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The "Genomic Novel" and "Priority Mapping Tool": Using Empathic Design to Develop Innovative Patient-Centered Decision-Making Tools for the Genomic Testing Experience

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Abstract

Background: Genomic testing is now being conducted in clinical practice. There is a deficit of patient-oriented tools for learning about and making decisions regarding results from whole exome/whole genome sequencing (WES/WGS).

Methods: Empathic, novel, and multi-disciplinary design approaches to creating new products or services were utilized to develop our materials.

Results: Interventions to promote articulation of personal priorities and hopes related to WES/WGS included a: (1) *Patient Results Priority Mapping Tool*; and (2) *Genomic Novel*, which included a worksheet called *Spectrum of Influences*.

Conclusion: Using the empathic design process to identify key needs and develop interventions in the context of WES/WGS results disclosure provides the opportunity to identify unique needs and to develop novel study materials. The materials have the potential to facilitate communication about patient preferences and values and to address the practical challenges of large-scale decision making.

Keywords

Genomics; Genomic testing; Whole exome sequencing; Patient-centered; Shared decision making; Decision aid; Genetic counseling

Introduction

The volume and complexity of data discussed between a genetic counselor and patient and the unavoidable generation of incidental findings related to whole exome sequencing (WES) or whole genome sequencing (WGS) have created challenges for patients and their providers. Gone are the days when a genetic counselor could focus on discussing one or a handful of gene testing results with their patients. Instead, healthcare providers are presented with the challenge of figuring out how to disclose multiple potentially clinically meaningful results, many of which could not have been anticipated.

Recent literature in this area suggests a framework for results disclosure based on concepts of disease severity and clinical actionability, age of onset, and psychiatric versus somatic disease [1]. Holm et al. [2] developed guidelines for return of individual genomic research results within a framework that considered severity of condition, age of onset, actionability, reproductive implications, and ethical/legal/social issues, with an oversight board that adjudicated whether a finding fits as returnable or not (http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3969739/). Meanwhile, the American College of Genetics and Genomics published recommendations for reporting incidental findings, recommending the results for 56 genes be returned to all patients undergoing WES [3]. Though, after vigorous debate over the apparent loss of autonomy or depersonalization implicit in this approach, the guideline was revised to include an opt-out choice for patients [4]. The best clinical practices for return of WES/WGS results remain undefined [5-10]. Given the time required for discussions of adequate depth to allow for informed decision making (i.e., for WES/WGS), there was a need for innovative tools to facilitate and solicit individual patients' choices regarding incidental results disclosure.

Empathic design is an innovative method from the product design field for gathering the information necessary to create a *new* user-centered product, service, or innovation such as WES/WGS decision-aid tools. Because the designers are not in the genomics field, they do not bring their own preconceived opinions into the research and rather approach qualitative research activities as a collaborative and co-creative discovery process. Designers use a range of approaches to elicit patient preferences and to develop empathy with current behaviors and preferences that they use to develop tools and processes. These methods include observations and interviews [11,12] to help enable designers to gain insight into experiences that do not yet exist, such as the lead user approach [13], analogous inquiry [14], and probe and learning [15]. In combination, such approaches can guide the design of a new set of tools and processes [16] that could be useful in genomic results disclosure.

The purpose of this paper is to describe a novel and multi-disciplinary design approach to the development of a decision aid for facilitating choices for disclosing WES/WGS that emphasizes patient preferences, understanding, values, and feelings. This approach was not engaged in for the purposes of research, but rather for the improvement of the quality of the services we could provide to WES/WGS recipients. However, after going through the process, it was determined that our experiences might benefit others going through similar challenges in delivering patient-centered genomics care, and so we sought institutional review board (IRB) approval to share the results of our quality improvement project.

