Understanding Patient Data
Annual Report

2023-24

Understanding Patient Data

# Chair and Head of UPD's Foreword

We are delighted to report another successful year for Understanding Patient Data (UPD), and the first with the NHS Confederation as its host organisation. Building on the solid foundations and strong reputation of UPD at Wellcome, the new team of core staff was able to get up to speed and establish an exciting phase of work, delivering a valuable contribution to the UK health data community during an important year.

The team has led three key projects - 'What Are The Best Words To Use', 'Integrated Care System Data', and 'Data for Planning and Population Health'. As well as these projects, they have established themselves as strategic leaders, joining senior level groups such as the Data Strategy Advisory Panel and the Welsh Data for Research Working Group. They convened relevant stakeholders to support communications and public understanding in the roll out of the Federated Data Platform in England, and presented to members of the public on the use of health data in clinical trial recruitment for a public deliberation in Wales. Their detailed briefing on the potential impacts of the Data Protection and Digital Information Bill for health organisations was used in the Bill's scrutiny in the House of Lords, and their previous work on easy-read guides won the 2024 Health Data Research UK Patient and Public Involvement and Engagement Award.

Looking forwards to the next year, there will be a need to balance agreed priorities with emerging opportunities. The team has plans to produce more resources, commission further research and continue to influence health data policy at a strategic level. We are prepared for heightened attention on the topic of health data, particularly in relation to the delivery of health services and the role of the life sciences industry in the UK economy. A key focus for the year will be on developing UPD's long term sustainability, with the opportunity for greater partnership working.

Dr Peta Foxall CBE – Chair of UPD Steering Group
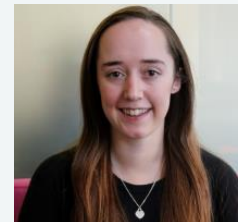
Nicola Hamilton – Head of UPD

Understanding Patient Data

UPD Vision:

Health outcomes for all are improved through the responsible and trustworthy use of patient data

UPD Mission:

To bring together diverse voices, research and resources to create a trustworthy system for the use of health data

UPD Aims:

Patients & publics are empowered to make informed choices about use of their health data

Health data users and custodians handle data in a trustworthy way to improve health and support innovation

Policy makers recognise the importance of patient data and support the environment around its use

Policymaking reflects the latest evidence about data use and public attitudes, and invest into building the evidence base

How we work

We do this through...

Producing **resources** to demystify uses of routinely collected health data

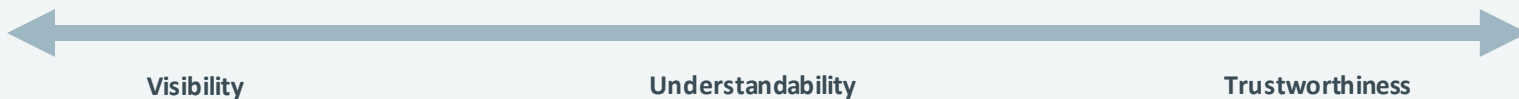Understanding views through **engagement** and **research**

Convening and supporting patient data communities and advocates

We advocate and influence health data **policy** and practices

We provide commentary to the **media** and create content for online channels

Visibility　　　　　　　**Understandability**　　　　　　　**Trustworthiness**

All our work is underpinned by three key principles

History and period of report

- Understanding Patient Data was set up in 2016 to support conversations with the public, patients and healthcare professionals about uses of health and care data. It was originally a two-year initiative, supported by Wellcome, the Medical Research Council, the Economic and Social Research Council, the Department of Health and Social Care, and Public Health England.

- The programme was then extended, continuing to be hosted at Wellcome until the end of September 2021.

- Previous annual reports until September 2021 can be found here. Between September 2021 and April 2023, ongoing projects were finished and discussions continued about whether to close down UPD or whether it was possible to find a new hosting organisation and suitable funding. In this report, we refer to these projects as 'legacy projects', as these benefitted from further activities and dissemination after April 2023.

- In April 2023, UPD moved to a new hosting organisation, the NHS Confederation, the membership organisation that brings together, supports and speaks for the whole healthcare system in England, Wales and Northern Ireland. The relationship of UPD to the NHS Confederation is similar to that of UPD and Wellcome; it remains an operationally independent initiative, although there have been some changes, e.g. in the steering group structure and membership.

