Understanding
Patient Data

Annual Report
2020-21

UPD's mission

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.

UPD 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 is also core funded by MRC and NIHR.

This report covers the period 1 October 2020 – 30 September 2021.

Communications

Website & resources

- We updated a number of our resources and added a few new ones too.
- That includes video resources on trustworthy use of patient data, tips for communicating patient data and what we know about public attitudes.

Trustworthy use of patient data

Dr Natalie Banner, Understanding Patient Data Lead

Highlights from our blog

- Our perspective on the new system for GP data: initial response from the team about the GP data programme.
- The what & why of Trusted Research Environments: guest blog by Professor Cathie Sudlow, Director of the British Heart Foundation Data Science Centre.
- The future of Understanding Patient Data: post explaining the changes to UPD's funding.

> “The UK has some of the richest health data in the world. By making it available to researchers, we can improve our understanding of diseases, and seek ways to prevent, treat and cure them. TREs are a vital tool in enabling this to happen.
>
> Prof Cathie Sudlow, Director of the British Heart Foundation Data Science Centre

Quote from Cathie Sudlow's guest blog

Twitter performance

This year we achieved:

- **802** new followers
- **953,000** impressions (the number of times our tweets were seen)
- **1.4** average engagement rate (which is considered very good)

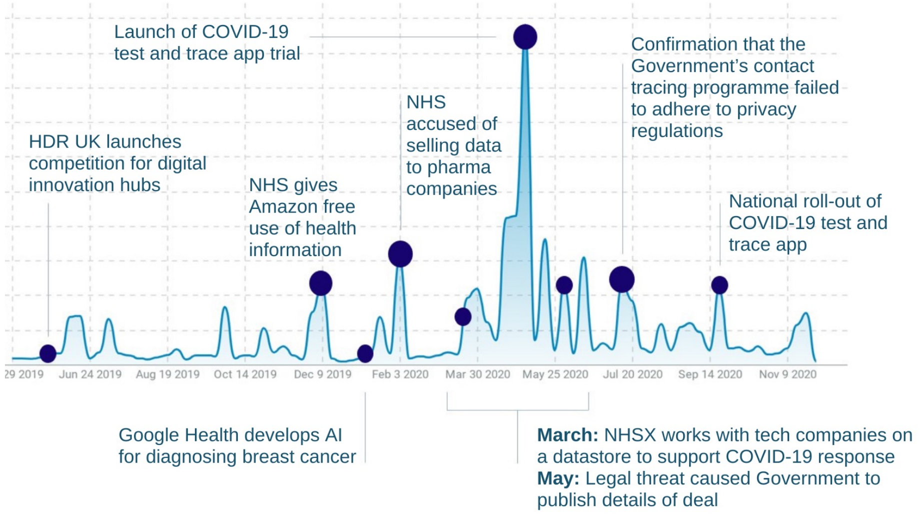
Media

Media engagement

- Over the year, the team developed our reputation as a balanced and reliable source for media.
- We've adopted a variety of approaches, from providing comments, to correcting inaccuracies off the record, to passing requests over to reliable partners in our network.
- We've engaged with a number of different publications and outlets including: the FT, The Times, the Mail on Sunday, The British Medical Journal, the Health Services Journal, Channel 4 News, BBC News.

Media analysis

- Research into how news stories about health data are reported in the UK media.
- The report looks at how different outlets cover the issues, which stories have the most cut-through with the public and how coverage changed during the pandemic.
- The team presented it to some key partners, who reported that it was useful for shaping their communications and media strategies.
- UPD have used the findings to shape our approach to media engagement and it informed our decision to take a neutral, balanced line on controversial stories.



Launch of COVID-19 test and trace app trial

Confirmation that the Government's contact tracing programme failed to adhere to privacy regulations

NHS accused of selling data to pharma companies

HDR UK launches competition for digital innovation hubs

NHS gives Amazon free use of health information

National roll-out of COVID-19 test and trace app

Google Health develops AI for diagnosing breast cancer

March: NHSX works with tech companies on a datastore to support COVID-19 response
May: Legal threat caused Government to publish details of deal

Graph showing media coverage of health data stories Apr 19 – Oct 20

Research projects

Foundations of Fairness report evaluation

We commissioned m2 to conduct an independent evaluation of the policy impact of *Foundations of Fairness*, which was challenging to assess in the context of the pandemic. Through two phases of research an interviews, m2 found that:

