Data saves lives: how do we build belief and trust in data in patient communities?

Pieter van Galen

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We sat down with Pieter van Galen – freelance trainer and consultant, person with multiple sclerosis, and a member of the Lumanity Expert Patient Council – to talk about "big data" why it is important to the patient community. Pieter shares his experience with the MS Data Alliance who are committed to finding multistakeholder solutions to the issues around health data collection and usage, and importantly building the necessary trust and education within patient communities.

Trust is built on a 'FAIR' approach to data generation, collection and sharing

Findable

Is it obvious where stakeholders can find the data they need?

Is it organised in a sensible way for both humans and computers?

Accessible

Is the data available for use?

Do privacy safeguards prevent use of data that might be legitimate and helpful?

FAIR

Reusable

Can the data be used for multiple audiences, settings and purposes?

Are there additional applications for data beyond the original objectives?

Interoperability

Can the data be integrated and assessed with other data, systems and languages?

Q&A

Please introduce yourself and give us a brief history of your involvement with patient advocacy?

My name is Pieter Van Galen and I'm from The Netherlands. I've been living in Belgium for 20 odd years or so now. I got involved with advocacy when I was diagnosed in 2006 with Multiple Sclerosis (MS). I discovered my neighbour was the director of the European Multiple Sclerosis Platform (EMSP), an umbrella advocacy organisation for people living with MS. He invited me to share my personal experience and training background with other patient groups and also to pharma. Since then, I have become involved in many different projects and steering groups involved in supporting patients living with MS and their families.

One particular project I got involved with through EMPSP is the MS Data Alliance. Through this group, I have been able to engage with different stakeholders trying to use health data in order to advance research and better outcomes for patients. I had often heard the slogan "Big Data", which was certainly very interesting because I've always worked with computers. I didn't really understand the relevance to disease until I got involved in this project. For me, the more important and impactful slogan is "Data saves lives". Now, that is really my thing, and that's how I got involved.

How would you define the purpose of the MS Data Alliance?

The MS Data Alliance is a multi-stakeholder non-profit organization and we are looking at all the data that people accumulate either through research, wearables, apps, or just taking notes in their little notebooks of what is happening to them. We look at ways this can be turned into evidence that can be used by pharma, researchers and others too, to advocate but also find ways to improve the care of people with Multiple Sclerosis. Nowadays, people are collecting data left and right, all over the place. So you have doctors collecting data in their hospitals, researchers have data from trials, and patients themselves are accumulating and using health data at an increasing rate. But the problem is that we are not sharing or using it most effectively. The MS Data Alliance are working to try to ensure all data is 'FAIR' which stands **for Findable, Accessible, Interoperable and Reusable.**

Findable
Anyone looking for data has to know how to find it. As a researcher, If you don't know where to look for the data you're interested in, it's looking for a needle in the haystack. For instance, if you're looking for a house, you go to a dedicated website and say, 'I want a house of this size. Show me the bedrooms and the location.' The website responds with a tailored answer. Now, if a researcher has a similar question, "I am looking for special data for a certain disease", there is no such catalog.

Accessible
If you are lucky enough to find the data you want, it needs to be accessible. As we know, data needs to be protected for privacy reasons, so there are all sorts of silos set up to do this It is often anonymized so it can't be related back to a certain person. There are very good reasons for this, but there are also good reasons for researchers to be able to use anonymised data to answer very specific research questions.

Interoperability
If you have different researchers and people in different countries, different centers, using different devices to code simple data, it does not mean that the data can be shared or combined. One person may use 'M' for male or 'F' for female, but a second center might encode it as 'male' and 'female'. A third center might encode it in a different language or even use a picture. In other words, they are all collecting the same type of data, but because it is captured differently, it is not 'interoperable' and it can't be collated or analysed easily. It's important that the data becomes interoperable and people use the same setting, formatting and encoding for data which correlates to accepted standards.

Reusable
If data is only used once, it's not very useful. If I go into a center and I have a scan done for a heart problem for example I am hoping the results are interpreted based on knowledge from looking at similar scans from millions of people worldwide. This helps me to have confidence in treatment recommendations and allows the doctor to be able to say "Ah, the chance of survival or the chance of you becoming better after this operation is such and such". And it gives me, as a patient, a much clearer view on the risks behind it and also what it entails for me. And hopefully, if my scan can be reusable, it will help someone else by feeding into Big Data.

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What does making data FAIR mean to a patient?

I use myself as an example; I received my diagnosis in 2006, but I know I had episodes from 20 years prior, effectively from the age of nine. All issues that I had were never really picked up or connected until a final diagnosis after 20 years. I think that if doctors had the benefit of seeing data about other people like me, using the power of 'big data', I could have had a much earlier diagnosis. Earlier diagnosis means people can start treatment earlier and have a better long-term outcome. Secondly, I think that by using this big data idea of healthcare, treatment can be improved upon because you have much better information about things like side effects. By understanding how a medication works in the real world, outside of the lab or clinical trials, researchers can improve medication. And I think certainly for me, to understand why we're collecting data and reusing that data, it empowers me to actually share data and say, "Okay, I'm doing something. I'm doing something good for everybody and not just myself." That might be a bit holistic thinking, but I think that's a noble idea.