- This report covers the period of UPD's first year at the NHS Confederation, April 2023 to April 2024. The NHS Confederation uses the UK financial year, which marks a change from previous reporting in academic years.

Meet the Steering Group

- A new steering group has been established and meets quarterly. The members are listed here, and the minutes are published here.
- The steering group is underpinned by a new Terms of Reference.
- UPD's funders for this two-year period are Wellcome, NHS England, the Medical Research Council and the National Institute for Health and care Research. We have also appreciated the support of the UK Health Security Agency for the secondment of a staff member.
- The group has undertaken an equality, diversity and inclusion survey to understand its composition. This has helped identify gaps in representation and experience which can be recruited to as the steering group develops over time.

Activity types and work programmes

	Developing the health data community	Commissioning research	Influencing and advocating	Communications and media	Creating resources
Health data policy and legislation	Event speaking, panels (UK and EU) Co-hosting discussions, e.g. with Connected By Data Welsh government health data deliberation	What Are the Best Words to Use Sharing health data – lessons for the UK from the European Health Data Space	Data Protection and Digital Information Bill Data Strategy Advisory Panel Consultation responses	Blogs on clinical trials, one year of DSL, etc Quotes to the media (BMJ, Telegraph) and editorials (BMJ)	Health data policy explainers Easy Read Guide comms campaign
Health data infrastructure	Involvement in the NHS England R&D Programme's Patient and Public Engagement and Communications working groups	Integrated Care Systems (ICS) Data	Federated Data Platform engagement Data for R&D Programme engagement Use of GP Data for Planning and Research	Quotes to the media Blog on Federated Data Platform	What Are the Best Words to Use (Secure Data Environment / Trusted Research Environments content)
Population health data, management and use	ICS Data Diversity in Data: Ethnicity Coding project involvement	Data for Planning and Population Health Equitable data collection for Gypsy, Roma & Traveller communities	Co-authoring Health Data Alliance ethnicity report	Comms campaign for Equitable Datasets R Number long-read publication	Updated and new case studies
Sustainability and international reach of UPD	Sharing resources with Canada, Australia, Ireland, etc Intern recruitment	Income generation strategy	Commenting on European Health Data Space legislation	N/A	Updates to resources and website

Examples of new resources

Choices in how your data is used beyond individual care

Summary

The Picture Across the UK

FAQs

Further Information on Opt-Out Policy in England

There are some choices that individuals have in relation to how their confidential patient information is used beyond their individual care. It's quite a complex picture across the UK and will depend on where in the UK you receive care. This is because health is a devolved policy, which means each nation has its own rules, processes and data systems.

Your Choices

CASE STUDY

How is health data used in the current measles outbreak?

Summary

What is measles and what is happening?

The journey of an individual's data

Other useful links:

This case study explores how the UK Health Security Agency uses health data to track the spread of measles and supports the health service to respond

What is measles and what is happening?

Measles

Explaining Health Data Policy

Health data policy can be complex, with legislation and policies from numerous sources interacting with each other. On this page we outline some key documents and what they mean for you and your data.

Explaining Health Data Policy

Examples of new publications and research

Understanding Patient Data

February 2024

research **WORKS**

Understanding Patient Data: "What words to use when talking about health data" Rapid Evidence Review

Contents

[What Are The Best Words To Use](#)

Understanding Patient Data | **NHS Confederation** | **wellcome sanger institute**

Sharing health data - lessons for the UK from the European Health Data Space

Rosie Richards[1], Maili Raven-Adams[2], James Maddocks[1], Sarion Bowers[2]

