

Co-Producing Health Using Patient Generated Data: A Review of the Challenges and Opportunities Facing Patients and Providers

Dialogue Interviews Synthesis Report

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Introduction

People can now generate large amounts of data about their health with a wide range of technology. These data create new opportunities and challenges for health care delivery in general, and for the clinical encounter specifically. In spite of all the new data and its promise, few have been able to turn the data into useful, compelling information that makes the human interaction between patient and health professional better, richer, safer or more efficient. Many would like to find ways to help patients and health professionals use this patient generated data (PGD) so that it improves the time patients and health professionals spend together and improves care.

Crucial questions being asked in the field include:

- *How can large amounts of data be turned into comprehensible and relevant information that can be used by patients and providers in service of achieving the best outcomes for patients?*
- *How can enhancing the use of patient generated data deliver a positive and valuable healthcare encounter for both patients and providers?*
- *What are the range of tools and approaches that can deliver on the promise and potential of patient generated data?*

These, and other related questions were discussed with 24 healthcare thought leaders: patients, healthcare providers, academics, technologists, human centered and service designers, and government institutions. The purpose was to uncover, from a variety of perspectives, what people saw as the challenges, opportunities, trends, and required activity in order to optimize the use of PGD in service of improving health outcomes for

patients. These insights are discussed below, along with the implications for the kinds of use cases that are required to accelerate the adoption and use of patient generated data in the clinical encounter.

The report is organized as follows:

1. Challenges Associated with Fully Leveraging and Using Patient Generated Data

- I. *Data is not understood in context and this makes it hard for patients and providers to maximize its potential*
- II. *There is an assumption that data is not being collected in a rigorous way*
- III. *An environment that enables the use of PGD in the healthcare system is lacking*
 - a. *The clinic of the future could include a “digital guide” that optimizes the use of patient generated data*
 - b. *There needs to be a shift in medical education to accelerate the uptake of PGD*
- IV. *Privacy and data ownership issues create obstacles*

2. Emerging Shifts and Opportunities to Take Advantage of

- I. *Incentives for doctors, insurance companies, patients, and hospitals to fully adopt PGD as a core element of healthcare delivery*
- II. *The potential of PGD as a tool for patients*
 - a. *A tool for the co-production of health, fueled by better communication and an effective decision-making relationship*
 - b. *A tool for patients to feel empowered and in control of their bodies*
- III. *Customizing PGD approaches to ensure no one is left behind*
- IV. *Putting the human element of healthcare at the center*

3. **Conclusion:** *An invitation to work in a cross-disciplinary way on the quest to move PGD forward*

1. Challenges associated with fully leveraging and using PGD

1. Data is not understood in context and this makes it hard for patients and providers to maximize its potential

“I believe every piece of data that a patient generates might be useful when put in the right context.”

“Data cannot be accumulated for the sake of accumulating data, it is important that there are some guidelines not only for the collection, but also for the use of the data.”

“The collection of data is not enough. The analysis and feedback loop that you do and the learning are important.”

“Passively or actively collected, data needs to be in context.”

“To think that everything is relevant is wrong. It can be relevant and not interesting or the other way around.”

“The reason for data is to understand patterns and trends. So if you are not collecting data in a way that it can determine these, then you are wasting your time.”

“People’s information is very valuable. When well guided, we could figure a lot out by using data collected by people outside of the clinical context.”

Implications:

Many interviewees spoke about the importance of the context in which data is collected. That is, numbers can only be truly understood if one knows what led to those numbers in the first place. In other words, not everything that is collected is useful and some data may just contribute unnecessary “noise”. Further, the *way* data is analyzed and represented is what really enhances its usefulness. At the moment though, there is not a sufficient, straightforward way for interpreting large amounts of data in such a way that it can be more easily understood. This makes it difficult for most data to be immediately useful during the patient-provider encounter.

Implications for potential use cases:

There is a need to experiment with data collection and data representation that illuminates the context in which that data was generated.

- What could help patients and providers better understand what data is needed and how it needs to be collected in order for it to be useful?
- Is there an app or a program that can organize different kinds of data to make them easier to read and use?

II. There is an assumption that data is not being collected in a rigorous way

“Doctors are overwhelmed and reluctant to take the information that patients provide and add it to their electronic record where it becomes official. Rather, the information is conveyed incidentally as part of the conversation and the doctor may make notes based it, so their interpretation is noted into the official record but the patient’s information is rarely incorporated into the official records.”