What are the biggest challenges you face with this project?

There are lots of challenges. Everybody now knows about GDPR and people are genuinely worried about their privacy. They are afraid that their (health) data will be used for negative things. Fears of their employer finding out about a diagnosis, or personal data getting into the wrong hands are real concerns. Trust is a big issue. On the other hand, people need to be educated. Some people will return from hospital and post a photo of their MRI scan on Facebook. People need to know that data can be used for good but that safety and security is a key factor. And it's not just patients that need to be educated about how data can and should be used, it is the much wider audience in healthcare too.

Education is important for helping healthcare providers (HCPs). They're very busy. It's not their primary task to just sit there and look at data. Some of them are very early adopters of technology and embrace the use of things like smart watches and apps, but the data needs to be useful and well presented for them as well. They need to see how it can help them prescribe the right medication, the right treatments, the right physiotherapy, whatever is needed. Developers of wearables and apps also need to be informed. They don't need to create their own standard again - look what's out there already and see if they can collaborate with others because one plus one can be two, but it can also be three.

How can we build trust with patients and HCPs around sharing data?

Education obviously is key, especially for patients. When I joined a clinical trial, there were lots of complicated documents that I had to sign that talked about how my data would be collected and used. Simple steps to simplify, reduce in length and make information really clear for patients might help them better understand that researchers are doing everything possible to safeguard the data and use it in an anonymous fashion. To do this, I think trust needs to be created within the entire population of all stakeholders.

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What role could the pharmaceutical industry play in supporting better use of data?

I'm not going to point fingers at pharma specifically because I believe it's a multi-stakeholder endeavor. Governments have a role because they need to create certain rules and regulations, and insurance companies and patients too have to want to support it. But the key thing is needing to develop standards and interoperability, so we are all doing and encoding in the same way. I have, for instance, a Samsung phone and the next person may have an iPhone which currently makes interoperability difficult. So finding a 'gold standard' process that we all use and could be built into different devices, systems and process would be very useful. Pharma can build research around this to have the most impact. Patients would like to share their data. So wearables proposed by pharma companies, apps and things like this need to be done using the FAIR model. As a patient, I need to feel comfortable with my special watch from pharma and understand how to collect data and get it back to my healthcare professional. I would also like to be able to share it again with registries or patient groups so pharma and other key stakeholders can have access to it in an anonymised way. That could be something very beneficial to all stakeholders.

Pharma can help with education of HCPs, because of their frequent contact with them. They can reinforce the importance of good quality data, and the way they show and share data could help educate both young physicians but also the wider audience and patients in general. If pharma have examples where data is used in such a way that it had a tangible benefit to patients, it would convince people sooner (e.g. marketing/improving a product, pull something off the market...). I used an injectable machine which was a huge pen type of thing. At the press of a button, it slammed into my flesh and it was really uncomfortable and painful to use. Obviously, I relayed my experience back to my neurologist and I would like to think he shared this with the pharma company. After a couple of years a new injectable, kind of an iPhone-machine, emerged with a very small needle that injected very gently and was much less noisy. I think this is just one example of how data passed between patient, HCP and pharma and made a positive difference. And that creates trust.

Another example is what we recently saw with COVID research. Pharma and researchers were really on board and collected data from all over the world but also actually shared data between multiple stakeholders to use. We saw that in a very short time medication or vaccines were developed by using multistakeholder data and initiatives and collaboration. Otherwise, usually if one company tries to develop a new drug in isolation, it takes years before they actually get it to the market.

The other important component is artificial intelligence. Normally, in partnerships we have my brain and your brain, but if you add a computer brain to this it becomes very powerful. Computers are able to quickly recognize key data, analyse it and make something useful out of it.

What needs to happen to ensure the biggest benefit and value for patients?

Ideally, a patient would have full access and control of their data and electronic health record. They could take it anywhere. So, if they were to go on a holiday or move somewhere, a click of a button would allow the doctor to look at their entire files and know exactly what their health situation is.

I think the key is to create trust and belief within the entire population of all stakeholders. The message of the MS Data Alliance, and others like it, is to please try and share as much as you can in a FAIR way, work together and trust that people will use data for the betterment of healthcare and society.

Pieter van Galen is a freelance trainer and consultant with broad professional experience as a speaker.

He was diagnosed with multiple sclerosis (MS) in 2006 and is now an active member of the European Multiple Sclerosis Platform (EMSP) and various Steering Groups. Through his advocacy work, he hopes to help raise awareness of MS and improve patients' experiences and empower others.

Pieter is also active in the MS Data Alliance initiative, raising awareness of the value of real-world health data to different stakeholders. He regularly works with companies that produce medical aids for patients that can help them in their daily lives and in their rehabilitation.