1. NHS Confederation, 2nd Floor, 18 Smith Square, Westminster, London SW1P 3HZ
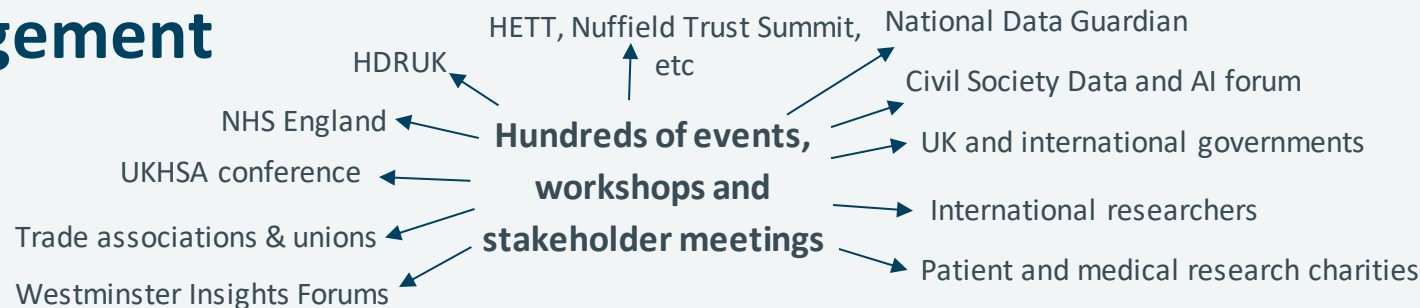2. Wellcome Sanger Institute, Wellcome Genome Campus, Hinxton, CB10 1SA

Abstract

The European Health Data Space will enable the sharing of European citizens' health data. 25 European countries, including the UK, worked together in the "Towards a European Health Data Space" (TEHDAS) Joint Action, funded by the European Commission, to develop the initial recommendations for realising this complex and transformative infrastructure. Understanding citizens views and concerns around the sharing of their health data is essential to ensuring the success of the European Health Data Space. To this end, a consultation targeting citizens in Belgium, France and the UK was carried out. In this paper we analyse the responses from citizens identifying as from or in the UK, and discuss how the findings from the consultation might relate to ongoing UK endeavours to share health data.

[Lessons for the UK from the European Health Data Space](#)

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Engagement

HDRUK

HETT, Nuffield Trust Summit, etc

National Data Guardian

NHS England

Civil Society Data and AI forum

Hundreds of events, workshops and stakeholder meetings

UK and international governments

UKHSA conference

International researchers

Trade associations & unions

Patient and medical research charities

Westminster Insights Forums

Total Social Media Engagement April 2023-April 2024					
Twitter		**LinkedIn**		**Newsletter**	
Views	109,512	Views	38,609	Followers	153
Followers	5814	Followers	1153		
Engagements	3707	Reposts	109		
Retweets	285	Reactions	777		
Likes	454	Comments	36		
Comments	43				

Countries accessing the UPD website
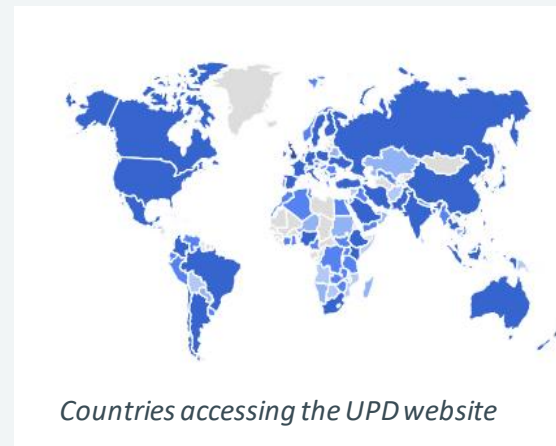
Top pages by # of views		Top pages by # of users		Top pages by engagement time	
Home page	28,025	Home page	1,342	Policy Explainers	34m 32s
How is data kept safe	866	How is data kept safe	558	Case study: Supporting research in rare diseases	10m 28s
About us	790	About us	402	Case study: Asthma	8m 12s

Collaborations

At UPD, we recognise we are part of a much larger community that spans across civil society, research, academia, government, health services, charities and the private sector.

