

From Concept to Care: The Evolution of a Genetic Screening Report through Clinical and Design Collaboration

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Background

User experience (UX) design is the process used to create products that provide meaningful and relevant experiences to users. Often, it is an iterative process that uses interviewing, observation, and prototyping techniques together to generate insights that inform the design of more effective and impactful products and experiences.

Gathering feedback from a variety of stakeholders is crucial when attempting to understand the context in which the product is used. Here we describe how the iterative UX design process informed report design for a multiple prenatal screening product.

Methods

- UX designers and researchers in conjunction with clinical experts employed by the laboratory met with a clinical administrator with a nursing background, three OBGYNs, two genetic counselors, and three patients for a series of web-based interviews and observations between January and November 2022.
- Three rounds were completed and informed the following:
 - ▶ **Round 1** centered on creating a journey map of genetic screening results. This exercise focused on healthcare providers and their needs as well as their perceptions of their patients’ needs to yield insights that designers used to create a report prototype.
 - ▶ **Round 2** collected feedback on the prototype from the same

providers, identifying pain points and opportunities to improve the layout and design.

- Round 2 insights informed the design iteration. The changes were significant enough to warrant another round of feedback from providers and patients to validate the updates.

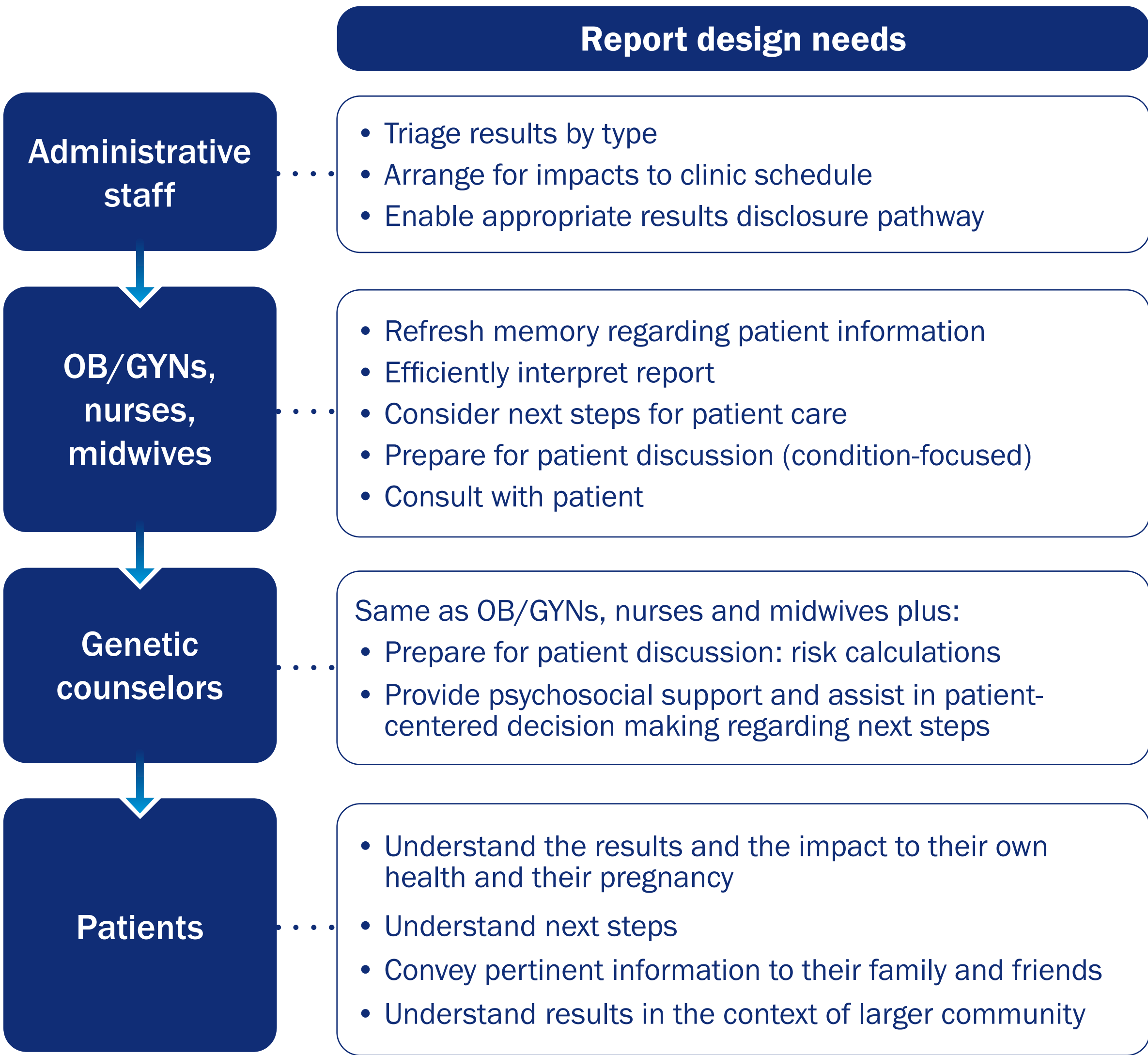
▶ **Round 3** repeated the process with clinicians and staff to gather feedback on a subsequent version of the prototype. In this round, patients were also interviewed and were observed in order to gauge their understanding of the report as well as their preference between two potential visual representations of risk.

