Health Data Basics KOL Interviews

Key takeaways & themes

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KOL List

As part of *FasterCures'* Health Data Basics project, we completed 15 one-on-one interviews with key opinion leaders in the health data space. They ranged from data scientists to funders to patient advocates and many other roles.

- Rebekah Angove, Stakeholder Engagement, REACHnet
- Jason Bobe, Associate Professor, Icahn Institute at Mount Sinai; Personal Genomes; DIYbio
- Patricia Brennan, Director, National Library of Medicine
- Malay Gandhi, Executive in Residence, Greylock Partners
- Marnie Gelbart, Director of Programs, Personal Genetics Education Project
- Christopher Khoury, Vice President, Environmental Intelligence & Strategic Analysis, American Medical Association
- Karen Kmetik, Group Vice President, Health Outcomes, American Medical Association
- Leslie Krumholtz, CEO, Hugo
- Sally Okun, Vice President, Advocacy, Policy, & Patient Safety, PatientsLikeME
- Jodyn Platt, Assistant Professor, University of Michigan Medical School
- Jane Sarasohn Kahn, Health Economist/Advisor, THINK-Health LLC
- Sue Sheridan, Patient and Family Engagement Officer, Centers for Medicare and Medicaid Services
- Jane Thorpe, Professor of Health Policy & Management, The Milken Institute School of Public Health, George Washington University
- Chris Waters, President/CEO, Rare Science
- John Wilbanks, Chief Commons Officer, Sage Bionetworks; *FasterCures* Fellow

Themes

What's your preferred definition of health data?

- Health data is not bound by setting of care; it is everything that is associated with patients' health that is documented and contextually useful. Define health data as broad as possible: clinical data, collectable data (sensors, wearables, Fitbit, etc.), what people think about their own health (diaries, questionnaires, etc.), public health, research projects, quality improvement data – what gives people a fuller picture of their mental and physical well-being both in the health care delivery setting and in longitudinal daily life.

- The current definition is of traditional data, which is claims generated out of encounters. The emerging definition is person-generated-daily-living-data that feeds health, bolsters health, or diminishes health. We are still living in the old world, the claims data world of health data. EHRs is claims data, what the insurance company knows, or things done in the health care system. In the emerging world that we are welcoming, we are considering getting social determinants of health data, patient generated data, and real world data (what we eat, health and wellness, where we live, how much do we drink). The new world is where we are going.

- Within the health movement there is no agreement; we all talk about it but do something different and then wonder why things don't connect.

Key takeaways about access

- Most people who access their data now are just moving it from one provider to another and not using it for decision making. There's a another level of understanding the data for meaningful use that is a long way off but education can be helpful for.

  - *If people could read the notes from doctor encounters, they are motivated to download the records. Education means motivation to access and resilience to put up with the system means someone better use.*

  - *Right now, only the most able and resourced have access so not enough people are participating to get us to the future. While there are technical barriers, access is often determined by means and one's fight to get access. Breaking down barriers and paving the way for the whole community is essential. Its about really believing in hope.*

  - *People expect convenience from the system, especially when moving or switching jobs; they expect their health information will be portable like their cell phones. In time, having access to health information will become something that people just expect, like financial records. The system is archaic and it is difficult to move from one area to another. Right now, the default practice is to not give access to anything; getting records from hospitals, physicians or insurance claims is not easy. Even if you do get access you wonder about completeness-- is the data you're getting consumable by the person who is getting it? Is it in a useful form? Is it a complete record or a summary of data?*

- There's a legal distinction between ownership and access. HIPAA is the right to access data. If you can access it, why can't you own it? Because you have no place to put it. Once you get it, you own the data in paper form, but there's not much you can do with it. Once you can get it in digital form that changes things because then you own and control it. You can't control what others are doing with it, but you can control what YOU do with it. Its not of interest right now because there's no place to put it, it's onerous, and what are you going to do with it?

Key takeaways about data sharing

- Patients need to be able to trust the organization, the project or the person who has their data to keep it safe and share only where it is needed. By in large, most health care providers take good care of patient data, most patients are willing to share data, and understand that in sharing data we can generate new knowledge that will have a societal impact.

- Patients do ask, "how is my health data being used?" That's the darkest corner of this whole space and it is really important to shine a brighter light on it. Vulnerabilities need to be treated with respect and care.

  - *If I participate in research can law enforcement have access to it? If you're part of a health system, can you go and take your data to another health system? Do you have a right to control and change who has your data? If you are in a health system, who has the data and have I consented/is that okay with me? On a system level, where are the guiding points on this?*

  - *Its all linked together on the back end; I'm told that I can't have it all linked together but you see health systems managing thousands of patients with lots of data linked together.*

  - *Patients are hesitant to give email/phone number or contact info because they're afraid that health systems will get hold of it and harass them for billing purposes.*

  - *Patients are concerned about their health information getting to the wrong entities. They would be astounded to know that organizations can legally sell their data or that claims data don't have much security. We have let patients down.*

  - *Hacking and risk is on the minds of corporations. Ransomware is different than data being leaked from the system. One can be catastrophic and the other is not great for business. Over the next few years, consumers may accept that their health data is just out there.*

Key takeaways about education

- There's another level of understanding the data itself that education can be helpful for. Education can be good at getting people motivated to access. If we do want people to access or use their health data, we have to educate them on why its important. Patients need to know how it can make them a healthier person today. The challenge with this project is giving people the right information and giving them a tool to ask the right questions of data holders.