“Hopefully things will change and there can be an agreement between the patient and the doctor as to how that data is collected so that it can be used as part of the record and not just data of the patient’s own invention that isn’t incorporated.”

“Doctors have to trust patients, and I believe a lot of them don’t because they think their data might not be accurate.”

“The challenge is what data to bring in because the profession is skeptical about it. Since they don’t think it has been collected rigorously enough, they don’t want to make decisions based on it.”

“I think subjectivity and objectivity is at the heart of this work. Information that is related by the patient and information that is collected by instruments are treated very differently.”

“We have realized that our memory is not reliable, so asking something every three months is not helpful. Tracking in the moment, snapping photos or keeping track might help with accuracy.”

Implications:

Interviewees spoke about the fact that many providers are not open to looking at PGD because for them, data collected by individuals outside of the clinical context is not “scientific” and therefore, it should not be trusted or relied upon when it comes time to make decisions.

At the same time however, patients and other stakeholders expressed a desire to have this data taken into consideration in a meaningful way. Many believe it is more accurate than relying upon our own memory to answer the doctor’s questions during a clinical visit.

Implications for potential use cases:

There is a need to experiment with how to stimulate change in the clinical mindset such that there is trust that patient generated data is useful in contributing to a more comprehensive view of a patient’s well-being.

- What are the leverage points for bringing about this shift in mindset?
- What is a useful and effective balance between clinically generated and patient generated data?
- What minimum standards of “rigor”, if any, are required?

III. An environment that enables the use of PGD in the healthcare system is lacking

a. The clinic of the future could include a “digital guide” that optimizes the use of patient generated data

“I have an idea for a ‘digitalist’. Not necessarily an MD, but someone with an expertise in data who can help patients and practitioners make sense of it.”

“Maybe this ‘concierge’ can help weave together the various perspectives and what is the combination of apps and the areas to focus on and what to measure.”

“What if you could provide data in advance of an appointment to have the doctor process it beforehand to have a discussion around it? And then being able to use the data to set goals against the data in the field?”

“Shorten and improve the clinical encounter with a pre-visit report incorporating an analysis of the patient’s data since the last doctor’s visit... because relying on the retrospective interview is a horribly inaccurate process.”

“We need less intermediaries. The more middle men we have, the more problems we have. Every middle man wants to own something.”

Implications:

Many interviewees spoke about the need for introducing a new role into the clinical encounter: a data “guide” that can accompany both patients and healthcare providers in the data-collecting and analyzing process. At the same time, some interviewees warned against the potential “over complexifying” of care should a role like this be introduced. As such, just how such a role could be optimally leveraged remains unclear.

As an extension of this idea, many interviewees also spoke to a “clinic of the future” which entailed a significant transformation in how patients and providers communicated. They speculated that electronic interactions, including the exchange and interpretation of data, would eventually make the physical, clinical encounter needed on much less frequent basis.

Implications for potential use cases:

There is a need to explore if and how a digital “guide” becomes part of the clinical care team.

- What structures are required to enable this “guide” to be introduced?
- How would this effect current business models?
- Would this allow for the patient to play a more equal role and thus be more in charge of decisions that effect them?

b. There needs to be a shift in medical education to accelerate the uptake of PGD

“Fundamentally, physicians are still trained in a model of an individual 1:1 visit with a person, and what happens before or after that visit isn’t of concern to them. If you’re not concerned about what’s happening with patients when they aren’t with you, PGD isn’t going to matter.”

“How are new doctors being exposed to the possibilities here? Without a change in the training it will be hard to make a change later.”

“Very little of this is integrated within medical school curricula at the time. Some schools are starting to explore this. It is still premature and difficult to integrate this into the program.”

“There’s culture in schools of medicine of public health, there’s culture in education and other health professions that really works against making progress in these areas.”

Implications:

Systemic change takes a significant amount of time. Many interviewees reflected this when they identified the need to focus on evolving the perception of PGD for the doctors of the future. They spoke about medical school and the absence of courses focused on, let alone understanding, PGD in any of the curricula. Introducing PGD as a medical intervention in medical school may be an important leverage point to accelerate its update in the healthcare system.

Implications for potential use cases:

There is a need to meaningfully insert patient generated data into medical school education.

- What would incentivize medical schools to introduce the concept of patient generated data into their curriculum?
- What content could be tested?
- What approaches for stimulating a mindset shift have worked elsewhere that could be applied to healthcare?

IV. Privacy and data ownership issues create obstacles

“If the moment we take information into the patient record we have to start treating it as if it’s the property of the institution we are going to squelch all innovation in this area.”

