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Proem

Kistein Monkhouse invited me to participate in a 30-minute panel at September’s Academy Health’s Datapalooza conference titled ‘Patient Insights on Health Access, Technology, and Public Policy.’ I thought, ‘OMG, this thesis-worthy topic can’t be addressed in 30 minutes.’ However, the opportunity begged to be embraced, especially with the citizen expert panel members: [Kistein Monkhouse](#), the moderator, founded [Patient Orators](#). My peeps are [Christine Von Raesfeld](#), founder of [People with Empathy](#) and with the [Light Collective](#), and [Claire Sachs](#), founder of the [Patient Advocate Chronicles](#) and [TPAC Consulting](#). We had a blast preparing and presenting. Here goes. For readers, this newsletter was edited for readability. The audio can be found at <https://health-hats.com/pod224>.

Podcast intro

Welcome to Health Hats, the Podcast. I'm Danny van Leeuwen, a two-legged cisgender old white man of privilege who knows a little bit about a lot of healthcare and a lot about very little. We will listen and learn about what it takes to adjust to life's realities in the awesome circus of healthcare. Let's make some sense of all of this.



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Level set – Get Your Patient On

**Kistein Monkhouse:** Danny, as it relates to patients, their care partners, and clinicians, where do you see data playing a role in improving health access?

**Danny van Leeuwen/Health Hats:** I want to do some level setting. We're here about data. The fuller picture is that data leads to information, knowledge, and understanding, and then Lord helps us gain wisdom.

Next, imagine yourself as a patient, whether you are a partner, a parent, a child, a neighbor, a relative, or a navigator. Let's give the umbrella name to those support people: caregivers.

When I query people who care as part of every week, locally or remotely, I talk to them about the tools they use or need. Here's what they say:

They use lists and spreadsheets first and foremost. They use calendars, phones, the internet, and portals. They rarely use apps. An exceedingly small proportion of people use apps and rarely use them for more than a month.

People use tools to **manage** projects - people call that **life**. But what are they managing? They're managing medications and team members, whether those are medical people or support people. They manage tasks, appointments, records, learning, sharing, and coordinating. So, after assisting with activities of daily living, most of their effort is spent managing time. Managing time, people, records, behavior, and tasks in no particular order, they would love to make any administrative tax tasks more accessible. Still, once they find a practice that works, whether it works for you or me, they're reluctant to change those methods. Don't mess with what works unless it's easy to learn and fits their current pattern.

They describe project management (my words) as disruption occurring every week, if not every day. So, I propose that data geek clinicians, academics, and policy people here create a use case. I propose you create a use case for anything you're working on. That is a use case in which you have lived or know somebody who's living, and if you can't, for sure, someone intimately who can self-reflect.

Learn more about that scenario, and then invite people with lived experience as patients or caregivers to join your team as full-time members.

**Kistein Monkhouse:** Thank you, Danny. It sounds like a concise summary; invite people with lived experience to the table to have these discussions. Correct?

90% Similar, 100% Human

Claire, is data playing the role it should be, and if not, what's missing?

**Claire Sachs:** Data does play a vital role in healthcare, especially as we move forward. But healthcare is not a one-size-fits-all operation. I have over a dozen conditions, and if you had my clone right next to me, the solutions and outcomes they seek could be diametrically opposite from what I'm seeking.

I would love to see what I think needs to be added, partially because it's not seen as legitimate or because people are a little afraid of attempting it, as it is a qualitative piece. People fail to realize that



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patients have more in common if you step away from the disease itself, much more in common than you think.

So, there are ways to incorporate qualitative data. I can think back to one experience I had with building [ontological systems](#), where you use data dictionaries to ensure that a common language is understood. But you go to a higher level in the data umbrella. In that case, you can not necessarily code but categorize qualitative answers to create a space for flexibility when talking about tailoring outcomes.

I would summarize to patients who deal with complex conditions by saying to keep the qualitative data in mind. It really can serve a purpose. And if you're talking about meeting patients where they are, you can't do that with just what you must incorporate, such as why.

