

## **Open Data Institute (ODI)**

At the ODI, we want a world where data works for everyone and work with companies and governments to build an open, trustworthy data ecosystem. This means getting data to those who need it, particularly in response to the [UN Sustainable Development Goals](#).

Trustworthy governance of health data is essential to support the advancement of data-informed healthcare systems and the emergence of new uses of data and technology to deliver better health outcomes. Our [research](#) indicates that when data and organisations are trusted and trustworthy, there is an increase in data flow, leading to increases in value created in the form of products, services, analyses and insights created from the data, and better decisions by governments, companies and communities, informed by data.

To realise the benefits of good governance and build trust in organisations stewarding and using health data we need to be able to assure ourselves that the data itself, and practices of those organisations, are trustworthy. We launched a new programme of work looking into the topic of data assurance in April 2021.

We are **improving the data practices of organisations** so that they can build and manage adequate health data infrastructure and data use. For example, during 2021 we are [working](#) with Roche to help improve the way data is governed in the healthcare projects they contribute to and fund. In 2020 we worked with the Health Foundation to [explore new ways of collecting and stewarding health and care data](#) resulting in three use cases where data stewardship models are able to help private and public sector organisations share sensitive data. Finally, within the [INSIGHT](#) Health Data Research Hub we involve the public, patients and other stakeholders in data stewardship through a data advisory board which makes recommendations on appropriate use from a data ethics, equity, data protection and social perspective.

We **tackle challenges so that the health data ecosystem works better**. For example, we worked with Wellcome during 2019-20 to produce a [playbook](#) on how to identify a health problem and ensure it fits within the challenge prize model, which can be a great way of producing innovative solutions to a problem. We also support [OpenActive](#), in partnership with Sport England, to help organisations in the UK physical activity sector publish open data in a standard way so that it's as easy to book a tennis court as it is a hotel room.

Finally, we **gather and create research, evidence and knowledge** about data and the benefits of open, trustworthy data access, to inform companies and policymakers as they create data infrastructure, assets, practices and policies. The last year we have focussed our efforts on activities to support management of the coronavirus pandemic including exploring the [Covid-19 symptom tracking ecosystem](#); encouraging data intermediaries to share and make use of data; and reporting on who's using [mobility data](#), what they are using it for and the challenges are they facing. Finally we looked at data to understand the [impact of the COVID-19 pandemic on children's lives](#).