



Pathways: a fertility preservation patient decision aid website for women with cancer – implementation feasibility and adaptations for women from the LGBTQ+ community.

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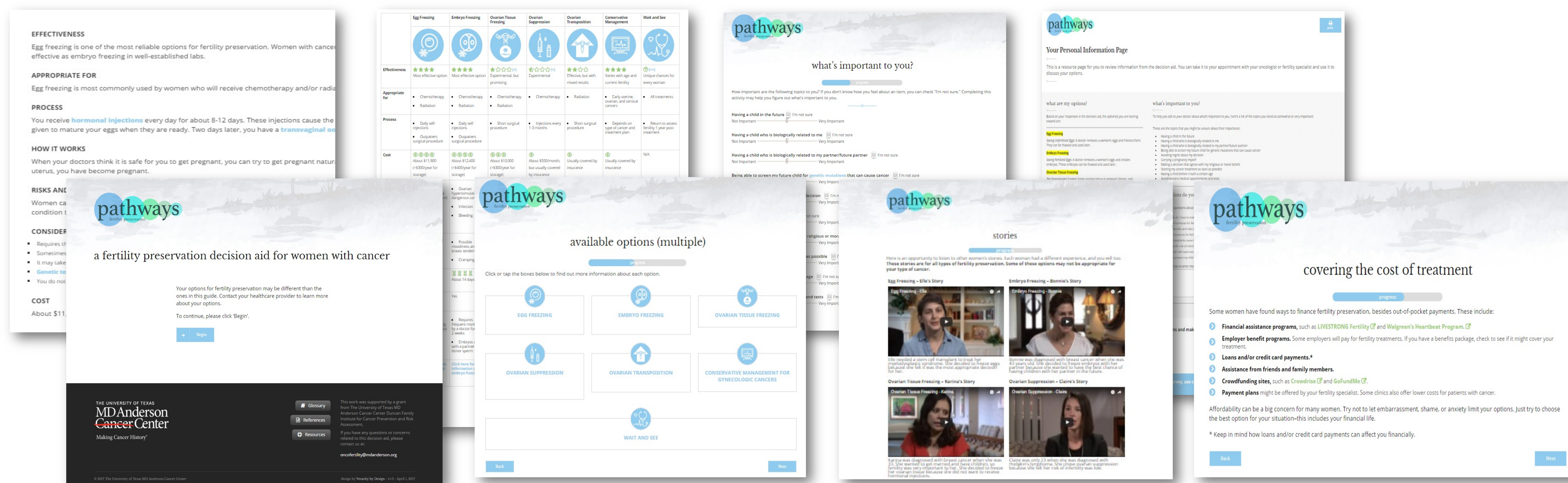
OBJECTIVES

1. To identify optimal implementation strategies across different types of cancer centers
2. To identify what adaptations are needed to ensure Pathways is meaningful and appropriate for patients from the LGBTQ+ community?

BACKGROUND

- National guidelines recommend that all reproductive-aged women be offered fertility preservation counseling before starting cancer treatments; however, as few as 5% of women from diverse communities receive counseling.
- We previously designed the Pathways website to provide women with direct access to information about their fertility preservation options, as well as decision support activities, survivor testimonials and resources to support navigation and financing.
- However, studies are needed to ensure it can be implemented at other sites and adaptations are needed to ensure it is inclusive for women from the LGBTQ+ community.

The Pathways Fertility Preservation Patient Decision Aid Website



METHODS

This study has been conducted in three parallel efforts:

1. Decisional Needs Assessment phone interviews were conducted with 10 Members of the Alliance NCI Community Oncology Research Program (NCORP) to assess feedback on a) the acceptability of Pathways, b) feasibility of clinical implementation, and c) any recommended adaptations. Transcripts were reviewed by three coders using deductive analysis and themes constructed based on frequency and congruence, with inclusion of unique recommendations by cancer center type.
2. Interviews with adult, English-speaking cancer survivors from the LGBTQ+ community who previously underwent fertility care were also analyzed thematically to identify survivors' experiences, perspectives, barriers, and recommendations regarding awareness, understanding, access, and utilization of fertility care.
3. Critical review of Pathways assessed the content, wording, and graphic design to identify non-inclusive areas and to propose adaptations to increase inclusivity

RESULTS

Provider/administrator interviews:

1. All Alliance members supported implementation of Pathways at their cancer center; however, half noted persistent concerns about offering fertility preservation to women for whom they were concerned about financial status.
2. Half of participants recommended minor changes to the content and design, and a few noted potential strategies to improve delivery and uptake, such as having the oncologist personally recommend viewing the website.

Survivor interviews:

1. Survivors described a multistep, complex process with limited and inconsistent information and multiple decision points
2. They recommended clearly stating the importance of these decisions for future fertility, and providing younger women with a clear picture of what that may mean for their future when they find a partner.

Critical Review of the Pathways website:

1. Reviewers identified one page, titled "other pathways", which details the non-biological parenthood options for adaptation. Changing the language choice removed the assumption of a heteronormative partnership in its explanations.

DISCUSSION

Overall, there is strong support for implementing Pathways across a variety of cancer centers nationwide in order to improve adherence to clinical practice guidelines.

Targeted and tailored dissemination strategies are needed to optimize delivery and uptake at each site, including:

- Providers referring patients to the website
- Delivery through the patient portal
- Delivery on clinic computers
- Integrating the patient questionnaire into the electronic medical record.

Some providers/administrators cautioned that biases still persist regarding offering fertility preservation to women with lower financial status; a provider education seminar may be needed.

Survivors from the LGBTQ+ community also strongly supported providing Pathways to women, with an emphasis on explaining to young women the potential impact of infertility later in their lives.

They also provided examples of the unique barriers faced, and tips for women in the future.

A revised version of Pathways will be created to address their needs and incorporate their insight.

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REFERENCES

Woodard et al. Pathways: development and pilot testing. J Ca Surviv 2018