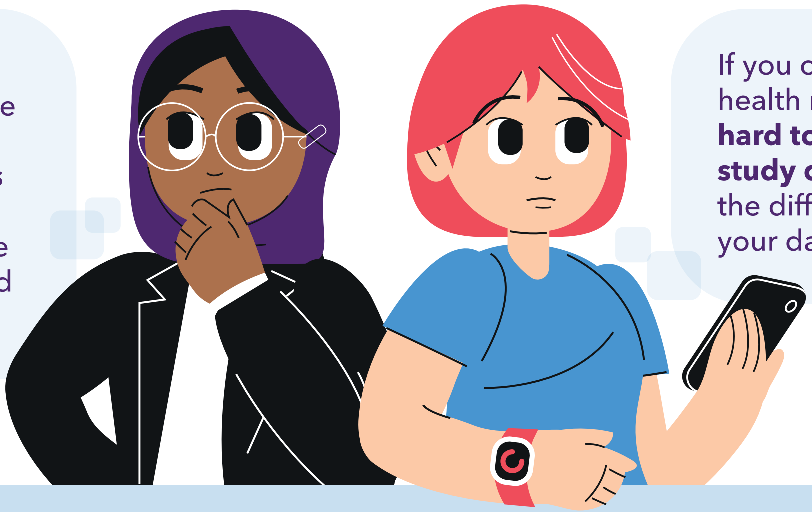
DataTrusts

How we share information about ourselves is a big part of our life - from social media to the smart watches people wear every day, **we share our data more widely than ever.**

With lots of new ways to collect and combine data, there is an opportunity for health researchers to use it to improve public health and patient care.

However, with these new opportunities comes new questions about how data is used and by whom - have you considered how you prefer your data to be used?

As a researcher, it can be difficult to know the **boundaries of what research participants find acceptable** and how to use data in line with their interests and preferences.



If you choose to take part in health research, it can be **hard to keep up with all the study developments** and the different ways in which your data might be used.

Academics and health researchers from the **Universities of Warwick and Edinburgh**, and the **Association for Young People's Health** are exploring a different way of managing data in health research through something called a Data Trust. This is where a group of independent trustees are dedicated to representing your interests, to help shape how your data is used.

In a data trust, **trustees** have a legal duty to act in your best interests and to ensure that data is being used for the purposes you agreed it could be used for.

Trustees could also be experts who can make decisions about new or unanticipated ways of using your data on your behalf.

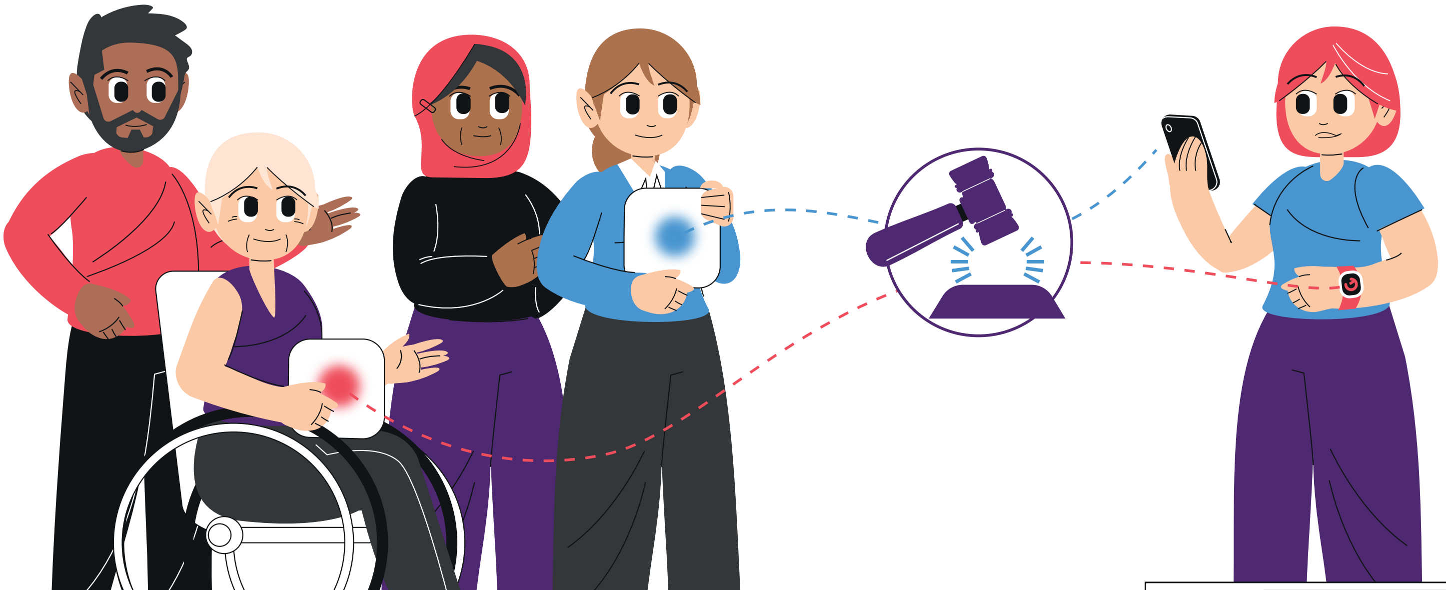
WARWICK
THE UNIVERSITY OF WARWICK

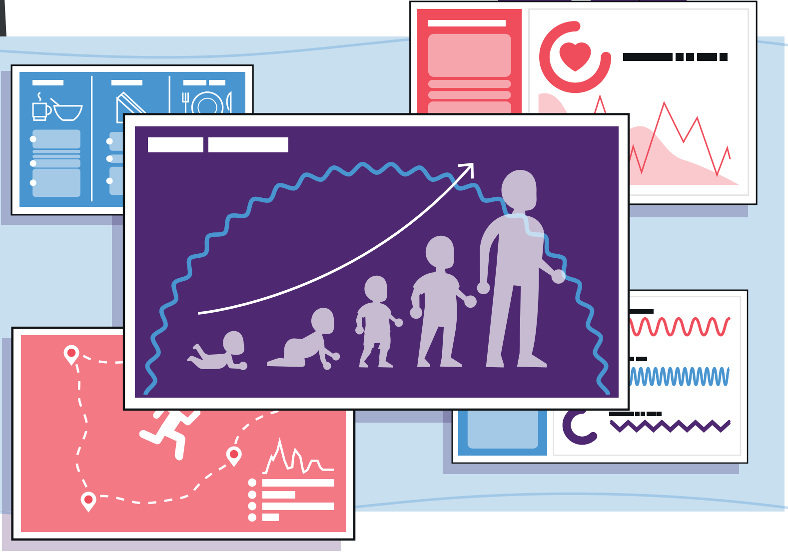
THE UNIVERSITY of EDINBURGH

Born in Scotland

ayph Association for Young People's Health

We know from other research that trustees could offer a way to manage data on behalf of people. But we don't know **HOW** this might work in health research and what **legal frameworks** are needed.





We are exploring how a data trust could work with participants in a **birth cohort study**. This is a study that follows a group of people and their babies born at the same time, throughout their lives to find out answers to questions like, for example, why are some babies born too early, or ill.

Our birth cohort study includes pregnant women and pregnant people, families, and carers, who consent to their data, and child's data, being used for research into the future.

Our goal is to find new ways to empower people to have a voice in how data is used for public benefit.

Let's build our data future together...

For more information

about the research and to get involved, visit:

https://bit.ly/datatrust1