to have them yourself to take with you because I think trying to (...) coordinate that in with fertility clinical professionals, just knowing how the system works to get it to the right person in the right way for them to even see it, (...) it can be detrimental sometimes to have something like that where the patient thinks that the clinician has seen it, acted on it, thought about it is ready and prepared, has read it, and then they get to the consultation and they haven't seen it, they never got the email, they didn't know about it, that annoys patients"* HP3. In terms of data tracking, YP1 and YP2 expressed they would not wish to share information about their viewing experience (content watched or skipped) with clinicians (*"you then go into those consultations and feel a little bit told off for not [watching the full content]"* YP1). HP1 commented on the fact that this type of data could be too complex for a clinician to understand in advance of patient consultation unless the data is accompanied by dedicated training packages.

Some discussion addressed the context in which the prototype should be viewed by patients. TS1 wanted it to be provided in an app that can be accessed by the young people at any time through their phones. However, YP1 argued that this type of content rather calls for a private and focused viewing experience, which would not take place on the go: *"this is something I'd want to do in private, I don't think I'd really want to watch this in a public space"*.

8 DISCUSSION

The prototype of Exploring Your Options received overall positive responses from former young patients and health professionals alike in our acceptability evaluation, with the gap between the views of these groups narrowing compared to an earlier design concept. We interpret this as a sign the revised design can accommodate the divergent needs of these stakeholders. In the following sections, we reflect on key design features of Exploring Your Options, to provide insights and recommendations we hope can inform future research on using responsive videos, and modalities sharing in their qualities, to support complex healthcare decision-making.

8.1 Balancing Personalisation and Neutrality

Findings from an evaluation with health professionals, including those who raised concerns around risks to neutrality posed by content personalisation, suggested that design strategies in the prototype could offer ways to successfully modulate content personalisation so as to not restrict the field of exploration available to patients. These include an approach to personalisation that does not withhold information from patients, even when some options may at first sight appear irrelevant to certain categories of patients. Our findings suggest being well-informed about every option, even those which might not be available to a patient, can still be beneficial in terms of awareness, and ultimately an assessment on the suitability of options can only be performed by health professionals who have a direct relationship with a specific patient. The role of personalisation in support materials and decision-aids should, therefore, not aim at discriminating different options on a patient's behalf. Rather it should aim to package information in a way that is engaging and more easily digestible for patients, to help them gain a full picture of the different elements which can affect their decision-making, especially in contexts where it can be particularly challenging for patients to absorb and actively engage with information.

Our findings suggest personalisation can be harnessed to help engage patients with the information at their disposal by offering choice-based navigation, and that this can stimulate a more active viewing modality able to counteract the passivity often experienced by newly-diagnosed patients when receiving medical information. Personalisation can also be used to organise content in a way that is responsive to a patients' circumstances (e.g. prioritising side effects of treatments in the patient's current treatment plan) as long as the full range of information is still available to view. Embedding a rationale for exploring seemingly irrelevant content in the narration (e.g. a narrator explaining it is advisable to explore side effects of every treatment as plans can change in the future) can make explicit some of the reasons behind the neutrality of traditional decision-aids, helping patients become aware of why certain information can be crucial to consider. This can be made more powerful when these recommendations come from a lived-experience narrator, who can relate the relevance of the medical information to their experience.

8.2 Prioritising Narration

While we anticipated video-based human narration would present advantages in terms of relatability and emotional support when designing our preliminary concept, the design consultations and the evaluation of the prototype brought the importance of carefully designed human narration to the forefront. Embedding lived-experience narration throughout the whole prototype and interspersing medical information with reflections provided by a narrator with lived experience emerged as one of the most successful strategies for achieving this. Our findings suggest that this approach was made more impactful by allowing patients to choose these narrators from a diverse pool, where lived-experience narrators would be chosen for their relatability with the viewer, and medical narrators for their professional background. Our findings suggest that bringing lived experience narrators to the foreground can help to fulfil a deep need for relatability identified during concept design feedback. While decision-aids tend to not feature recognisable narrators to avoid issues of affiliation and bias that could detract from patients being able to objectively assess the medical information provided, young people tend to still look for accounts of personal experiences online, and might encounter questionable or even misleading information which poses a much higher risk than the strategies adopted in our design (e.g. patient testimonies associating preservation choices with successful or unsuccessful outcomes, which may not be the same for the patient viewing) [26]. We argue embedding lived-experience in ways carefully designed to avoid leading patients towards certain options (e.g. avoiding disclosing details on the success of the fertility options experienced by the narrator, while still sharing feelings and experiences around the diagnosis and the decision-making process) may help fulfil young patients' needs for relatability in a safer environment than browsing the internet at large.

