## BACKGROUND

Our health information is often spread across different locations like our GPs, in hospitals, private clinics and now even on our phones as the use of smart wearable devices that track and collect our fitness data increases. A decentralised space that can store these different types of data could improve people's access and control over their own data.

"Data Pods", such as SOLID, are personal online data storage spaces. These are a new way for people to store their own data on their own Pod and not online resulting in more control over who they want to share it with. With Solid, users have full control over the data in their Pod, and can decide what data to share with individuals, organisations and apps. Access can be revoked at any time.

## SCENARIO

Jane recently went to her GP for a health checkup. She also wants a checkup for her 5 and 8-year-old daughters, Emma and Anne, and her 80-year-old father John. At the appointment, her GP informed her that they have a new way of managing patients' data at the clinic. A secure personal datastore ("Pod") is now being offered to patients to manage their own health data. They can share the Pod with their family members if they wish. The Pod will hold data from family members' phones and other devices.

Jane goes home and thinks about it and does some research into these data Pods and how access to the data is controlled. She agrees to have her personal data stored in a shared family Pod, along with Emma and Anne's data. She is happy to use a data Pod as long as she is the one responsible for giving access to said data. However, she does not want her father's data to be stored in the Pod before discussing the matter with him.

A few months later, Jane's 8-year-old daughter, Anne, is diagnosed with diabetes. Jane ensures her Pod now also collects data from Anne's blood monitor. The GP contacts Jane to ask for permission to check Anne's health-related data. Jane authorises the doctor to view her daughter's data and gives the doctor permission to now be able to view the data in the family's Pod without having to request it whenever he needs it. That same week, Jane's GP calls her about sharing Anne's diabetes-related data for research purposes. Jane agrees, as long as the data is used by the medical and academic community to do research on diabetes.

Shortly after, Jane starts receiving requests on her Pod management app asking for specific data from her daughter's medical record for a medical trial. Jane can browse the request, agree or not to some or all of the request, and can ask for more detail from the requestor.

## DISCUSS

Are there any circumstances where you would be willing to make decisions about sharing your family's data?

Would you be happy for family members to make decisions about sharing your personal data with third parties?

## BACKGROUND

Information about ourselves and our families is constantly collected through our phones and devices. Data about our location, preferences, interests and, even more sensitive information such as our health or wealth is collected and stored by apps and other services. However, the purpose of this data collection is not always clear, in particular when it comes to this data being shared on.

Several alternative solutions have emerged in the last few years to help individuals manage their digital footprint. Organisations have been set up as trusted data stewards, such as data trusts or data co-ops. These are legally constituted to serve the interest of data subjects, i.e. you and me and not the companies, and may also address broader public interests. New EU legislation has been proposed with the aim of providing a legal framework that can then be used to identify such trusted data stewards.

## SCENARIO

Mary is Sarah's mother. Sarah has just turned 15 and for her birthday, she wants a smartwatch like her friends. Mary decides to get Sarah an Android smartwatch.

The watch has health tracking and data sharing features. These are an added benefit, given that Sarah suffers from epilepsy. Mary can now keep track of both Sarah's health indicators as well as her location in case she has a seizure while out somewhere. The information is collected by the smartwatch and transmitted to Mary's Android phone thanks to Google Cloud's services.

Mary attempted to read the terms and conditions agreement when it popped up on the screen while setting up the watch for her daughter. However, after spending a couple of frustrated minutes trying to understand the language, and with pages more to read through, she just accepted the terms and conditions and the privacy notice and moved on. Agreeing to the privacy notice allowed Google to share any collected information to "third party partners" in order to "offer personalised services".

A couple of weeks later, Sarah had a seizure on the way home from school and the smartwatch immediately informed Mary. She quickly phoned the local emergency service and they arrived quickly to help Sarah.

A few days later Mary started to receive marketing emails from insurance companies offering their neurological service coverage. She found this situation concerning and decided to look for alternatives to manage the data generated by the smartwatch. In particular, she is interested in finding a solution that explains to her clearly and in a timely manner, what is happening with her and her daughter's data, who it is shared with and for what purposes.

## DISCUSS

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