

Evaluating Understanding Patient Data

Sept 2016 – Nov 2018

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1. Background

Understanding Patient Data (UPD) supports better conversations about the uses of health information. Our aim is to explain how and why data can be used for care and research, what's allowed and what's not, and how personal information is kept safe. We work with patients, charities and healthcare professionals to champion responsible uses of data.

UPD is an independent initiative set up to run for two years and led by a small core team, based at Wellcome. UPD is funded by Wellcome, MRC, ESRC, PHE and DHSC. Our views and outputs are independent of Government and the other funders. Our aims and objectives can be read [here](#).

UPD is a stand-alone initiative but sits within a broad landscape of different sectors and organisations all actively working on issues surrounding patient data. UPD is a relatively unique approach to funding which sees the team hosted at Wellcome yet able to operate independently from the governance of its funders.

2. Introduction

This evaluation aims to demonstrate how and where UPD has been strategically effective in the context of the wider patient data landscape. Following the Steering Committee's guidance, it is not intended to answer whether each objective has been achieved.

The aim of this evaluation is to:

1. check whether UPD achieved what it set out to do
2. identify key lessons from how and where UPD has been strategically effective
3. inform decisions about the future aim, role and scope of UPD.

The evaluation findings will be used:

- to report back to the funders.
- by the UPD team to develop recommendations for the future aim, role and scope of UPD.
- by the Wellcome data priority area development team to inform decisions on how UPD could fit within, or alongside, the priority.

3. Methodology

As agreed by UPD's steering committee, this evaluation is relatively light touch, mostly qualitative and completed by internal staff. There was also a time constraint. Therefore, limitations include:

- no baseline data for public attitudes. The steering committee agreed it was not feasible to capture this data during the set-up of UPD.
- using a series of interviews and narrated examples to better understand how and where UPD has been strategically effective.
- the examples explored provide only a snapshot of the activities undertaken and the impacts they may have had.
- many of UPD's contributions to the patient data sharing landscape have happened in partnership with others.

With the above in mind, the findings should be taken as indicative rather than definitive proof. However, the evaluation does provide a sense of the many ways in which UPD has had a demonstrable impact over the last two years.

Six questions (Box 1) were developed to help answer the evaluation aims. These questions were explored using a series of examples and short interviews selected on the following basis:

Box 1. Six questions guiding the evaluation.

1. Did UPD achieve its **expected outcomes**?
2. Are UPD's **resources** fit for purpose?
3. In the context of a rapidly developing landscape, how well does UPD act as a **broker**?
4. How and where is UPD **strategically effective**?
5. What **factors** are important for UPD's success?
6. What would have happened if **UPD didn't exist**?

1. A manual tracking exercise captured a set of 100 examples of where UPD resources, activities and policy advice had been used. The examples broadly reflected the original aims and objectives set for UPD. This tracker was not meant to be exhaustive but helps indicate UPD's reach.
2. This long list was reviewed and categorised.
3. Individual examples were selected to explore further depending on how much information was already available. Those with only limited information were discarded. Examples were selected to represent different UPD resources and different audiences.
4. Interviewees were selected to collectively represent a wide range of UPD partners and stakeholders, including researchers, charities and government. Annex 1 lists the 11 interviewees and three additional sources of feedback. For simplicity, all 14 sources are collectively referred to as key informant interviews (KIIs) in this evaluation. All interviewees were from external partners and organisations. 86% of the feedback came from wider beneficiaries of UPD.
5. Whether providing feedback via interview or email, the same semi-structured questions were used to explore: how interviewees use UPD's resources and what impact they had; where and how UPD had the most influence; what would have happened if UPD didn't exist; and what the interviewees thought UPD could do next.
6. The findings of the KIIs were analysed qualitatively to draw out the key themes and address the evaluation questions (Box 1). These themes are visualised in Fig 6 at the end of this report.

Wherever possible we tried to source other independent sources of information which demonstrated the impact of the activity, though this was not always possible.

4. Context: the patient data landscape

In 2016, Dame Fiona Caldicott's Review called for a fuller conversation with the public about how data is used within the NHS. With the legacy of *care.data* there was considerable anxiety over how to talk about and engage people with how patient data could be used for purposes beyond care. UPD was set up to *"help develop a framework for open and accessible discussions with the public, patients and healthcare professionals on the use of data to improve outcomes in care, public health and research"* (quote from the Memorandum of Understanding for UPD).

This evaluation can only talk about what UPD has achieved in the **context of the patient data landscape**, as UPD's responsiveness to this is a large part of *why* it has been strategically effective. By 'landscape' we mean the policy, media, technical, cultural and social environment in which discussions about patient data are situated.

The landscape is **complex** in several ways:

- Patient data is **technically complex**. There are 57,000 health and care organisations in the NHS all of which collect, store and use patient data on some level. There is no consistent way in which this is done across the NHS with many processes varying within the same organisation.
- There is an **increasing number of players** interested, and getting involved, in patient data. It's challenging to keep tabs on who is doing what unless you're already in the know. This lack of transparency, particularly around industry involvement, fuels public mistrust.
- The landscape is **disconnected**. Interviewees used phrases such as **fractious**, **muddled** and **not joined up**. It's disconnected because, while people do want to work together, organisations didn't always have the capacity and head space to make the connections and get a holistic sense of what's happening.
- Communication and engagement about patient data is **underfunded**. With no clear leader or dedicated resource committed to supporting these activities, many feel **concerned** about trying to engage with patients and the public. Organisations were **nervous** following *care.data*. Interviewees described a sense of **fear** and **hesitancy** around talking about patient data.

5. UPD resources

There was a lack of consistent, clear and publicly accessible ways of informing people about the use of patient data.^{1,2} There was a particular gap in talking about the benefits of using patient data in research. A large proportion of UPD's workplan was to address this urgent, unmet need.