Materials and Methods

Empathic design process

Empathic design aims to foster creative understanding of the users and their everyday lives that will lead to the development

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of innovative products and interventions. According to Wright, Blythe, and McCarthy [17], creative understanding is generated through cognitive, affective, and empathic understanding of the user's needs. While empathic design comes from the field of product design, it shares similarities with the tenets of participatory research with the following four principles: (1) integration of cognitive and affective process in understanding users' experiences; (2) need to make empathic inferences about users and their future needs; (3) involvement of users as partners in the research/product development process; and (4) the use of multi-disciplinary research/design teams to develop interventions (this includes designers, researchers, users, and clinicians as a unified team). The designers from the Center for Innovation (CFI) are non-medically trained individuals who work within the Mayo Clinic and collaborate with clinicians, researchers, and patients/users to develop creative solutions to clinical challenges (http://www.mayo.edu/center-for-innovation/).

The empathic design process for whole exome sequencing/ whole genome sequencing (WES/WGS) tools at Mayo Clinic

This project was deemed exempt from IRB approval by the Mayo Clinic IRB as it was intended for quality improvement rather than research purposes. Despite this exemption, the design team collected all data in a confidential and de-identified manner to ensure the confidentiality of all participants involved in the process. To acquire an appreciation of the issues/choices of patients coming to WES/WGS, the designers first used observation of clinical encounters, including multiple diverse genetic counseling sessions, to learn the overall flow of sessions, the content discussed, and patient experience in a variety of contexts. The types of sessions observed included pre-test genetic counseling for diagnostic odyssey patients (patients with undiagnosed disorders who have been on an "odyssey" to find a diagnosis), pre-test genetic counseling for prenatal testing and screening, pre-test/ post-test genetic counseling for hereditary breast cancer, and pre-test/post-test genetic counseling for a variety of medical genetics patients who were seeking testing for specific known genes based on their presenting symptom. Next, the designers conducted in-depth, 2-hour qualitative interviews with three diagnostic odyssey patients and two advanced cancer patients who were considering WES of tumors to find therapeutic targets for a Phase 1 clinical trial. Interview discussions included details of the patient's health journey, details of the decisions they have made along the way (defining easy vs. hard decisions, rationale, and what was learned), the role of values and preferences in making these decisions, and the importance of roles and relationships in supporting the decision-making process. At the end of each patient interview, in order to collect feedback, preliminary decision-aid concepts were introduced to the patient. Such preliminary concepts included: (1) index cards with potential categories of choice for genomic reporting; and (2) statements of values and preferences to be ranked by importance or influence it would have over the individual's decision making (Table 1).

Since the experience around receiving WES/WGS information is so different from other experiences within healthcare, the team felt it was important to be open to solutions that are quite different from existing decision-making tools. Traditionally within design, analogous inquiry is often used to get deeper insight into behaviors and values that may lead to new solutions and new approaches. Thus, the CFI designers also used analogous inquiry to look beyond current experiences in genomic testing and to learn from decision-making processes and tools used in other fields that might be adaptable. Analogous inquiry starts with defining key challenges and needs where analogous solutions from outside industries may be used as creative reference for designing a new product or service (http://www.designkit.org/methods) [18].

This approach to design helps a team to think beyond what is done in the specific domain of interest and to borrow from non-related domains that have explored related yet alternative approaches and processes. In this case, this investigation consisted of interviews with experts in other fields (e.g., an executive coach and career counselor, a drama therapist, an architect, a personal chef, and a professional storyteller) that focus on related issues such as using tools and techniques for preparing for an unknown future, making highly emotional decisions, making risk more tangible, and helping others make highly personal choices. Interviews were also conducted with researchers from Stanford's Virtual Human Interaction Lab [19] where immersive, virtual reality experiences allow users to explore alternate realities or moments in time in order to understand the potential for how such capabilities might help users explore the implications of their decisions during the WES/WGS decision-making process. These prototypes incorporated findings and inspiration from clinic observations, interviews with analogous professional fields, and previous CFI projects work in the area of decision-aid development for chronic disease care [20].

