Carrier Testing
Design Guidelines

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Summary
These Design Guidelines are intended to provide insight into strong interface design practices and techniques for a digital carrier testing report experience.

In evaluating the typical carrier testing process, meeting with stakeholders, and delving into clinical user feedback and response, our team has identified 5 persistent interface guidelines.

1. **Speak the Truth**
    - Say what the test can and cannot provide.
    - Provide the most accurate data.
    - Do not make guarantees.
    - Do not use speculative language.
2. **Minimize Stress**
    - Be mindful of the already stressful situation.
    - Set expectations and identify the benefits of the test.
    - Right amount of information being initially presented depends on place in time (pre-pregnancy, prenatal, etc).
    - Respect the individual wishes (“I don’t want to know X”).
    - Reveal data in context (you with partner, family, ethnic+general population).
    - Provide short bulleted checklist of results and actionable steps in order to reduce clinician workload.
    - Don’t make me wait / know where I am in the process.
    - Don’t make me hunt: aggregate the key decisions/findings in one summary.
3. **Speak Clinician, Speak Patient**
    - Communicate to each on their terms and don’t assume knowledge.
    - Be approachable and trustworthy, but serious: this is not a toy.
    - Avoid stigmatizing language and framing; accommodate non-nuclear families.
4. **Give Direction**
    - Tell the patient what to expect.
    - Spell out next steps for patients and clinicians.
    - Provide tools for decision making.
    - Provide human support for both patients and clinicians.
    - Direct focus appropriately through visual emphasis and priority of information.

Methodology

Over the last five years we've worked with many healthcare organizations that are informing our designs for carrier test reports. These clients include BD, California Healthcare Foundation, Cure Forward, Glytec, HHS, Infobionic, Johnson & Johnson, Mount Sinai, NIH, Partners, Personal Genome Project, Segterra, SeniorLink, Walgreens. During these activities we've interviewed 16 clinicians, 7 genetic counselors, 5 research scientists, and 26 patients. This has enabled us to learn about how different types of people interact with genomic results.

These Design Guidelines are the culmination of our past experience working in healthcare and genomic software. We recommend genomic organizations apply these Design Guidelines to your carrier screening software design activities. This will best position your service to develop carrier screening experiences that have the positive impact for your clinicians and patients.

Ecosystem Analysis

As part of the initial stages of the design process, we launched a significant effort to understand the ecosystem of carrier testing services. This included conducting scientific literature research, as well as outlining the customer experience, feature set, and value propositions for the top competitors in the industry to understand what opportunity gaps exist.

Expert Contextual Inquiry

Through our connections with local medical institutions and clinicians, as well as a guerilla effort to acquire more industry experts through social media and survey tools, we conducted exploratory interviews to understand the ecosystem and problem set. These efforts were two-fold. On the patient side, we aimed to understand the customer journey of carrier testing for patients or prospective parents. On the clinician side, we hoped to outline the workflow of OBGYNs, pediatricians, genetic counselors, and any other clinicians involed in carrier testing.

Usability Testing

After translating insights gathered from literature and exploratory primary research into version one for multiple projects, we then approached our interview subjects again to obtain valuable feedback on designs. For all projects involved, this was an iterative process. User feedback was used to evolve designs, which were used to gather more feedback, and so on. We employed the use of few "champion" users, whom we contacted frequently for shorter cycles of feedback and iteration.

Industry Experience

As a software design consultancy, we have worked with Mt. Sinai Hospital, Personal Genome Project, and two other leading genomics organizations to design the digital experience for a variety of genetic testing products. Our one-on-one engagements with some of the top professionals in the industry have provided essential feedback on clinical feasibility and scientific accuracy.