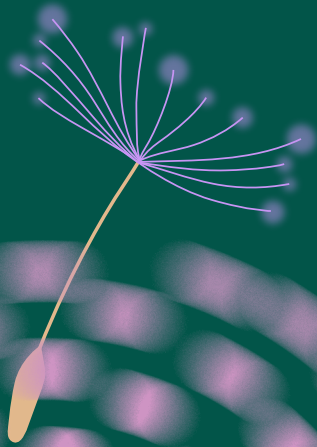

Exploring and Addressing

JULY 2021

Diagnostic Error Disparities



**Related to Cognitive
Reasoning Pitfalls**

The Society to Improve Diagnosis in Medicine
Johns Hopkins University

Funding for this project was provided through a grant from
the Coverys Community Healthcare Foundation

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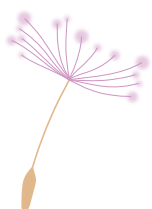
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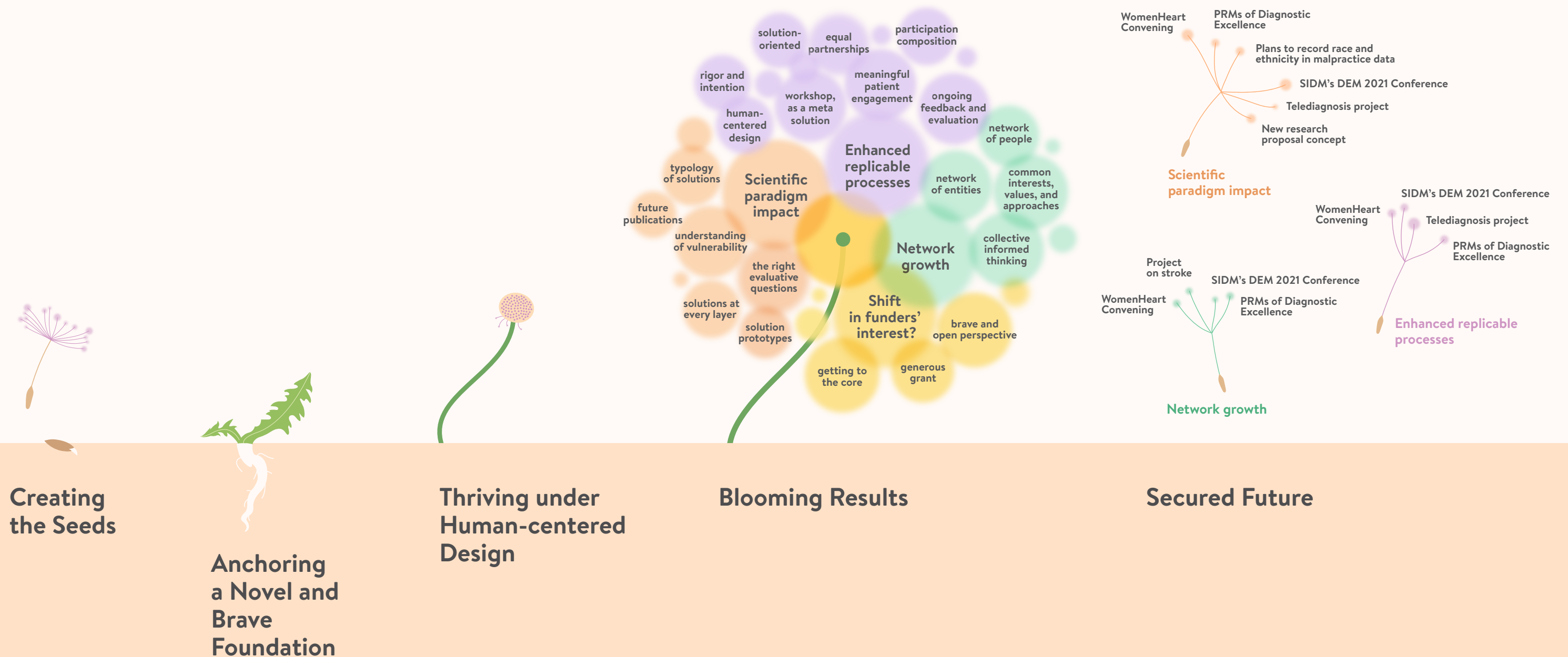
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Changing the Field of Diagnostic Error Disparities Research

Creating the Seeds

On November 28, 2018, Coverys Community Healthcare Foundation (the Foundation) announced their \$3 million investment in “projects providing solutions to improve the diagnostic process.” Among the 10 awardees was the Society to Improve Diagnosis in Medicine (SIDM) in partnership with principal investigator Dr. Kathy McDonald (Johns Hopkins University Schools of Nursing and Medicine, previously at Stanford University). The team planned to explore how cognitive reasoning pitfalls—mistakes in the way someone thinks or comes to a conclusion—among physicians contribute to the risk of diagnostic errors for people from historically vulnerable populations, and begin to identify potential solutions to end those disparities. For example, a clinician may incorrectly rule out cancer in a patient because they are “too young” or make false assumptions about a patient's symptoms because of their race or ethnicity.