"Data sharing can be complicated and there is a lack of high quality, clear materials to support discussions with the public. UPD have helped fill this gap with visually appealing, easy to understand and well researched material." AMRC

UPD developed resources to provide objective evidence about the uses of health and care data. Intended for a wide range of audiences across research, healthcare professionals, charities and government, they are freely available to everyone through a **CC-BY licence**. The resources:

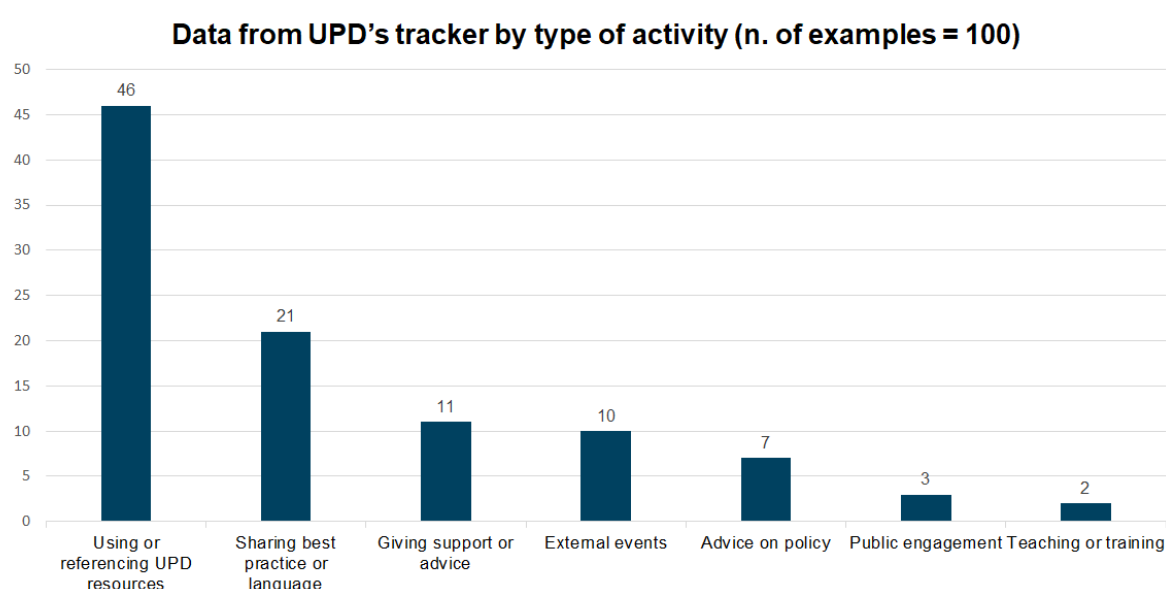
- can be used directly with patients and members of the public
- have proven to be easy to use and reusable
- have been used in unexpected ways showing broader relevance and adaptability.

¹ See page 16 of The Richmond Group of Charities' [My data, my care report \(2017\)](#)

² See also pages 42-43 of The National Data Guardian's [Review of Data Security, Consent and Opt-Outs \(2016\)](#)

UPD is a new brand, so it's impressive uptake was so quick and far-reaching. After its launch in April 2017, the UPD website was quickly referenced in places such as the #DataSavesLives [leaflet](#) produced by Connected Health Cities (May 2017), [information](#) shared by Bristol Health Partners about how data can improve health (June 2017), and [blog posts](#) by the Centre of Excellence for Information Sharing (Sept 2017). Interviewees described the resources as **engaging, visual** and **clearly explained**. The website has been referred to as a **national central hub** and has on average 5,800 unique page views per month.

"UPD has helped AMRC provide our members with the necessary tools to discuss the benefits and risks of data sharing with their communities. UPD has given the sector more confidence to discuss data including answering some of the more difficult FAQs." AMRC



(Graph 1). Breakdown of UPD tracker into type of activity.

67% of the activities captured in the tracker are about how the resources have been used. 21 of these describe how best practice around language, including the identifiability spectrum, has been implemented (Graph 1). This far outweighs the other types of support UPD provides, showing **high demand** for these materials.

Using knowledge to influence practice

UPD resources are aimed at professionals having conversations with patients and the public; for example, researchers, clinicians and charities. Their value comes from being **clear, consistent** and **engaging**. Those who use the resources have saved time and their own resources (including money) by being able to use UPD tools **directly in with patients and members of the public**.

"Using the case studies in conversations with patients is brilliant at dispelling myths very quickly. Having all the information on the UPD website saves me from having to be the expert." Kwesi Afful, NWL Collaboration of CCGs

UPD promoted three key messages to be used when talking about patient data (Box 2). This changed the **practice** of how professionals and national bodies communicate the uses of patient data: talking about the benefits became a common standard. Before UPD, benefits were rarely talked about and where they were it was usually unclear and inconsistent.

Box 2. Three key messages for talking about patient data.

1. Using patient data could help save lives
2. Patient data should be kept safe and secure, to protect privacy
3. Everyone should be able to find out how patient data is used.

“UPD led a consistent voice with others. It helped bring together major charities and major research organisations. Helped them to pursue a more common agenda and have a consistent message.” John Marsh, Patient representative

At a local level, UPD resources are being used by individuals and teams leading engagement work. They can learn from best practice and benefit from not having to start from scratch. Many rely on UPD resources as a credible, central hub.

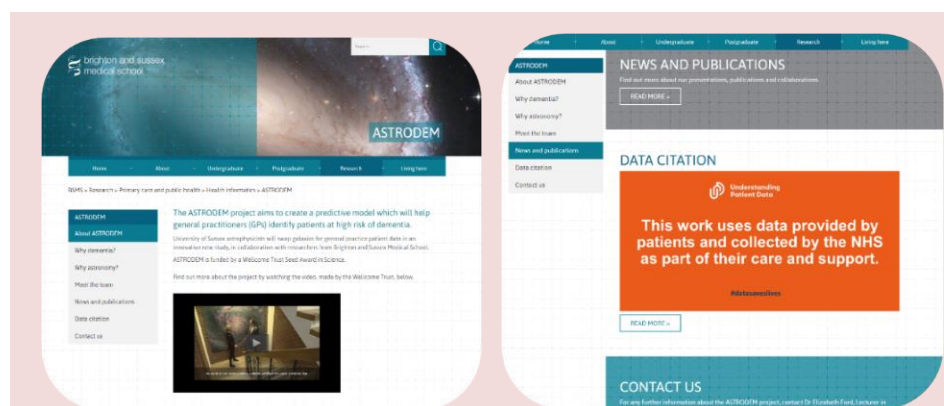
“UPD helps standardise information for patients, without too much jargon or acronyms.” Kwesi Afful, NWL Collaboration of CCGs

“We had greater impact with patients using UPD resources. Because the right language was used, rather than alienating them with technical words, it helped us secure patient support early in the planning stages.” Oliver Watson, Bristol Health Partners

Reaching professional audiences

UPD resources are used by **researchers who use health and care data**. For example, the Astrodem project is a collaboration between University of Sussex, and Brighton and Sussex Medical School. The project website includes a UPD video, the data citation and a link to the UPD website (Fig 1).