- What about people who don't know what data is? We need general literacy (ability to read at a level and comprehend it), health literacy (getting a prescription from the doctor, how to take it, etc.) and digital literacy (do people have access to getting online? Broadband, wifi, etc.).

- Education can help make consumers feel empowered. If you don't have the education, you're not on the cutting edge of accessing your health data. But it's a big step to go from access to understanding about what to do with it and how to interpret it (which has its own risks).

  - *Important for anyone doing any kind of caregiving – parents consolidating children's records, caring for adults or parents, rare disease/complex undiagnosed illnesses, managing a complex medical issue.*

  - *There is a difficult transition from pediatric care to adult care especially because 18 year olds are fully cognitively responsible for their care, but might not actually be ready to take care of themselves. Beyond that they need to find a way to get their records because someone else has managed their care for so long.*

  - *In underserved communities, patients often defer to a higher authority which develops almost a learned helplessness. This creates a psychological barrier where patients assume that because they are not an expert they cannot navigate the system.*

  - *We need a campaign on knowing yourself through your data and letting them know they have the right to know their conditions through their data as well as get the data. We also need to educate patients on ways in which to give caregivers access to their records.*

Key takeaways about patient-centeredness

- It always has to come back to benefit. Presumably everything a doctor does and shares will benefit the patient; when sharing/research doesn't directly benefit an individual, there's a community benefit. Researchers are now being challenged to be transparent about what the benefits are.

- Always maintain the autonomy of the patient; give the patient all the information in a way they can understand it, process it and make a decision that will be best for them or that they will be comfortable with.

  - *It's important for them to have data that is actionable and useful for managing their own health.*

  - *People want to have their records available if they move but people don't really want to store all their health data, unless it has personal interest and value.*

  - *If you let patients lead the conversations with their questions they will find the sweet spot for patient empowerment. It empowers them to feel like they're able to impact decision making around their health status and are able to engage with health providers around them, but there's a point where it would become like paralysis, just overwhelming.*

  - *People get empowered more and get more savvy when they see information displayed in a way that they can understand it. The power of having the data is that they can see trends that clinicians would miss. Especially for patients with tricky conditions who really want to be able to manage their data this is deeply meaningful. Consolidate the data and you can empower them.*

- There has not been an attempt to define health data through the patient lens. With patient reported outcomes, patients are motivated to contribute and follow them because it is about them. Patient generated data is also a place where patients have an interest in understanding the data. The first part of the journey is getting the information together, and what that means as a patient community vs. an individual. Patients and citizens have a responsibility to do their due diligence and ask questions, but how are you ensuring privacy/security? That matters to them.

Key takeaways about trust

- Nothing happens without trust in healthcare. The patient doctor relationship really matters because that human to human interaction is really important for trust. Trust is built in these relationships; it can't just feel like a revolving door.

  - *There are three things that underpin engagement: trust, authenticity, and satisfaction.*

  - *Need to personalize the conversation to different communities. Increasing diversity within the organization is important to be able to connect with these communities and build trust. This will help communities dealing with issues of trust, trust in what researchers are doing or how genetic information will or will not be used.*

  - *Why should anyone trust anyone with what we hear and read in daily news? We are embarrassed to talk about why we have lost trust and trust is hard to earn once you lose it.*

  - *We have to earn trust and the only way we can do this is ensure that we are providing people some sense of security and safety so they will share information that is personal or intimidate. The flip side of privacy and security is that information provided for care must actually be used for care.*

- The crisis of trust is true across society but its time for healthcare institutions to get around to it.

  - *Patients have to trust the organization, trust the project, or trust the person will keep their data safe and share only where its needed.*

  - *The less people who are healthy access their health information the more they depend on the system to be a good steward of their information.*

- Trust moves data toward new entities but the longer they lock it up and hold it tighter to their chests, the more alternate sources of data will open up. The longer you keep data hidden, the lower trust can be – transparency is a trust building exercise.

Key takeaways about transparency

- The longer you keep the data hidden, the lower trust can be – transparency is a trust building exercise. It is about expectations and clarity leading to the outcomes; transparency about where the rules and decisions come from.

- Design is a process that you can include people in and explain how you got to the solution. This allows you to show intent.
  - *Putting issues on the table first puts people at ease but science needs to be discussed in accessible ways, without technical terminology, and an emphasis on ideas about complexity.*
  - *There is a need to improve levels of care. Education is the first step because it creates a transparent way to look at things. Monetization might grow industry and help patients but without this transparency people cannot know what they are agreeing to.*

- Only in looking at collective data will we be able to understand and personalize medicine. How do we create a system where the rising tide lifts all boats?
  - *It is up to providers and health organizations to show why they're making things accessible to patients – transparency, encouraging a behavior change. So we need to rethink the whole system to create transparency and also give patients/families the access to technology that they need.*