Initially, the project was going to be focused on diagnostic errors among women. Dr. McDonald felt that the field of diagnostic research needed something even more foundational, focusing not just on women, but rather on the bigger issue of unreasonable or unfair assumptions about a patient based on any of their characteristics. The team revised the focus to be on any population of patients who are vulnerable to diagnostic errors because of visible factors that can trigger cognitive reasoning pitfalls among physicians. This re-framing of the project took on even more importance with the medical community's increased awareness of health inequity during the COVID-19 pandemic.

Cognitive reasoning is the perceiving and thinking process to make sense of information or make decisions.

Cognitive biases and pitfalls are common in human decision-making.

At the beginning, the team was concerned that doing a deep exploration of how inequities might relate to clinical thought processes, workflows, and professional education could feel uncomfortable for clinicians. The team brought clinicians to the table to balance worry using a partnership model of research. The team also brought diverse voices and perspectives of patients and patient advocates. Together they explored first-hand experiences of diagnostic errors. By design, conversations among the project team were casual and open, allowing all of the team members to offer experiences and ideas for what other issues may contribute to diagnostic disparities beyond cognitive reasoning pitfalls. Exploring these additional reasons for diagnostic disparities led to thinking of different solutions targeted beyond individual clinician behavior to entire health systems. For example, the exploration included looking at a hospital or health system's internal cultures, policies, communications, methods for supporting clinicians, medical and patient education approaches, and health IT systems. Additionally, the project scope was made broad enough to include potential diagnostic disparities before people from historically vulnerable populations even interact

with the healthcare system—and before practitioner cognitive reasoning pitfalls could even occur. Therefore, while the project's ultimate goal was to investigate cognitive reasoning pitfalls as a source of diagnostic error disparities, it was structured to allow for unanticipated discoveries beyond these pitfalls.

Anchoring a Novel and Brave Foundation

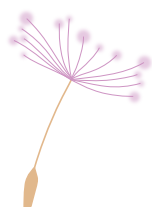
The team saw a need for effective meeting and collaboration processes that could become potential models for future efforts in the field to accomplish such ambitious goals. The value of not only using these meeting and collaboration processes and documenting how they worked and how others might use them was an important part of the project. Another key component was valuing the people involved in the project and thinking about how each team member may be able to go forward and carry these best practices and knowledge into other work.

An active Patient and Research Advisory Board of 16 members (listed in Acknowledgments) met regularly throughout the project. Its membership was purposefully selected as a mix of researchers and clinicians – doctors and nurses – of different specialties, and patient advocates of diverse backgrounds. The Board members reviewed the current “best available” research to inform workshops and were asked to share their own lived experiences. They participated in a series of 4 workshops and contributed to regular discussions with the research team about the potential reasons for and solutions to diagnostic disparities.

To prepare for the initial workshop, held in November 2019 (hosted within the SIDM annual Diagnostic Errors in Medicine [DEM] conference), the team reviewed findings of an evidence scan on the role of cognitive biases in cancer diagnosis, stroke diagnosis, cardiovascular disease diagnosis, and infection diagnosis. Those findings mostly showed that there was not much research about potential contributors to disparities in diagnostic performance. There were some examples of physician cognitive biases that may contribute to these disparities, and some ways that patients' underestimation of their own risk for cancer or cardiovascular disease contributes to cognitive pitfalls—for example, on the part of the patient, not seeking follow-up care under the belief it is “not possible” to have cancer. The Board also evaluated the medical malpractice data from the National Practitioner Data Bank and CRICO Comparative Benchmarking System. Both the literature and malpractice information showed how important it was to include specific, first-hand patient and/or family experiences of diagnostic disparities.

To supplement this existing research, six Board members volunteered to share their stories of diagnostic disparity for use by the project team. The six personal stories were merged into a single “combined story” to use in the November 2019 workshop, showing common themes of contributors to diagnostic disparity, and preventing any potential discomfort of Board members telling their own lived experiences verbatim. However, the individual stories, along with the combined story were used during the small-group portion of the workshop in a “design challenge” and tabletop solutions-brainstorming exercise.

[See Figure 1]



General Goals:

- Frame a design challenge based on what you have learned so far today, and what you know from your own experiences with visible factors influencing diagnosis, for better or for worse.
- Define a challenge that relates to reducing diagnostic error disparities arising from visible factors (age, gender/sex, race/ethnicity)
- Design challenge to meet human needs (patients, families, doctors, nurses, etc.)

Tips on coming up with a design challenge: (drawn from IDEO, a design firm)

- Write and rewrite until satisfied
- Single sentence that conveys what we want to do
- How might we (“HMW”)

Examples: How might we accomplish X? How might we prevent Y?

• A well-framed design challenge will:

- Drive the solutions effort toward ultimate impact
- Allow for many solutions
- Consider constraints and context
- Rewrite to incorporate these elements

• Not too broad, not too narrow

- Too broad makes getting started on solutions hard
- Too narrow reduces creativity and impact
- Rewrite to find the sweet spot for a design challenge

Figure 1 - The Design Challenge

That first workshop proved that it was possible to begin thinking about and creating potential solutions, with two key steps: 1) the use of summaries from literature, medical malpractice data, and personal stories; and 2) the process of small-group discussions facilitated by pairs of patient and clinician/researcher partners. We got feedback from some members of the Advisory Board that some of the small groups were rushed or not facilitated well enough for contributions from all the participants, which the team noted as a key learning to improve upon for next time.

Thriving under Human-centered Design

The COVID pandemic caused the project team to shift from hosting in-person meetings to hosting them virtually. Because of this shift and earlier workshop feedback, the team partnered with an expert in human-centered design with a particular focus on equity.

