



Understanding
Patient Data

Annual Report 2018-2019



A note on this year's report

Understanding Patient Data was set up in 2016 to support better conversations about uses of health information. A small core team is based at Wellcome in London.

UPD was originally funded for two years. This annual report provides an update on UPD's activities as that period of funding drew to a close towards the end of 2018, and the next steps as the team looked to renew its funding and mandate in 2019.

UPD's activities were limited in 2018-19 owing to this transition period and staff turnover.

Aims and objectives

UPD aims to support discussions with the public, patients and healthcare professionals about uses of health and care data by:

1. providing objective evidence about:
 - how and why data can be used for care and research
 - the benefits and risks
 - what is allowed and not allowed
 - how personal information is safeguarded
2. helping people make informed decisions when they have options about how data might be used
3. developing advocates who can champion the responsible use of data
4. bringing together, and partnering with, other engagement initiatives to strengthen the voice of individual activities
5. working with the media to present an even-handed portrayal of stories relating to health data
6. providing analysis about public attitudes to help inform NHS England, Department of Health and NHS Digital policy and communications
7. examining emerging issues from new data-driven technologies and the implications for public confidence.

Developing ‘Understanding Patient Data 2.0’

In February 2019 the Steering Group agreed that UPD should seek a further period of funding, as conversations about data were becoming more important and prominent in light of advances in data-driven technologies and increasing societal awareness of data use for different purposes.

The UPD team explored several options for continuation, including:

- A. Spinning out UPD as a membership organisation, funded through fees from supporters or fees charged for resources.
- B. Transitioning UPD to a consultancy model, funded through commissions taken to undertake research and/or provide advice to developing data initiatives.
- C. Retain UPD as being based within Wellcome, primarily funded as part of proposals for Wellcome's developing Data for Science and Health Priority Area.

Funders agreed to prioritise efforts into developing option C.

Core funding from Wellcome was approved in July 2019, for a five year period. Additional funding was subsequently also sought from MRC and NIHR.

As of September 2019, funding has been provisionally agreed subject to a Memorandum of Understanding between the funders.

Research and Resources

This year focused more on strategy and research than creating new information resources. However, UPD did collate existing work to produce new resources intended to act as straightforward reference points for stakeholders:

- **Quick guide:** brings together UPD resources into one place and acts as a short, simple summary of much of our work, answering key questions about data use. It has been developed following feedback from our reporters, who wanted to be able to share UPD work with others more easily and save time when trying to find the right resource for their needs.
- **Public attitudes research summary:** collates a range of studies on public attitudes to patient data. There has been a significant amount of research, including systematic reviews, that can be challenging to navigate. The resource organises these into two summaries, one exploring key themes and the other summarising findings by study.

WHEN EXPLAINING IF PATIENT DATA BEING USED IS "PERSONAL DATA"

Be aware that the words used to describe whether a person is identifiable from data can be technical and complicated

It is important to clearly explain:

- whether data is "personal data" as defined by the law
- what steps have been taken to remove identifiers
- the risk of re-identification when different types of data are used.

When talking about whether data counts as "personal data", it's important to consider the environment in which data is being used, as well as what's in the data itself. Depending on the risk of re-identification, different controls are needed.

Bear in mind that it may also be possible to work out who someone is by combining information from different sources — like joining together different pieces of a jigsaw puzzle.



03 WHEN EXPLAINING WHAT HAPPENS TO PATIENT DATA AND WHO SEES IT

Be open. People are unlikely to know about the different types of organisations that use patient data, why they use patient data, or how access to data works.

Be aware people may want reassurances, including that:

- a patient's full record will only be seen by healthcare professionals who are directly involved in their care.
- there are strict controls on how anyone else can access patient data.
- patient data can only be used beyond individual care if there is a public benefit.

