Understanding
Patient Data

Annual Report
2019-20

UPD's mission

This year, UPD has refreshed its mission and ways of working to reflect our new priorities:

UPD exists to make uses of patient data more visible, understandable and trustworthy.

...visible – because people (whether patients, public or health professionals) shouldn’t have to work hard or be data experts to find out how and why data is used, what the risks are and how it’s kept safe.

...understandable – creating consistency, clarity and accessible language for explaining data use and data science, so that everyone can engage with the important concepts and ideas if they want to.

…trustworthy – channelling the insights and views we gather through attitudes and engagement research into policy and practice, and challenging those responsible for decision-making and governance for data use to demonstrate how they are worthy of people’s trust.

As part of its renewed 5-year funding term, UPD now sits within the Data for Science and Health team at Wellcome, which aims to ensure trustworthy data science transforms how science addresses urgent health challenges. UPD has also secured core funding from MRC and NIHR.

This report covers the period 1 October 2019 – 30 September 2020.

Steering Group

We are delighted to have established a formal Steering Group, which meets 2-3 times per year. The Group has Terms of Reference to:

- provide strategic advice and act as a critical friend to support and help UPD achieve its aims;
- facilitate access to Steering Group members' networks of stakeholders so that knowledge, resources and involvement with the initiative is shared with a diverse range of audiences;
- provide independent assurance to the funders that their investment is achieving its objectives.

The Steering Group is chaired by Sir Nick Partridge and includes:

- Representatives from UPD funders: Wellcome, MRC and NIHR
- A representative from the National Data Guardian's Panel
- Members with expertise in: public health; primary care; social care; nursing; health research; data analytics; data governance and policy; public and patient engagement.

In the coming year, UPD will work with the Steering Group to identify additional skills and expertise needed on the Group's membership, including exploring meaningful public and patient participation in the group and widening the range of perspectives from minoritised groups.

UPD Team

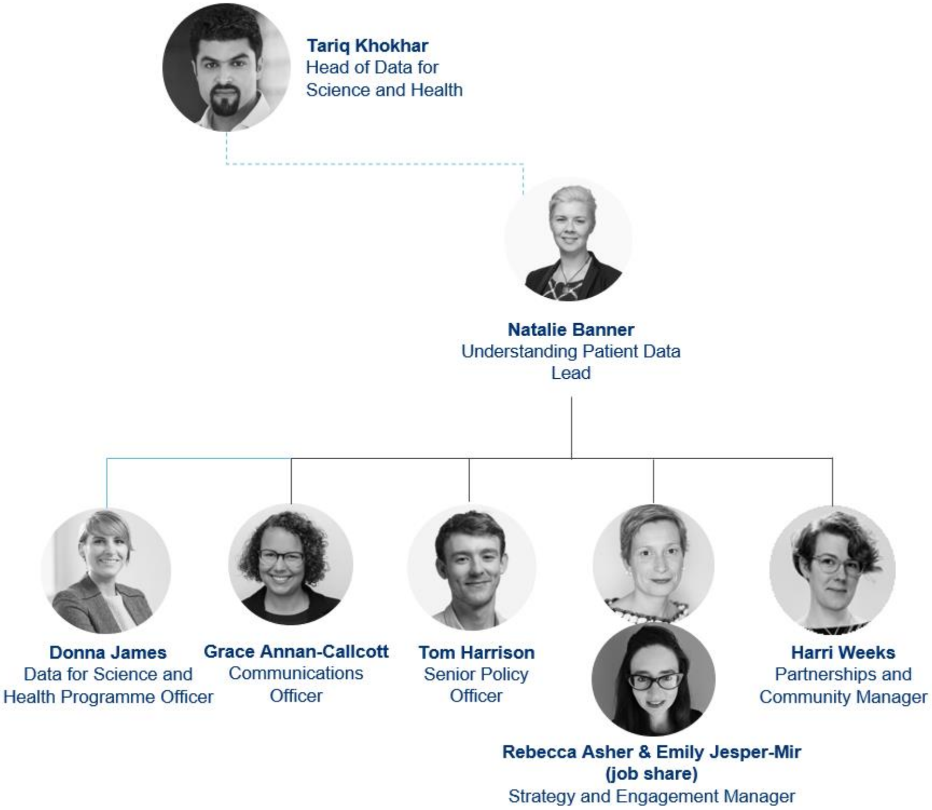
Over the past 12 months we have grown the team to 6 people, bringing a wealth of new expertise and insight into our work.