Project Steering Groups:

- Welsh Government's 'Using Health Data for Recruitment to Clinical Trials – A Public Dialogue'
- National Data Guardian's 'Creating Reasonable Expectations' project
- NHS England's 'AI Deployment Platform' project, and the NHS AI Lab Designing Data Stewardship Models for AI
- DHSC / NHS England large scale public engagement project steering group

Steering/Advisory Groups

- Clinical Practice Research Datalink (CPRD) Scientific Advisory Group
- Department of Health and Social Care Data Strategy Advisory Panel
- Health Data Patient and Public Engagement and Communications Advisory Panel (co-chair)
- Public Engagement in Data Related Initiative (PEDRI) Delivery Group
- Health Data Research UK Patient and Public Involvement and engagement Strategy Steering Group
- Federated Data Platform Check and Challenge Group
- NHS England Data for Research and Development Programme Patient and Public Engagement and Communications Working Group

Memberships:

- International Patient and Public Involvement Network
- Healthcare Information For All
- Use MY Data
- UK Health Data Research Alliance
- Connected By Data (Head of UPD is a fellow here)
- PEDRI Governing Board

Other:

- Signatory to an Open Letter on the UK AI Summit led by Connected by Data
- Signatory to an Open Letter to make the Algorithmic Transparency Reporting Standard a requirement for all government departments led by the Public Law Project
- UK Open Government Multi-Stakeholder Forum
- Discussions with other governments / internationally

Deep Dive: What are the Best Words to Use?

Background / aims:
- Understand public understanding of, and attitudes towards, Trusted Research Environments (TREs) and Secure Data Environments (SDEs) for the analysis of large-scale health datasets, including relevant language choices and terminology
- Explore where there might be gaps in information provision
- Co-develop specifications for non-organisation-specific public-facing resources for UPD to create
- Develop recommendations for resources that other organisations within the TRE/SDE community could create

What happened:
- A rapid evidence review identified existing resources used to explain TREs and SDEs, most of which were organisation-specific or aimed at researchers, rather than members of the public and patients
- 14 workshops with members of the public across all four UK nations, including one face-to-face session with digitally excluded groups to consider the concepts, comment on existing resources, define what they did/didn't want to know, and develop proposals for resources.
- A further stage of testing with two workshops with new members of the public, and interviews with 8 subject matter experts, to refine and check for accuracy

Key take-away findings:
- The preferred format for a resource was a brief animated video with a voiceover, covering topics such as: an introduction to health data, definition of an SDE/TRE, types of data included, who accesses the data, and the benefits
- Additional content was suggested to cover topics such as: how approval to access is granted, how data is kept safe from hackers, and case studies, and the five safes
- Areas that public participants did not want to know more about included: differences between SDEs and TREs, and technical models (federation vs storage approaches)

Next steps:
- Get the resources professionally developed and create an area on the UPD website specifically about SDEs and TREs
- Enhance the UPD glossary
- Share recommendations with other key stakeholders to embed language recommendations and suggestions for other resources, particularly within the NHS England SDE network and the wider UK TRE Community.

Led by Nicola Hamilton, supported by Emma Morgan

Deep Dive: Integrated Care System (ICS) Data

Background / aims:
- Following the statutory implementation of ICSs, there are clear opportunities and high expectations for ICSs to use data to improve health.
- Data maturity assessments show variation across the country, but limited in-depth evidence as to how systems are using data and what is driving differences between systems.
- UPD sought to undertake a qualitative research project to improve understanding and transparency around where ICSs are on data, what the challenges and opportunities are, and what should happen to drive improvements and reduce unwarranted variation.

What happened:
- A qualitative research project was undertaken by a supplier (White Tail Consulting): 37 stakeholder interviews across 11 ICSs : 10 senior leader leaders (e.g. Chief Digital Officer, Chief Medical Officer), 13 technical leads (e.g. Director of Business Intelligence), and 21 wider ICS stakeholders (e.g. Information Governance (IG) lawyer, public engagement leads) followed by a roundtable with research participants and ICS data stakeholders to discuss findings and refine recommendations.
- A research report was produced, outlining how ICSs currently use data, barriers and enablers of progress, and future opportunities, and recommendations for national policymakers to support the data agenda in ICSs.
- In addition to the report, four case studies were produced highlighting best practice in specific areas, and a public-facing lay language explainer.

Key findings:
- There is significant variation in the maturity of data infrastructure, sharing and use cases. Some systems have advanced infrastructure with mature analytical and population health capabilities, whereas others are primarily using data for operational/performance management reporting. There is also large variation in analytical workforce and the extent to which data has executive buy-in and is placed at the heart of ICS strategy.
- Systems have taken varying approaches to IG, and systems perceive a lack of clarity from the national level about what is permitted.
- Many ICSs believe there needs to be more engagement with members of the public and that PPIE is important, but there are mixed views on who should own this, and there is a desire to do more.

