



Understanding
Patient Data

Annual Report 2017-2018



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. This annual report provides an update on the second year's progress, and our plans for Q1 of year three.

AIMS AND OBJECTIVES

We aim 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.

WORKSTREAMS

1. RESOURCES AND TOOLS

Providing objective evidence about benefits, risks and safeguards.

2. SUPPORTING LOCAL CONVERSATIONS

Sharing best practice, and developing advocates across the sector.

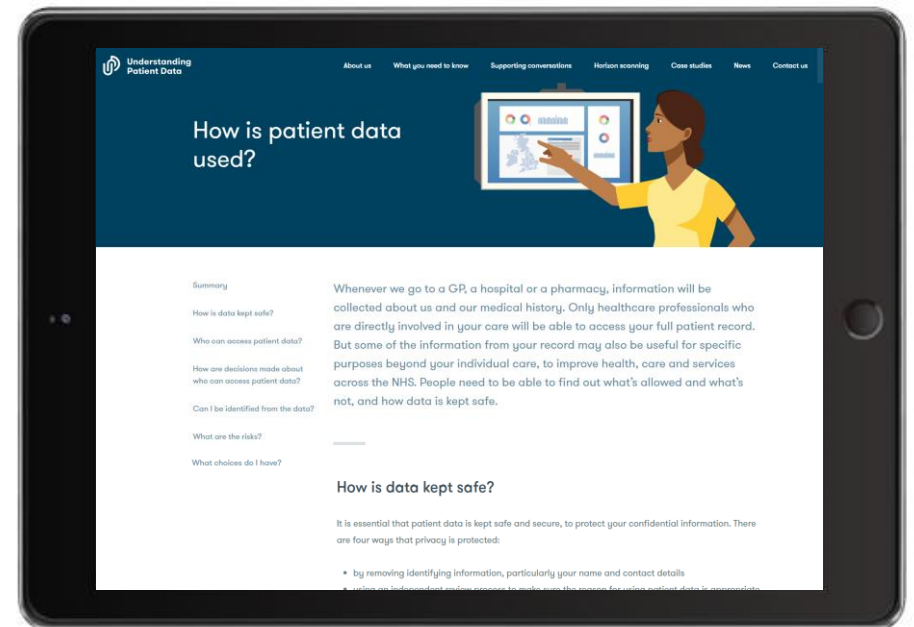
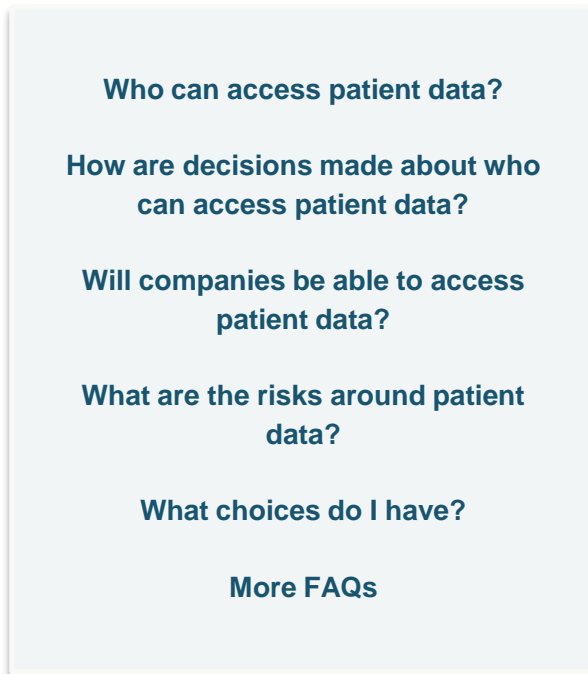
3. HORIZON-SCANNING AND ANALYSIS

Examining the implications of new and emerging digital technologies.

1. Tools and resources

In year two, we have focused on completing our set of resources to provide objective evidence about how and why data can be used for care and research, and how data is safeguarded.