- Insights from the qualitative research informed the design and development decisions for the FirstGene report.

Results

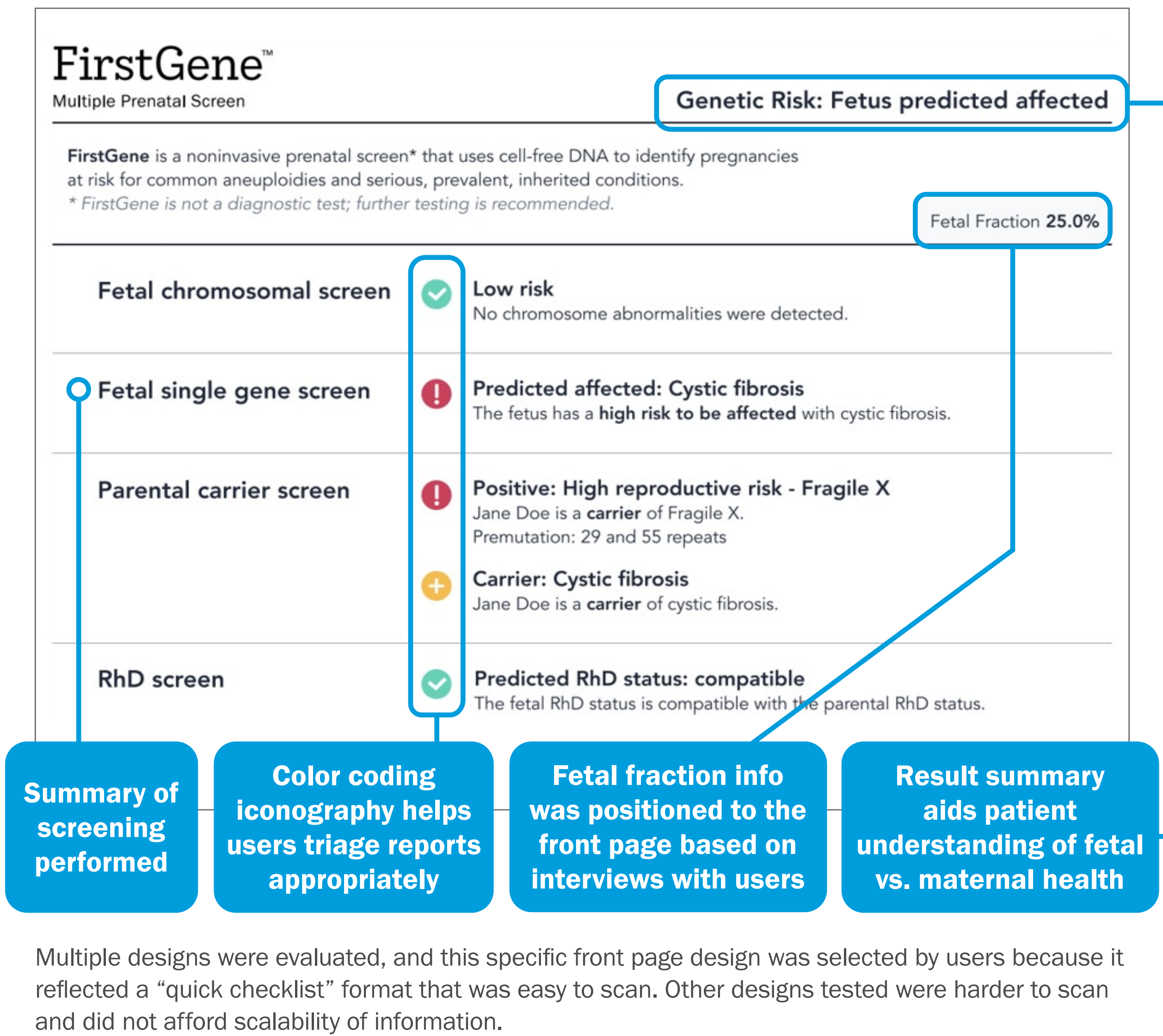
- Feedback was solicited from a variety of stakeholders to help understand how they used the results for patient care (**Figure 1**).
- Qualitative results from **Round 1** revealed that each stakeholder utilized the report in different ways, and therefore, the report design should incorporate each stakeholder’s needs to facilitate better clinic workflows and patient and clinician understanding.