Human-centered design (HCD) is a design approach that centers on problem-solving, and in this project’s case, using a lens of equity, it centers around the wisdom of people most likely to be directly impacted by structural inequities. The process is intentionally inclusive and collaborative, approaching members of any community as experts in their own life challenges. These community members are active participants and creators of knowledge in every step of the process, not passive subjects to be measured or manipulated. HCD was used to shape many activities and processes of this project, including questioning approaches, framing design challenges and opportunities, composing teams of participants, structuring the workshops, creating brainstorming activities, and eliciting feedback from participants. An important foundation for HCD is to work with fluidity and a multiplicity of processes to respect all involved.



In August and November of 2020 and in May of 2021, the remaining workshops continued to focus on clinician/researcher-patient partnerships and ongoing discussions about diagnostic vulnerabilities and potential solutions. Using the human-centered design expert, the team was able to achieve an open, interactive, and casual setting despite the inability to meet in-person.

The reasons for and proposed solutions suggested in the November 2019 workshop were reviewed, reorganized, and categorized during the 2020 workshops. To accomplish that, the solutions were grouped into four focus areas (see Figure 2)

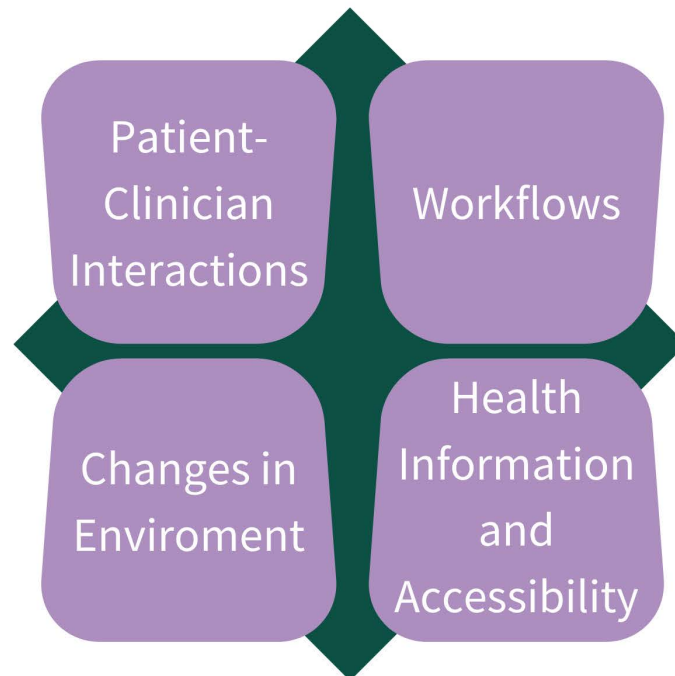


Figure 2 - Solution Focus Areas

That grouping served as a launchpad for a broader typology—or classification—of solutions that addressed diagnostic disparities more holistically, beyond the original situations informed by the 6 patient stories and the combined story from the first workshop. The workshop participants also developed principles for prioritizing, developing, and implementing solutions for reducing diagnostic error disparities. In other words, in addition to identifying and suggesting solutions, the participants thought about and documented the process they went through for suggesting and prioritizing those solutions, which can serve as a guide for future work in this field.

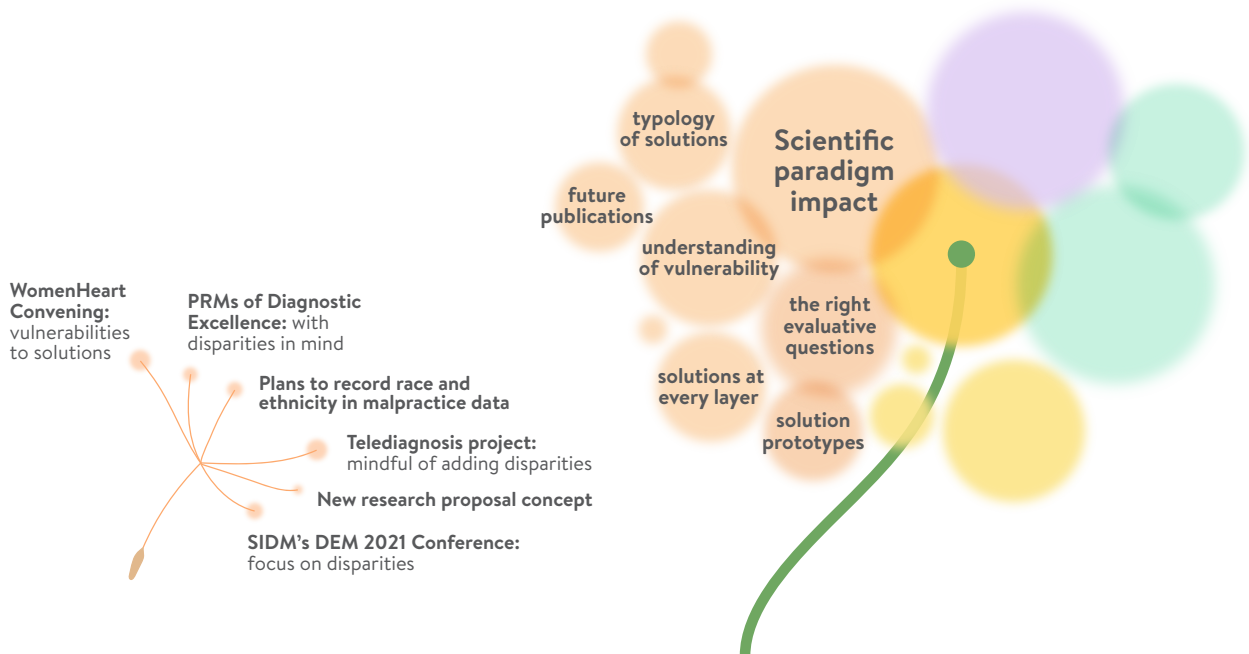
The enhanced human-centered design process matured through the series of the workshops and was embraced by the Board as an effective method for identifying, prioritizing, developing, and bringing about different solutions. While the typology of solutions produced by these workshops – two of which were modeled at the May 2021 workshop – were valuable contributions, the deliverables of this research project were more than just a list of ideas and existing resources.