We produced resources to explain:



These resources, combined with those produced in year one, collectively address the **most common questions** from patients and the public.

Data saves lives animations

Publics do not know how patient data is used in the NHS, nor in health and care research. Awareness remains very low. To help overcome concerns, it's important to set the scene, explaining why data sharing is beneficial.

What we did

We worked with **12** partner organisations and design agency Brickwall to produce an **animations series** that can be used to help raise awareness, and create reassurance, that patient data is used to benefit health and care.

Six animations brought to life why and how patient data is used, following the stories of a heart attack, a cancer diagnosis, managing diabetes, a dementia diagnosis and an asthma attack. Scripts and storyboards were reviewed and tested by members of the public, patients and clinicians.

We created a **toolkit** to help others use the animations and images which are available for re-use under a **CC-BY** licence.



Impact (Mar - May 2018)

- **Over 1.5 million views**, six times the 245,000 target.
- **Won** the UKIACR Infographic and Data visualisation competition 2018 and **won silver** in the Best Specialist category of the Content Marketing Association Awards 2018.
- Engagements on Twitter: **6,490** / Facebook: **50,896**.
- **53% increase** in UPD twitter followers, many of whom were members of the public, NHS nurses and doctors.
- Traffic to UPD website more than doubled from 350 users/wk to **750 users/wk**.
- No measurable change in number of shares, comments and content of comments between week one and two of the campaign even though the **Cambridge Analytics/Facebook scandal** hit the news in the weekend between the two.
- Non-social media dissemination was varied, ranging from embedding onto websites, internal sharing, blogs and showcasing at conferences. They are referenced on the **Royal College of Nursing**, **Royal College of GPs**, **NHS England** webpages.

1. Tools and resources

Videos

- Following feedback about the lack of real people on the website we produced **five video case studies**. They feature researchers, clinicians and patients explaining why and how patient data is used to make a difference.
- A talking head video shows **people explaining** the importance of using patient data and why we need to talk about it more.
- We developed a **seventh animation** with the Professional Records Standards Body explaining why it's important to share information for individual care, acknowledging the frustrations of poorly joined-up data between care providers at the moment.



Impact

The animations and films have a **CC-BY** licence and have been used by:

- research teams such as Astrodem and ClinTouch
- charities including Kidney Research UK and AMRC
- NHS Digital in public workshops.

NEXT STEPS

- An updated spectrum of identifiability with use-case vignettes to reflect GDPR and mitigate the risk of ‘de-personalised’ being perceived as a legal category of identifiability.
- A toolkit that brings all our resources together in one place, for ease of dissemination and use.
- Creating new resources that help people explain the use of patient data in data-driven technologies.
- Addition of social care case studies to explain how social care data can be used for care and research.

2. Supporting local conversations

In year two, we have focused on connecting people to help share best practice in public engagement and talking about health data. We published further research and analysis, and brought together people from different sectors to help set a common agenda.

Providing independent analysis

We have continued to develop background research, ideas and advice to help improve conversations about the use of data. This includes:

- An ongoing collation of research on **public attitudes** to health data use. A thematic analysis of existing literature has been downloaded over 100 times.
- Publishing a report, with Involve and Carnegie Trust, that unpacks what people mean by **public benefit**. It proposes a list of questions to help better assess public benefits of data sharing versus potential risks.

Providing advice

We are continuously asked for advice on work ranging from **communication** to **policy**, and from local projects to national level programmes. Examples include:

- Advice to NHS Digital and NHS England on the national opt-out implementation programme around the national public campaign and 'Your NHS data matters' website.
- Reviewing the updated PHE patient leaflet explaining the National Cancer Registry.
- Sitting on the review panel for Local Health and Care Records selection as well as supporting individual sites directly such as OneLondon.
- Advising and supporting Health Data Research UK public engagement strategy and activities.

