Understanding Patient Data

Annual Report
2016-2017

Understanding Patient Data was set up in 2016, as a two-year initiative, 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 first year's progress, and our plans for year two.

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.

Understanding Patient Data: highlights from year one

- Establishing UPD as a new initiative, and developing our strategy in consultation with patients, charities, researchers and healthcare professionals. Launching the UPD website in **April 2017**.

- Building support and awareness: we have given more than 50 presentations, and UPD has five funders and 27 supporter organisations.

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

- Producing a bank of **70 case studies** setting out why it is important to use data.

- Creating a **tool kit** to provide objective evidence about how and why patient data is used. The first resources provide information about how data is used, how data is kept safe, the identifiability of data, and FAQs.

- Undertaking public attitudes work to determine the best **vocabulary** when talking about data, leading to new concepts and images to explain the **spectrum of identifiability**.

2. Supporting conversations

- Working with charities to **champion** the responsible use of data: workshop with AMRC members, and writing an **open letter** from 12 charities welcoming the Government response to the Caldicott review.

- Providing **advice** to NHS Digital, NHS England and the national opt-out implementation programme, as well as advising Public Health England, the MRC Regulatory Support Unit, and CPRD about communications.

- Bringing together existing **public attitudes** work into one place, and supporting a series of workshops to explore what people mean by 'public benefit'.

- Raising **awareness**: promoting a 'data citation' to ensure that everyone who uses patient data, acknowledges it in a consistent way.

3. Horizon scanning

- Mapping the ways **new digital technology** could be used in health and research. Bringing together industry, policy makers, clinicians and ethicists to explore the opportunities, challenges and implications of new and innovative uses of data. Scoping work has prepared the way for further public attitudes work.

1. Tools and resources

The initial focus of our work has been to develop resources to provide objective evidence about how and why data can be used for care and research, and how data is safeguarded. The aim is to help people make informed decisions when they have choices about how data might be used, by addressing patients' key questions.

We have produced resources to explain:

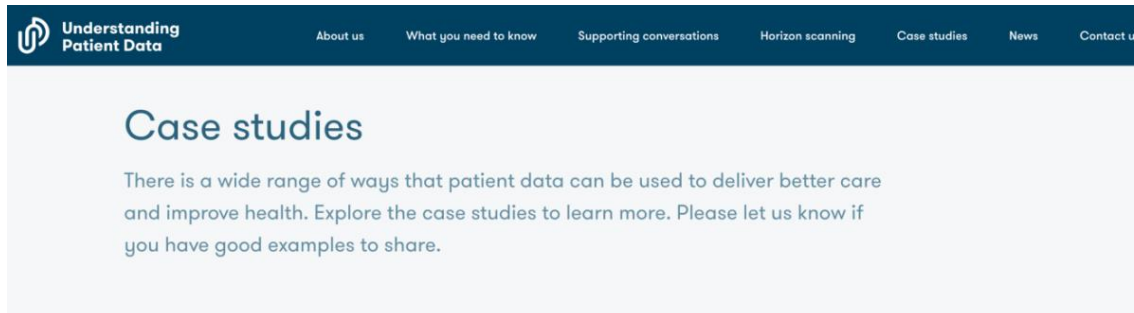|	
Why is it important to use data?	**How is data kept safe?**
Can I be identified?	**FAQS**
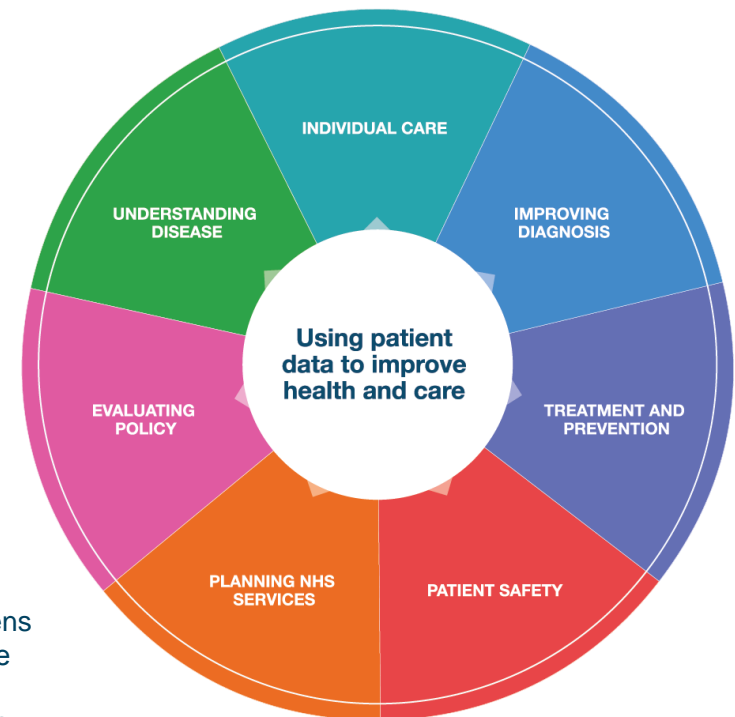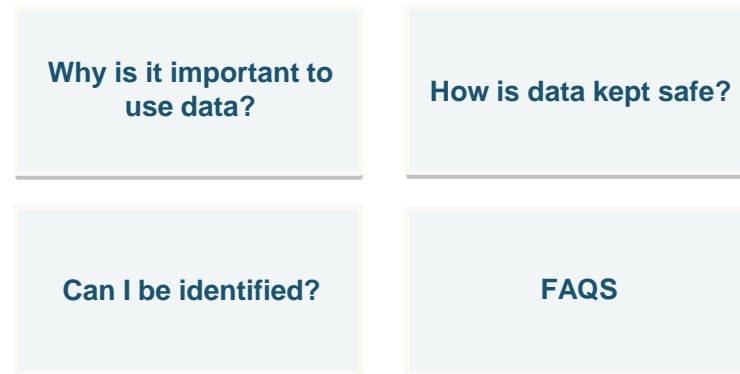
What happens to your data?