Research institutions use UPD resources. The Farr Institute proactively **recommended all UPD resources to their researchers**. Farr collated information into a toolkit which was circulated in its December 2017 newsletter (Fig 2). Resources are used by **health and care professionals**. For example, the Royal College of Nursing (RCN) produced a pocket guide on



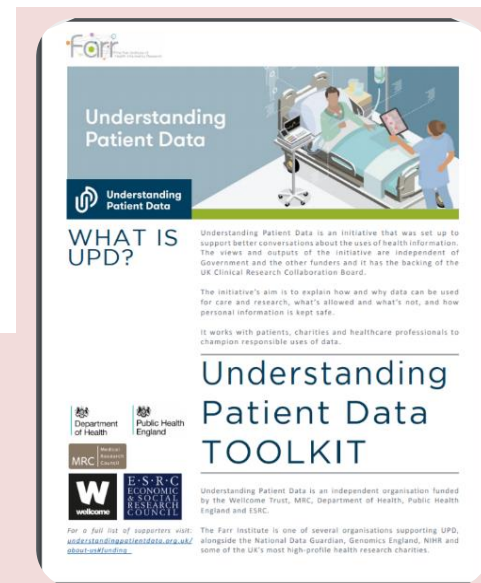
(Fig 1). Astrodem project website featuring UPD resources.

the national data opt-out for nurses, midwives and care staff. The guide references UPD twice under 'What are the benefits of sharing data' and 'Who might use health and care data' (Fig 3).

Similarly, the Royal College of General Practitioners (RCGP) uses UPD resources in its [Patient Data Choices Toolkit](#) for primary care teams. UPD is referenced under 'Use of Data' in the section on 'Trust' with direct links to the animations and 'How data is kept safe' briefing.



(Fig 3). The RCN pocket guide for talking about the national data opt-out.



(Fig 2). Front page of the UPD toolkit created by Farr and circulated to its researchers.

This reach within health and care professionals is significant. The RCN and RCGPs were **not directly involved** in the development of UPD resources and are well known for being selective in the work they promote. What's more, health and care staff are more likely to have negative views on the uses of patient data. Having national membership bodies such as the RCN and RCGP referencing UPD work with minimal engagement is evidence of not only confidence in the quality of UPD work, but also that UPD achieves the **right neutral tone**. These examples also demonstrate resources are **sufficiently standalone** to be used without a guide or bespoke advice.

Reaching government departments and national programmes

Government uses and references UPD resources. For example, the DHSC response to the Caldicott review *Your Data: Better Security, Better Choice, Better Care* (July 2017) references UPD nine times including in the executive summary. It talks about the language work and includes four UPD case studies. In addition, The *Life Sciences Industrial Strategy* (August 2017) footnotes UPD in relation to better public conversations and uses three case studies. The report itself uses UPD recommended language.

UPD resources are used in **national NHS programmes**. For example, the **National Data Opt-out Programme** (NDOP) heavily uses UPD resources both internally within NHS England and NHS Digital, and as part of the national public campaign. For example:

- Language work is embedded into all communications wherever possible.
- Case studies used in guidance for professionals and internal staff presentations.
- Content on challenging issues such as commercial access and keeping data secure directly used on the '[Your NHS data matters' website](#), fact sheets and guidance for professionals.
- NHS Digital's suggested text for transparency statements directly recommends the UPD website.

Resources are also being fed into other NHS programmes such as the Local Health and Care Record Exemplars (LHCRE) and Digital Innovation Hubs (DIH).

Detailed insights into how UPD resources have influenced government thinking are limited and there is no way to measure how the NDOP would have been publicly received without UPD's input. However, the use of UPD language and case studies at both national and local levels demonstrates how UPD resources can support government thinking and help match local practice with national policy.

Partnering with, and leading, charities

Many **charities** and **patient groups** use UPD resources. For example, the animation series overachieved its goals (Box 3) because of significant engagement and support from charities and patient groups. At least **22 AMRC member charities** shared the animations via Twitter between 12-23 March 2018, and some continue to do so. This is **17 additional charities** beyond those involved in the working group. Similarly, Health Watch England and the Patient Information Forum also shared the animations (internally and externally) even though they had little involvement in production. The animations are an example of how UPD **material is spread and reused with little or no intervention**. They were picked up by many new audiences most of which were clinical-facing such as CCGs, hospitals and digital health programmes based in the NHS. New engagement came from different England geographies and organisations continue to use the animations eight months post launch. These animations are an example of where UPD demonstrates **credibility** and **clear leadership** to marshal charity views and activities.

Box 3. Results of the data saves lives animation series (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**.
- Average cost per engagement on Facebook and YouTube of **£0.01**, Twitter **£0.39**.
- On average, **49%** of Facebook viewers watched past 10 seconds, and nearly **10%** watched over half-way.
- 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.

UPD **amplifies and shares existing best practice**. For example, patient group useMYdata developed a citation to acknowledge the use of patient data. While the citation had been implemented in cancer data publications and Public Health England's Office for Data Release, UPD endorsing it has further encouraged its use on all work underpinned by patient data. UPD coordinated a launch of the citation on social media and facilitated wider circulation. As a result, it has been adopted by the following funders and organisations:

- MRC Regulatory Support Centre
- [NIHR](#)
- CPRD
- [Genomics England](#)
- MRC.

These new policies have begun to have an effect. This [paper](#) from the British Journal of Cancer was profiled in the media and uses the citation. In addition, the citation has been showcased at several **conferences** including the 2018 Wellcome Trust press officer conference, 2018 ABPI annual conference and 2018 PHE Cancer Services, Data and Outcomes Conference (Fig 4).

Value to the wider data community

UPD resources reach **unexpected audiences** and are used in unexpected ways. For example, they are referenced numerous times in the Office for Statistics Regulation's report *Joining up data for better statistics* (September 2018). Recommended language, the identifiability spectrum, case studies and videos are discussed in the context of the wider statistics system. The report suggests learning from UPD's experiences (Fig 5). This shows the relevance of UPD to the **wider data landscape** and the ease with which its expertise can be built on by **other sectors**.