Qualitative analysis/Data synthesis

Following standard design practice, the findings from these patient interviews, observations, analogous interviews, and role plays were synthesized in order to look for common themes, meaningful insights, and opportunities for actionable solutions [21,22]. During synthesis, the data collected was analyzed from different perspectives in order to understand the physical, cognitive, and emotional needs of the patient, their families, and the practitioners through different stages of the decision-making process. This framework allowed the collective design team and clinical team (bioethics, genetic counselors, and geneticist) to create guiding themes (Table 1), which were used in the creation of initial concepts and their iteration through role-playing the experience of having genetic counseling for WES/WGS with genetic counselors at Mayo Clinic. The goal of this activity was to experience and evaluate how the concept prototypes performed together in a live session with emphasis on understanding their impact on the flow and dialog of the session, and their usability by both the genetic counselors and the person playing the patient. This process of creating the final tool was undertaken by the empathic design team alone after completing their research/needs assessment described above, without influence or input with non-objective parties. Taking the designing out from under the direction of clinicians at this stage promoted full consideration of non-traditional perspectives and approaches that might not have been recognized or contemplated in a typical medical setting. The designers synthesized the information through a process where each bit of data collected was discussed, organized, interpreted, and put together. The goal of the process was to determine what the actual needs were of the users of genomic data.

Table 1 summarizes the essential elements/lessons learned from the observations, interviews, and literature reviews.

Results

Clinical tool development

Synthesis analysis of the data revealed that the two most pressing needs for patients facing choice related to WES/WGS were:

Table 1: Lessons learned from observation, interviews, and literature reviews that contributed to development of the subsequent tools.

Patients need to engage both their analytical and emotional side when making difficult health-related decisions.
Patients need additional knowledge about WES/WGS to participate in decisions.
Patients need to understand their own attitudes and beliefs and what influences their decisions. Providers also benefit from this knowledge about individual patients.
Patients and providers must recognize that there are external pressures that may cause differences in patient choices.
Patients reach decision fatigue at some point and can no longer make more decisions.
People often look to/want to hear what others have done in a similar situation in order to help them in making their decisions.
People are better able to understand an abstract concept if they are given concrete examples, but can fixate on the example.
People don't want to be "type-cast" as a certain kind of person (worrier, planner, proactive) and context or role is often more predictive of behavior than personality type.
People probably can't accurately predict what they are going to want in the future and may even be contradictory over time.

a) A decision aid/patient choice tool to help the patient and provider determine the sorts of incidental findings defined here as results unexpected or not relevant to the diagnostic indication for which sequencing was performed, that the patient did or did not want to learn from WES/WGS.

b) A practical way to collate information to support the patient through their clinic visits documenting their personal goals and information provided to them in their counseling, decision-making, and testing journey.

To address these expressed needs, the design/research team developed two tools that would work within the framework of the everyday life of users (patients and their healthcare providers) of genomic testing results: the *Patient Results Priority Mapping Tool* (PRPMT) and the *Genomic Novel*.

Patient Results Priority Mapping Tool (PRPMT)

PRPMT originated with the perception that providers needed a way to better discuss the types of incidental findings that may be identified from WES/WGS, especially the need for a strategy to group ("bin") results to simplify communication about thousands of potential genetic conditions where no standard system for binning exists. The goal of the PRPMT tool was not to figure out how to bin specific genes, but to allow for the patient and providers to have a meaningful communication, enabling the patient to distinctly identify certain disease categories and form an opinion on which they thought they did or did not want to learn about for themselves. Emerging from the background work described above, the definitions of the bins were chosen because patients seemed to understand, related to, and identified these categories as important.

The PRPMT that emerged from the design and piloting phases is a physical tool that helps patients and counselors work through the various options for the types of incidental findings a patient may be interested in learning, in an organized and progressive fashion. The prototype tool (Figure 1) consists of a visual and tactile board with shading ranging from "yes", "undecided", and "no" segments, and includes cards with categories of results for placement on the board to reflect the types of results patients wanted from WES/WGS (Figure 2). Interviews with patients and experts from analogous situations indicated that having something tangible to look at and to manipulate helped people to feel more involved in their decision making.