- The recommendations are seen by stakeholders as useful, appropriate and relevant
- The report offers a credible evidence baseline for others to use and contributes to their own advocacy efforts
- The mixed methodology used gives the report authority
- Covid-19 has offered opportunities for UPD to advance these debates, but it has also brought challenges as policy efforts were focused on handling the crisis in the short term

Key quotes from the evaluation:

> *"UPD's work is a cornerstone in a range of works that advocates for increased transparency. UPD are a driving force and a lot of other organisations look to them for guidance."*
>
> *"UPD's [report] is the gold standard on how to engage people in complex subjects."*
>
> *"UPD's report has been very impactful... in an area where there is such little consultation and such little engagement, UPD's report is gold dust."*

Parliamentary engagement

Gareth Thomas, MP, asked a PQ on the recommendations in the report. The Minister of State for Health responded positively: "*The Centre for Improving Data Collaboration is working with Understanding Patient Data to operationalise the findings from the Foundations of Fairness report, working with a range of other partners in the data-driven innovation space to best understand how these recommendations can be put into practice.*"

Influencing and advice

The data policy landscape has evolved rapidly in response to the pandemic. UPD's focus was been providing advice at national level on being responsive to public views and values about how data should be managed and used, advocating for trustworthiness in practice. 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.

Influencing activities with NHSX: Data strategy

NHSX published a draft Data Strategy for Health and Care in June 2021. The Strategy outlined a broad ambition for how the health and care system can share data effectively in light of the Covid-19 pandemic. It contained a number of proposals for progressing and advancing the uses of health data for care, planning and research, including new legislation. UPD fed back on the draft and held discussions with the Strategy team about positive actions that NHSX could commit to in the Strategy on trustworthiness and transparency in particular.

In July 2021, UPD coordinated a workshop with the Ada Lovelace Institute and the Open Data Institute to help to improve the Strategy and challenge NHSX on some of its policy objectives. We produced a write up and sent a **letter to the Secretary of State Sajid Javid** outlining our concerns in greater detail. These were broadly around:

Ada Lovelace Institute
Understanding Patient Data
open data institute

Date:
29 July 2021

To:
Rt Hon Sajid Javid MP,
Secretary of State for
Health and Social Care,
House of Commons
London
SW1A 0AA

Dear Rt. Hon Sajid Javid MP,

CC: Lord Bethell, Parliamentary Under-Secretary for Innovation; Jo Churchill, Parliamentary Under-Secretary of State for Prevention, Public Health and Primary Care; Matthew Gould, CEO, NHSX; Dr Nicola Byrne, National Data Guardian.

- Deepening the consultation process
- Providing clarity of the future of the opt-out system
- Meaningfully involve people
- Demonstrating value from NHS data partnerships

Influencing and advice

Putting Good into Practice: public dialogues on assessing public benefit

The 'Putting Good into Practice (PGiP)' project was a public dialogue on making public benefit assessments when using health and care data. UPD co-commissioned the dialogue with the National Data Guardian (NDG). The dialogues ran in Q4 2020 after which the NDG began a guidance development process, drawing directly on the findings.

UPD supported broad stakeholder engagement of the draft guidance and advised on numerous iterations. The team advocated strongly the involvement of dialogue participants and health and stakeholders who will responsible for implementing the guidance. The NDG will run a short consultation on the statutory guidance, which applies every health and care organisation in England, later in 2021.

Findings of the project's independent evaluators, 3KQ:

"The strength of the project team and effectiveness of its meetings ensured good overall oversight of the project management and delivery throughout the process."

"The projects management of the dialogue process by the contractor was strong, particularly in the context of adapting the process to new circumstances and shifting the whole process to an online format."

"The June reconvened workshop and the additional road-testing workshop held in May were crucial mechanisms for directly involving potential users of the NDG guidance in its development. Both of these workshops enabled the [...] guidance to be tested for practical use, informed by example scenarios, and both led to further refinement of the emerging guidance. "

GP Data for Planning and Research

The GPDPR programme was initially launched in June 2021, intended to replace the existing General Practice Extraction Service (GPES) with a richer, more consistent data collection from process from primary care to NHS Digital. There was significant public, media and political pushback about the programme, driven by anxieties about commercial exploitation of GP records.

Media

- As media interest about the GP data programme increased, so did media requests to UPD.
- We responded to some with direct comments. For example, see this long-read and podcast in the BMJ.
- Others we passed on to partners in our network who were better placed to give a credible response. For example, we referred journalists to HDRUK for requests about implications for research.
- We also supported the Science Media Centre's response to the story. This included a written comment and input to shape a media briefing. Natalie also presented at the SMC media briefing to journalists, explaining the issues behind GPDPR and commenting on public views and concerns about the use of health data.
- We heard direct feedback from journalists that our balanced approach was valued as the story became highly political and it was difficult to ascertain the facts.