“How is the data released and shared openly is the main challenge, and there is skepticism about whether this is good or not.”

“People are sometimes afraid to share information, but I believe this will change.”

“Privacy is a very contextual thing as well, culturally and nationally. In the US, we don’t have the data privacy laws we have in Europe, so we have very little regulation of what Google does with your data.”

“All apps have great intentions about what they offer, and when we look behind, we can see that this data can be used by others.”

“People are not aware of what might happen to the data and they are not really thinking about the implications, the information they are giving away.”

“What can be learned from the ‘open contracting’ and transparency field and applied in this domain?”

Implications:

Privacy issues were a big worry shared by interviewees. First, individuals pointed to concerns about ownership and the legal boundaries of the data people are generating. For example, does it belong to the patient? To the health system they share the data with? To the app the data was generated through? Second, interviewees were apprehensive about the variety of ways decisions are made about control of data. For example, who can make decisions about what data can be shared and in which ways? Third, without clear guidelines, there is uncertainty about how the widespread use of patient generated data could effect the patient-provider relationship. For example, would patients be forced to provide the data and what might the implications be if they choose not to?

Implications for potential use cases:

There is a need to develop tools and approaches that both ensure individual privacy but which also are not so constrained that they limit the potential of the information that is being generated.

- What guidelines and regulations could help guide all users of patient generated data?
- What current privacy guidelines and laws are unexpected barriers to the adoption of PGD?
- What insights can other fields offer?

2. Emerging shifts and opportunities to take advantage of

1. Incentives for doctors, insurance companies, patients, and hospitals to fully adopt PGD as a core element of healthcare delivery

“Insurance companies need to see the benefits of PGD. Not only for doctors to feel like they have the time to look at this information, but also to provide incentives for people to look at their health and collect the information.”

“If we start to increase the use of PGD, return it to patients quickly, and provide them with tools that let them make decisions with it, then we might actually reduce the number of encounters that they’ll have with clinicians, which are the things we can feel positive about in the healthcare system.”

“If the insurance companies could see that these types of wearables are useful in prevention and care, there might be a way to make the technology available to people who don’t have the money.”

“When the protections and incentives within the Affordable Care Act go away, what will happen? What happens when not everyone is covered and insured, what happens to digital health then? This might affect this industry forever.”

“What does the healthcare system get out of this (PGD) and how do we incentivize the system to use it?”

“I think a different incentive or payment structure is important to create some incentive to getting patients more involved in their care; there is the ethical incentive but it’d be helpful to have a financial incentive as well.”

“Even the doctors that have good intentions fail in adapting PGD because they cannot get paid for it. The economic incentives are working against it.”

“If incentives go away, we’re in trouble.”

Implications:

A topic repeatedly addressed by interviewees concerned the incentives providers, patients, and insurance companies have, or could have, to more widely adopt, use, and integrate PGD into the clinical encounter in a meaningful way.

For example, many interviewees referred to the need for insurance companies to recognize the value that patient generated data can bring to healthcare. If used well, it can repurpose the doctor's visit and potentially lead to better health outcomes, in turn potentially reducing the overall time patients spend at the doctor's office. In short, this could translate to a new business model for insurance companies.

In addition, many interviewees hypothesized about the incentives for patients to track more of their health data on a more regular basis. Emerging research suggests that tracking one's health is quite empowering and results in a much more engaged patient, yet it remains unclear how to reduce the burden of time and encourage people to start this practice.

Finally, many spoke about the uncertain political climate in the US, particularly with regards to the future of the Affordable Care Act. At the moment, people are wary of investing in new technology, approaches, or tools for fear of what the future of healthcare may look like. When this is resolved, the potential incentives for PGD may emerge.

Implications for potential use cases:

There is a need to experiment with a range of possible incentives to accelerate the adoption of patient generated data for clinical care.

- What incentives are needed for which stakeholders?
- What value needs to be created such that different stakeholders commit to embedding patient generated data into healthcare?

II. The potential of PGD as a tool for patients

a. A tool for the co-production of health, fueled by better communication and an effective decision-making relationship

“Doctors and patients are so estranged from each other. Medicine and humanity are about conversation. But if we are going to start collecting data, we need to talk more and listen more, and the data we collect should enable these conversations.”

“The role of a patient as an innovator has started to become part and parcel of solutions in healthcare. We have to look beyond the typical players; because at the moment patients are the most untapped resource in developing solutions in healthcare.”

“How do we engineer tracking so that it both solves problems of relevance to all the parties that are involved in it, but mostly that it leverages and fits into and augments the social relationship?”