Actionability has been used in the literature as a parameter for binning genomic results based on traditional medical practice that has emphasized the importance of optimizing what can be done to manage or treat a condition [23-26]. There is no yet-agreed-upon standard of care regarding what genomic testing results are considered "returnable", though all schemes incorporate the concept of clinical "actionability". Because actionability of genetic findings is clearly an important concept in medical decision making, it was included in the PRPMT (Figure 2).

The cards developed included several categories of potential genomic results based on differing levels of actionability. The concept of actionability is complex, is increasingly recognized as a continuum, and warrants detailed conversation in the genetic counseling sessions. So, while two categories were felt to be too few, too many bins were perceived as unwieldy and confusing. By consensus, four categories were selected (though this choice has not been validated). The categories presently used were:

a) Actionability Level 0 – No specific medical management can be offered to change the most significant, serious, or debilitating aspect of the disease.

b) Actionability Level 1 – Limited medical management is available but the most serious aspects of the disease are not improved or fully prevented.

c) Actionability Level 2 – Conditions for which medical interventions are recognized as helpful; however, medical interventions do not eliminate all the medical issues and risks.

d) Actionability Level 3 – The condition can be essentially treated and managed with medical or surgical management.

In addition to the quality of actionability, additional parameters were introduced by means of cards that could be manipulated and placed on the board. These other parameters included disorders that affected primarily physical abilities versus cognitive function; gene mutations that were carried silently versus those that represented medical risks to the individual themselves; a card learning about "unanticipated family relationships" (e.g., non-paternity); and a card for pharmacogenomics results.

The counselor can use this tool with the patient/parent to help them "map" their preferences through an open dialogue and conversation. The patient can physically move their choices around until they feel comfortable with their decisions for each type of result. This exercise results in a qualitative understanding of the types of information that a patient wants to learn and enables the genetic counselor to adjust the time spent on different aspects of the decision in accordance with the patient's needs. This information is recorded in writing and/or photography of the PRPMT with final choices for inclusion in the Genomic Novel and the consent document, which can be referenced by both the laboratory and patient.

Development of the genomic novel

Both the clinical providers and the designers perceived that patients need ongoing access to educational and other supportive materials. Given this, the concept of a binder with hard copies of

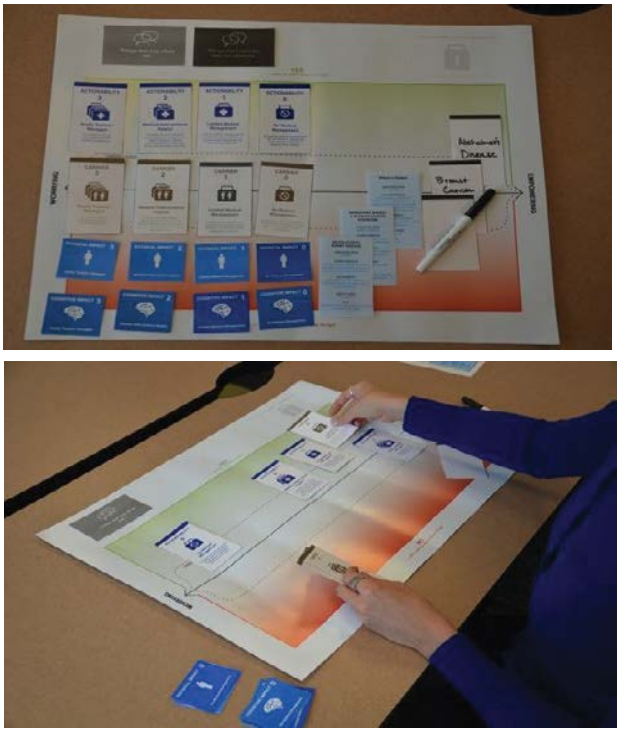

Figure 1: *Patient Results Priority Mapping Tool* (PRPMT).