Blooming Results and Secured Future

Innovative processes, meaningful multi-stakeholder engagement, and the use of methods to specifically focus on inequities, allowed the project to produce fruits beyond those of typical research projects. In the next chapters, we will review how the project delivered this collection of results. Each chapter begins with a part of the "Changing the Field" picture developed in the HCD process, and shows other projects that have been influenced by this effort and even grown directly from it. We anticipate that these outgrowths and others will extend this project's life and positive impact far into the future.

CHAPTER 2

Scientific Paradigm Impact



What has the project produced?

By exploring the reasons for cognitive pitfalls in clinical reasoning, the project uncovered a shared way to think about vulnerability and allowed us to see that people from different vulnerable communities may have the similar kinds of experiences that lead to disparities, regardless of what their visible factor is (race/ethnicity, age, or gender/sex). As a result, the solutions the team formed or identified were focused on addressing vulnerability itself, and not necessarily targeted at specific issues of race/ethnicity, age, or gender/sex.

This shared understanding of vulnerability allowed the team to develop the right questions to evaluate solutions—what we called “evaluative questions”. For example, these evaluative questions were used when reviewing existing examples of solutions to diagnostic errors (without specific focus on whether it was an issue of race, ethnicity, age, gender, or other visible factors) to determine whether they would help or worsen diagnostic disparities. We believe these evaluative questions could be used by others who want to address diagnostic disparities. For example, those who work in health services research, outcomes research, or in healthcare delivery organizations can use these questions to assess approaches for addressing diagnostic disparity. An important aspect of these questions is their ability to uncover whether a proposed solution—even if well-intended—can still cause harmful impacts if misused.

These would include questions like:

- Do we need to challenge the status quo?
- Are we limiting solutions with binary thinking?
- What are the aspects and consequences we are not thinking about
- Who is being left behind?



The exploration of vulnerabilities and the underlying reasons for cognitive pitfalls led back to long-standing and challenging societal constructs. For example, problematic provider behavior can be traced to ineffective or incomplete medical education that perpetuates racial/ethnic, gender, or age-based stereotypes, and a lack of providers who are people of color can be traced back to the inadequate state of STEM education in the school system, particularly the school system in vulnerable communities.

Racism, inequality, power differentials and hierarchies, the digital divide, historic mistrust, and social determinants of health repeatedly surfaced as issues throughout the project's lifespan. From a practical standpoint, it meant that solutions are needed at every layer, ought to be interconnected and complement one another to address diagnostic disparities over time. Creating single, one-component solutions, while likely easier and quicker, would be ineffective and, in the longer term, an inefficient use of resources.

As part of the project, the team had to reimagine the way solutions to diagnostic disparities are created. To be effective, they need to be based on the long-term engagement of different stakeholders and allies who can support their creation and sustainability at every layer. Because of this, the project can serve as an example of bringing together different disciplines and expertise, including patient voices, to promote and streamline the process of creating an array of solutions to diagnostic disparities.

The categorization of potential solutions highlighted the need for different types of expertise: that of healthcare systems, educators, multidisciplinary researchers, and health IT experts – all in partnership with patients – to produce these solutions.