Grace Annan-Callcott – *Comms Officer*.
Grace manages all our communications, social media and press activity.

Tom Harrison – *Senior Policy Officer*.
Tom provides project support, develops our advocacy work and manages relationships with our key policy stakeholders.

Rebecca Asher and Emily Jesper-Mir – *Strategy and Engagement Manager*.
Rebecca and Emily work in a job share and focus on public and patient engagement, particularly with seldom heard voices.

Harri Weeks – *Partnerships and Community Manager*.
Harri leads projects with partners and works to develop our patient data community with health professionals, charities, patient groups and data custodians.



Tariq Khokhar
Head of Data for
Science and Health

Natalie Banner
Understanding Patient Data
Lead

Donna James
Data for Science and
Health Programme Officer

Grace Annan-Callcott
Communications
Officer

Tom Harrison
Senior Policy
Officer

Harri Weeks
Partnerships and
Community Manager

Rebecca Asher & Emily Jesper-Mir
(job share)
Strategy and Engagement Manager

Website and resources

Website

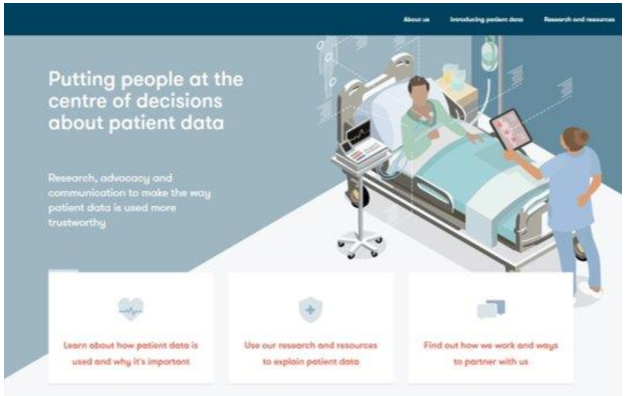
- **58,000** visits from **45,000** visitors.
- Refreshed the website to tell a clearer story of what UPD does and how people can partner with us.
- Used analytics to make navigation to popular content easier and got feedback from partners as we developed it.

Resources

- Updated our identifiability explainer to reflect feedback and the nuances around ‘personal data’ in light of GDPR.
- Produced a new deck that pulls together key qualitative public attitudes research between 2018-2020.
- Updated our resource on public engagement.

Highlights from our guest blog series

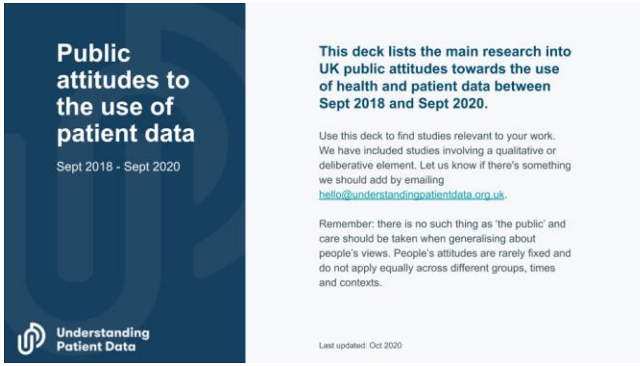
- There's no single truth about Covid-19, by Miles Sibley, Director at the Patient Experience Library.
- The role of routine data in the fight against Covid-19, by Dr Marion Mafham of the RECOVERY trial.
- Using NHS Digital data to improve care, by Dr Tom Foley, Senior Clinical Lead for Data at NHSD.



Putting people at the centre of decisions about patient data

Research, advocacy and communication to make the way patient data is used more trustworthy

Refreshed website homepage



Public attitudes to the use of patient data

Sept 2018 - Sept 2020

Understanding Patient Data

This deck lists the main research into UK public attitudes towards the use of health and patient data between Sept 2018 and Sept 2020.

Use this deck to find studies relevant to your work. We have included studies involving a qualitative or deliberative element. Let us know if there's something we should add by emailing hello@understandingpatientdata.org.uk.

Remember: there is no such thing as ‘the public’ and care should be taken when generalising about people's views. People's attitudes are rarely fixed and do not apply equally across different groups, times and contexts.