Figure 2: Cards used in PRPMT.

important items was adopted. The graphic designers researched the concept of a "graphic novel" approach used in other healthcare designs to determine which elements might be applicable [27,28].

The *Genomic Novel* is a binder ideally provided to the patient at the time they are scheduled for an appointment, so they can familiarize themselves with the appointments they will be having, who their care providers will be, some of the information they may need to bring with them, and what kind of testing will be discussed. Pieces of the *Genomic Novel* can be added as they are completed, such as the genetic counselor's pedigree drawing of the family history, the patient's choices for incidental findings based on using the PRPMT, their signed consent form(s), their WES results, and clinic notes from their providers. The *Genomic Novel* also includes graphics that help a patient visualize the steps of the WES counseling and testing process, educational materials describing WES details, and prompts for individual and family-based reflection. Table 2 shows the contents and Figures 3 and 4 illustrate specific pages in the *Genomic Novel*.

The *Spectrum of Influences*

A novel element of the *Genomic Novel* is called the *Spectrum of Influences*. This worksheet was intended to facilitate recognition and promote articulation of personal priorities and values related to the patient's hopes and concerns with having WES/WGS by placing opposing-type statements together and asking patients to mark where on the spectrum they fall (Figure 4; all statements shown in the Supplementary File). It was intended to facilitate discussion of what types of incidental genomic findings a patient may want based upon their general attitudes toward aspects of medical knowledge, information, uncertainty, and healthcare. It was designed to be filled out by the patient prior to being seen by the genetic counselor with the aim being promotion of focused reflection by the patient on their feelings, hopes, motivation about WES/WGS, and to gain understanding that there was a range of how different people might perceive the same choices related to genomic information.

Refinement of tools

The PRPMT was qualitatively piloted in a role-play setting (emulating a diagnostic odyssey patient/counselor experience) in front of a subset of members of the Mayo Clinic Biobank Community Advisory Board [29]. The PRPMT and the *Spectrum of Influences* worksheet were also used in counseling 10 scientifically-educated individuals having WES for a separate research project. As WES/WGS has not yet been offered in-house at Mayo Clinic, additional clinical use of these tools has been delayed.

Discussion

The development of the PRMPT and the *Genomic Novel* (with the *Spectrum of Influences* worksheet) was accomplished in a unique and exciting manner. Empathic designers who were not medical experts and knew relatively little about genomics at the outset, thus being able to appreciate a patient perspective, utilized their training in observation and critical thinking to address the new challenges encountered in the setting of clinical genomic testing: how to provide

Table 2: *Genomic Novel* table of contents.

Welcome introduction
A guide to individualized medicine at Mayo Clinic.
What to expect
Introduction to the steps involved in evaluation and conduct of WES/WGS.
Who's who
Introduces you to the people you will meet in the Individualized Medicine Clinic.
Preparation
Provides areas to reflect feelings and questions about process and prepare.
What is whole exome or genome sequencing
Provides educational information.
Spectrum of Influences
Provides statements for you to reflect on and make choices about how strongly (or not) you identify with each statement (text shown in the Supplementary File).
Reference sections throughout
Provide places to record your contact information, to affix your family pedigree drawing, your clinical and/or research consent forms and result preferences, your results and our consultation notes from your providers.
Thinking ahead
Information that will prepare you for your next visit.

Figure 3: Example pages from the *Genomic Novel*.