We're developing a series of **animations** that show what happens to patient data and who sees it. We're working with the NHS, the Professional Records Standards Body, charities and research institutions to map different patient journeys, and show how data flows for individual care, improving NHS services and research. The series will be available by the end of 2017.

Using patient data to improve health and care

- INDIVIDUAL CARE
- IMPROVING DIAGNOSIS
- TREATMENT AND PREVENTION
- PATIENT SAFETY
- PLANNING NHS SERVICES
- EVALUATING POLICY
- UNDERSTANDING DISEASE

1. Tools and resources

Case studies

- We have produced **70 case studies**, setting out why it is important to use data, across a range of different types of uses and disease conditions.
- The searchable library is the most visited part of our website.

Impact

The case studies have been used in:

- The Government response to the Calidcott review and the Life Sciences Industrial Strategy
- Bristol Health Partners work to create an inventory of local health and social care information
- testing for the national opt-out programme.

NEXT STEPS

We are working on the following new resources to be available by January 2018:
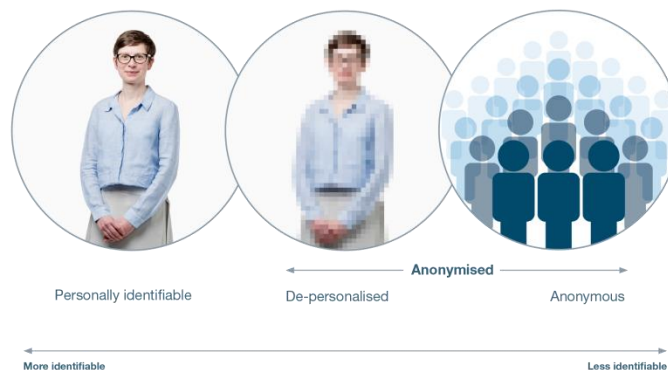– Balancing the risks.
– Why do companies need access to patient data.
– What's allowed and not allowed, and the choices you have.

What are the best words to use when talking about data?

The vocabulary for the use of patient data in care and research is complex and confusing, which acts as a significant barrier to building confidence. An important part of improving conversations about patient data is getting the words right, in a way that is accurate but also accessible and meaningful.

What we did

We commissioned Good Business to consider the **best words** to use when talking about the use of data for care, treatment and research. They held a creative workshop with a range of language experts, and then tested words and imagery with the public, patients and healthcare professionals, using quickfire focus groups. As a result we have developed a new **spectrum of identifiability**, using **pictures** to explain clearly what it means when information is 'anonymised' and what the likelihood of re-identification is when using different types of data. We have produced an **explainer**, and images are available to re-use under a CC-BY licence.

Personally identifiable   De-personalised   Anonymous

Anonymised

More identifiable   Less identifiable

Impact

– The concepts and imagery were launched in April and have been very well received.

– The briefing on identifiability has been downloaded 300 times, and the images more than 100 times.