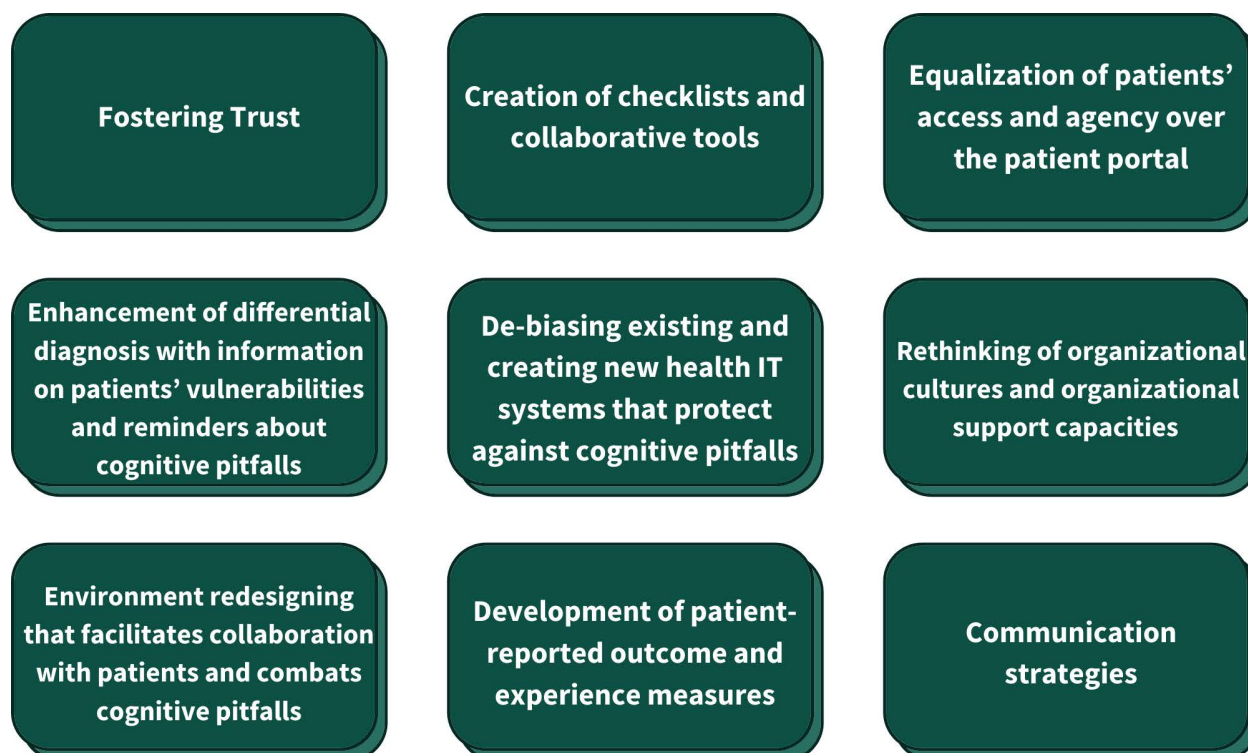


Figure 3- Potential Types of Solutions

For each of the solution types, the research team identified existing examples of solutions, validated them with the Board, and identified gaps where solutions more specific to diagnostic disparities should be developed.

At the May 2021 workshop, participants collectively created two solution prototypes--or models-- that address two such gaps in existing solutions. The gaps were pre-selected by the participants as the most feasible and promising for rapid prototyping in a virtual workshop format.

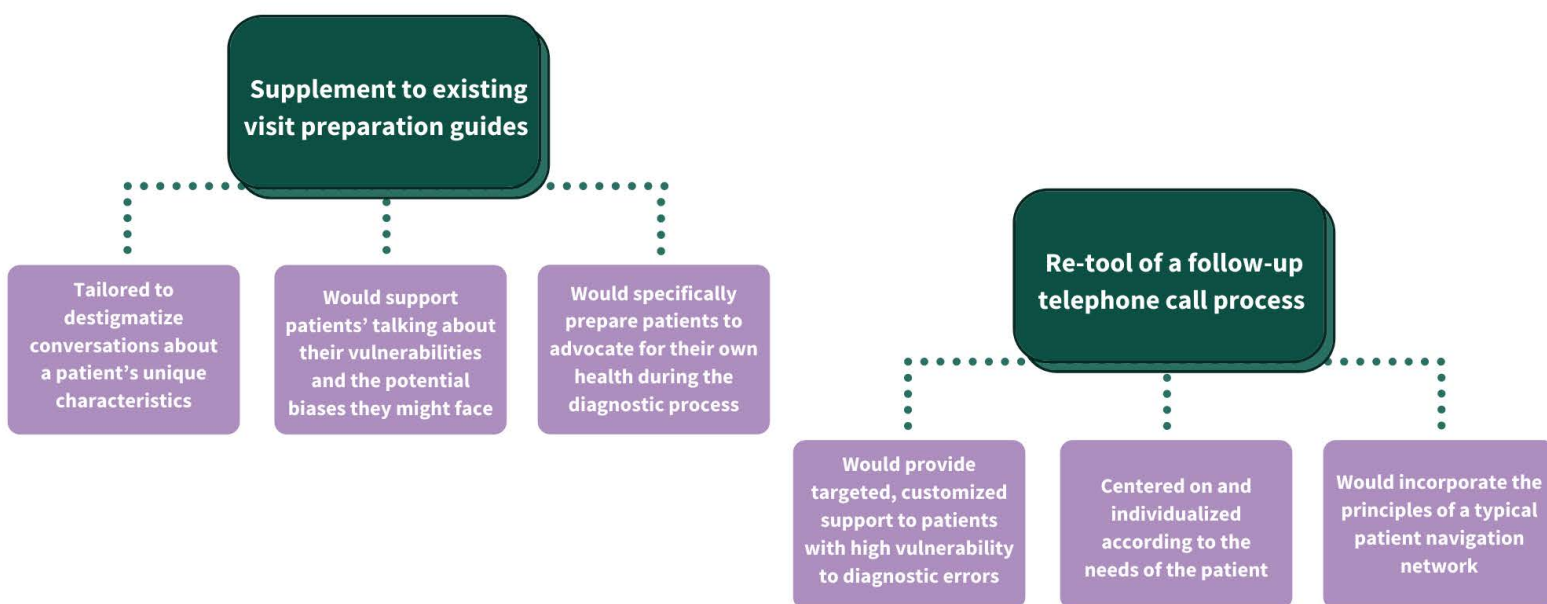
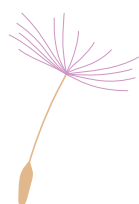


Figure 4 - Solution Prototypes

The project to date is working on two future publications that would disseminate the potential solutions and our processes mentioned above to a broader scientific and patient community. First, we hope to engage others by presenting a guideline document that would allow other stakeholders and organizations to implement workshops in their settings based on our experience. The guideline would outline a way to formulate design challenges that tie visible and salient vulnerability factors to diagnostic disparities, and to conceptualize and prototype solutions that address these challenges. The second piece would discuss the multitude of solutions that were identified to address diagnostic disparities, highlight the gaps between aspirations for these solutions and the reality of existing examples, identify the areas that need to be further developed and the necessary expertise and collaborations for creating those solutions.