WHEN EXPLAINING THE RISKS OF USING PATIENT DATA

Patients' concerns typically include:

- Loss of privacy, or information about their medical history being revealed to others.
- Loss of control if data is passed outside the NHS (including data being used to discriminate and for targeted marketing).
- The possibility of cyber attacks or hacking.

Risks around not sharing patient data include:

- NHS resources are not used as efficiently as possible and are potentially wasted.
- The safety and effectiveness of drugs and treatments are not monitored.
- Less is known about how to improve the health of some groups of patients.

Remember that:

What is an acceptable balance between benefit and risk will vary from person to person. People may accept greater risks if they are more likely to benefit directly.



Influencing and Engaging

UPD developed and led a major piece of public engagement research explicitly to feed into the UK's Life Sciences Sector Deal 2, which drew heavily on the potential of NHS data to drive innovation.

Foundations of Fairness: where next for fair health data partnerships?

- UPD co-ordinated a letter to the Secretary of State for health calling for greater patient involvement.
- The Government's response initiated the 'Fair partnerships' project to understand public attitudes towards NHS data use by third parties.
- UPD began commissioning a mixed-methods research programme, co-funded by NHS England and with a contribution in kind of staff time from the Ada Lovelace Institute.
- The project is due to complete at the end of 2019 and is intended to feed into the Office for Life Sciences' developing policy framework for third party partnerships using NHS-held data.



Understanding
Patient Data

amrc

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5th December 2018

Dear Rt. Hon. Matt Hancock MP,

We are pleased that the Life Sciences Sector Deal and Code of conduct for data-driven health and care technology take positive steps to ensure the UK can unlock the value of health data and drive exciting healthcare innovation. You and others^{1,2} have acknowledged that public trust and confidence are essential to underpin these advances, but this trust is fragile.

Patients and the public can be powerful advocates for better use of technology in health and care, but they have to be brought along the journey. The National Data Opt-Out has provided a good basis for people to express their choice. However, with increasing commercial partnerships to drive innovation, such as the Accelerating Detection of Disease programme, public anxieties present a significant challenge: there is a very real risk of a backlash³ or of some people being left behind.

The Sector Deal and Code provide a fantastic opportunity. They set the groundwork to engage meaningfully with patients, publics and clinicians on how to ensure a fair exchange of value for the NHS and patients when dealing with technology developers and the use of patient data.

The UK has led the world on embryonic stem cells and mitochondrial donation: success underpinned by extensive engagement with patients and the public, resulting in a thriving gene and cell therapy sector for UK plc. The same could be true for data-driven technology, if we get the engagement right.

In partnership with your department, we are keen to jointly lead and support research with publics, patients and health professionals to explore attitudes to the different models for NHS data use. This would help shape policy decisions and guidance on data-driven technology in a way that ensures nobody is left behind by the technology revolution. The recent Academy of Medical Sciences report "Our data-driven future in healthcare"⁴ provides an excellent springboard.

We would be happy to discuss our concerns and proposed ways forward in more detail.

Yours sincerely,



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Association of Medical
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¹ <https://publications.parliament.uk/pa/b0001719/bvfiles/100/100.pdf>

² <https://www.theacademyofmedicalsciences.org.uk/press/2018/05/17/2142-8/fulltext>

³ <https://www.ft.com/content/2a03b24c-4a2c-11e8-9a2c-20098a1b7274>

⁴ <https://www.theimscs.ac.uk/articles/people-posed-to-profit-from-nhs-patient-records>

⁵ <https://acmedsci.ac.uk/policy/projects/use-of-patient-data-in-healthcare-and-research>

Influencing and Engaging

Guest blogs

We gathered expert opinion pieces from stakeholders to increase engagement with partner organisations. Examples that were popular with readers include:

- 'Building public trust in the use of health information to improve health and care' 30 July 2019 **Amy Darlington, Involvement and Engagement Lead, OneLondon** outlined its report 'Understanding Public Expectations', which UPD provided the foreword for.
- 'People powered genomics' 9 May 2019 **Vivienne Parry, Head of Engagement, Genomics England** summarised the findings of '*Time for a New Social Contract*', calling for a national genomics medicines service.
- 'How can third sector organisations support a transformation of patient care through data?' 2 Oct 2018 **Taz Cheema, Business Analyst, The Brain Tumour Charity**

Communications

Twitter

- The main focus of Twitter activity was sharing updates on research projects with a range of partners, including One London, Ada Lovelace Institute and Academy of Medical Sciences.
- UPD Twitter activity had 557,700 impressions and attracted 1,002 new followers.

