



Understanding Patient Data

Resource quick reference guide

June 24 v4.2



This is a quick-guide to help navigate UPD resources for explaining how health data is used in UK health services and beyond.

UPD believes patients and publics should not just be informed, but should be part of meaningful conversations around how health data is used.

To get the most from this guide, we encourage you to consider your own audiences and how best to provide the information they'd want. UPD resources are a starting point to edit and adapt to your own specific needs.

Excluding reports, UPD resources are freely available on a [CC-BY licence](#).

If you have any feedback or comments to help us improve this guide, please let us know at hello@understandingpatientdata.org.uk.

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EXPLANATORY RESOURCES AND REPORTS

Resource	Most likely to help people interested in...	Updated
Uses of patient data wheel	...a visual tool to show the range of ways patient data is used to improve health, care and services through research and planning.	March 2018
Data saves lives animations / Video case studies	...engaging animations and short videos describing stories of how patient data can save lives.	April 2018
Easy read guides	... information about health data in an accessible format, co-produced with people with disabilities.	July 2023
What happens to health data: a guide to large datasets	... information about how health data is gathered, stored and used, and information about key terms such as anonymisation and pseudonymisation.	October 2022
Research into the use of data by Integrated Care Systems (ICSs)	...how Integrated Care Systems (ICSs) in England collect, use and share data and how the use of data in these systems can be improved.	June 2024

WEBSITE EXPLAINERS

Resource	Most likely to help people interested in...	Updated
Explaining health data policy	...information about the legislation and policy governing the use of health data.	March 2024
Your choices	...information about what your choices are about your data.	October 2023
How and why your health data is used	...information about why it is important to use patient data and how it is used.	Sept 2023
FAQs	...answers to common questions about patient data.	Sept 2023
How data is kept safe	...information about what safeguards are in place to protect your data	Sept 2023
Can private sector organisations access patient data?	...information about what health data private sector organisations can access, and why.	Sept 2023
Who decides	...information about how decisions around the use of patient data are made, and who makes the decisions	Sept 2023
Weighing up the risks	...what the benefits and risks are of using patient data, and how these are mitigated.	Sept 2023

PUBLIC ATTITUDES

Resource	Most likely to help people interested in...	Updated
Summaries and key themes from public attitudes research	...understanding how people feel about the use of patient data.	Sept 2021
Public views on third party use of NHS data	... understanding of public attitudes to different kinds of organisations accessing NHS data.	May 2021
Analysis of UK reporting on health data	...how stories about health data are covered in the UK media and discussed on social channels.	Jan 2022
The right moments to explain data to people	... the best times and contexts to explain the use of patient data.	Sept 2021
Primary care professionals' views on health data	... what primary care professionals' views and expectations around data are.	August 2022
Insights from Black and South Asian people on patient data	... how Black and South Asian people feel about the use of their health data, and how gaps in data collection and use can be minimised.	July 2023
Public attitudes about patient data for planning and population health	...understanding people's understanding of and attitudes towards the use of patient data for planning and population health.	May 2024
Sharing health data – lessons for the UK from the European Health Data Space	...understanding how people feel about how health data should be used and shared.	June 2024

PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT

Resource	Most likely to help people interested in...	Updated
Public and patient engagement activities	...good practice, tips and advice from existing engagement activities.	May 2021
Co-production guide	...guidance for how to co-produce accessible health information.	May 2023
Data citation	...a way to acknowledge the use of patient data.	Sept 2017

GUIDANCE FOR TALKING ABOUT DATA

Resource	Most likely to help people interested in...	Updated
<u>Guide to talking about health data</u>	...a summary guide on how to explain how patient data is collected, used and kept safe	October 2023
<u>Best words to use</u>	...how to describe patient data to audiences who are less familiar with technical language.	July 2023
<u>The right moments to explain data to people</u>	... the best times and contexts to explain the use of patient data.	Sept 2021
<u>Explaining how patient data informs health information</u>	...how to explain the role of patient data in developing health charity guidance and information.	July 2023
<u>What words to use (Secure Data Environments/Trusted Research Environments)</u>	...how to describe and explain Trusted Research Environments/Secure Data Environments, based on workshops and co-development with members of the public	May 2024

DEVELOPING OUR THINKING ABOUT HEALTH DATA

Resource	Most likely to help people interested in...	Updated
<u>Putting transparency into practice</u>	...what transparency in health data means in practice	August 2019
<u>Defining public benefit for data use</u>	...what counts as 'public benefit' for the use of data and the trade-offs involved.	Sept 2023
<u>Trustworthy use of patient data</u>	...what constitutes elements of trustworthiness in the use of health data.	July 2021