Influence, advice

- UPD was asked to join the Comms and Engagement panel set up by NHS Digital in July 2021, following the pause of the GPDPR programme. We gave advice on connecting comms to policy decisions, improving transparency and setting the programme within the wider context of health data use.
- UPD also engaged with Foxglove, the law firm campaigning to stop the programme until better safeguards, transparency and accountability mechanisms were put in place.

Current projects

Primary Care Professionals' Attitudes to health data use

UPD’s understanding of attitudes towards the use of routinely collected data for purposes beyond care focuses on patients and the public, with a gap in knowledge around what Professionals working in Primary Care know.

Understanding Patient Data (UPD) and the Royal College of General Practitioners (RCGP) co-commissioned a project which will undertake a series of qualitative investigations to understand:

- primary care health professionals’ views on the use of health data,
- whether these views represent any barriers to appropriate and timely access to and use of high quality data,
- the impact of initiatives and interventions on these views and barriers.

Mott Macdonald is undertaking the project, with oversight from UPD and RCGP. A literature review and interviews with ‘key informants’ working across the health system and in General Practice shaped the fieldwork portion, wherein Mott Macdonald conducted virtual site visits at GP practices around the UK. Field work is ongoing, with a sense-checking meeting being arranged for December and the final report due early next year. Early findings are being shared as appropriate with NHS and other sector colleagues to inform time-sensitive work.

The final report will be shared with policy makers, NHS leaders and professional bodies so they can use the findings to inform how they approach and structure changes to how data is used and how it moves around the health system.

Current projects

Data in Health Information

The Data in Health Information project involves UPD working with a Community of Practice (CoP) of eight health charities. It builds on work from the ‘How to Talk About Data’ project and aims to support CoP members to update their health information. We want to make it clear that this information has come from data from people.

Since the first meeting with the CoP in May 2021, the project has seen regular workshops and optional “spotlight sessions” with CoP members to support them in making these changes to their health information. The aim of these spotlight sessions is to create an atmosphere where CoP members can share their ideas and progress with the UPD team and with the other health charities.

In the run-up to December 2021, it will be important to maintain communication with the CoP members as this is when they will be making the changes to their health information. We will need to ensure these changes are being made and that the new outputs are accurate.

We will also be looking ahead to the evaluation and analysis phase of the project from December 2021 to March 2022. UPD is working with an evaluator, Rocket Science, who will produce a report on DIHI’s findings and its impact on CoP members and their beneficiaries. This report will build on desk and field research (via surveys and focus groups) to evaluate the overall impact of the CoP. A final report will include recommendations and areas of good practice, and will be informed by CoP members' insights. This report is due to be published in April 2022.

Current projects

Black and South Asian public-led change: equitable data collection

The pandemic has highlighted the existing health disparities experienced by Black and South Asian people and the frequent gaps in patient health records on ethnicity, as well as clinical information and social determinants of health. Better research and planning to tackle health inequalities requires better health data. And we can't expect better data without listening to the experiences, expectations and concerns of the people who provide that data in the first place.

UPD has commissioned a multi-stage public engagement project to learn from Black and South Asian members of the public and healthcare professionals about the barriers to health data collection and cocreate resources to support improvement. Throughout the project we are taking soundings from an advisory group made up of clinicians, service providers, researchers and campaigners, to provide us with a range of expert perspectives.

ClearView Research is leading the public engagement element of the project, using a mix of peer research community interviews and focus group discussions with Black and South Asian people around the UK. These conversations will carry through from autumn 2021 to early next year. Once we have a better understanding of people's views, we will work with members of the public and health care staff to cocreate 'best practice' resources for use by staff on the ground, to support better transparency about health data and why it's used. It's important to us that we support open and honest conversations about data that give people the full picture, rather than seeking to persuade.

We will then share our findings and the resources with policy makers, NHS leaders and professional bodies so they can use them to improve health policy, practice and training. And we will carry on the conversation with communities that we have worked with on this project.

Current projects

The Story of the R number

UPD has commissioned freelancer Gavin Freeguard, formerly from the Institute for Government, to research and write the “Story of the R number”. R0 has been a hugely influential statistic during the pandemic and widely discussed, but little is publicly known about the data different models of ‘R’ are built on, and how it has been used to influence public health decision-making. With UPD’s focus on making uses of data more visible and understandable, the use and prevalence of ‘R’ in public discourse provided an opportunity to explore and explain the origins of the figure.