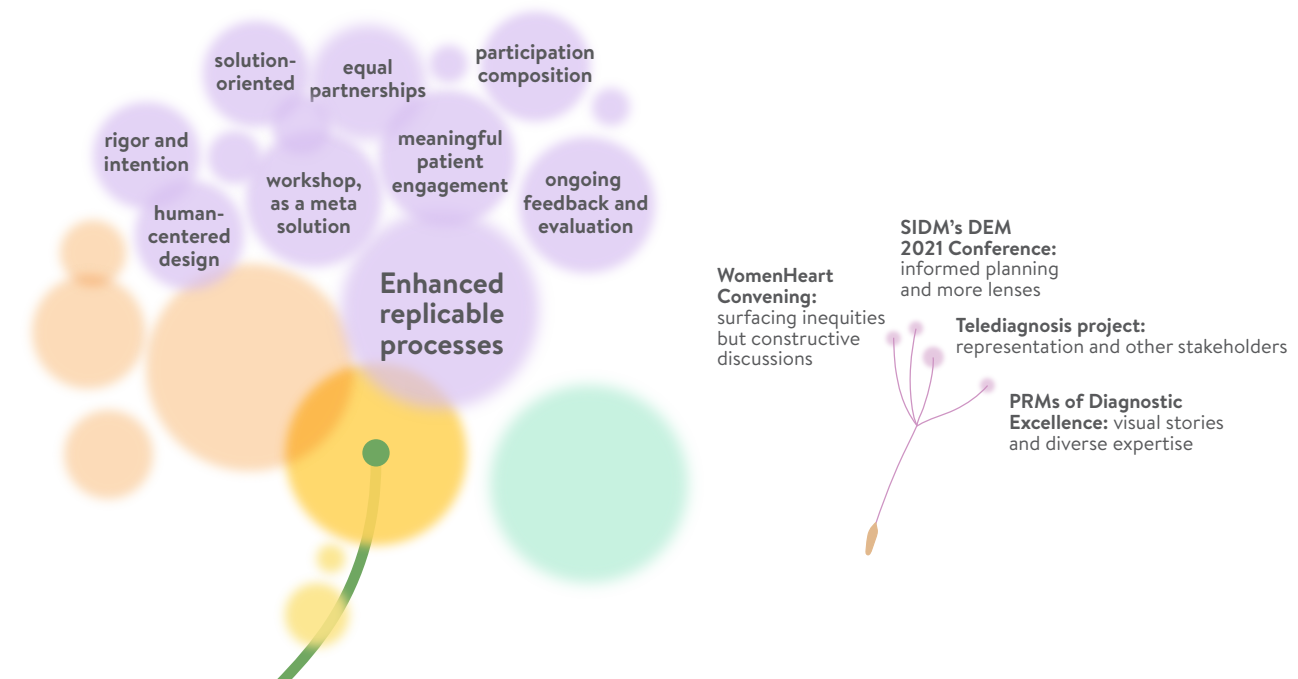
Why does this work matter?

This chapter illustrates that beyond the research project outcomes – classification of types of solutions and two solution prototypes – our project impacted the scientific paradigm of diagnostic disparities research in a revolutionary way. The groundwork included the expanded and shared understanding of vulnerability, the identification of the “right evaluative questions”, and the concept that solutions must be created as interconnected and complementary to holistically address the problem. For the relatively new field of diagnostic disparities research, the project outputs lead to future breakthroughs and foster strong coalitions to produce solutions and eliminate diagnostic disparities.



CHAPTER 3

Enhanced Replicable Processes



What has the project produced?

The backbone of this project were the four workshops from which the project outcomes were generated. These workshops were carefully planned and conducted to be responsive to all voices, and to move the team toward important outputs and impacts. Importantly, as the workshops were being planned, conducted, and evaluated, the research team and the Board were careful to document the process itself. Our workshop model can be used to bridge gaps between different stakeholder perspectives and produce new solutions to diagnostic disparities. In this way, our workshop model is actually a "meta-solution", a solution that produces other solutions. Through a SIDM DEM conference session and an upcoming guideline document publication, the project team is disseminating guidance to replicate and implement these types of workshops. Other stakeholders and organizations can use this project's workshop design to apply to their circumstances, environments, and goals.

The workshop design was very intentional and rigorous. Adopting techniques and principles of human-centered design, the workshops balanced perspectives of doctors, nurses, patients, family care partners, and researchers, bringing their views into collaborative exercises. The workflow of activities was designed to make sense and feel natural to participants. The time and structure invited open and honest conversations, sometimes starting "from scratch" with only a basic understanding of the routes to diagnostic disparities, and other times using a more structured or facilitated approach. The series of workshops was iterative, with participants having opportunities to reflect upon, revisit, and refine or build upon previous decisions. Given that the timeline coincided with the COVID-19 pandemic and lock-downs, we were able to explore the rapidly changing clinical workflows and newly emerging aspects of vulnerability to diagnostic disparities.