Working with the media

While we have done less work with the media than expected, between Oct 2017 and Sept 2018 UPD:

- Has been quoted or referenced in **20 online and print news stories, one podcast** and **one radio programme**.
- Published a **blog series** alongside the national data opt-out launch clarifying why it is different from care.data, the potential impact and why it's an opt-out.
- Provided **quotes** or **commentary** in response to DeepMind Health, the MoU between NHS Digital and Home Office, PHE cancer registry data release to a tobacco company and TPP error for Type 2 opt-outs.
- **Co-authored an article** with Wellcome in the Guardian on why we can't leave AI for healthcare in the hands of big tech companies.



2. Supporting local conversations

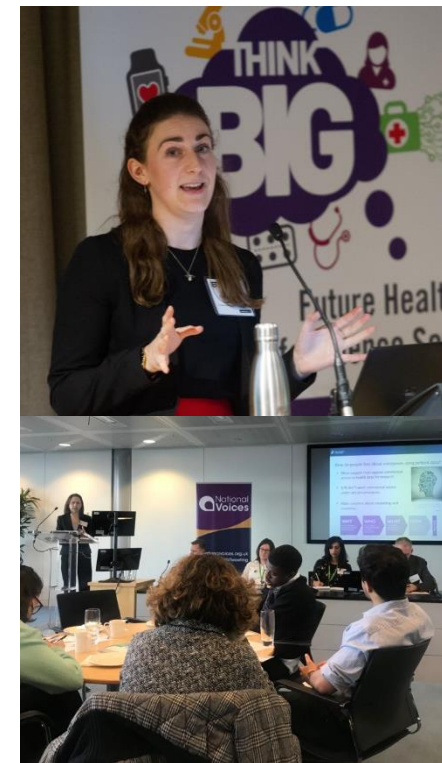
Ensuring a common voice

We've continued to facilitate **consistent messaging** across the sector. We've visited and spoken to many of our partners and other organisations, including presenting to:

- AMRC CommsUnity (Jan 2018), King's Fund staff (Jan 2018), Public Health England Office for Data Release (Apr 2018), Caldicott Guardian conference (May 2018), HQIP staff (Jun 2018), Wellcome Press Officer Conference (Jun 2018).
- Co-convended a *Health Data Summit* with National Voices (Feb 2018).

Acting as a central hub

- We have sent **5 newsletters** to over **480 people** and published **11 guest blogs** which continue to be well read.
- We've been able to **connect people** working on similar projects. For example North West London CCGs and Bristol Health Partners creating public lessons on patient data use.



Convening cross-sector discussions

We have convened or co-organised events designed to bring people together from different organisations and sectors, including patients, health professionals, academic researchers, policy makers and industry. For example:

- A meeting with **80+** participants organised in conjunction with Julian Huppert, Director of the Intellectual Forum at Jesus College Cambridge, and Hal Hodson, Technology Correspondent for The Economist - *Healthcare and data: how do we get it right?* (Sept 2018).
 - It brought together a diverse range of stakeholders to drive at practical actions for ensuring trustworthy uses of patient data, especially in the context of emerging data-driven technologies
 - The meeting was followed by a closed roundtable of **20+** senior stakeholders, designed to create a series of concrete actions and collective buy-in.

2. Supporting local conversations

Engaging patients

We have increased our direct and indirect engagement with patients by:

- Attending and supporting a number of useMYdata workshops, including presenting at their workshop on Plain Language Summaries (Sept 2018).
- Working with the HQIP service user network to review the UPD website and act as a judge for their inaugural Public and Patient Involvement award.
- Directly involving patients in the review and testing of new resources, particularly the animations.
- Expanding our partner and supporter base to increase UPD's reach.

A key focus for year 3 will be on reaching seldom heard communities and developing links with the social care sector.