Last updated: Oct 2020

New public attitudes slide deck

Social media and press

Twitter

We use Twitter to:

- Show UPD is a leading advocate for trustworthy patient data.
- Highlight good practice from others.
- Surface patient voices and more diverse perspectives.
- Provide accurate and balanced media commentary.
- Promote UPD research and resources.

This year we achieved **832,000** impressions, **962** new followers and an average engagement rate of 1.5, which is considered ‘very good’.

> The Test and Trace programme depends on the public's trust and compliance. It’s vital to be clear how the information collected will be managed and used, but the current privacy notice lacks detail and raises lots of questions. There may be good reasons for retaining data to better understand the pandemic, but Public Health England must urgently clarify the rationale for keeping some data for 20 years, where this data will sit and the controls around its use.
>
> Dr Natalie Banner, Understanding Patient Data Lead

Example of media commentary on Twitter

Media

Through our media engagement work we aim to encourage more accurate and balanced commentary on media stories about patient data.

Highlights this year include:

- Natalie interviewed by Kay Burley on *Sky News* about Covid-19 Test and Trace data.
- An op-ed published in *Nature Medicine* on “The human side of health data”.
- Quotes from UPD in articles in *Wired, BMJ, HSJ* and *Mail Online.*

Natalie's interview on Sky

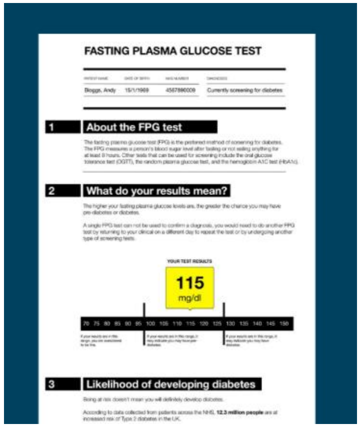
Research projects

How To Talk About Data

A design project to research and prototype moments when people would be open to learning about patient data – starting from where people are rather than leading with the data 'story'.

Key findings:

- People are more likely to be interested in how data is used if it helps them learn more about their condition/treatment, especially during moments of change.
- There's only so much you can explain in one interaction – which is dependent on the context.
- Explaining data over multiple small moments raises less anxiety than explaining everything in one go.



FASTING PLASMA GLUCOSE TEST

Bloggs, Andy 15/1/1969 4567890009 Currently screening for diabetes

1 About the FPG test

The fasting plasma glucose test (FPG) is the preferred method of screening for diabetes. The FPG measures a person's blood sugar level after fasting or not eating anything for at least 8 hours. Other tests that can be used for screening include the oral glucose tolerance test (OGTT), the random plasma glucose test, and the hemoglobin A1C test (HbA1c).

2 What do your results mean?

The higher your fasting plasma glucose levels are, the greater the chance you may have pre-diabetes or diabetes.

A single FPG test can not be used to confirm a diagnosis, you would need to do another FPG test by returning to your clinical on a different day to repeat the test or by undergoing another type of screening tests.

YOUR TEST RESULTS

115 mg/dl

70 75 80 85 90 95 100 105 110 115 120 125 130 135 140 145 150

3 Likelihood of developing diabetes

Being at risk doesn't mean you will definitely develop diabetes.

According to data collected from patients across the NHS, **12.3 million people** are at increased risk of Type 2 diabetes in the UK.

Prototype of blood test results letter

Foundations of Fairness report

A mixed methods engagement project using citizens' juries and a survey to explore people's views about third party use of NHS-held data. Co-funded by NHSE and in collaboration with the Ada Lovelace Institute and Office for Life Sciences.

Key findings:

- The public generally support NHS bodies permitting access to health data provided public benefit is the primary focus.
- People are concerned about the NHS being exploited by private companies in data agreements.
- The public want to be involved in data partnership decisions.

Foundations of Fairness

Where next for NHS health data partnerships?

March 2020

Understanding Patient Data

Ada Lovelace Institute

Foundations of fairness: views on uses of NHS patients' data and NHS operational data

A mixed methods public engagement programme with integrated Citizens' Juries

Findings Report

February 2020

Report authors: Henrietta Hopkins, Suzannah Kinsella, Anita van Mil

Hopkins Van Mil: Creating Conditions Ltd

Creating Connections

Hopkins Van Mil

Foundations of Fairness reports

Influencing and advice (UK)

UPD seeks to ensure policy and decision-makers understand and are responsive to public views and values about how data should be managed and used, advocating for trustworthiness in practice. This year, the data policy landscape has developed rapidly and our focus has been on influence and advice at national level. This includes several Government and arms-length bodies' consultations and providing ad-hoc advice to bodies such as NHSX, NHSD, HDR-UK, DHSC as well as charities and industry bodies.