Next steps:
- Share report findings and recommendations with key stakeholders in NHSE, DHSC, ICSs, local authorities, policy organisations, charities. Work with NHSE Intelligence Functions team through FY 24-25. Reactive/opportunistic sharing with parliamentary stakeholders if relevant debates arise.
- Use the report to help with conversations about internal NHS data platforms, such as the Federated Data Platform.

Led by Emma Lagerstedt

Deep Dive: Data for Planning and Population Health

Background / aims:
- Desk research and conversations with stakeholders revealed that there is a relative lack of public attitudes research done on data for planning and population health specifically. Much of the existing evidence either asks about secondary uses generally, or is focused on research (possibly given the involvement of third parties such as pharmaceutical companies and academics).
- UPD sought to fill this gap by commissioning research to understand: public awareness/understanding of the use of data for planning and population health, views on the acceptability of using data for these purposes, and what factors/use cases drive views on this topic.

What happened:
- A mixed-methods research project was undertaken by a research agency (Qa Research), including a UK-wide representative survey (N=1000) and a series of four workshops with 31 participants.
- A research report was produced, setting out members of the general public's level of awareness and understanding of the use of data for planning and population health, and their views on these data uses, including how views on planning and population health compare to views on other use cases, and which specific examples of using data for planning and population health garnered the highest levels of support.

Key findings:
- The majority of people knew 'nothing at all' or 'a little' about how patient data is used, and people are less familiar with the use of data for planning and population health than for individual care or research.
- People are overwhelmingly supportive of the use of data for planning and population health (90% support).
- Most people believed that the NHS should have automatic access to data for planning and population health, but a sizeable portion (20%) believed access should not be automatic.
- People generally preferred the use of de-identified data over identifiable data, but the use of identifiable data was understood and broadly considered acceptable when it can make analysis more accurate, as long as there are safeguards to prevent misuse.

Next steps:
- This project is phase one of a two-stage programme of work, the second phase of which will likely focus on producing resources to support conversations about the use of data for planning. It will also help with conversations at national level about legislation, policies such as opt-outs, and public engagement and deliberation in future.

Led by Emma Lagerstedt

Deep Dive: Income Generation

Background:
- UPD has been fortunate to have attracted funding from a small number of secure sources since its inception in 2016.
- In 2023, UPD moved to be hosted at NHS Confederation with the same funders as a transitional arrangement.
- With current funding due to end in 2025, UPD wanted to explore options for securing funding past this date, and what it could look like under such funding models.

What happened:
- UPD commissioned Eastside People to develop a funding and income generation strategy for UPD
- The approach involved: a review of UPD's current finances and funding; consideration of competitors and collaborators; SWOT analysis with the UPD team; reviewing and updating the Theory of Change; testing ideas and assumptions with stakeholders and our steering group; a desktop review of fundraising opportunities; developing a core offer with additional bolt-ons; and proposing methods of diversifying income such as membership models, corporate sponsorship, or selling services or products.

Key take-away findings:
- Although the report concluded that funding opportunities are limited, it also proposed a range of recommendations of avenues for potential sustainability if not growth.
- The report recommended that UPD should: prioritise securing ongoing funding from existing funders; consider the time and cost of diversification options; explore potentials for expanding remit e.g. to include Artificial Intelligence due to increasing interest and investment; clarify the core offer as opposed to bolt-ons; and further develop the evidence of impact of our work.

Next steps:
- Continuing to negotiate with our existing funders and networking with potential funders.
- Discussions with wider community (e.g. Office for Life Sciences, Association of Medical Research Charities, Academy of Medical Sciences, Health Data Research UK, etc) to further consider potential operating models in line with the ecosystem's needs.
- Consider bidding/co-bidding for small commercial opportunities where appropriate as a proof of concept.
- We plan to make a decision about the funding approach for spring 2025 onwards in Autumn 2024.

Led by Emma Morgan

Celebrating Success

Financial Summary

The financial summary covers April 2023 – March 2024 only.

This is a change from previous UPD reports which were based on Wellcome's academic financial year.

Please refer to previous annual reports for finances until September 2021, and underspend was then used between September 2021 and April 2023 to complete projects, so no specific summaries were produced.

