Using interactive video to support cancer-diagnosed teenagers and young women in making fertility preservation

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Women diagnosed with cancer often have to make time-sensitive decisions in terms of fertility preservation, facing possible decision-conflict and having to process a considerable amount of information while still coming to terms with their diagnosis. Decision-aids can support women in their decision-making process by complementing health professionals' consultations, but text-based tools can at times prove overwhelming, with a wealth of information which does not necessarily apply to all women. This project explores how cutting-edge forms of personalized video storytelling can support female patients, in particular teenagers and young women, in making fertility preservation choices following cancer diagnosis by building personalised pathways through the content and rating options by relevance to each patient while also leveraging the potential of video as a media form to present complex information in an approachable and empathic way.

CCS CONCEPTS Human-centered computing ~ Empirical studies in interaction design

Additional Keywords and Phrases: interactive film, fertility preservation, cancer

1 INTRODUCTION

Women of childbearing age with cancer must often make time-sensitive decisions about fertility preservation. These decisions are dependent on a variety of issues, including age, type of cancer, facilities

availability, financial considerations, and women's values in terms of family planning [7, 11, 14]. All these factors need to be considered timely by patients while they are still coming to terms with their diagnosis. Research shows that this creates a considerable additional burden for any patient, and in particular young women [10]. Clinicians might feel unprepared on how to support conversations about this topic [4], and some young women experience decisional conflict and regret [1].

Research shows that decisional tools in combination with conversation with clinicians can support fertility decision-making for female patients [5]. Cancer, Fertility & Me is a decision support aid developed by a consortium of clinical and academic partners [2, 6]. The aid is a printed booklet and website explaining fertility preservation options available to women beginning cancer treatment. It is meant to be used by women to explore options in preparation for conversation with health professionals and family and as a support tool to formulate questions. A study with 41 women has shown patients who received the aid "described a positive impact on their ability to make fertility preservation decisions and support them at a stressful time" [8]. However, discussions with young women and clinicians have highlighted some challenges. These relate to the overwhelming amount of information included, much of which is not relevant to each patient based on their individual partnership status, nature of cancer and treatment.

2 CREATING A PERSONALIZED VIDEO PLATFORM TO FACILITATE FERTILITY PRESERVATION DECISION-MAKING IN YOUNG PEOPLE

Object-based media is a technique where "media objects are dynamically – therefore automatically – assembled during delivery, as opposed to being locked within a linear sequence at authoring time, as is the case with the traditional approach to media production" [13]. As a technology, object-based media, enables the creation of video stories that can change and adapt depending on information about their viewers and their interactions. In our research, we are exploring how the application object-based storytelling techniques developed within our Digital Creativity Labs [3] can enable a *personalised video* decision support aid that offers both in-depth personalization of information to individual needs and preferences alongside benefits of video-based presentation.

We envision a video-based decision aid that could be provided to patients following an initial consultation with a clinician and in preparation for meeting with fertility care teams. This video would leverage properties of story-based visual media to provide patients with an emotionally sensitive exploration of the topics of fertility preservation through interviews with clinicians and testimonials from cancer-experienced women who have previously made those decisions. Moreover, using object-based media approaches, the content of this video would be personalised to show information and perspectives that are of most relevance to the situations, priorities, experiences, and choices available to individual viewers. Anticipatory discussions with clinicians and patients (included as part of an NHS public involvement in research meeting [12]) have highlighted a rich variety of ways in which video media could be personalised to better support decision making. These include: providing patients with a guided path through treatment options, based on patient or clinician input of data; offering opportunities for exploring particular treatment options in more detail based upon individual interest; tailoring the level of background information provided based on patients' prior knowledge; featuring curated patient experience testimonies based upon treatment options of relevance and preference to patients; offering localised introductions

to clinicians and facilities; the potential for using analytics data about elements viewed to guide subsequent conversations between patients and clinicians; use of interactive elements to support patients in preparing questions for their next consultation.

To date, we are in the process of developing a design for this aid, which will include regular consultations with healthcare professionals and cancer-experienced young people. The proposed design expands the content and structure of the previously clinically-validated paper decision-aid (Figure 1) to create a non-linear structure (Figure 2) which will be experienced by young patient through different forms of personalisation: by clinicians' input (clinicians will be able to pre-set the film according to the patient's medical information); by patients' previous knowledge (patient will only be shown generic fertility information to the level of details required); by patients' preferences (patient will be shown options rated according to relevance not just to their medical information, but also to their values and family planning orientation); and by commonality (patient will be show testimonials that are more relevant to their circumstances). Interactive elements will also support patients in preparing questions, which will be compiled in a brief text report that patients can take with them to their next clinical consultation.