Conclusion

UPD resources are fit for purpose. The large breadth of users includes researchers, charities, clinicians, patient groups, government, local and national NHS organisations. Resources are usable by individuals as well as teams and whole organisations. The resources developed are those that were most needed, particularly in the context of a complex, changing landscape. Reach is considerable: many users weren't directly involved in production, showing confidence in the quality and messaging. Several resources, such as the animations, are beginning to demonstrate sustainability because they are easy to find, use and adapt for other purposes. Overall, the resources **build confidence** for those explaining and engaging directly with patients and the public about the uses of patient data. Where there was previous hesitancy and caution, now many more players are actively talking about patient data.

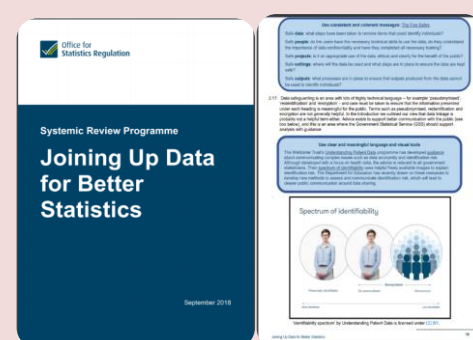
6. UPD as a broker and partner

Establishing an active network

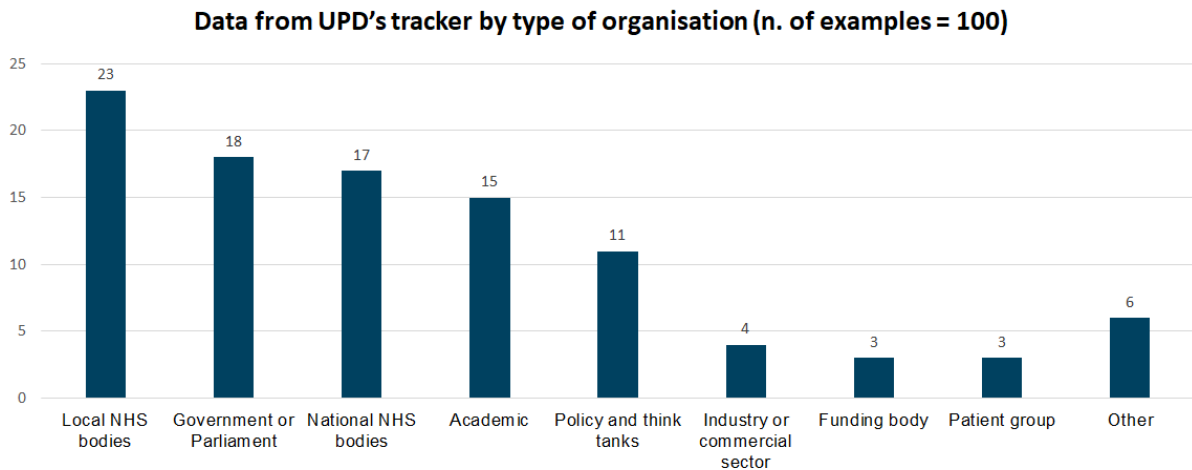
UPD collaborates with a **wide range of partners**, working with many national and local NHS organisations (Graph 2). These are predominantly NHS England, NHS Digital and Public Health England, as well as Clinical Commissioning Groups, Sustainable Transformation Plans, Academic Health Sciences Networks and local NHS data initiatives. Other sectors UPD heavily engages with are government and parliament, and academia. See Annex 2 for a fuller list of organisations using or partnering with UPD.



(Fig 4). The citation postcards at the 2018 PHE Cancer Services, Data and Outcomes Conference. Researchers must use the citation as a condition of access to registry data. Richard Stephens (NCRI) pinned postcards to posters where it was not included, making it hard to miss.



(Fig 5). Office for Statistic's report references UPD and features resources.



(Graph 2). Breakdown of UPD tracker into type of organisation. Note that these numbers are indicative and do not represent all of UPD's interactions. See Annex 2 for a fuller list of organisations working and engaging with UPD.

UPD's partner relationships are not just about gathering insight and disseminating resources but more importantly bringing together, and **unifying**, disparate groups to share consistent messaging on patient data. In the messy landscape, it is common for several organisations to tackle the same issue in silos, using slightly different language which can reduce its effectiveness. UPD brings not only needed clarity to what is happening within the landscape but also **bridges inter-agency discussions** and partnerships.

"I couldn't image which other organisation would have unified the players as well as UPD. Without UPD, the landscape would have got by but wouldn't have been as well thought through or as well unified." John Marsh, Patient representative

The processes and methods behind the development of UPD resources also demonstrates the way it acts as a partner and broker. For example, both the language and animation resources were **large collaborations** and **research-type exercises** to help build consensus across many organisations.

Other methods used to develop the resources and help bring people together include:

- getting the right people in the room, representing diverse viewpoints and opinions
- external review
- user testing, and
- revisiting or updating published resources following feedback.

Areas for improvement

While the list of organisations in Annex 2 demonstrates a wide variety of UPD partners, there are **areas for improvement**. Firstly, UPD has not fully achieved its objective to **work with the media** to present an even-handed portrayal of stories relating to health data. While UPD is the go-to source for quotes and expertise for the Science Media Centre, it is not the go-to source for journalists in general.

“UPD always promptly gave a quote and was happy to speak to anyone. I can’t say UPD was responsible, but it was part of the mix for media feeling less frenzied and more balanced.” Fiona Fox, Science Media Centre.

UPD has provided quotes and comments through a Science Media Centre briefing and in response to articles about the Caldicott Review, DeepMind Health and PHE cancer registry data. UPD has had interviews with the Times, HSJ, HIMSS and Wired and co-authored articles in the Guardian and HSJ. Between March 2017 and October 2018, UPD has been quoted or referenced in **44 online and print news stories** and **one radio programme**. However, there is still more for UPD to do directly with the media, especially with non-specialist news.

Secondly, UPD has not completely fulfilled its objective to **develop advocates** who champion the responsible use of data. There is anecdotal evidence to suggest UPD has laid the ground work for a network of advocates. For example, section 5 gives examples of specific working relationships with individual engagement leads and researchers (Kwesi Afful and Oliver Watson) which has led them to become more confident and advocate on UPD’s behalf. But the limited examples captured in UPD’s tracker means this objective has not been fully completed. The tracker will need to be amended so that it can better measure the development of advocates as a direct result of UPD activities.