Website

In total the site had 50,000 visits, from over 39,000 users. We plan to use insights from the site analytics to improve the content in the next year.

The top 3 most visited page on the site were:

1. [News item about GDPR and patient data](#)
2. [Research on the best words to talk about patient data](#)
3. [What you need to know](#)

Top 3 downloads:

1. [Why patient data is important to use \(the 'wheel'\)](#): 620 downloads
2. [Resource quick guide](#): 410 downloads
3. [Identifiability briefing](#): 320 downloads

Media highlights

The top three media references to UPD's work were:

1. Digital Lancet, [Data sharing: keeping patients on board](#)
2. HSJ, [Revealed: National plan to share 'rich detail of clinical encounters'](#)
3. BMJ, [#DataSavesLives—Patient participation ensures data are accurate and useful](#)

The UPD 'wheel' was the top download over the year



Partners

These organisations (at Sept 2019) support the work of Understanding Patient Data, sharing information and engaging with their membership to help develop ideas, research and resources.



Highlights of the year

Securing further funding from Wellcome as part of the Data for Science and Health Priority Area was a major milestone for UPD. We received strong backing from a range of stakeholders in the patient data community to continue and expand its work. As part of this development, we now have a clearer strategy and vision for the next phase of UPD.

Kicking off the 'Fair Partnerships' project has also enabled UPD to forge a clear connection between undertaking engagement work and using these insights to inform trustworthy policy development and governance.

More widely, the creation of several new initiatives in the UK highlight the increasingly important role of health data in innovation and society, including: the Ada Lovelace Institute, the Centre for Data Ethics and Innovation, the HDR-UK Health Data Hubs, the NHS AI Lab, the Health Foundation's programme on Data Analytics. As the UPD team expands over the coming year we look forward to working with these partners to develop further ways to build trustworthiness into how patient data is used.

Next steps for Understanding Patient Data

Priorities for late 2019-2020 will be:

- Recruiting a team of up to 7 to build and expand UPD's work, covering:
 - Communications and media
 - Policy and advocacy
 - Public and community engagement
 - Partnership and community building
 - Team co-ordination
- Confirming additional core funding from other funders: MRC and NIHR
- Developing a new strategy and vision for the next 5 years
- Establishing and formalising a new Steering Group to provide advice and critique on UPD's strategy and direction
- Establishing UPD within Wellcome's Data for Science and Health Priority Area team.

Budget

This outlines the complete actual spend for the period September 2018 – September 2019 (Wellcome operates on an academic financial year).

The UPD funders agreed to permit the underspend to be rolled over into the future budget for UPD.

Actual 2018-19 Income & Expenditure Breakdown	
INCOME	
External contributions**	40,000
Wellcome contributions***	106,274
Balance brought forward	187,271
TOTAL INCOME	333,545
EXPENDITURE	
Project Costs	
Web development	21,314
Meetings	4,038
General staffing costs	660
Staff travel expenses	3,435
Local Health & Care Record Exemplar (London) Project	2,000
Fair Partnerships Project	41,356
Contracted staff costs outside of Wellcome's MoU scope	47,579
Sub-total (project costs)	120,383
Staffing	
Salaries (incl. on costs)	106,274
Balance carried forward	40,888
TOTAL EXPENDITURE	267,546
Underspend****	65,999

** NHS England £40k

*** Staffing costs (seconded only)

**** Underspent amount to be used in future years