“How is this data either helping or hindering collaboration in the healthcare?”

“Collaboration is at the heart of PGD. The question is how will this data allow healthcare professionals – nurses, doctors, whoever – to interact with the patient in a more meaningful way?”

“We need connection between health providers and patients. How can we create a more wholesome relationship and then improve health?”

“The community of people with PGD are now given a voice in scientific meetings, and this has moved their PGD into a place where it has an impact on decision making.”

“We are realizing we need to work on the health system and make sure its listening to the patient voice and not thinking because the patient wants to make a different decision than we would that its wrong in some way.”

“Data from patients is sitting outside concentric circles, but if we bring it in, then that data can have more importance in decision-making.”

“Creating the psychological safety for disagreement in the clinical setting”

Implications:

Many interviewees clearly stated that patient generated data is the means not the end when it comes to improving health outcomes. It is an extremely important tool for enhancing the quality of the conversation and interaction between patients and providers. Relationships can become stronger and more equitable, thanks in part to the increased two-way flow of knowledge and the opportunity for patients to make informed decisions in partnership with their health providers. At the same time, by listening to what patients have to say, providers can better understand what patients need and want based on their values and preferences. Over time, patient voices are only more likely to truly influence the pathway their care follows.

Implications for potential use cases:

There is a need to experiment with the processes for using patient generated data as a tool for equitable, two-way communication between patients and providers.

- How can data create the conditions for conversations that enable the co-production of health?
- How does data need to be presented such that it opens up the space for discussion and learning between patients and providers?
- How can decisions about care and treatment plans be informed by data and made in an equitable way?

b. A tool for patients to feel empowered and in control of their bodies

“The data gathering is both for the physician and for the relationship it creates with myself and my condition.”

“There is a level of self-awareness that self-tracking can bring to the individual about their own experience and health. And this can be powerful for people in being able to actualize their own health outcomes.”

“Let’s aspire for more data literacy – people will go from ‘I have a crappy problem’ to ‘I have a handle on this, I know what the triggers are.’”

“We have to break free of the idea that conveying information is designed to increase knowledge and it instead should be designed to provoke helpful action.”

“Inherently everyone wants to be healthier or more in control of their own bodies, and the way we have paternalized healthcare makes people feel helpless, or that someone else is responsible of how they feel. So if we put it back on their own hands, we see really good adoption of this. It feels empowering ‘it’s my body and I know how to take care of it.’”

“For example, a pre-visit report: Shortening and improving the clinical encounter; relying on retrospective interviews is a horribly inaccurate process.”

Implications:

Interviewees spoke about the deeper impact self-tracking, and the ensuing data, can have for patients. For example, many patients reported a greater sense of empowerment that comes from a better understanding of one’s body and health condition. In turn, this can lead to increased feelings of control and autonomy and the ability to demand a more equitable relationship with their care team. For many, this was an important end in and of itself, even if their primary health challenges persisted.

Implications for potential use cases:

There is a need to experiment with introducing self-tracking to patients such that it enables them to maximize the use of the data they generate.

- What is required to guide patients through the process of learning how to collect and use their own data?
- What different “kinds” of patients exist and what different types of guidance do they need?
- What incentivizes patients to collect and use PGD?

III. Customizing PGD approaches to ensure no one is left behind

“There are a lot of Americans that do not have the literacy and/or numeracy skills to engage with this work. Socio-economic issues are present, so I worry about who gets left behind in this new world. For this reason, I think there needs to be a backup system for all the people who don’t or won’t use the new system.”

“On the social side we should not make assumptions.”

“There are plenty of patients who have mobile phones and there will be way more in the future. How can we use this?”

“80% of homeless people in Boston have smart phones and are using Wi-Fi.”

“It is expensive for people to have the tech and extra help it takes to understand PGD.”

“Healthcare tries to squeeze us into a box that no one fits into.”

Implications:

There is a need and opportunity to develop a range of approaches for incorporating patient generated data into the clinical encounter. In truth, no “average patient” exists, and if the field tries to design as if there were, efforts are bound to fail. There is a risk that many could be left behind if unique needs and histories are not acknowledged. For example, the field needs to consider: people for whom data literacy is limited, equitable access to technology and other data tracking tools, and different needs regarding the function that data could serve. It is essential that there is customization in the field, as opposed to a “one size fits all” approach.

Implications for potential use cases:

Those working to accelerate the adoption of patient generated data in the clinical encounter will first need to clarify who they seek to serve and the “pain point” they are addressing such that they can create solutions that enable people to have access to health in a way they did not have before.