Actual Spend 2023-24
Income & Expenditure Breakdown

INCOME*	
Wellcome contribution	£299,816.00
MRC contribution	£197,878.56
NIHR / DHSC contribution	£101,937.44
NHS England contribution	£300,000.00
Income brought forward from 2022-23	£50,600.00
TOTAL INCOME	**£950,232.00**

EXPENDITURE	
Project costs	
What Are the Best Words to Use	£28,573.00
Data for Planning	£28,626.00
ICS Data	£13,650.00
Income Generation Strategy	£15,120.00
Sub-total (project costs)	**£85,969.00**
Staffing	
Salaries (including on-costs, training, subscriptions)	£188,003.94
Travel and subsistence (staff and steering group)	£1,725.79
Overheads (including contribution to hosting organisation, website running costs and development)	**£56,933.40**
TOTAL EXPENDITURE	**£332,632.13**
Income carry forward **	**£617,599.87**

* All income noted above is over a two-year period, mostly April 2023 - April 2025
** Income from NHS England covers December 2023- December 2025 and therefore applies to more than just the following financial year

Publications and References

- Rapid evidence review for "What are the best words to use", stimiulus materials and final review
- Data for Planning
- ICS Data
- Health Data Policy explainer resource
- Resource on how health data is used in the current measles outbreak
- Got the first and second instalment of 'The Story of the R Number' published in Significance journal
- Referenced in Newmarket Strategy on harnessing primary care data for clinical research and trials
- Scrutinised the proposed Data Protection and Digital Information Bill from a health data perspective, which was shared with ~30 members of the House of Lords, and referenced as an excellent briefing in the House by Baroness Bennett
- Editorial in the BMJ about proposed policies to 'sell' NHS data
- Participated in HSJ roundtable and associated resource
- Referenced in Connected by Data's Health Data Stories
- Referenced in the Action Plan for the Digital Patient by Marlene Winfield OBE
- Written many other blogs about the Federated Data Platform, NHS England's Data Partnerships Guidance, Learning Disabilities Week, and the Lord O'Shaughnessy review on commercial clinical trials.

Looking ahead

- The 2024 – 2025 year includes a number of priority projects:

  - Producing resources on Secure Data Environments and Trusted Research Environments

  - A follow-on ICS Data project

  - A follow-on Planning / Population Health Data project

  - Equitable Data Collection for Gypsy, Roma & Traveller Communities project

  - A possible project on GP Data

- We will also be evaluating our work so far, and working hard to secure more funding, particularly for April 2025 onwards when most of our current funding agreements come to an end.

- We look forward to seeing how current initiatives and the policy environment progress – DHSC/NHSE large scale public deliberation, possible progress on the Control of Data Processing Act implementation in Northern Ireland with the Assembly back, and progress with the European Health Data Space to name a few examples.

Our resources

UPD has an extensive library of explainers, case studies, resources and research materials

Explainers and web pages

- Explaining Health Data Policy (NEW)

- Blogs (NEW)

- Guide to co-producing accessible health information

- Examples of public and patient engagement activities

- Case studies - when you need an example of the benefits of using patient data

- FAQs - pre-written answers to common questions from the public

- Data saves lives animations - a series of animations explaining how data saves lives following five patient journeys

- Data citation - a short statement to acknowledge when you use patient data

- Safeguards explainer - to help explain how data is kept safe

- Weighing up risks explainer- to help explain how data is kept safe

- Identifiability explainer - to help explain what anonymous means

- Identifiability spectrum pictures - re-usable pictures for explaining different levels of identifiability

- Data glossary - explaining technical terms and written by Connected Health Cities

Research and resources

- ICS Data (NEW)

- Data for Planning (NEW)

- 'What are the best words to use' rapid review, discussion guides, stimulus materials and final report (NEW)

- Healthy Data Consultation report (NEW)

- Case studies (updated and NEW)

- Easy read guides to health data

- A guide to large data sets

- Closing the ethnicity gap in data collection

- Public views on third-party use of NHS data

- Primary care professionals' views on the use of data

- Finding the right moments to talk about data

- The best words to explain data

- What counts as a 'public benefit'

- Balancing the risks and benefits of data sharing