Engaging healthcare professionals

This is an area we have not made significant progress and will seek to develop a clearer strategy for engaging with healthcare professionals in year 3. So far we have:

- Spoken at an Royal College of GPs event on the National Data Opt-Out, about communicating choices to patients (May 2018).
- Held early discussions with a group of medical students engaged with data issues to establish how to engage with early career clinicians on the importance and potential of data use and technology.

NEXT STEPS

- To do more direct work with journalists and the media, especially with non-specialist news.
- Explore the different ways that information about data use can be meaningfully transparent and informative, without overwhelming people, and what people expect transparency to look like.
- Commission public engagement research to better understand what else is needed to build public confidence in the use of patient data, beyond providing information.
- Provide support for the Discovery project in North East London to engage further diverse communities with patient data issues while testing our resources with seldom heard voices.

3. Horizon scanning and analysis

Data-driven technologies was a constant theme in year two. Our horizon scanning work became more focused by convening experts across the health sector to develop a shared understanding about what's needed to ensure public confidence in future uses of data.

Public attitudes and principles

- We worked closely with the Academy of Medical Sciences to develop their project on *Our Data-Driven Future in Healthcare*. Comprising a substantial **public dialogue and a policy report** it sets out principles for those involved in the development, deployment and regulation of data-driven technologies in healthcare.
- UPD continues to collate and provide **commentary** on news and reports, helping stakeholders to make sense of an increasingly busy space.

Advice on data ethics

Although ethics is beyond UPD's remit, the issues of trustworthiness and public views about data use are pertinent to our role. We have had a bearing on several developing initiatives, by:

- Responding to the **Government consultation** on the function and scope of the Centre for Data Ethics and Innovation.
- Advising the Nuffield Foundation on the role of the Ada Lovelace Institute and the report it commissioned from the Leverhulme Centre for the Future of Intelligence to help devise its workplan.
- Participating in the first TechUK Digital Ethics Summit (Dec 2017), making the case for broad engagement with publics about the developing role of data-driven technologies in healthcare and society more broadly.

Policy development

We engage in discussions to bring patient and public voices into policy and governance decision-making, by:

- Participating in the AHSN AI Network Core Advisory Group on the AI mapping report.
- Establishing **strong relationships** with DHSC and NHS England to push for patient, public and healthcare professional engagement on the developing *Code of conduct for data-driven technology in health research*.

NEXT STEPS

- Work with NHS England and others to develop data communications strategy across multiple data initiatives.
- Develop new resources for patients, publics and healthcare professionals drawing on the Academy of Medical Sciences report.
- Continue to provide advice and consultancy to major policy initiatives involving patient data use, championing trustworthiness and patient/public voices.

Communications update

We have continued to talk, and listen, to those involved in conversations about how patient data is used. We have increased our engagement by redesigning part of the website, establishing new social media channels and reaching new audiences at national conferences.

Outreach activities

We have continued to give a high number of talks and presentations, and attend roundtable discussions across the sector. For example, the keynote talk at the 2018 PHE Cancer Services, Data and Outcomes Conference, two sessions at eHealth Week 2018 and a panel discussion at CogX 2018.

We had **stands** at the IGA Conference (Nov 2017), eHealth Week (May 2018) and NHS Innovation Expo (Sept 2018).



Twitter (Oct 2017-Sept 2018)

- In Year two, the main focus of twitter activity was to share new UPD resources and patient data news.
- Tweets from the UPD account have made **1.6 million impressions**.
- 2,411 followers and 999 tweets as of Sept 2018.

YouTube (Feb 2018-Sept 2018)

- Hosting **14 videos** with >500,000 views collectively and 168 subscribers.

Facebook (Mar 2018–Sept 2018)

- Initially created to disseminate the animations, and later the case study videos.
- 409 likes and 425 followers.

Website (Oct 2017-Sept 2018)

- **Redesign** in Mar 2018 to repackage content in a more publicly accessible way.
- **40,548 sessions**.
- News section of the website was the most used path level, **double** the visitors to the 'What you need to know' section, showing others look to UPD to better understand what's going on.