– The words have been adopted in the Government Life Sciences Industrial Strategy, NHS Target Architecture, PHE data release register, Royal Society / British Academy report on Data Governance, and by DeepMind and Connected Health Cities.

– The ICO, Caldicott Guardians, Information Governance Forum and Information Governance Alliance are all supportive.

– We have presented the work to NHS England and NHS Digital Paperless 2020 Strategic leadership team, and the NHS Digital Board. NHS Digital have agreed to adopt words, and we are discussing next steps with the national opt-out implementation programme.

NEXT STEPS

– Once there is clarity on the implementation of GDPR, we will develop an animation to explain more about the spectrum of identifiablity and where controls are needed. Other animations could explain concepts such as jigsaw linkage.
– Further promotion of images as a reusable resource.

2. Supporting local conversations

Our second strand of work aims to share best practice to help support better conversations about health data. We are providing new research and analysis, and bringing together existing activities to develop advocates who can champion responsible use of data.

Providing independent analysis

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

- Bringing together existing **public attitudes** work in one place.
- Exploring the best words to use when talking about data.
- Unpacking what people mean by **public benefit**.
- **Providing advice** to NHS Digital, NHS England and the national opt-out implementation programme, the MRC Regulatory support unit, NCRAS and CPRD about comms activities.

What do people mean by public benefit?

People are much more likely to support data use if there is potential for public benefit. We have partnered with Involve and the Carnegie Trust to hold six workshops in Essex, Leeds, Manchester, Melton, Sheffield and West Midlands to explore how people balance public benefit and individual privacy. We will publish the findings in autumn 2017.

NEXT STEPS

– Host a workshop discussion to explore the most effective ways to improve transparency.

2. Supporting local conversations

Ensuring a common voice

- We've been working to strengthen the voice of individual activities and to ensure consistent messages are used across the sector.
- We're helping to amplify existing activities rather than duplicating effort, for example #datasaveslives and a new '**data citation**' developed by patients at use MY data.

Using patient data is vital to improve health and care for everyone

Patient data should be kept safe and secure, to protect everyone's privacy

Everyone should be able to find out about how patient data is used

Acting as a central hub

- Providing a quarterly **newsletter** to 400 people.
- Sharing examples of best practice and tips from **public engagement** initiatives through the UPD website.
- Convening **cross-sector discussion**, for example through our launch meeting.
- Using **guest blogs** to share information across the sector. A blog by the Royal Society on data governance has been one of our most popular blogs.

Understanding Patient Data

This work uses data provided by patients and collected by the NHS as part of their care and support.

#datasaveslives

Launch meeting: 6 April 2017

Over 100 people from medical charities, patient groups, NHS, researchers, industry and think tanks attended the UPD launch meeting. We unveiled our website, reported the findings of the vocabulary work, and provided an update on UPD's plans. There was widespread support for us to convene cross-sector discussions to share ideas.

2. Supporting local conversations

Engaging patients

There was clear consensus from our launch meeting that we should focus on **supporting discussions** at a grassroots level, by providing **resources** and practical **advice**. As an initial start we have:

- Held a workshop with AMRC member charities.
- Presented sessions at meetings of: useMYdata, Cancer52, Bristol Health partners PPIE, Connected Health Cities and Academic Health Science Networks.
- Worked closely with the CRUK/BHF patient panel to develop accessible resources.

NEXT STEPS

– Host a workshop with National voices and patient groups (Q4 2017).
– Work with Discovery in East London to pilot approaches to reach excluded communities.

Engaging healthcare professionals

Building advocates among clinicians and healthcare professionals (HCPs) is an essential way to develop trust in the importance of responsible uses of data. To this end we have:

- Had conversations with the Royal College of Physicians, the Royal College of Nursing, the Royal College of Psychiatrists and BMA.
- Presented our work to the Royal College academic leads working group and the Professional Records Standards Body board.

NEXT STEPS

– Providing information and developing advocates among HCPs will be a key focus of our activities throughout the next year.

2. Supporting local conversations

Championing the responsible use of data

We organised an **open letter** from 12 charities welcoming the Government response to the Caldicott review, and calling for better use of patient data to improve health and care.

Working with the media

We have been working with journalists to ensure an even-handed portrayal of stories relating to health data, including:

- Science Media Centre **briefing** for journalists.
- **Interviews** with the Times, HSJ, Bloomberg, HIMSS and Wired.
- Provided **quotes** in response to articles about the Caldicott Review, and DeepMind Health, emphasising the need to get this right for the benefit of patients.
- **Co-authored article** with Nicola Blackwood in the HSJ.