**Kistein Monkhouse:** Thank you, Claire. I appreciate that. Christine, we're going to move right along to you.

#### Inspiration from Data: Weak Link in our Health

Can patients use data to its full potential to improve their quality of life? If not, what's missing?

**Christine Von Raesfeld:** I hope patients can use data to its full potential. However, I'm finding that that doesn't always work.

One of the things that I think about when we think about data is how we empower patients and look at this differently. If I were a patient with access and agency over my raw data, I could look for researchers doing work related to what I'm looking for.

As a patient, I have multiple conditions, rare and undiagnosed: Cardiac, all these things. But when we look at the data and how we handle that data, I participate in a lot of research and studies where the information never comes back to me and never comes back from my care.

So, how do we look at data? We should develop a new idea of research and encourage a citizen science approach. When we consider rare diseases or any disease, most people would be willing to share their data for the right reasons and the right incentives. Our industry needs to have more aligned incentives.

I tell many patients that when you look at the data, in many of these companies, all they want is data. How do we then renegotiate and build a space where we can share that information, share it, and still progress?

I'm still reviewing my case. I'm collecting data and gathering it, trying to find people to work with, but getting it takes work. So, how do we make this accessible for everybody?

**Kistein Monkhouse:** Good points. Danny, I'm going to come to you. We just heard Christine speak of data autonomy. What are your thoughts on policies needed for data usage to benefit patients, their care partners, and clinicians?

#### Relationship Triad for Decision-Making: Patient, Caregiver, Clinician Partner

**Danny van Leeuwen/Health Hats:** When I think about policies, first, I don't think about patients because there's a vital triad. There's the triad of a person, a caregiver, as I defined it earlier, and then their clinician partner. We often think about not one stakeholder but the decision-making triad in our work



and policy. All this is for that triad to make sensible decisions that meet their preferences. I haven't seen that approach with policy, and I need wisdom about implementing it. I don't know, but it sounds like a significant problem.

#### Unintended Consequences – Crystal Ball Gazing

**Kistein Monkhouse:** Yeah. Claire, as it relates to policy, what ethical considerations do you think are needed for policy regarding health technology?

**Claire Sachs:** So, I wear a multi-device-based closed-loop system 24/7. I think that the possibilities that technology, specifically AI, offers are tremendous, and it's fascinating to look at these developments and think about how they lift the disease burden from patients because my life has changed.

When I went on an insulin pump, I wouldn't go into it because it would just take too long, but it's a complete 180 from what I had to do when I was on injections. Yet, the AI piece—maybe it's generational—scares me because I look at social media and what we got into without really thinking about unintended consequences.

I could see the same thing happening in healthcare, which could have even higher-level impacts on vulnerable people both physically and mentally. So, I would love to see the inclusion of bioethicists and futurists. People are trained to look down the road and see what I don't think about. It's tough for me to put myself in a futuristic state because every time I do that, I get a new diagnosis and have to adjust. But when you're developing new technology, just to have someone whose job it is to look down the road and see what the future could bring, both good and bad, and just keep that as a consideration as you go forward.