Lastly, there is a **lack of clinical NHS staff in UPD’s network** including clinicians, GPs and nurses. While Graph 2 shows UPD works the most with local NHS organisations, only a small proportion of these activities are with clinical staff. UPD does engage with the Royal Colleges and BMA but these have resulted in little action or follow up. There is considerable further work to be done to proactively engage and partner with clinical NHS staff.

Using knowledge to influence policy

UPD was in part set up to advise and support the implementation of the National Data Opt-out Programme (NDOP). This is where UPD spent a large proportion of its policy focus and had its most visible influence. UPD influenced NDOP policy decisions and how it was communicated to the public. There is no single factor as to why UPD was able to influence the NDOP to the extent that it did, but it relied on several interlinked factors and activities.

“The broker role played by UPD in various inter-agency discussions have supported the coordinated introduction of the opt-out, and it has therefore been very important during the past year.” Rachel Knowles, MRC

Firstly, it was UPD’s **expertise** and experience which stemmed from founder Nicola Perrin. Nicola is well known and respected in the patient data world. Her **leadership skills** and to-the-point working style made her influential at policy meetings. This enabled UPD to have **extensive policy engagement** through its membership on the National Data Opt-out Advisory Board and Editorial Board. Additionally, Nicola was invited to meetings with the Health Minister Lord O’Shaughnessy and was often the only invited observer in private decision-making meetings. At these, her contributions carried the weight of not just her own expertise but also the other voices she represented from

charity and research communities. Her expertise enabled UPD to broker a more 'adult' conversation on the opt-out following *care.data*.

Secondly, **setting the scene** publicly was essential. UPD was invaluable in laying the ground work in partnership with the research and charity sector. A case was built for more public conversations through the collation of recent public attitudes work. UPD worked in partnership to build up public conversations through recommended language, case studies and animations. The relatively short 'Your NHS data matters' campaign launched on the back of the animation series (a huge collaboration) which had been running for longer, and had enabled stakeholders to feel more confident about the messaging on data use landing well. Working in partnerships not only helped build confidence in using UPD resources, but also built confidence that UPD would represent stakeholder voices when brokering challenging policy decisions.

Thirdly, UPD provided the **tools** to tackle the challenges it raised. UPD resources would not have been taken up so widely were it not for Nicola's extensive policy engagement. Vice versa, UPD's critical advice around the NDOP would not have been acted upon had it not provided the resources for potential solutions.

"UPD's influence is giving confidence but also applying pressure to the NHS to talk more about data. It acts as a credible agency holding the system to account yet provides the tools and resources to help get it happening more in the NHS."
Anna Steere, NHS England

Connecting people across the landscape

UPD brings **clarity in a changing landscape**. For example, how new data driven technologies will be applied and rolled out in the NHS is a huge, current issue. But with an increasing number of organisations getting involved (including commercial organisations), and new ones being set up, it's difficult for stakeholders to understand who is doing what. UPD is proactive in collating the latest discussions in this area, providing accessible and transparent information. It has also advised formally on the need to have clarity on existing bodies and embedding public trust. For example, through oral evidence to the Lords AI committee which was taken up in their subsequent report *AI in the UK: ready, willing and able?* (2018).

UPD is seen as **high profile** and **well-connected**, meaning it's in a unique position to be privy to many of these activities. The team makes sure people doing similar things are talking to each other at the right time. For example, NHS England and DHSC's Technology Partnership Code of Conduct was being developed without sufficient patient or wider stakeholder input. As a **credible** voice, UPD not only commented directly on drafts but also ensured other perspectives and evidence were fed in. For example, linking similar work being done by the RCGPs and feeding in early insights from a public attitude study on future data driven technologies in health led by the Academy of Medical Sciences.

This brokering ability on new technologies originated from a UPD event in June 2017 (*Future technologies and the use of patient data*) which brought together perspectives from industry,

academics, clinicians and policymakers. UPD, with **no vested interests**, can bring together different perspectives in a neutral space for discussion.

“By having no bias, UPD has been able to present a really balanced evaluation of the data environment.” AMRC

Overall influence and reach

There is no robust way of measuring UPD’s direct influence on those who it partners and brokers with. However, examples help provide a sense of where and how UPD reaches, and potentially influences, a broad audience.

Firstly, UPD convenes large **cross-sector discussions** such as the *UPD launch* (Apr 2017), *Health data summit* with National Voices (Feb 2018), and *Healthcare data: how do we get it right?* (Sept 2018). By bringing together different views, professions and sectors, and facilitating a discussion in a neutral space, UPD can potentially influence cross-sector relationships and design common goals for everyone to work towards together.

Secondly, UPD’s website and social media accounts **share information across the sector**. As of November 2018, 17 guest blogs have been published. The most popular blog with 457 unique page views talks about the data citation. On twitter, UPD has **2,529** followers and tweets from the UPD account have made **1.8 million impressions** in total (Apr 2017 – Nov 2018).

Thirdly, UPD gives **presentations** to a wide variety of audiences at influential events. Including the keynote talk at the 2018 PHE Cancer Services, Data and Outcomes Conference, two sessions at eHealth Week 2018 and a panel discussing trustworthiness and public expectations at CogX 2018. UPD presents to audiences of varying levels of seniority, from students to senior decision-makers, and to different sectors, from CCGs to commercial companies.

And finally, UPD is a member of **ten advisory groups** including the Ministerial Data Strategy Board and NHS Digital Research Advisory Group. This gives UPD a direct route to influence government thinking.

With the existing UPD tracker, it is not possible to measure UPD’s influence. However, the range of ways UPD reaches and works with others, and its overall achievements, suggests that it has been able to influence organisations and groups across its network.

Conclusion

UPD is a broker and partner because it can act as a **critical friend** and help provide evidenced-based guidance and resources at the same time: able to articulate problems but also provide the tools to help develop solutions. UPD has brokered information sharing between parties and enabled feedback across the landscape where previous tension existed. It has defused some of the sting in the patient data debate. By using a range of collaborative methods and processes, UPD involves diverse voices in the development of its resources. There are numerous examples of where and how UPD have reached different audiences, particularly those at a senior level; however, UPD’s direct influence cannot be quantified in a robust way.

7. How and where is UPD strategically effective?

From the key informant interviews (KIIs), key themes emerged that help evidence UPD as strategically effective (Box 4 and Fig 6).

What makes UPD strategically effective?

