



# Table of contents

---

	Page
1. <u>Headline evaluation findings</u> .....	3
2. <u>About UPD</u> .....	10
3. <u>Evaluation scope and methodology</u> .....	17
4. <u>Findings</u> .....	21
a. <u>Impact across UPD's key areas of work</u> .....	22
b. <u>UPD's 'cycle of impact'</u> .....	41
c. <u>UPD's influence and value at a system level</u> .....	47
5. <u>Implications of these findings for UPDs ongoing practice and development</u> .....	51

*All stakeholder quotes included in this report represent the views of individuals and may not necessarily reflect the views of the organisations they work for.*



## 1. Headline findings

# 1. Headline evaluation findings

---

This section of the report presents the key findings from this evaluation set against each of UPD's potential strengths (as identified by the UPD team), and the ways in which it generates impact and value across the patient data landscape. In each case we identify the relative strength of evidence based on our findings, and what that evidence tells us.

We then present five emerging narratives that describe UPD's importance and impact in this space, and which could usefully inform future funding and planning decisions.

Section 5 of this report sets out a number of considerations for UPD as it moves beyond its current funding period, and which could form part of its future strategy and operating plan.

# 1. Headline evaluation findings

The following two tables set out the strength of evidence from this evaluation (our external assessment) in relation to each of UPD's self-identified strengths, which are based on previous reviews of UPD's work and the current team's ongoing monitoring.

UPD's strengths	Strength of evidence from this evaluation
We are <b>independent</b> . We don't hold patient data and aren't responsible for decisions about it.	<b>Strong evidence.</b> UPD is viewed as being independent from policy-making bodies and neutral regarding the use of patient data. UPD is not known for holding patient data, nor do stakeholders see that as its role. UPD's neutrality, combined with its distinct insider-outside position, makes it a valued partner for a wide range of organisations.
We are <b>objective and balanced</b> . Not "pro" or "against" the use of health data, but supporting uses that demonstrate good values (visibility, transparency, trustworthiness, etc).	<b>Strong evidence.</b> UPD is widely respected for its neutral stance and for producing evidence-informed outputs that seek to improve transparency and understanding regarding how data is used, and support organisations to gain public trust in using patient data.
We specialise in <b>all uses</b> of health (and care) data (research and non-research).	<b>Promising evidence.</b> The broad remit of UPD, whilst maintaining a specialism in the use of patient and healthcare data, is highly attractive to many stakeholders. However, there is some appetite for UPD to increase its focus on the full data 'pipeline', including data provenance and collection practices and the technical infrastructure used for collecting, analysing, and sharing patient data.
We convey the thoughts and attitudes of <b>all publics and patients</b> (not representing specific members or groups), providing the big picture.	<b>Strong evidence.</b> Stakeholders view UPD as being distinct from other organisations through its ability to accurately represent the thoughts and attitudes of all publics and patients, with the ability to provide segregated analysis and insight where appropriate.

# 1. Headline evaluation findings

UPD's strengths	Strength of evidence from this evaluation
<p><b>We are close to health leaders</b> in the NHS, as a result of being hosted at the NHS Confederation.</p>	<p><b>Promising evidence.</b> There is promising evidence that UPD holds good relationships with health leaders, both across NHS organisations and within research and policy institutions. Holding good relationships with health leaders positions UPD as having up to date knowledge of policy and practice, increasing their legitimacy in the eyes of stakeholders and their ability to advise and inform. There is also evidence that being hosted by a neutral, independent organisation such as the NHS Confederation, with values that align to UPD's values, is important for UPD's broader positioning in the health data system. This isn't specifically in relation to UPD's relationships with health leaders, but the team feel that there is mutual benefit from this hosting relationship.</p>
<p>We can speak to, and work with, people on <b>all sides of the health data debate respectfully</b> and <b>with trust</b> – civil society, health services, governments, charities, academia, researchers, private companies.</p>	<p><b>Strong evidence.</b> UPD occupies a special and distinct position in this regard, and it is the mechanism by which lots of UPD's 'soft' value is generated. UPD is a vital 'boundary-spanning' organisation, which is trusted, respected by, and holds working relationships with a varied range of actors.</p>
<p>We have a <b>reputation for excellence</b> in all the following: the provision of <b>public-facing resources</b>, <b>standardisation and socialisation of the language</b> that is used, <b>strategic policy analysis</b>, commissioning <b>research</b> and <b>engagement</b> through exercises like <b>public deliberations</b>.</p>	<p><b>Strong evidence.</b> We have strong evidence that all of the statements given are true; external stakeholders report that UPD produces high-quality and accessible outputs and analysis. UPDs outputs provide a shared and common language, notably for PPIE professionals. UPDs research and engagement exercises not only cover valuable topics and produce useable insights, but demonstrate methodologies that are mirrored by other research and engagement professionals.</p>

# 1. Headline evaluation findings – five emerging narratives

---

## 1. UPD is highly regarded and trusted by a wide range of individuals and organisations from across the patient and health data ecosystem

- UPD is valued for its **neutrality** regarding the use of patient data, and its **balanced, evidence-informed** stance. It is valued for its ability to produce empirically validated resources that explain complex topics and debates in intelligible, useful and reproduceable formats.
- We frequently heard that UPD's functions **would need to be replaced**, should it cease to exist.
- Given the limited resources available, the UPD team is praised for the quality and impact of its work, and there is a widespread recognition that UPD's ability to inform and influence **would increase with more resources**.