#### Data Sovereignty – Self-Governance

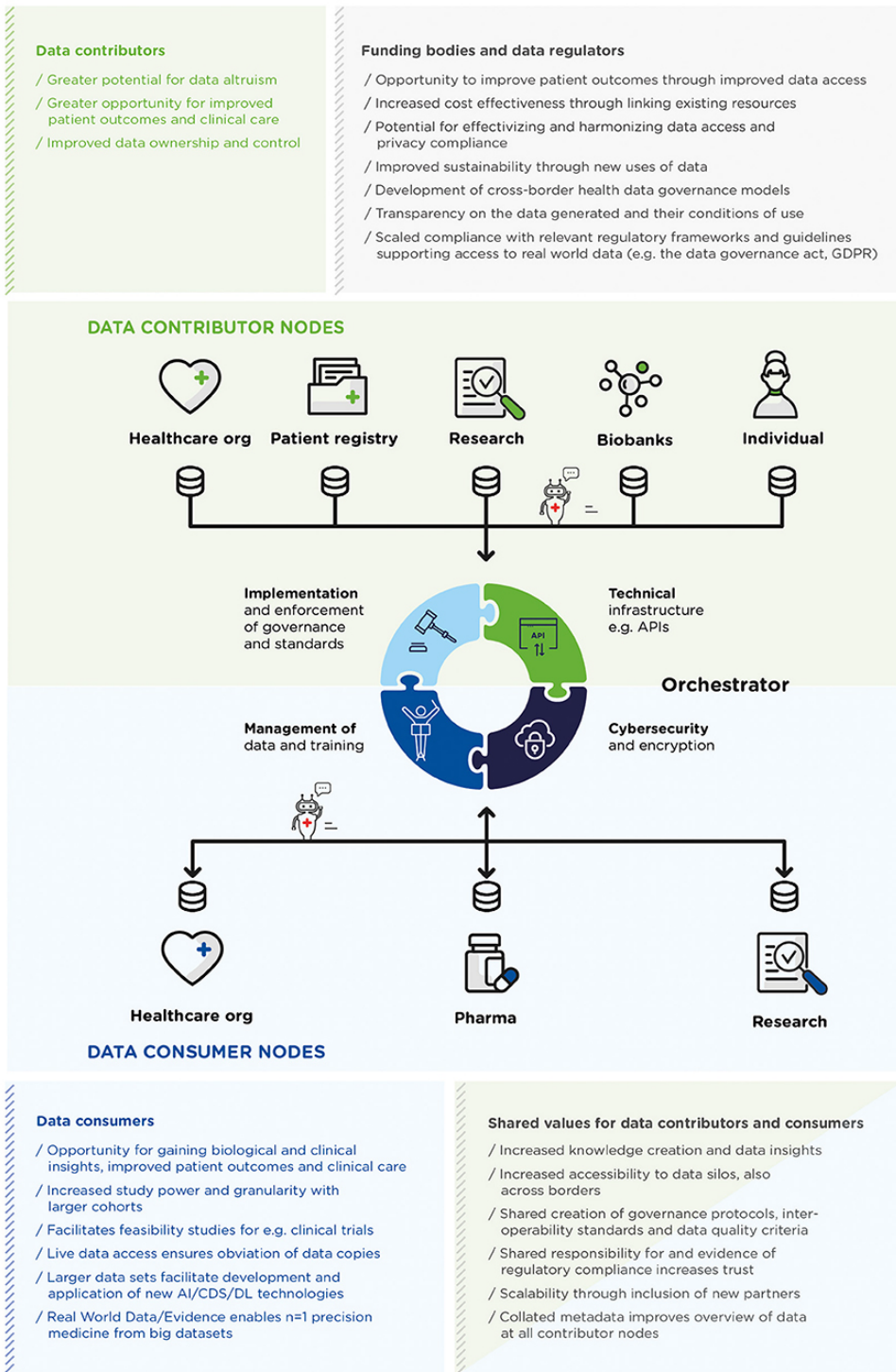
**Kistein Monkhouse:** Christine, why is data sovereignty important at this moment?

**Christine Von Raesfeld:** We're building new technologies and drugs using data with unknown origins. We need data sovereignty to ensure transparency in the data. AI will never scale without data sovereignty. How can we tag data to determine what's real, what's not, and what's synthetic? We will run into many problems if we don't look at data ethically and consider all those factors while moving forward.

#### Federated Model of Data (Confederacy of Confederacies)

**Kistein Monkhouse:** Let's look at a [federated data model](#) for patient data.





Christine Von Raesfeld: Maybe too technical, but if we're looking at a federated data model, it incentivizes the patient to give your data some agency over that data that allows you to use it more



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beneficially.

*PCORI (Patient-Centered Outcomes Research Institute) has been instrumental in developing and supporting federated data models for clinical research networks.*

*PCORI defines a federated data network as a system where data is maintained in repositories at local partner sites, with these local data mapped to a common data model. This approach allows for a broad range of queries to be pushed out centrally from the network and executed locally without requiring changes to the query itself.*

*PCORnet is a prime example of a federated data system.*

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8596061/>

When I lost my Medicare disability coverage, I started looking at the data I contributed from a different perspective. When looking at patients and the data we're using, how we incentivize and build a model allows them to build off that data to help them in their future lives.