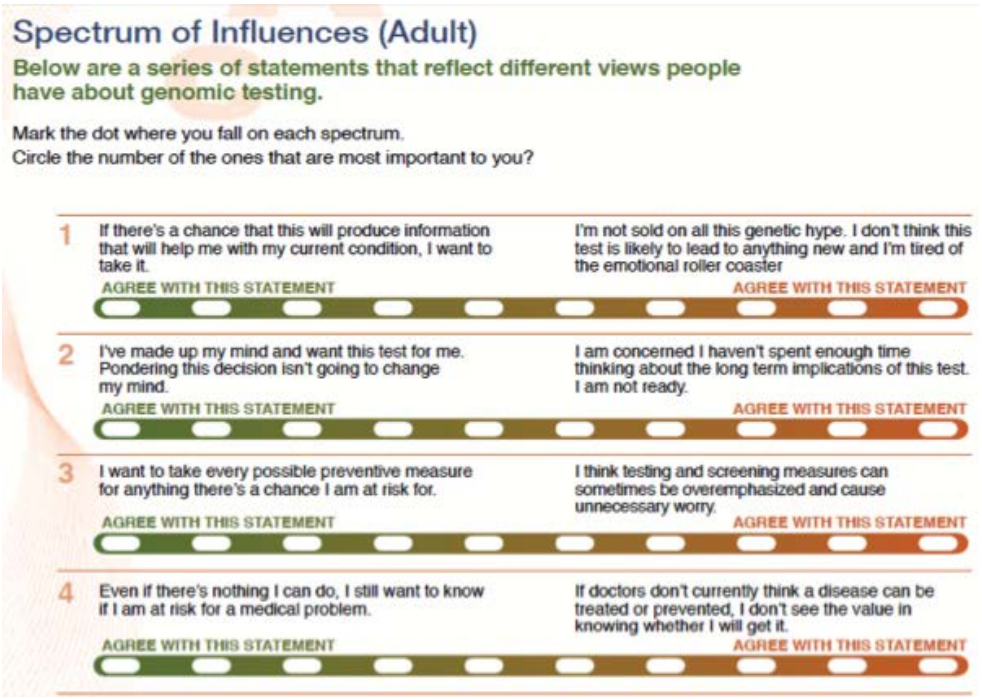

Figure 4: Example section of the *Spectrum of Influences* worksheet found in the *Genomic Novel*. The full tool (text shown in the Supplementary File) had 20 such lines.

relevant information and personally meaningful choices about disclosure of genomic testing results at varying levels of significance without getting stuck in the old model of delivering education, getting consent, and disclosing results for single germline mutation testing results. Designers achieve this aim through their objectivity, lessons imported from analogous design problems in non-medical arenas, and close observation of all of the stakeholders in the genomic disclosure process. Our designers observed experts from diverse backgrounds in bioethics, genetic counseling, and clinical genetics, working within limits of time and resources in anticipation of the radical changes being wrought by clinical WES/WGS. Through this work, the team found that **getting to a place where the patient and provider feel comfortable with whatever results get reported is less about doing a good job cataloging patient desires and more about creating a shared experience where the genetic counselor learns about the patient and the patient feels supported and heard.** The *Patient Results Priority Mapping Tool* and the *Genomic Novel* were developed as tools to facilitate development of this type of understanding, not as replacements for the counselor/patient encounter. Developing a clear understanding of individual patient priorities and preferences is more vital than ever as patient choices today do not map cleanly to defined genetic bins [30]; so, there will be an ongoing important role for clinical judgment in interpreting what an individual patient was hoping to achieve through genetic testing. Thus, the creation of the concept of a mutual understanding journey, where the patient and clinician move through information together and develop shared understanding, establish a rapport, and provide confidence to both the patient and provider was a key element to this work.

The genetic counselors who have used these tools with patients reported that the PRPMT allows for a more organized and focused approach to reviewing the types of results that come from WES/WGS and it creates more opportunities for explaining the types of potential results The physicality of the tool helps patients grapple with one concept at a time at a pace that works for the patient, while enabling the genetic counselor to layer on the complexity of the decisions. By presenting these prototype tools in manuscript form, we hoped to promote ideas that may help providers continue to facilitate patient satisfaction by respecting their priorities and preferences despite the challenges presented by the complexity of genomic testing.

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