## 2. UPD occupies a distinct and important insider-outsider position, while maintaining independence and neutrality

- Due to its **highly regarded and trusted** position and the specialist knowledge areas and skills of its staff, UPD occupies a distinct and valuable insider-outsider position. It holds **strong relationships** across the system, including those with conflicting perspectives, yet it is **trusted to fairly represent all sides** and exercise judgement.
- UPD's close position to health leaders means that **it is invited to comment on, and influence, emerging policy developments**. However, it possesses **the independence** required to publicly challenge and critique individual policies or the general direction of travel in relation to the use of patient data.
- It is **distinct from other organisations** in this space through its focus on all uses of patient data (rather than only secondary uses), and the expertise of the team.

## 1. Headline evaluation findings – five emerging narratives

---

3. Much of UPD's impact comes from its position as a 'boundary-spanning' organisation across the patient and health data ecosystem. It does this by:
  - **Holding and sharing specialist knowledge** of how patient data is used, **public attitudes** towards the use of patient data, and **live knowledge of policy and practice** within the UK's health and social system.
  - **Developing and maintaining trusting relationships** with actors from across the patient data landscape and **making connections** between individuals and organisations.
  - **Providing support to organisations** through commenting on draft policy documents and proposals, sharing expertise in 1:1 settings, contributing knowledge and guidance through advisory committees and steering groups, and publicly challenging and steering the work of national bodies.
  - Providing **well-evidenced resources** that have been tested with the public and are highly accessible.
4. UPD's work leads to patients, clinical practitioners and policy professionals being better informed about how patient data is used, increasing the trustworthiness of organisations
  - Dataloch, a data service that has been developed in partnership between the University of Edinburgh and NHS Lothian, using *'some of the lay-person language from UPD to support conversations with the public about our own Data Services. Most often the language around de-identification / pseudonymisation, etc.'*
  - Supporting the Chief Clinical Data Officer for HDRUK. It has *'significantly impacted our work by educating the public, patients and PPIE reps about the benefits of using routine healthcare data. Acting as an arm's length trusted brand to independently guide clinicians and academics in the best way to do practice.'*



# 1. Headline evaluation findings – five emerging narratives

---

## 5. UPD's work 'saves' money elsewhere in the system and increases the impact of other strategic investments

- **Developing research and resources** which provide foundational knowledge for researchers and practitioners, meaning they are aware of live issues and do not need to produce resources themselves.
- Improving the **quality of patient and public involvement and engagement work**.
- **Informing public communications** regarding the use of patient data so that they are proactive, increase trustworthiness, and use language that the public can understand.
- Providing the rationale for organisations to **commit to building greater trustworthiness** in relation to the use of patient data.
- Providing **confidence that an evidence-informed voice is present** in internal and external policy and practice discussions, meaning that other organisations and professionals feel that they do not need to be present.

*'It makes everyone's job easier, letting teams working in health research focus on work that's unique to their priorities. Speaking with colleagues in government and other funders, many would agree that if UPD didn't exist, you'd probably end up creating something like it again, for the efficiency it offers the field as a whole.'*

*(Tariq Kohkhar, Head of Data for Science and Health, Wellcome Trust)*



## 2. About UPD

---

UPD was set up in 2016 as an initiative of the Wellcome Trust, with the aim of bringing together different voices concerning the use of patient data, and to start building new evidence for what a trustworthy patient data ‘system’ might look like. At that time, there was a relatively limited understanding of public attitudes concerning the use of patient data, and little useful evidence to support constructive debate between clinicians, researchers, and policy makers. There was also a limited amount of useful information that could be used to inform the public.

Today, UPD operates as a largely independent entity (albeit ‘hosted’ by the NHS Confederation), with oversight by a steering group made up of professionals from across the patient data landscape. UPD’s vision, however, remains much the same: to support improved health outcomes through responsible use of patient data (see Figures 1 and 2 – UPD Theory of Change). Over the longer term, UPD’s work aims to ensure that:

- Patients and the public are empowered to make informed choices about use of their data
- Health data users and custodians (healthcare professionals, researchers, academic institutions, charities and the private sector) handle data in a trustworthy way, and
- Policies in place reflect the importance of using data responsibly and with integrity.

This is achieved through three core areas of work:

- **Collating and developing the evidence base** for what a trustworthy system needs to be
- **Providing information in an accessible form** for health data users, in order to help create and promote good practice
- **Making issues around the use of patient data more visible**, including from those whose voices may otherwise not be heard.

UPD currently receives funding from the Wellcome Trust, the Medical Research Council, the National Institute for Health and Care Research and NHS England. This is due to be reviewed before the end of the current financial year. This funding provides for a small

## 2. About UPD

---

dedicated team of three people, as well as money for externally commissioned work (such as research, and for the creation of external facing resources). UPD's work has, since its inception around eight years ago, always been delivered by a relatively small team.