8.3 Designing an Emotionally-supportive Viewing Experience

The importance of taking into account the emotional well-being of patients in a particularly vulnerable stage of their care journey has been another fundamental finding in conversations with stakeholders. Cancer-experienced young people and third sector consultants stressed young patients' need for reflection and breathing space when consuming potentially upsetting medical content following an already concerning diagnosis. We made an effort to design an emotionally supportive experience for viewers through the gentle guidance by lived experience narrators, by providing regular question spaces where the delivery of information is paused in favour of an opportunity to collect thoughts and questions, and by curating a section fully dedicated to emotional support in the decision-making process. Our evaluation highlighted how the young people involved in the study favour a slower-paced and more intimate viewing experience than is usually expected of them. While professionals expressed some concern over the slow pace of the information delivery as possibly frustrating for young audiences who tend to be used to fast-paced social media environments, the young people who evaluated the prototype stressed the value of decelerating the rhythm of information delivery in a moment in which they are bombarded with fast-paced changes. For the same reasons, the young people expressed they would imagine consuming this content in private spaces at planned times, rather than on-the-go through a mobile app. These suggestions indicate young patients in this context might prefer a different approach to media consumption to which they adopt for entertainment.

9 CONCLUSION AND FUTURE WORK

We began exploring the application of responsive video in the context of medical decision making with a strong focus on how the technology's personalisation capabilities could be used to address information overload. Involving a range of relevant stakeholders in the design of the Exploring Your Options prototype has suggested that while young patients would benefit from personalisation of content as a way of making information more relatable and easier to absorb in a moment of high distress, such opportunities come with risks of inadvertently directing patients toward particular options based on assumptions about complex circumstances that can only be appropriately assessed in dialogue with medical professionals. Stakeholder feedback from a patient perspective also emphasised the potential power of using relatable human narrators as a means for delivering information in decision support resources, but insights from health professionals revealed key risks stemming from varying levels of narrator affiliation.

By iteratively developing a prototype in response to stakeholder feedback, we have developed design strategies aiming to negotiate a balance between young patients' needs for focused and relatable information and the importance of neutrality expressed by health professionals. Central to the design of Exploring Your Options is a storytelling model wherein emotionally-sensitive, video-based narration is provided by a combination of health professionals who deliver medical information and lived-experience narrators who introduce, reflect on, and relate medical content to their own experiences of decision-making; where choice is offered to pick from a pool of narrators from different professional, cultural, and ethnic backgrounds; where personalisation is limited to displaying content in ways that make their consumption more digestible for young patients at a vulnerable stage of their care journey; where interactivity is deployed to offer choices to young patients as to the order and amount of content they wish to explore at a given time; and where regular reflection spaces are offered to gather thoughts and formulate questions for future consultations.

The findings of this paper are based upon the appraisal of a prototype at increasing stages of fidelity, and not its use in practice during patient decision-making. Also, the patient perspective was based on retrospective reflection by people who had previously experienced fertility decision-making, as well as the experiences of others who work regularly with patients. These kinds of findings are valuable because they contribute to evidencing that our proposed approach is sufficiently acceptable [3] to the target population and organisational setting for safe and ethical evaluation with patients who are in the process of making decisions — which is a crucial prerequisite for future patient trials. We note our acceptability evaluation included participants who were also involved in previous stages of the research, including the design of the overall concept and the stakeholder feedback. While we acknowledge that involving contributors at different stages of the research might introduce the risk of positive bias due to familiarity, we considered this choice appropriate as, at this stage of the research, it was our aim to seek ongoing critical feedback which could shape the design process, rather than to conduct a validatory evaluation of a completed prototype. By reporting findings of this kind, and at this stage in our work, we aim to enable other researchers to benefit from the in-depth healthcare professional and patient perspectives that have been so valuable in shaping our thinking and design practice on how responsive videos, and related modalities, can be appropriately used in they context of healthcare decision-making. We will, however, address these limitations in the next stage of our work through further analysis with additional stakeholders external to the research team and, most crucially, patients who in are the process of making fertility preservation decisions.

ACKNOWLEDGMENTS

This research was supported by the EPSRC (EP/M023265/1); the University of York's Internal Development Fund; and the Children's Cancer and Leukaemia Group (CCLGD/2023/01).

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