CARRIER TESTING DESIGN GUIDELINES

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EXECUTIVE SUMMARY

Genetic carrier testing results are complicated. We typically don't have the expertise to understand our genetic results, let alone know what to do with them. In fact, the results are often too complex for our doctors to interpret.

This framework is a proposed set of design guidelines for delivering digitized carrier testing results in a way that patients and clinicians can feel a sense of understanding and empowerment. It is based on:

- Secondary research on existing carrier testing processes
- Primary user research interviewing over 50 patients and clinical professionals
- Market research into existing products and services

These design guidelines provide specific, evidence-based insight into interface design practices and techniques for a digital carrier testing report experience.

The open source code, found at genomicsdesign.com, uses synthetic data to populate a design framework based on 4 persistent interface guidelines identified throughout our research. This white paper outlines these guidelines, as well as information about the research methods and usage. We recommend genomic organizations apply these design guidelines to their carrier screening software design activities. This will best position your service to develop carrier screening experiences that have the positive impact for clinicians and patients.

THE 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.

THE RESEARCH

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 Genomics, National Institutes of Health, Partners, Personal Genome Project, Segterra, SeniorLink, Walgreens, and WuXi NextCODE. Over the course of our research (2014-2017) we've interviewed a sample of:

16
Clinicians

7
Genetic Counselors

5
Researchers

26
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 guerrilla 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 involved 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.

HOW TO USE THIS TOOL

CLINICIANS

Let your management and IT teams know about this tool and how it'll help improve your practice and the patient experience.

HEALTH IT AND DEVELOPERS

Leverage the design guidelines and source code to transform your production service to fit patient and clinician needs.

CUSTOM REPORTS

Looking for a carrier testing report or other genomic service designed just for your organization? Let's work together to create something impactful and beautiful.

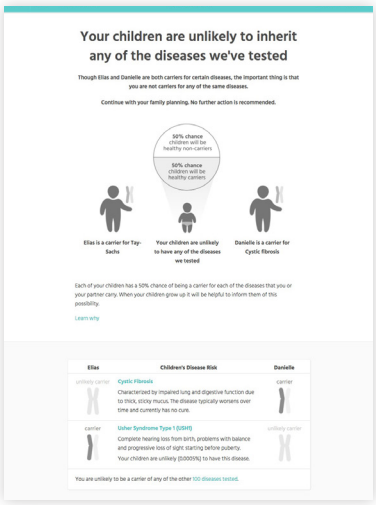
MAKE IT BETTER

Many eyes makes genetic reporting better. This open source project needs your design, engineering, and clinical critique. Anyone can get involved by providing clinical or patient-focused feedback, joining the community, submitting code, and evolving the service.

LIMITATIONS

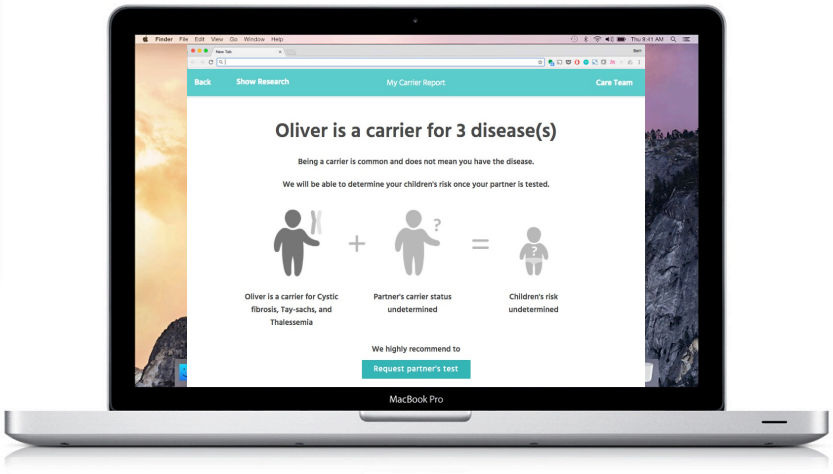
While this framework accommodates the most common types of autosomal recessive carrier results, it is important to note that not ALL results are currently accommodated. Below are important limitations in the report capabilities:

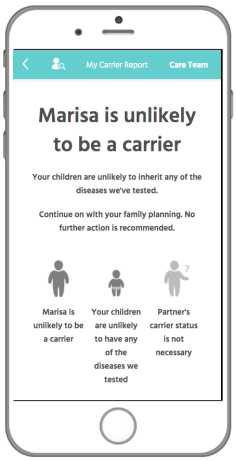
- Sample patient, disease, limitations, and test detail content in the report designs should be specific to your organization, and is therefore synthetic and not intended for production.
- Non-autosomal recessive disease carrier status (X-linked, autosomal dominant, mitochondrial, deNovo, etc.) is not supported.
- Care team permissions design is to be determined.
- Disease detail design is to be determined.
- This framework is designed to convey results to patients accompanied by clinician support.



SEE THE REPORTS IN ACTION

GENOMICSDESIGN.COM





ABOUT goinvo

GoInvo helps healthcare technology companies design magical software for personalized medicine. We work with organizations such as 3M, Johnson & Johnson, Walgreens, WuXi NextCODE, Mount Sinai Hospital, Partners Healthcare, National Insititutes of Health, Personal Genome Project, and AstraZeneca. We're located in Arlington, Massachusetts.