The composition of workshop participants were key to exploring and addressing diagnostic disparities, as we needed to hear directly from those with experience of these vulnerabilities to diagnostic errors. The group activities in which one Patient Advisory Board member and one Research Advisory Board member worked on design challenges or solution-brainstorming exemplified equal partnerships. The workshops reflected the full promise of meaningful patient engagement, where patients are partners with equal control over decision-making at all stages and in all types of decisions. The workshops employed a system of ongoing feedback and evaluation of the processes used and results generated. Each subsequent workshop was modified based on those assessments, as the team aimed to develop better processes and results.

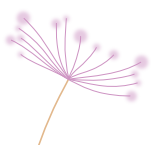
The workshops were built with a human-centered, equity-lens design process, but were also solutions-oriented. Human-centered designed activities helped to transition the participants from describing the problem of diagnostic disparities to thinking about and generating solutions. While the participants believed it was important to discuss and identify all the right problems, they also felt it was key to prioritize the most critical of the problems. This allowed solutions-generation to focus on fixing the most pressing issues.

Six principles for developing and prioritizing solutions were identified as unique to diagnostic disparities:

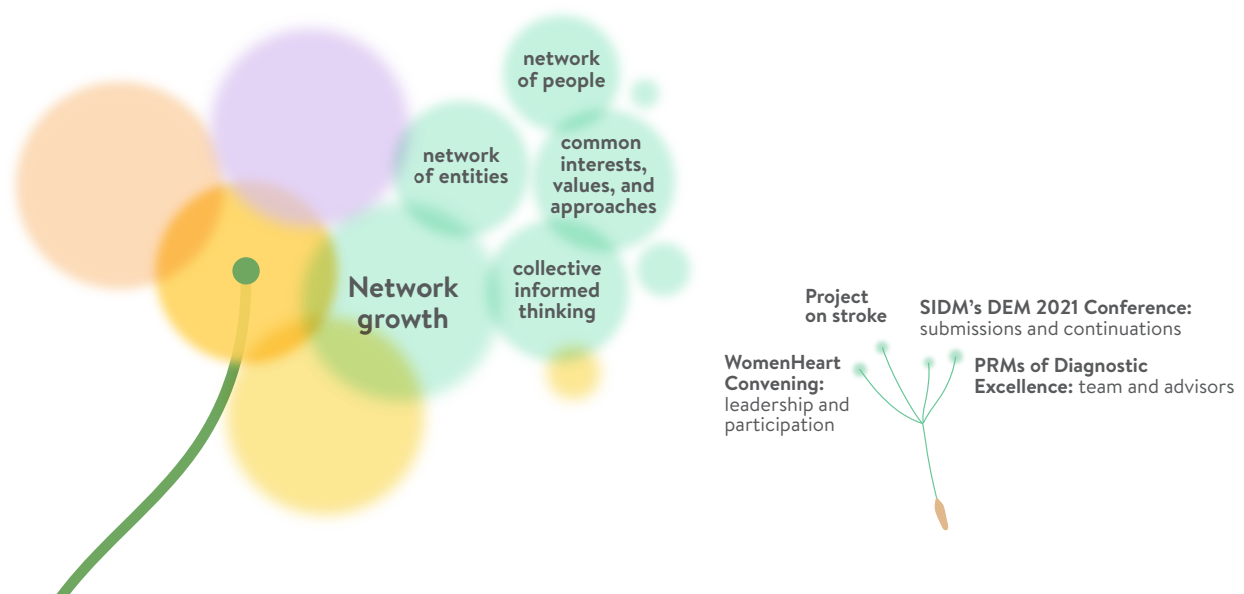
- 1 Ensuring equity, such that the solutions to address existing diagnostic disparities do not exacerbate or create new disparities**
- 2 Treating bias as an inherent but addressable phenomenon**
- 3 Incorporating patient-centeredness (the concept that patients are unique and have a critical role to play in their diagnosis)**
- 4 Supporting patient empowerment (the work of overcoming asymmetry of knowledge and power, and of harnessing the importance of one's own lived experience) at all levels**
- 5 Emphasizing the importance of engendering patient trust, and acknowledging how this process may be different within different subpopulations**
- 6 Embracing patient engagement throughout the process of solving diagnostic disparities, including positioning patients to lead change and engagement of others to join in it**

Why does it matter?

The project team carefully studied and documented its processes, which resulted in producing a replicable workshop model for addressing diagnostic disparities and highlighting the principles needed to achieve diversity, equity, and inclusion. The project has identified a method to intentionally and carefully design new solutions for disparities through equal patient and clinician partnership. This sets the stage for similar processes for further development and implementation of solutions.



Network Growth



What has the project produced?