3. Horizon scanning and analysis

New and innovative uses of data will provide exciting opportunities for health care and research, but also challenges. The horizon scanning stream is focused on convening experts across the health sector to develop a shared understanding about what's needed to ensure public confidence in future uses of data.

New and emerging technologies

• Our ESRC PhD intern **mapped** the ways new digital tech could be used in health and research, including wearables, AI, machine learning, image recognition, data mining and blockchain.

Diagnosis in Primary Care

Treatment

Service Planning & Delivery

Understanding Disease

Specialist Diagnosis

Everyday Monitoring

Fitness & 'Wellness'

Infection Surveillance

Workshop: future technologies and the use of patient data

• In June 2017, we held a meeting with 60+ participants including industry (international and start ups/SMES); policy makers; clinical academics; NHS managers; and ethicists. The meeting explored the opportunities, challenges and implications of introducing new technologies. A number of clear practical actions emerged, including focusing on defining what '**partnerships**' should look like for data use between NHS, academia and industry.

Public Attitudes

• We are working with the Academy of Medical Sciences who are commissioning **dialogue** work with clinicians, patients and the public. This will explore views about new digital technologies and how they may be used in healthcare and research.
• We hope to publish the findings early in 2018.

NEXT STEPS

– Host a two-part meeting (public forum and smaller closed session) to discuss how best to take digital innovations forward in the NHS, considering regulatory issues and new approaches to collaboration (Jan 2018).

– Explore new approaches to protecting privacy, for example uses of synthetic data and blockchain technologies, and consider how to explain them in an accessible way.

– Examine the opportunities of linking patient data with other types of data to provide greater insight into health and disease.

Communications update

We have been talking, and listening, to those involved in conversations about how patient data is used. We engage through our website, social media and taking part in conferences and meetings.

Outreach activities

We have given more than **30 presentations** about the work of UPD, including the introductory plenary at the King's Fund Digital Health and Care Congress; taken part in **15 roundtable discussions** about the importance of better uses of data, and had many individual meetings across the sector to provide advice and support our work.

We are a member of the following advisory groups

- OSCHR health informatics sub-group
- NHS Digital Research Advisory Group
- National opt-out model programme advisory board
- Connected Health Cities Advisory Board
- Mainstreaming Genomics Consent Model – NHS England working group
- European Reference Network rare disease consortium – patient communications steering group
- Joint Health Research Authority/Human Tissue Authority public dialogue project on sharing patient data with tissue for research.

Twitter (as of Sept 2017)

- Tweets from the UPD account have made **200K impressions** in total.
- 523 followers, 305 tweets
- The main focus of twitter activity has initially been to direct followers to case studies and new resources, and recently to promote the 'data citation'.
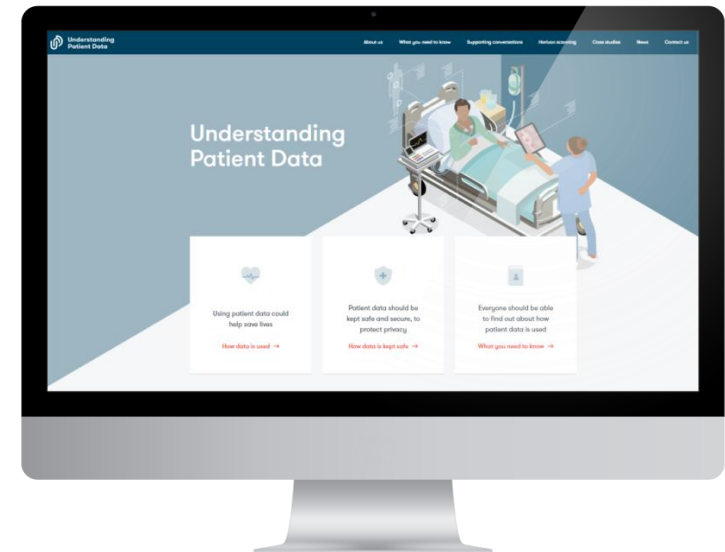
Website

- Aimed at professionals having conversations with the public about data (rather than the public themselves).
- **13,100 sessions** in five months since launch.
- There is now a roughly 50:50 split in returning versus new visitors, showing viewers are kept engaged.
- There were **1,610 unique sessions** during the week of the Government response to the Caldicott review.

Funders

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

Supporters

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