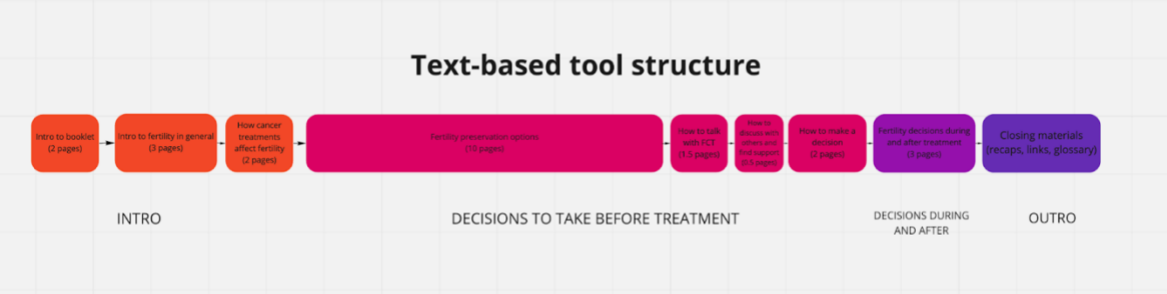

Figure 1 Text-based aid structure

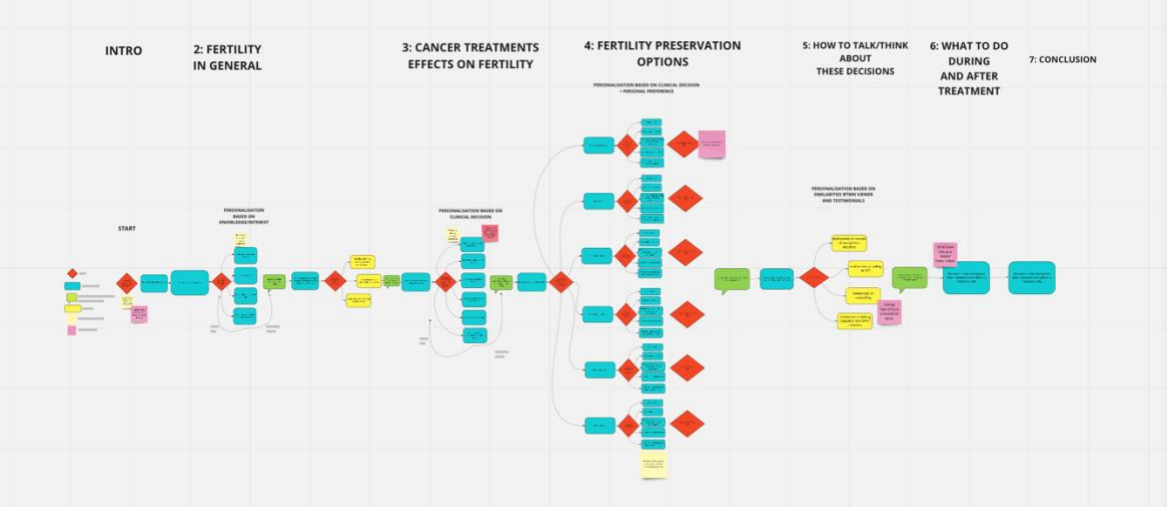

Figure 2 Interactive video design

This project entails the development of a functional prototype of the personalised video decision aid based upon our preliminary design. The prototype will provide a functional representation of the concept that can be used to analyse specific options for narrative personalization and the approach in general – through initial stakeholder analysis conducted during this project and (subject to further NHS ethical review) future trials with patients.

3 FUTURE RESEARCH AND APPLICATIONS

In the future, we plan to evaluate the completed prototype on a long-term basis with patients in order to fully understand how effective different approaches to personalization are in supporting patient decision-making and offering broader emotional support. This will also inform future research on personalized interactive storytelling platforms in digital health contexts.

According to preliminary conversations with clinicians, future applications of this technology could include producing the same platform for boys and young men facing similar challenges: due to the flexibility of object-based media, the skeleton of the film can be maintained while video content can be replaced and relationships amongst video materials and young people's choices easily adapted to cover options available for boys. The platform could also include the possibility for clinicians to monitor, within privacy constraints, which parts of the content young people spend more time watching and which parts they might find particularly challenging, with opportunities for refining content and supporting more effective decision-making for the young people.

Another future area of research will address how the tool might be extended to work beyond the preliminary decision-making stage, to include options for young people to keep engaging with the content throughout their treatments, monitoring symptoms, or even including footage or text produced by the young people themselves to reflect on their experiences. This would move towards transforming the tool into an ongoing health assessment

creative platform where patients can express themselves in a confidential and emotionally supportive environment [9].

This kind of technology could also be adapted to support other complex health needs where multiple stakeholders are involved and careful decision-making needs to be facilitated.

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