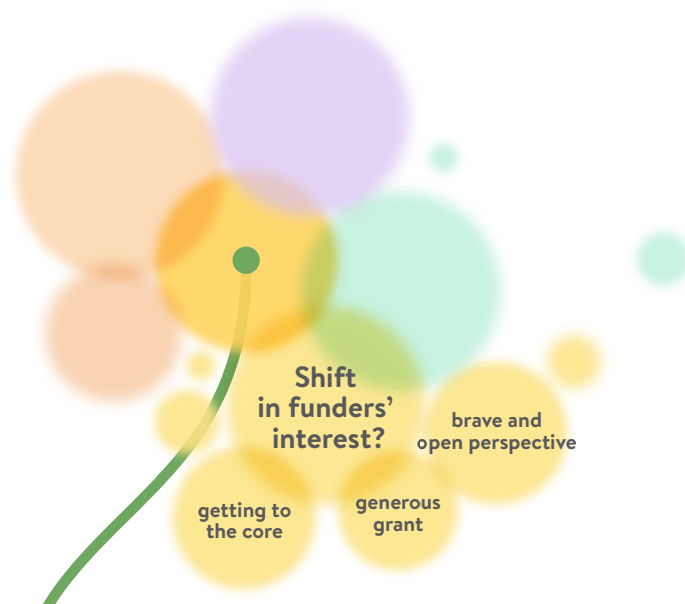
Through its Board and extended workshop participation (please see Acknowledgments) the project created a collaborative network of people that has been growing as envisioned in the original plan for the project. The team disseminated opportunities for others to join throughout the project. Through the expanding network, the project has been projecting a broader awareness of diagnostic disparities and a shift in thinking about conducting diagnostic disparities research. The project's emphasis on meaningful patient engagement included efforts to stimulate patients to be more actively involved in sharing their diverse perspectives and becoming agents of change for diagnostic disparities. The upcoming publications and dissemination plans aim to attract both the scientific and patient community to explore and address diagnostic disparities. With more people involved in the project's network and with more interactions between them, diagnostic disparities work will continue to grow and evolve.

People in the network are connected by common interests, values, and approaches, while representing and advocating within different institutions and communities. These qualities enable them to both attract similarly motivated individuals into the project's network and to influence their colleagues and for our collective informed thinking about the future of diagnostic disparities research. As more individuals work on this important issue, they are coming together in their organizations and applying elements of this project's approach for addressing diagnostic disparities. Through this work, we see the beginnings of a community of people and organizations, growing to partner and learn together in pursuing equity in safe diagnosis.

Why does this work matter?

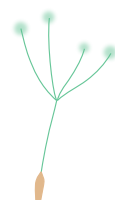
The growth of networks of people, entities, and allies concerned about diagnostic disparities has been intensified by this project. A stronger network can support more informed thinking about the challenge of diagnostic disparities and generate more activities to address those disparities.

Shift in Funders' Interest?



This project would not have been possible without a generous grant from Coverys Community Healthcare Foundation. At the time of the award, other funders were not investing in the nascent field of diagnostic disparities. In general, the area of diagnostic errors has not been sufficiently explored, so digging into subgroup analysis might have been seen as premature. And yet the imperative of social justice to help those most disadvantaged and vulnerable to diagnostic errors were seen as compelling by this research sponsor.

Selecting this project's brave and open perspective - many revisions that enhance process and thinking was a clear shift from the more traditional objective of “seeking concrete products and outcomes” as research project deliverables. The strong interest by the sponsor allowed the project to be flexible and through that evolution, get to the core of the issues rather than prematurely producing a list of concrete solutions as its primary output. The project is still spinning off additional seeds for further growth beyond the current funding award. Moreover, one potentially important outcome of this project may be a shift in the funding community's interest. The funding community has become receptive to diagnostic disparities and to expectations that only together, strengthening over time, can we amass an array of solutions that will address diagnostic disparities. By investing in this project and its potential to expand to a larger initiative, Coverys Community Healthcare Foundation has shown others how to invest with social justice in mind and yield greater opportunities for developing diagnostic disparities solutions.



Acknowledgments



NAME	ROLE
Jeanette Averett	Patient Advisory Board
Susie Becken	Patient Advisory Board
Lyn Behnke	Patient Advisory Board
Io Dolka	Workshop participant
Helen Haskell	Patient Advisory Board (Chair)
Sarah Kiehl	Patient Advisory Board
Daniel Motta	Workshop participant
Kimberly Rodgers	Patient Advisory Board
Shani Weber	Workshop participant
John Brush	Research Advisory Board
Yvonne Covin	Research Advisory Board
Carmel Crock	Workshop participant
Rob El-Kareh	Research Advisory Board
Traber Giardina	Research Advisory Board
Kelly Gleason	Research Advisory Board
Prashant Mahajan	Research Advisory Board
Andrew Olson	Research Advisory Board
Art Papier	Workshop participant
Gordy Schiff	Research Advisory Board
Anjana Sharma	Research Advisory Board
Dana Siegel	Research Advisory Board
Janiece Taylor	Workshop participant
Thilan Wijesekera	Workshop participant
Dan Persky	Society to Improve Diagnosis in Medicine
Suz Schrandt	(Co-lead) Society to Improve Diagnosis in Medicine
Sue Sheridan	Society to Improve Diagnosis in Medicine
Kathy McDonald	(Principal Investigator) Johns Hopkins University (JHU)
Andrea Banuet	Stanford University team
Sheryl Davies	Stanford University team
Leta Ashebo	JHU team
Vadim Dukhanin	JHU team
Anushka Jajodia	JHU team
Owen McManus	JHU team
Izzy Rubin	JHU team
Taharat Sheikh	JHU team
Robab Vaziri	JHU team
Aaron Wiegand	JHU team
Jill Williams	JHU team
Fateha Zannath	JHU team
Lily Zhu	JHU team