1. In June, we responded to **Health Data Research UK's (HDR-UK)** consultation on its approach to *Trustworthy Research Environments* for its research Hubs. It's since altered its approach to language, prioritising plain-English and engaging clinicians and other health care professionals.

2. In September, we responded to the **National Data Guardian's (NDG)** proposals to revise the Caldicott Principles. They subsequently invited us to join discussions with the Health Research Authority on a proposed principle about informing public expectations.

3. In October, we presented findings from the *Foundations of Fairnes*s to the All-Party Parliamentary Groups on Health and on Data Analytics, in an event chaired by Lord Hunt. We drew on the importance of data for the Covid-19 response and in anticipation of the NHSX **Data Strategy for Health and Care**. The event received positive feedback from the attendees and we are following up with Lord Bethell, Minster for Innovation, DHSC on the discussions.

4. The **Centre for Improving Data Collaboration, NHSX** has been launched, which will seek to provide advice to NHS bodies about third party data partnerships – we have been in close discussion with the team on embedding the recommendations from *Foundations of Fairness* into their guidance. This activity will continue into 2021.

Highlights of the year

Covid-19 response

Data has been at the forefront of the Covid-19 response, along with the importance of public trust in managing the public health crisis. As the response now shifts from crisis mode to longer-term management, it is important that UPD's core messages about what it takes to manage and use data in ways that are perceived as trustworthy reach those responsible for making decisions about data.

This year UPD been vocal in articulating the necessary ingredients for trustworthy data use in the UK context. We have developed a clearer public profile to advocate for greater transparency, accountability and public involvement in decision-making about how data is being managed and used in the pandemic and for the longer-term.

The *Foundations of Fairness* report has been instrumental in allowing us to develop and champion these insights, in a year that has otherwise been dominated by the pandemic.

Team

We have built up the UPD team and now have considerably greater capacity to:
- develop further partner and community relationships,
- undertake and commission research,
- share good practice with new audiences,
- do more proactive media work to ensure balanced reporting on data issues

It has been challenging to recruit and start new team members remotely and in the context of the pandemic, but the team is now settled in and working effectively.

Priorities and pipeline for 2021

Comms and media priorities

- Currently commissioning a media analysis of the narratives and themes of media and social media stories related to patient data use over the past 18 months (covering pre-Covid and Covid periods). This will help inform our approach to media engagement in the longer-term.

Influencing and advice priorities

- Feeding into NHSX Data Strategy and Centre for Improving Data Collaboration guidance.
- Providing advice on trustworthy governance to data initiatives and institutions being established, including internationally.

Partnerships and community priorities

- Currently commissioning research to further our engagement with, and understanding attitudes of, primary health care professionals towards use of data, in collaboration with the RCGP.
- Building on insights from the 'How To Talk About Data' project by supporting health charities to include how data has been used in research into their research-based health information.
- Supporting the development of good governance through connecting and supporting projects piloting the ‘Learning Data Governance’ concept.