Through desk research and interviews with epidemiologists, statisticians, clinicians, public health officials and political advisers, Gavin is writing a piece of long-form journalism accompanied by infographics to described how ‘R’ is created, the data that goes into the different models, the assumptions made in different models, challenges faced, and how the figure has been used in practice. It will show how different types and sources of data lead to different conclusions and highlight the limitations of these.

The piece will be user-tested with public and patient audiences to ensure it is accessible, understandable and clear. It aims to be published by the end of 2021.

Current projects

The use of large data sets in health research: an easy read guide

UPD has commissioned Thinklusive to produce accessible resources about the use of large data sets in health research.

Over summer 2021, Thinklusive ran co-creation workshops with young adults with learning disabilities and/or autism, to produce draft resources. It worked in collaboration with Ace Anglia, a user-led advocacy organisation, working with people with learning disabilities. Once the drafts are complete, Thinklusive will collaborate with the Centre for Ethnic Health Research, running further co-creation sessions to adapt and translate the resources into at least one other language. The resources will then be disseminated to relevant audiences across the UK, drawing on UPD, Thinklusive and the Centre for Ethnic Health Research networks.

Our aim is to enable people with learning disabilities to access clear, comprehensive and engaging information about the use of large data sets in health research. We also anticipate that the resources will be of use more broadly, as a guide to anyone who is new to the areas of data and health research. As such, we hope that the guide will demonstrate the potential for producing informative and engaging guides to complex issues.

Current projects

Information resources on 'Why large-scale datasets?' and 'What is pseudonymised data?'

This project started through conversations with the OpenSAFELY research team about their communication and engagement plans as OpenSAFELY develops into a more established platform for use of primary care data. It became clear that generic information resources on different key concepts would be of value to many in the patent data community who work with large-scale health datasets. These resources, available in multiple formats, could be a valuable scaffold for conversations about the appropriate safeguards and governance for data use at a population scale.

In September 2021 UPD ran a cocreation roundtable to develop a tender for potential suppliers. The session was held with clinical and academic experts in pseudonymisation and large-scale datasets, communications, medical charity, policy and engagement professionals. This informed our plans to commission an organisation to develop two engaging resources for a wide public audience. We aim for the resources to empower members of the public with:

- an understanding of what large-scale datasets are, their value and risks and how the risks are handled
- an understanding of pseudonymised data
- scrutinising questions to ask in order to assess whether large-scale data sets are being managed in a responsible way

The dissemination of the resources, published under creative commons, will be taken on by the supplier and will include embedding the resources in the NHS at a regional level. The request for proposals will go live in October and the outputs will be launched in Summer 2022.

Wrapping up UPD

Wellcome is the main funder and host of UPD. In 2020 it launched a new strategy, and it was subsequently decided that UPD did not align with the aims of this new strategy. As a result, Wellcome took the decision to withdraw support for UPD from the end of 2022.

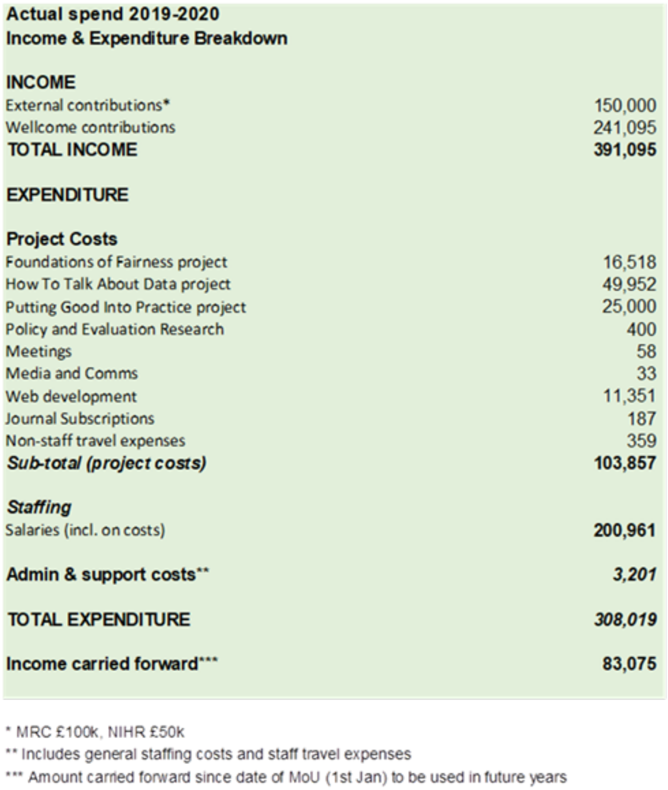
Owing to a structural reorganisation, most staff who have to date been full time in UPD have been redeployed into new roles within Wellcome from September 2021. See here for more detail.