Independence repeatedly came up as essential for UPD's effectiveness (79% of KIIs). Most critically, stakeholders value that UPD has **no vested interests**. Charities are, rightly or wrongly, perceived as vested in specific health outcomes and want access to data. Similarly, NHS Digital is vested in delivering programmes on time. With no vested interest, UPD can be **pro using data but advocate that it must be responsible**. By having no perceived bias, UPD presents a balanced evaluation of the data environment. UPD provides a clear, intelligible voice in the public conversation around data. Not only are the resources communicated in a neutral and balanced way (addressing benefits and risks equally) but so are rapid responses to the media.

Box 4. Key themes from KIIs

UPD is...
independent
focused
experienced
a leader.

UPD does...
consistent messaging
high quality resources at pace
partnering and brokering
confidence building.

In a landscape that is...
complex
disconnected
concerned
changing.

"Wellcome, in creating UPD as a separate entity, has been able to be more influential than other large charities, such as CRUK, because it was away from vested interests. It was helpful for UPD to be standalone. It distanced itself from vested interests but still worked well with all the players." John Marsh, Patient representative

UPD's independence means it's welcomed as a **critical friend**. Interviewees talked about being challenged by UPD, but this was helpful to them.

"UPD can act as a critical friend – say things which people don't like, but in a constructive, persuasive, respectful way." Simon Denegri, NIHR National Director for Patients, Carers and the Public

Other interviewees mentioned that having backing from strong funders, yet being separate from them, is important. Independence makes UPD **approachable** from many sides – in or outside of the system and across disagreements – enabling its broker and partnering role.

UPD's single, **focused mission** is a second key ingredient (79% of KIIs). UPD is described as having one dedicated role with head space to focus on it.

"This isn't anyone's day job, they can't think as holistically. UPD can do that, which is hugely valuable." Michael Chapman, CRUK

"UPD created things that no one else could do so quickly. UPD was created to have dedicated head space to influence one thing in particular – one mission." Julie Flynn, Macmillan Cancer Support

Practically, this means UPD gets work done and keeps the **focus on the right things**. For example, keeping the communication about patient data on top of the priority list. Having a single focus made

it easier for UPD to take the lead and for partners to join. It also enabled UPD to apply pressure and hold others to account. The focus made UPD a **go to source** for comments and advice.

Having a focussed mission is linked to UPD's **small and agile team**. Operationally, the team had to keep a narrow focus and interviewees said not to underestimate the impact of a small team. Ultimately, UPD's narrow focus stems from its independence. It has the **autonomy** to act quickly, make decisions and adapt priorities independently.

The team's **expertise and experience** is another essential factor (79% of KIIs). Nicola Perrin's leadership and expertise makes the UPD voice carry weight. Nicola and the team are well known, viewed as **credible** and **speaking from evidence**. Having the right people leading UPD was repeatedly stated as important.

Close working relationships with team members is highly valued. 21% of KIIs described how knowing a UPD team member is only a phone call away for guidance is valuable to them.

UPD acts as a **leader**. This key factor was implied when interviewees were describing what would have happened to the landscape if UPD didn't exist.

"Without UPD, the landscape would have lacked leadership and focus. UPD plays a very unique role that doesn't have parallels." Michael Chapman, CRUK

Interviewees said it's not clear who else could have done the work of UPD. Without it, some of the resources may have been produced elsewhere but would have remained fragmented and not as well thought through. No other organisation is collating information on what's going on and who's doing what. Nor are other organisations as effective at bringing people together and leading consistent key messages.

On a practical level, UPD **led commentary** on patient data issues. For example, the blog on GDPR and patient data is the second most read page on the website (between Mar – Oct 2018) and has a read time of over eight and a half minutes. Between April 2017 and October 2018, the news section of the website is the most used path level, almost double the visitors to the 'What you need to know' section. Stakeholders look to UPD to better understand what's going on.

Where is UPD strategically effective?

UPD **enables consistent language and key messages**. 79% of KIIs cited this as one of UPD's most effective roles. UPD set a consistent way to talk about patient data that has **buy in** from many stakeholders. This help set a **common agenda**, setting the scene nationally to influence the nature in which patient data is debated publicly.

By using an evidenced-based approach to align key messaging and common language, UPD **led a consistent voice** with others, including charities, researchers, government and national NHS bodies.

"Without UPD, every other organisation would have come up with a way of doing it – and we would not be consistent when talking about the benefits of using patient data in research." Amanda White, Health Data Research UK

Following *care.data*, this helped take the heat out of the patient data conversation. Consistency in approach allowed the debate to move forward in a more adult way.

UPD makes **timely, high quality resources**. This was reiterated in 79% of the KIIs with many interviewees giving specific examples of resources they find useful and why. Users found the resources effective because they are made in an **inclusive** and **evidenced-based** way. 43% of KIIs described how their **time was saved** by having easy to use tools. 14% of KIIs also described how they were planning on creating similar things; therefore, UPD saved them financial resources as well. Overall, UPD's central hub of resources helps make practice more consistent and nurtures an environment more conducive to data conversations.

Partnering and brokering are the roles most cited as effective during the interviews (86% of KIIs). UPD acts as a **conduit for discussion** which would have otherwise occurred in a fractured way.

"UPD is omnipresent in all the conversations and meetings with an information gathering and sharing function. UPD is the common thread."
Michael Chapman, CRUK

Interviewees acknowledge UPD collaborates with a wide range of partners, bringing together, and unifying, disparate groups. Described as a credible broker, it facilitates collaborations. Factors that enable UPD to be a broker and partner include it being neutral, representing other voices, **well-connected** and **high-profile**.

Alongside enabling consistent key messages, its brokering and partnering role enables UPD to neutralise the previous tension in the patient data debate.

Combining many of the factors above means UPD has been able to **build confidence**. Not necessarily public confidence, but those who engage the public directly are more confident. This was described explicitly and implicitly during the interviews.

"Without UPD we would have been less bold with the scale of our public engagement, we would have stayed in our comfort zone. Because we could ask UPD for advice it gave us confidence." Oliver Watson, Bristol Health Partners

"UPD's overarching influence was on building confidence among others, showing it is possible to lead conversations that end in a better place." Jenny Westaway, National Data Guardian's Office

"More strategically, it gives capability and capacity to think differently about the data debate in the research community. Created a space and the right sorts of discussions." Simon Denegri, NIHR National Director for Patients, Carers and the Public

Future steps and challenges

57% of KIIs talked about **future steps and challenges**. No interviewee said that this is the right time for UPD to stop. They called for UPD to continue its key roles and adapt to the landscape's changing priorities. Overall, they felt that not only did **public conversations** need to continue but also the **pressure** to have public conversations.