#### Call to action

I now have one URL for all things Health Hats: <https://linktr.ee/healthhats>. You can subscribe for free or contribute through Patreon. You can also access show notes, search the 600-plus episode archive, and link to my social media channels. Your engagement by listening, sharing, liking, and commenting makes quite an impact. Thank you.

#### Trust Communities – Relaxed Control

**Danny van Leeuwen/Health Hats:** I don't expect that as much as we proselytize for giving my damn data that we can manage it. It's a fire hose of garbage. I think the hard work of putting all that data together. I think it's helpful to have trust communities. A trusted community can be an agency you work with, a county, or a town. It's a group that you become a member of, and they manage that stuff. You have control of the details, but they're managing. That's when I think about federated as a confederacy of confederacies, which may contradict federated, but it still works.

I can trust something local but need to figure it out myself. We're a bunch of experts at this conference and bewildered. People are excited about some tiny part of owning their data but are mostly ignorant. That's appropriate because it's so complex.

**Kistein Monkhouse:** Danny, could you potentially train nonprofits to take a population-level health viewpoint of the data and be able to negotiate on their constituents' behalf?

**Danny van Leeuwen/Health Hats:** Maybe I have children with rare diseases, and I trust an advocacy group because we've worked together. It's like a union.

#### Transparency – Knowing What You Don't Know

**Kistein Monkhouse:** Claire, I hear the word trust, and I'm just curious to know how we make the data policy. Are all these issues relevant to the everyday patient on Medicaid or Medicare?



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**Claire Sachs:** The approach must involve transparency, which is a big buzzword. We need plain language because we are very empowered, activated patients in this room. 99% of patients aren't. They don't have the time, energy, or awareness of these communities, the communities of trust.

Transparency goes a long way. If you tell patients why you're requesting their data and the result and keeping them updated as far as the process goes, and I'm not talking about anything particularly in detail, just enough. It is essential to let them know that something they feel proprietary over is being used in a way that they agreed to and that they are using it in non-jargon language that would be considered plain language on their level. Then, they can understand it, won't feel as intimidated, and they'll feel like they can ask questions. Questioning must be there if people are comfortable sharing what could be very sensitive information, especially since they are aware that you are connecting their data to them. If it's not an anonymous donation of data, which it should be, but sometimes it's not that those things where you approach the patient on a more personal level where they can feel connected.

**Kistein Monkhouse:** Christine, I'm going to come right to you.

Anonymous Data. Really?

**Christine Von Raesfeld:** I'm afraid I have to disagree with anonymous data. If we conduct research, advancements, or anything tailored to individuals, we need more data, right? Everybody has this idea of personalized or precision medicine but doesn't want to participate in research. I'm mixed race, half Asian. Some of my issues with metabolizing meds happen unless I get other people involved in research and get them past this idea of privacy being the same thing as security. We need an open-sharing network. So, I'm afraid I have to disagree because I think we should be open and accept the conditions we have. We shouldn't put people into these things saying, don't worry, you're anonymized. Guess what? If you have a weird genetic mutation, you are identifiable.

Let's escape the lie of anonymized data when it comes back to us.

Guardrails – Safety and Privacy

**Kistein Monkhouse:** Danny, you said at the beginning that patients use spreadsheets to manage their health. What kind of guardrails do you see or foresee as needed for patients to participate actively but safely, and where do you fall in that?

**Danny van Leeuwen/Health Hats:** I don't think there needs to be any guardrails for people however they manage their data. The challenge comes when companies aggregate and monetize data. You can discuss guardrails for that, but I think for me and my data, whatever.

Stigma and Discrimination

**Claire Sachs:** On a certain level, I agree with both Christine and Danny on the non-anonymization issue. However, the problem is that in a society that still stigmatizes when it comes to health conditions, people often do not understand security. Data security is vital because many fear it might leak out to an employer or a community. If you want to negate that effect, you do have to increase the transparency and let them know that what they are giving you that is identifiable is safe, like nobody who can discriminate against them in a particular circumstance is going to be able to get hold of it.