Funders

The following organisations provide funding support for Understanding Patient Data. Our views and outputs are independent of Government and other funders.



Partners

These organisations (as of Sept 2018) support the work of Understanding Patient Data, sharing information and engaging with their membership to help develop the team's ideas and resources.



Understanding Patient Data: highlights from year two

- Establishing UPD as an independent, and trusted, voice. Becoming a sought after partner for advice and guidance. Supporting work which led to the successful launch of the National Data Opt-Out in May 2018.
- Building networks and partnerships: we have begun to help connect people and projects, and our network of partners grew to 34 organisations.

1. Resources to explain how and why patient data is used

- Producing a series of **animations** bringing to life stories of why data saves lives.
- Completing answers to more complicated and **contentious questions** about how and why patient data is used. Including commercial access, risks and how decisions are made.
- Refreshing the website so it remains fit for purpose, easy to understand and accessible to both **public and professional audiences**.

2. Supporting conversations

- Publishing prompt and objective **responses** to negative media headlines that helped the patient data community deal with potential backlash reactions.
- Participating in and organising **meetings** to bring diverse stakeholders together, seeking to establish collective buy-in for responsible and trustworthy uses of data, consistent language and messaging.
- Brokering **connections** between local/regional initiatives and individuals wishing to progress their conversations and resources around patient data use.

3. Horizon scanning

- Collaborating with the Academy of Medical Sciences to develop their **public dialogue and policy project** on data-driven technologies in healthcare.
- Influencing **policy and governance** stakeholders involved in implementing and regulating data-driven technologies, to ensure patient and public voices are heard and that responsible, trustworthy uses of data underpin innovation.
- **Advising** new and developing data initiatives on communications and engagement around patient data use.

Budget

The following outlines the complete actual spend for the time of the Memorandum of Understanding between the funders (Jan 2017 – Jan 2019).

| Actual spend Sept 2016 - Sept 2018 | |
|--|----------------|
| Income & Expenditure Breakdown | |
| INCOME | |
| External contributions* | 450,000 |
| Wellcome contributions** | 546,827 |
| TOTAL INCOME | 996,827 |
| EXPENDITURE | |
| Project costs | |
| Animations | 146,093 |
| Web development | 106,130 |
| Design work | 5,040 |
| Tools & resources | 151,512 |
| Horizon scanning | 13,553 |
| Meetings & conferences | 34,449 |
| Contracted staff costs outside of Wellcome's MoU scope | 68,680 |
| Sub-total (project costs) | 525,457 |
| Staffing | |
| Salaries (incl. on costs) | 277,384 |
| Admin & support costs | 6,715 |
| TOTAL EXPENDITURE | 809,556 |
| Carry forward*** | 187,271 |

| Forecast Sept 2018 - Sept 2019 | |
|---|----------------|
| Income & Expenditure Breakdown | |
| INCOME | |
| External contributions | - |
| Wellcome contributions**** | 177,491 |
| Balance carried forward | 187,271 |
| TOTAL INCOME | 364,762 |
| EXPENDITURE | |
| Project costs | 100,000 |
| Contracted staff costs (not seconded) | 20,637 |
| Staffing | |
| Salaries (incl. on costs) | 177,491 |
| TOTAL EXPENDITURE | 298,128 |
| Contingency plan fund***** | 66,635 |

**** Staffing costs (seconded only)

***** There is an estimated underspend for the Financial Year Sept 2018 - Sept 2019. This is in part because UPD's small team makes it difficult to administer the collective funding. The Steering Committee agreed this will act as a contingency plan fund to be used to wrap up current projects or be absorbed into new core funding pending future funding decisions.

* MRC £200K, Department of Health and Social Care £150K, ESRC £50K, Public Health England £50K

** Staffing costs (seconded), Admin & Support, plus 50% project costs

*** Amount that should have been carried over for projects in Year 3