This change means that UPD will no longer be undertaking policy and advocacy work from November 2021 onwards. The Steering Group will disband at this time as well. Live and upcoming UPD projects will continue to be managed and delivered into 2022, with staff resource dedicated to ensuring high quality outputs and dissemination. UPD as a brand and independent initiative will end after that point.

The main priority for UPD in 2022 will be to successfully deliver its ongoing work, and identify potential hosts for different types of resources. Over the past five years we have built up a diverse set of materials that we hope others in the patient data community will continue to find useful, covering:

- Public-facing information resources, such as our animations, FAQs, identifiability spectrum and data uses wheel;
- Professional resources to assist those creating public-facing information, such as our guides on language, bank of case studies and the data citation;
- Research evidence, such as our public engagement research, media analysis and other project reports;
- Policy and advocacy positions, such as our perspectives on what trustworthiness means in practice, thinking on meaningful transparency, and policy recommendations on 3rd party partnerships and GP data.

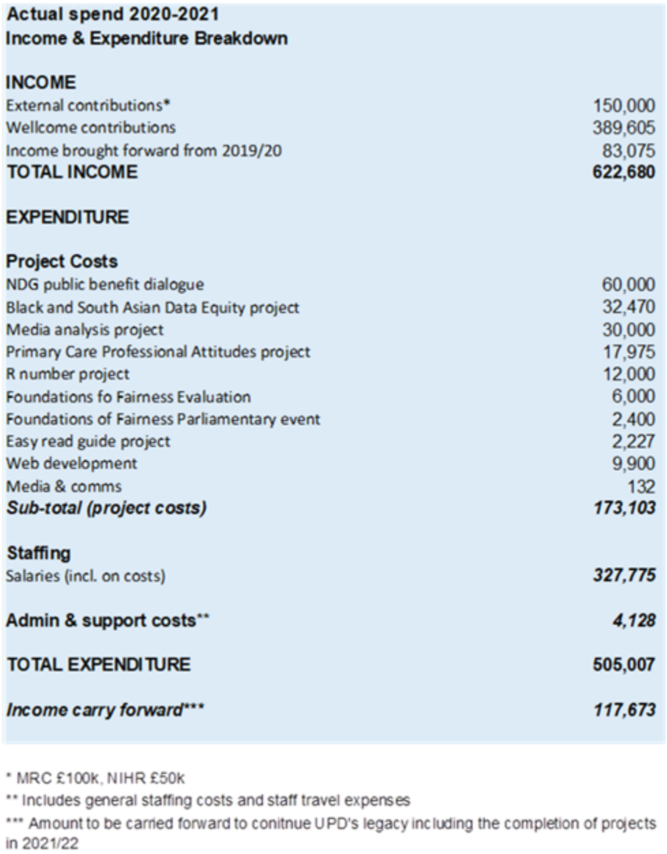
Budget



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



Actual spend 2020-2021
Income & Expenditure Breakdown

INCOME	
External contributions*	150,000
Wellcome contributions	389,605
Income brought forward from 2019/20	83,075
TOTAL INCOME	**622,680**
EXPENDITURE	
Project Costs	
NDG public benefit dialogue	60,000
Black and South Asian Data Equity project	32,470
Media analysis project	30,000
Primary Care Professional Attitudes project	17,975
R number project	12,000
Foundations fo Fairness Evaluation	6,000
Foundations of Fairness Parliamentary event	2,400
Easy read guide project	2,227
Web development	9,900
Media & comms	132
Sub-total (project costs)	***173,103***
Staffing	
Salaries (incl. on costs)	***327,775***
Admin & support costs**	***4,128***
TOTAL EXPENDITURE	**505,007**
Income carry forward**	***117,673***

* MRC £100k, NIHR £50k
** Includes general staffing costs and staff travel expenses
*** Amount to be carried forward to conitnue UPD's legacy including the completion of projects in 2021/22

This outlines the complete actual spend for the period 1 October 2020 – 30 September 2021 (Wellcome operates on an academic financial year). A further £107,000 is committed into 2021-22 for completion of current projects listed here.

UPD’s funders agreed to use underspend from 2021-21 to ensure projects are completed in 2022 and to fund activities that would secure UPD's legacy and influence.