**Christine Von Raesfeld:** Can I just interrupt because we don't know who will get the information? There are bad people out there. The [Light Collective](#) says you need certain guardrails to ensure bad actors do not get into the picture. Many discussions have been about where we need to be involved and what type of guardrails we should use. There are apparent ethical guardrails, but we'll only be partially prepared for somebody hacking into information or breaches. We just must assume it's going to happen. What measures do we take and put in place when this happens to protect you?

#### Pessimism or Optimism About the Future

**Audience member:** Danny, what would it take to have a system where people have control over and can use data effectively for their own outcomes?

**Danny van Leeuwen/Health Hats:** Wow. Do I have hope? I'm 72 years old, and when I was 18, I had a lot more hope. And I had a lot more energy, too. Sometimes, there's hope when I meet with younger people with energy. I think we did such a rotten job. I have no idea. I'm a terrible crystal ball gazer. Two things make a difference: persistence and incrementalism and the other is that some disasters happen. That makes it evident that change is motivated, and I'm pessimistic about the latter. That's a weak answer to a big question.

**Claire Sachs:** Dramatic change is difficult. An extraordinary example I can think of on the policy front is the Affordable Care Act. Before it was passed, people viewed health insurance as a perk of mostly private industry that you got as part of your benefits package. And in 10 years, a remarkably short time, it became a right. People started viewing it partially because of the process of passing the policy and the messaging around it. You're talking about a paradigm change. You are correct that there is reason for pessimism; that kind of thing would be challenging, but it is not without precedent.

**Kistein Monkhouse:** Any last words or insights on health data, access, or public policy?

**Danny van Leeuwen/Health Hats:** Data informs people making decisions about their health. That's the outcome: having information and wisdom to make the best decisions they can make about their health. Empowering people with the right tools

**Claire Sachs:** In another lifetime, I had a 20-year career in public policy involving patients in a better policy formulation stage. Any policy that requires a workaround, which many do, is bad and needs to be rewritten. Any data set where you're trying to use it and apply it to solve a problem will be more effective if you have a patient sitting next to you saying, This, if you tweak it this way, it will land better with patients. It's going to be more effective. So, incorporating our voices into your products and policies isn't just for us. It's for the people making the products and the policy as well. You don't want to go back and fix it or try a 2.0 version. If you want to hit your stride on the first try, we can help you.

**Christine Von Raesfeld:** AI and precision medicine can significantly increase when patients have access to their data.

#### Reflection

What have we learned about **Patient Insights on Health Access, Technology, and Public Policy** from we experts?





#### *Data and Decision-Making*

- Data should inform decision-making for a triad of patients, caregivers, and clinician partners.
- Patients often use basic tools like lists, spreadsheets, and calendars to manage their health information.
- Qualitative data is essential alongside quantitative data to capture patient experiences.

#### *Data Sovereignty and Management*

- Some patients desire data sovereignty - the ability to access, use, and share their health data.
- However, managing personal health data can be overwhelming for individuals.
- A federated data system with trusted communities could help patients manage their data.

#### *Ethical Considerations*

- Transparency about data usage and privacy is crucial for building trust.
- Anonymous data may not be truly possible, especially for rare diseases.
- There are concerns about potential stigma and discrimination from data misuse.

#### *Policy and Technology Development*

- Including patients in policy and technology development can lead to more effective solutions.
- Plain language communication is vital for patient understanding and engagement.
- Ethical guardrails are needed, particularly for companies' data aggregation and monetization.

#### *Outlook*

- There's a mix of optimism and pessimism about the future of health data management.
- Incremental changes, persistence, and occasional catalyzing events may drive progress.
- Collaboration with patients in development processes can increase the likelihood of successful outcomes.

If you squint just right, there's hope. My head hurts.

#### *Podcast Outro*

I host, write, and produce Health Hats the Podcast with assistance from Kayla Nelson, Leon, and Oscar van Leeuwen. Music from Joey van Leeuwen. I play Bari Sax on some episodes alone or with the Lechuga Fresca Latin Band.

I'm grateful to you who have the critical roles as listeners, readers, and watchers. Subscribe and contribute. If you like it, share it. See you around the block.



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