Cancerworld

GDPR: Why patient control over our health data might not be such a bad thing

Gilly Spurrier / 23 June 2022

Cancer patients want our data shared and used in ways that could help us, and those like us. Why wouldn't we? That's why patients and patient organisations are broadly supportive of EU proposals to create a Cancer Patient Digital Centre, which we hope will not only enable patients and survivors to exchange data and stay connected with their healthcare providers, but will also link into a wider European Health Data Space, where – under the right circumstances – patient data can be made available to researchers.

We know the value of our data for people seeking to understand more about cancer and how to prevent, detect and manage the disease, and support patients and survivors. We share the frustration of researchers at the current cancer data landscape, and would welcome a system that can overcome fragmentation and data 'hoarding', improve the quality of data sets, and ensure security, interoperability and fair access.

Where we may not be in complete agreement, however, is on how best to achieve that, particularly regarding permission to access our data. Ever since 2016, when the European Union adopted the General Data Protection Regulation (GDPR), discussions have focused around the obstacles it presents to health research and arguing the case for mitigating the requirements particularly around linking access requests to specific research projects.

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Having been involved in a number of research projects in my capacity as a melanoma patient advocate over recent years, I've begun to appreciate the thinking behind the GDPR. I think it is much smarter than people think. What it does is to put ownership of the data back in the right place.

The problem at the moment is that the people who hold the data are not the people with the greatest interest in ensuring it is put to the most effective use. They want to hold onto it, they want to do their own research, they need publications. They all have other vested interests.

That became painfully clear to me many years ago when I was involved, on behalf of the Melanoma Patients Network Europe, in a Horizon 2020 research project that was looking at how to incorporate Real World Data in drug development and decision-making. It was funded with EU money and the patient community saw this as an opportunity to contribute to efforts to ensure decisions around the development and use of treatments were informed by how those treatments work in 'real patients', not just those fitting the clinical trial inclusion criteria.

But when we asked melanoma registries in three European countries whether, for the purposes of this study, we could access the patient data they held, not one of those we approached agreed. The project ended up having to buy patient data, at a hefty price, from the US SEER cancer registry. One of the European registries that refused our request holds data from my husband. I thought: How dare you? The whole point is that you ask us for our data, and we sign this consent form on the understanding that you will use it in a way that will help us, or at least help the community. But they said no.

I know my husband's data was sitting in a registry where it just doesn't get used. And the people who hold it can just say: oh you are not good enough to use our dataset. But this is our data, and if we want it used for the right things, it should be used.

> Who will use it? For what? Has any thought at all been given to how it might ultimately translate into something that benefits patients?

At the same time, patient advocates like me are constantly fielding requests from researchers to give our support to the studies they are proposing, when they don't seem to feel the slightest obligation to think about how their research might benefit the patient community. They approach us, usually just as they are coming up to deadlines, because they are under pressure to demonstrate patient engagement. And they are surprised when we ask to see their research proposal. We want to know where the data generated by their research is going to go. Who will use it? For what? Has any thought at all been given to how what they are doing might ultimately translate into something that benefits patients?

We're not asking for specific plans or guarantees. Just an indication that they have thought about how their findings might contribute to progress for the patient community, and what steps they will take to make that available to people who could make good use of it. We're asking them just to think about that – and most of the time they don't.

So it's the same with data. If people ask to use our data for research, then that's something we would welcome, as long as we can say: "yes, that is a good project for a melanoma patient, this is something that we want to find out, and this might help us get there." Having been active in this

field for almost 15 years, the impression I get is that too much of this research is done for stuff that just doesn't ever impact patients.

It's true that not all patients will necessarily be interested or agree. But a lot of us will, and that interest is likely to increase rapidly as healthcare becomes more digitalised, and patients get more access to their own data, and learn more about its relevance. We frequently see questions on our patients' forum now, for instance about the significance of the LDH value in their blood results. Once they understand its significance in staging their disease, they start to pay attention to it, and they begin to engage more in understanding their data and imaging results and why they might be important not just for them but for research that could help the whole community.

Patients with chronic conditions are well ahead of the cancer patient community in this. They use their data to actively manage their health every day. And they are very good at sharing information, hacking devices to be more relevant, and asking questions among themselves: "This value was way off this morning, might that have been because of my alcohol intake last night? Or because I didn't eat all day, or I've started taking this supplement?" They use their collective data to try to find answers to their problems. And now that Fitbits and other health data wearables are becoming so popular, it's not just patient communities doing this: people are just becoming much more aware about what their personal data can tell them about their state of health. And those people – all of us – should be the ones to decide who can use that data and what for.

> If patients control how their data is used, researchers may think harder about how their research can make a real difference

For me as a patient advocate that is the crux. Patients who understand how their data can make a difference to them and their community are likely to be the first to say: let's get this interoperable, let's ensure the quality, let's get this shared by the right people, let's not just put it into a little bank where somebody could say: "I've got this many terabytes of data and no-one can use it."

Patients want somewhere that we can contribute our data – a patient data hub – where researchers come to us and say: "We want to do this. And this is why. And here are a few ways we hope that the data we generate, the outcomes of our research, might lead to progress in the clinic. And here's how we intend to make our findings available to help that happen." As patients and advocates our only interest is to see progress – surely it makes more sense for us to be the gatekeepers of our own data.

With the proposal to create a European Health Data Space, Europe has the chance to exploit the immense possibilities of 'big data' for the benefit of patients and society. Discussions are bubbling up everywhere about how best to achieve this. My hope is that those involved will at least be open to the possibility that GDPR is not the obstacle, but rather an incentive for researchers and research funders to think beyond… By giving patients a proper say over how our data is used, it offers a valuable incentive for researchers to think about how their research can make a real difference to the communities affected by cancer.

I think obliging open access publication for EU funded research and insisting on patients being usefully involved in all current Horizon 2020 and Horizon Europe Health projects really levels the playing field and knocks heads together. We are all grappling to find the best way to share data fairly and effectively, so all our reasonable vested interests are weighed. If patients and patient organisations contribute well in the research and personal data elements of European health

projects – as we are doing for instance as one consortium partner in iTOBOS.eu, which seeks to develop an AI diagnostic platform for early detection of melanoma – we are more likely to get a data win–win for research and patient outcomes. But an important early step is free and easy access of patients/citizens to their own health data, and a say over how it is used.