“UPD has punched above its weight in effectiveness for an organisation raising public awareness. People’s interest in how data is used will continue and the UPD model has been extremely effective.” Joanne Bailey, National Data Guardian Panel

29% of KIIs voiced concerns that national level commitment to public dialogue could wane. If no one held organisations to account, there is a concern progress will slip.

36% of KIIs called for UPD to have official involvement in national programmes such as the Local Health and Care Record Exemplars, to ensure the public voice is part of the governance of patient data. Every interviewee who talked about future steps identified places where the conversation needs to continue. These included public awareness at scale (57% of KIIs), with NHS staff (29%), around the value of patient data (14%), and around new data driven technologies (29%).

“The public debate will continue, challenges will crop up – UPD will be important to keep on top of and anticipate challenges, corralling people to do the right thing at the right time.” Simon Denegri, NIHR National Director for Patients, Carers and the Public

Conclusion

UPD has achieved what it was set up to do, influencing both policy decisions and the environment in which they landed. The need for better public conversations has increased regardless: GDPR and data scandals have increased the public profile of data use. Yet in a relatively short space of time, UPD is being held up as a model that works.

UPD has been strategically effective by: facilitating consistent messaging, making high quality resources at pace, partnering and brokering, and building confidence. While UPD hasn’t directly built public confidence, those who engage the public are more confident to do so. UPD has been successful here because it has: independence with no vested interest, a focused mission, expertise, and is a leader. It has **helped others to help themselves** to contribute to a balanced patient data conversation. In practice, the team strikes a **balance between leading and enabling**, through having a narrow, focused remit, communicating well and having the autonomy to stick to it.

8. Key lessons

In lieu of a summary, these reflections highlight some of the key learning points the UPD team have gleaned from this evaluation process, about what has made UPD effective:

Making sense of confusion

UPD has been able to take a ‘helicopter’ view of patient data issues, in a way that few on the ground have the capacity or resource to do. It is widely recognised that public trust and confidence are

important for providing 'licence' to use data, but staking steps to help inform and engage with people is frequently low on the priority list amid time and funding pressures.

When there's more clarity, people across silos feel more comfortable working together. UPD provides a better sense of what's going on, making others feel more in control, and empowered to start conversations about patient data.

Helping others to help themselves

It's no single organisation's responsibility to build and maintain public trust in the use of patient data, or to hold the system to account. UPD led the way to enable others to help themselves in less time and with less risk. It has been a compass, not being prescriptive but enabling others to orientate towards a particular direction in a consistent, unified way.

Responsiveness

UPD didn't have pre-set, expected outcomes. It achieved what it set out to do by being responsive to what was needed. It's difficult to say whether this continues to be the best model - being only responsive without pre-determined outcomes. But it does feel like for the initial two years, this *is* what was needed given the messy landscape and time pressure to deliver the NDOP.

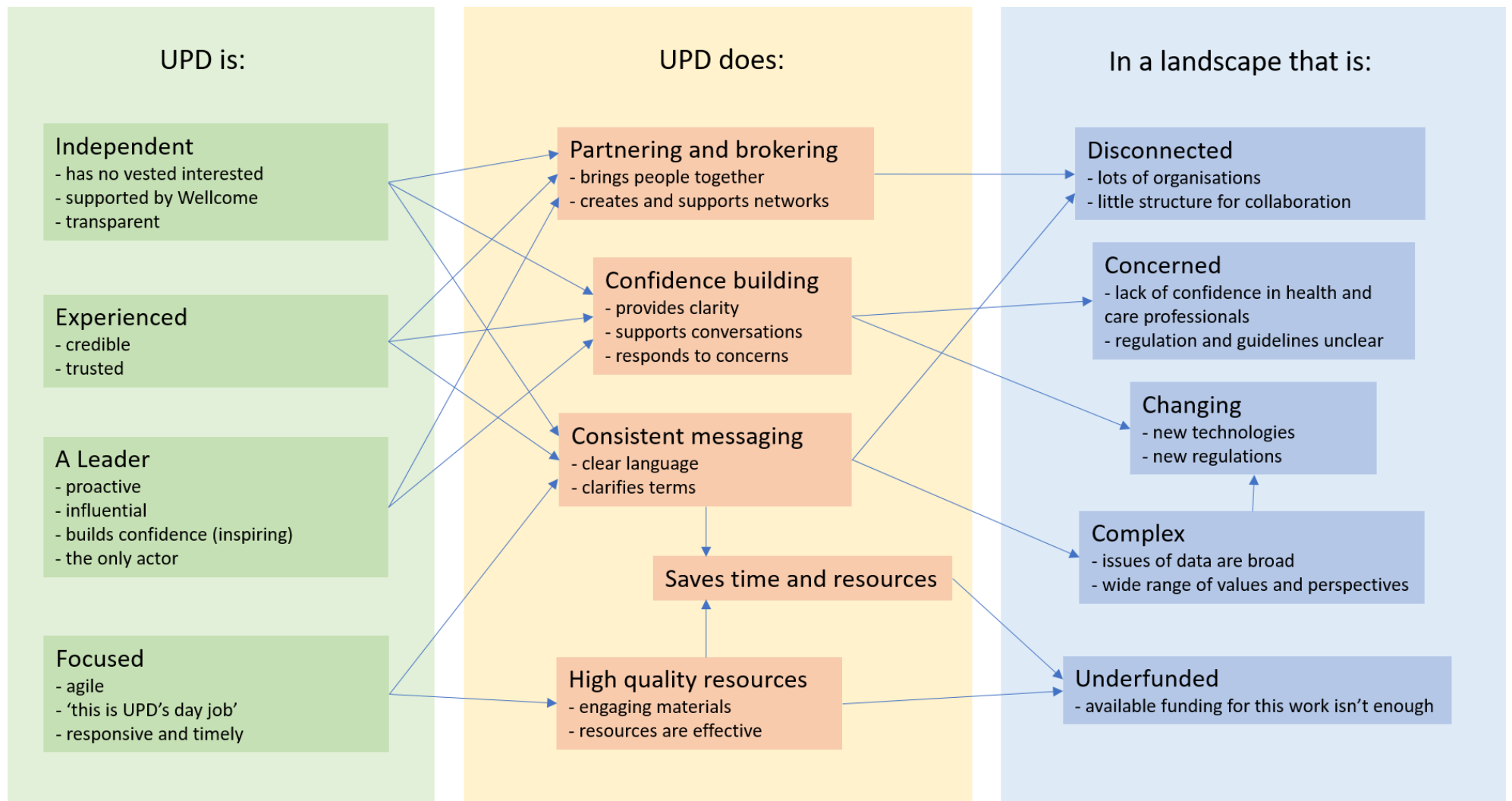
UPD's traits, rather than set performance indicators, have enabled it to be strategically effective. This must be considered when setting future goals.

