

## Wellcome

Through [Understanding Patient Data](#), we have developed a robust evidence base on UK public views about the use of health data for research and service planning. Concerns and sensitivities typically arise around the potential of commercial or third party access to data, the choices people have in relation to how data about them can be used, privacy and anonymisation, and who gets to decide on the rules and processes for data access.

Health [data comes from people](#) and they have a stake in how it is used, even if it has been through a process of anonymisation. Health data governance needs to be ambitious in terms of transparency and accountability if it is going to be trusted by the populations that health data innovations are meant to serve.

Insights from our research provide us with some clear prerequisites for what it takes to develop a trustworthy system for collecting, managing and using health data. This includes the types of governance mechanisms patients and the public expect to be in place to protect the data while ensuring it is useful and useable for innovative research purposes.

Through this research we have proposed a model of data [governance](#) that build public accountability into the decision-making loop and set out conditions for the [trustworthy](#) use of health data. These concern the institutional/organisation and socio-cultural elements of trust-building, which need to be considered alongside technical aspects of data governance such as privacy enhancing technologies and cybersecurity measures.