- Who are the most under-served patients that could benefit from new and different ways to access healthcare via patient generated data?
- How can the increasing reach of technology be leveraged to make sure those who are usually marginalized benefit from PGD?
- Can a “modular pathway” for the collection and use of patient generated data be defined and applied to different kinds of patients?

IV. Putting the human element of healthcare at the center

“We have not yet started to recognize the possibility of bringing non-traditional forms of data. Someone talking about their experience rather than the number of times it happens.”

“Current medical science is looking at people and conditions, and only a few doctors are willing to take people’s experiences seriously.”

“Doctors are trained to think in quantitative terms and so when the patient says, ‘I am not sleeping much,’ that is anecdotal.”

“I would have the focus move to when are people feeling good. How can we track those moments in the life of patients? Is it helpful for me to know the conditions that bring on a sense of wellness and wellbeing?”

“Medical listening has become algorithmic.”

“How do we track a fuller suite of useful data – beyond medical records and wearables, to data that enables patients to tell their whole stories?”

“Healthcare is about relationships, not technology.”

Implications:

Many interviewees stressed the fact that the human element needs to be brought back to the center of the clinical encounter and the way healthcare decisions are made. There is a need to steer away from an exclusive focus on numbers, tools, and technology, and to focus on patients as individuals with stories that are much more complex than what numbers can express on their own. Rather than having the patient-provider encounter be transactional, efforts to make it a space for a constructive relationship that acknowledges the patient as a “full person” can open up new opportunities for more effective diagnosis, care planning, and treatment.

Implications for potential use cases:

There is a need to experiment with ways that a patient’s lived experience and stories can be made into equally valuable data that can be used to inform the patient-provider interaction.

- How can a patient’s qualitative data be easily presented to and used by healthcare providers?
- How can stories about one’s lived experience be accurately analyzed such that they can be meaningfully included in healthcare conversations?
- How can the burden of recording large amounts of data be reduced?

Conclusion: An invitation to work in a cross-disciplinary way on the quest to move PGD forward

“We need to stop asking questions in silos and we need to bring people together to see what everyone can add to the conversation.”

“The way people think of PGD depends on where they sit in the industry.”

“Devices don't talk to each other, so it is hard to build a holistic vision of the data.”

“The start-up world is directed at consumer products, for example, and when I talk with people at the FDA, they are looking at it from point of view of regulating those devices, for accuracy; and people at the NIH, they are working on the discovery of patterns of PGD that could have an effect on the clinical trials that are going on. We all look at it from our perspective.”

“Unless we can get the buy-in from the medical community and the patient community together, we won't move forward.”

“If we try to shoehorn PGD into the typical clinical care mindset we have right now, it will fail, because it's really not needed. In fact, it'll be viewed as an add on. Unless people are willing to change practice, there's no way that the value of PGD will ever become realized.”

“If we can get doctors and patients and the community to look at this together, we can genuinely move the needle. But until everybody agrees things need to be collected cohesively, you will have a stuck system.”

Implications:

Over and over again, interviewees spoke about the need for boundary spanning, cross-disciplinary collaboration in order to truly manifest the promise of patient generated data. Working across different professions, experiences, and perspectives can expand the collective understanding of both the nature of the challenges and opportunities that currently exist in the field. In doing so, a new and more comprehensive understanding emerges about what needs to be done, which in turn can lead to new intentions and commitments about how to act to improve health outcomes through the optimization of patient generated data. The result can be a transformation in the way patients and providers co-produce health.

Closing Remarks

With this report, we intended to synthesize the major questions raised by the people we got to speak with in our Dialogue Interview Process. These people are representative of the diverse stakeholders dealing with PGD in the USA, and some of them working abroad.

We are hoping these questions and reflections will help initiate conversations and will work as invitations for the use cases that will come out of this project supported by the Robert Wood Johnson Foundation, and for those who might want to work on this in the future.

About Reos Partners

Reos Partners is an international social enterprise that helps people move forward together on their most important and intractable issues.

We design, facilitate, and guide processes that enable teams of stakeholders—even those who don't understand or agree with or trust one another—to make progress on their toughest challenges. Our approach is systemic, collaborative, and creative.

We partner with governments, corporations, and civil society organizations on challenges such as education, health, food, energy, environment, development, justice, security, and peace. Our work is pragmatic, professional, and tailored to the needs of the specific situation.

Our name comes from the Greek “rheos,” which means “flow.”