Bridging the local-national divide

UPD works at both ends of the scale - facilitating local conversations while having impact on national level policy and debate. In something as large as the NHS, it is difficult for on-the-ground level practice to feed upwards and influence national level decisions. The UPD approach begins to challenge this, enabling influence of good practise from one area to another where it may have not happened quite so easily before.

By working at both scales we can see more easily where something at one level doesn't fit with what's going on at the other. This connection and convening appears to have been critical: allowing UPD to orchestrate consistent messaging across a wide range of partners while enabling local, regional projects develop in ways that best suit their contexts.

(Fig 6). Visual image of key themes from key informant interviews



Annex 1. Key informant interviews

In addition to UPD's impact tracker, there were 14 sources of feedback used in the evaluation analysis: 11 interviews, two emails and one meeting. The same semi-structured interview questions were used regardless of whether feedback was collected via an interview, email or meeting. For simplicity, all 14 sources below are collectively referred to as key informant interviews (KIIs) in this evaluation.

Interviewees:

Kwesi Afful, North West London Collaboration of CCGs

Michael Chapman, Cancer Research UK

Simon Denegri, NIHR National Director for Patients, Carers and the Public

Julie Flynn, Macmillan Cancer Support

Fiona Fox, Science Media Centre

John Marsh, Patient representative

Rachel Merrett, NHS England

Anna Steere, NHS England

Oliver Watson, Bristol Health Partners

Jenny Westaway, National Data Guardian's Office

Amanda White, Health Data Research UK

Additional comments and quotes sourced from:

AMRC

Rachel Knowles, MRC

National Data Guardian Panel

Annex 2. Fuller list of organisations using or partnering with Understanding Patient Data

Due to the nature of UPD's open access resources, it's not possible to list every organisation using UPD work. However, below is a fuller list of organisations that are known to be using UPD resources, partnering with or engaged with UPD via meetings, events and other outputs.

AboutMe	Cardiff University
Academy of Medical Sciences	Carnegie Trust UK
Action on Hearing Loss	Centre for Data Ethics and Innovation
Ada Lovelace Institute	Centre of Excellence for Information Sharing
Alan Turing Institute	Children and Young People's Health Partnership
Alzheimer's Research UK	CitizenMe
Alzheimer's Society	Clinical Practice Research Datalink
Anthony Nolan	CLOSER (UCL Institute of Education)
Arthritis Research UK	CogX
Association of British HealthTech Industries	Confidentiality Advisory Group (HRA)
Association of Medical Research Charities	Connected Health Cities
Association of the British Pharmaceutical Industry	Coordinate My Care
Asthma UK	Corsham Institute
BCS The Chartered Institute for IT	DeepMind Health
BenevolentAI	Department of Business, Energy and Industrial Strategy
BMJ	Department of Education
Bowel Cancer Intelligence UK	Department of Health and Social Care
Brighton and Sussex Medical School	Diabetes UK
Bristol Health Partners	Dorset CCG
British Academy	Economic and Social Research Council
British Heart Foundation	ETH Zurich
British Medical Association	Ethox Centre (University of Oxford)
Cambridge University Hospitals NHS Foundation Trust	Genetic Alliance
Cancer 52	Genomics England
Cancer Innovation Challenge	Government Office for Science
Cancer Research UK	Great Ormond Street Hospital

Greater Manchester Academic Health Science Network
Health Data Research UK
Health and Social Care Alliance Scotland
Health Foundation
Health Foundry
Health Research Authority
Health Research Board (Ireland)
Healthcare Quality Improvement Partnership
Healthwatch England
IBM
Imperial College Health Partners
Imperial College London
Independent Group Advising on the Release of Data (NHS Digital)
Information Commissioner's Office
Information Governance Alliance
Innovation Agency (North West Coast Academic Health Science Network)
Innovative Healthcare Delivery Programme
Intellectual Forum, Jesus College Cambridge
Involve
INVOLVE (NIHR)
IQVIA
Kidney Care UK
Kidney Research UK
KQ Labs
Local Government Association
Lord O'Shaughnessy
Macmillan Cancer Support
Macular Society
MedConfidential
Medical Research Council

MQ Mental Health
MRC Regulatory Support Centre
MS Society
National Cancer Research Institute
National Data Guardian's Office
National Joint Registry
National Voices
Nesta
NHS Digital
NHS England
NHS Health Research Authority
NHS National Institute of Health Research (NIHR)
NHS National Services Scotland
NHS Scotland
NIHR Central Commissioning Facility
NIHR Clinical Research Network Primary Care
North West EHealth
North West London Collaboration of CCGs
Nuffield Foundation
Office for Life Sciences
Office for National Statistics
Open Data Institute
Oxford Internet Institute
Parkinson's UK
Parliamentary Office of Science and Technology
Patient Information Forum
PHG Foundation
Precision Medicine Catapult
Progress Educational Trust
Public Health England
Rare Disease UK

Reform	The King's Fund
Rethink Mental Illness	The Northern Health Science Alliance
Royal College of GPs	The Professional Records Standards Body
Royal College of Nursing	The Richmond Group of Charities
Royal College of Physicians	TPP UK
Royal Pharmaceutical Society	UCL
Royal Society	UCLPartners
Royal Statistical Society	UK Anonymisation Network
Sanger Institute	UK Clinical Research Collaboration
Science Media Centre	UK Faculty of Clinical Informatics
South Central West Commissioning Support Unit	UK Statistics Authority
South West London Health and Care Partnership	University of Bristol
Stroke Association	University of Edinburgh
TechUK	University of Leeds
Teenage Cancer Trust	University of Manchester
The AHSN Network	UseMydata
The Brain Tumour Charity	Wellcome Trust
The Data Lab	Wessex Academic Health Science Network
The Farr Institute of Health Informatics Research	Wessex NIHR CRN
	Wirral University Teaching Hospital NHS Foundation Trust