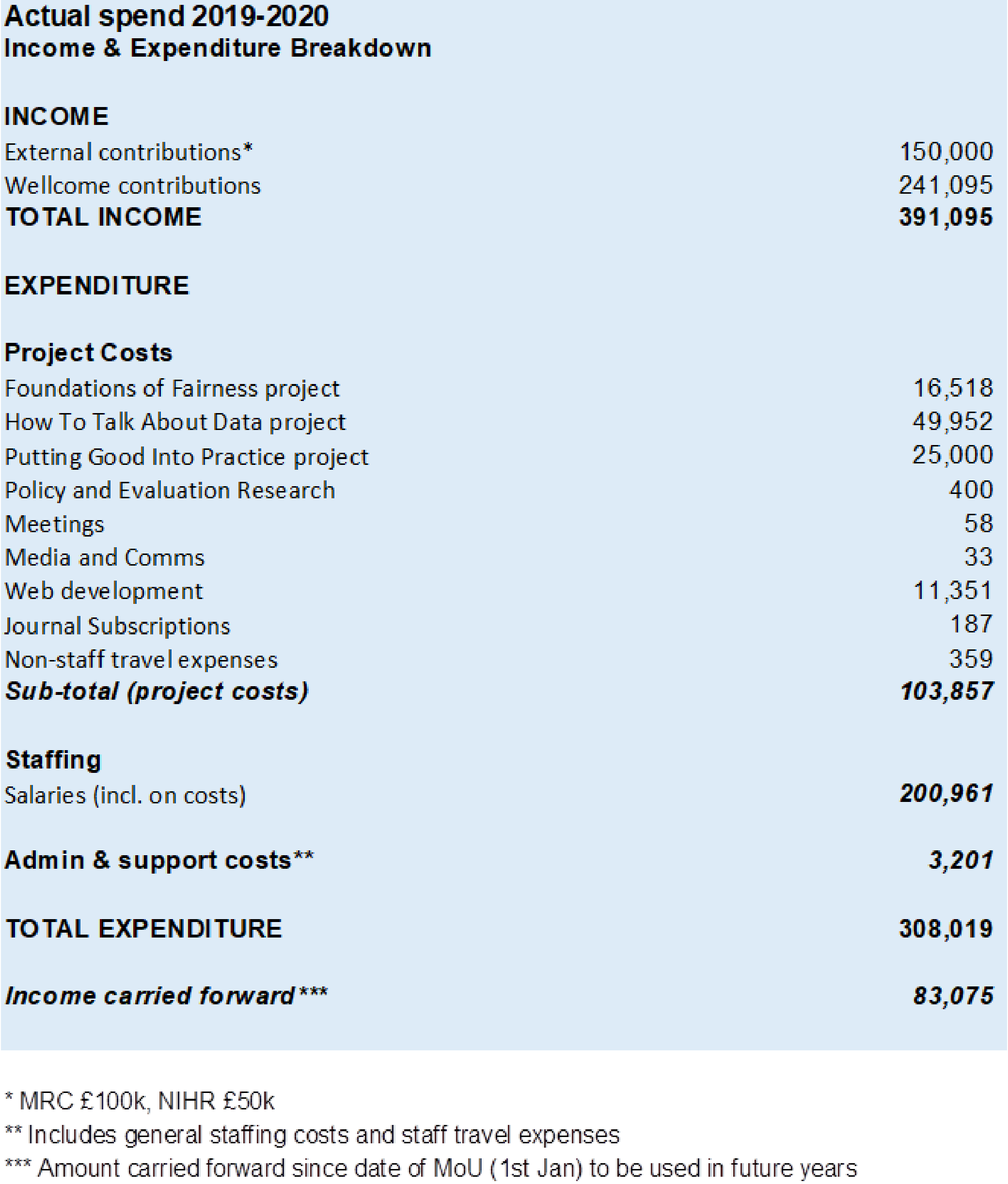
Engagement priorities

- In the wake of stark disparities in Covid-19 outcomes and paucity of data on ethnicity, we are planning a project to engage with Black and South Asian patients and health care professionals to support better conversations about data collection.
- Advocating for patients’ voices – and the public interest – to be at the heart of data use in health policy, planning and practice.
- Continuing co-commissioned public dialogue with the National Data Guardian on how to make ‘public benefit’ assessments for data projects – due for completion Spring 2021.

Budget

This outlines the complete actual spend for the period 1 October 2019 – 30 September 2020 (Wellcome operates on an academic financial year).

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



Actual spend 2019-2020
Income & Expenditure Breakdown

INCOME	
External contributions*	150,000
Wellcome contributions	241,095
TOTAL INCOME	**391,095**
EXPENDITURE	
Project Costs	
Foundations of Fairness project	16,518
How To Talk About Data project	49,952
Putting Good Into Practice project	25,000
Policy and Evaluation Research	400
Meetings	58
Media and Comms	33
Web development	11,351
Journal Subscriptions	187
Non-staff travel expenses	359
Sub-total (project costs)	***103,857***
Staffing	
Salaries (incl. on costs)	***200,961***
Admin & support costs**	***3,201***
TOTAL EXPENDITURE	**308,019**
Income carried forward***	***83,075***

* MRC £100k, NIHR £50k
** Includes general staffing costs and staff travel expenses
*** Amount carried forward since date of MoU (1st Jan) to be used in future years