Figure 1. Report journey and user needs



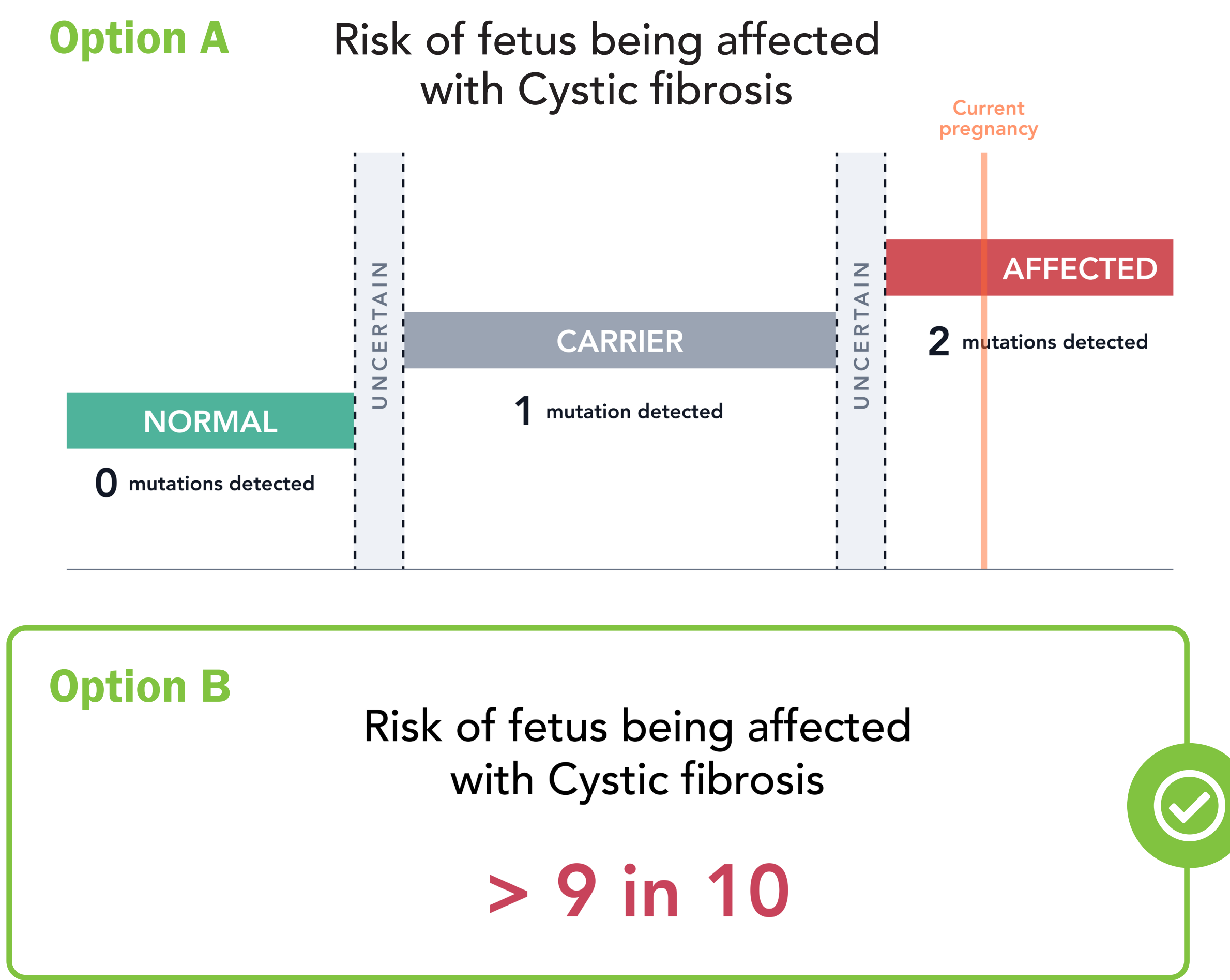
- In **Round 2**, the key reporting needs identified were the ability to: rapidly triage reports by urgency level, locate and understand disease phenotypes rapidly, efficiently and consistently interpret results, enable clinicians to confidently relay results and next steps to patients, and use reporting to express the concept of relative risk (**Figure 2**).

Figure 2. Summary page design supports all user types



- In **Round 3**, patient feedback was collected. Data indicated that patients preferred for risks be represented numerically as opposed to graphically, which was not anticipated by subject matter experts in the laboratory.
- Patients were also asked to consider a graphic representation of fetal risk versus a numerical representation of fetal risk (**Figure 3**). The graphic increased patient confusion, leading to multiple interpretations of the image versus the numeric risk.

Figure 3. Graphic versus numeric risk representation



Conclusions

- **Participatory design with clinical experts and the UX team** was critical to the design and development of the screening report adopted for a multiple prenatal screening product.
- In our research, it became clear that different user types are often unaware of the manner in which **other consumers of genetic test results used and interacted with them**. Different needs often highlight areas in which conflicting feedback may be given, but also allows us the opportunity to **identify areas of core needs** across all user types.
- Putting the **humans/users at the center** ensures that we create products/

services that address their needs. Success of the design is an understanding of the results to facilitate a conversation with patient and provider about their next steps for care.

- Continued user research testing with **larger groups** is important for refining the product.
- Another goal of user research is to **address assumptions that impact the success** of the report. What we learned from multiple rounds of **research informed the design exploration and refinement** so that the report meets the needs of our patients and providers.