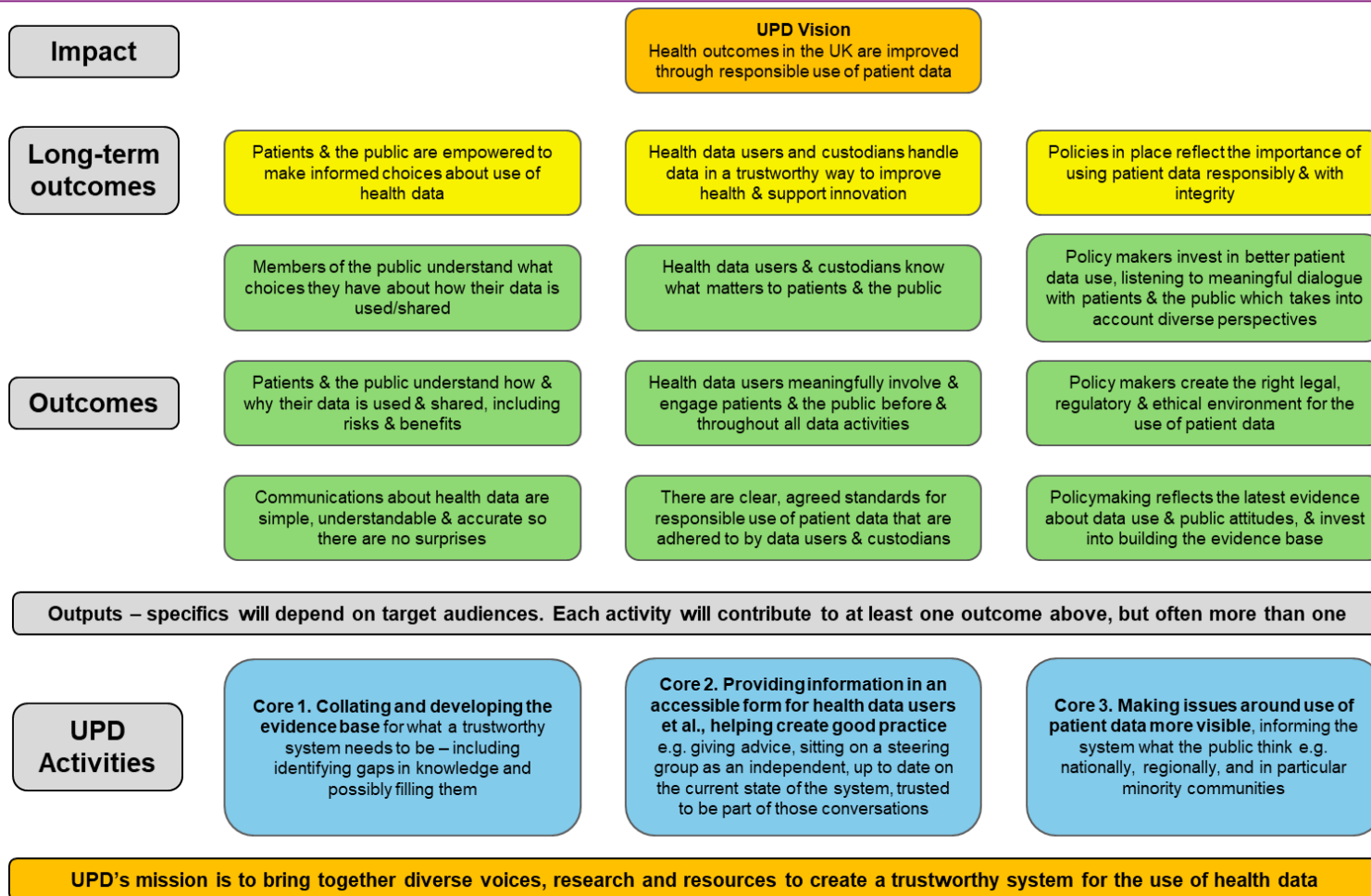
On a practical level, UPD's activities fall into five key strands of work:

1. Convening and supporting the patient data community including users, custodians, members of the public, clinicians, academics and advocates
2. Producing resources to explain the uses of health data
3. Understanding people's views through research and engagement, with a particular focus on minoritised or marginalised voices
4. Advocating and influencing health data policies and practices
5. Providing commentary to the media and creating content for online channels.

Going forward, UPD plans to continue to work towards its longer term outcomes through these strands of work, recognising that:

- Governments and health bodies are increasingly wanting the use of patient / health data to be a larger part of the provision and management of health services, powering UK health research, and enabling the UK's life sciences sector to reach its potential. Patients and members of the public also often want their data to be used more effectively.
- Given previous failures and setbacks in this agenda, such progress needs to be made carefully and with public support as once trust is lost it is hard to regain it, threatening future initiatives.
- Without the requisite focus on trust (and trustworthiness of organisations), there is a risk of public (and private) money being wasted on initiatives that don't have the desired effect.

## 2. About UPD



**Figure 1: UPD Theory of Change (note this is a live, evolving concept so UPD's vision statement is under development)**

## 2. About UPD

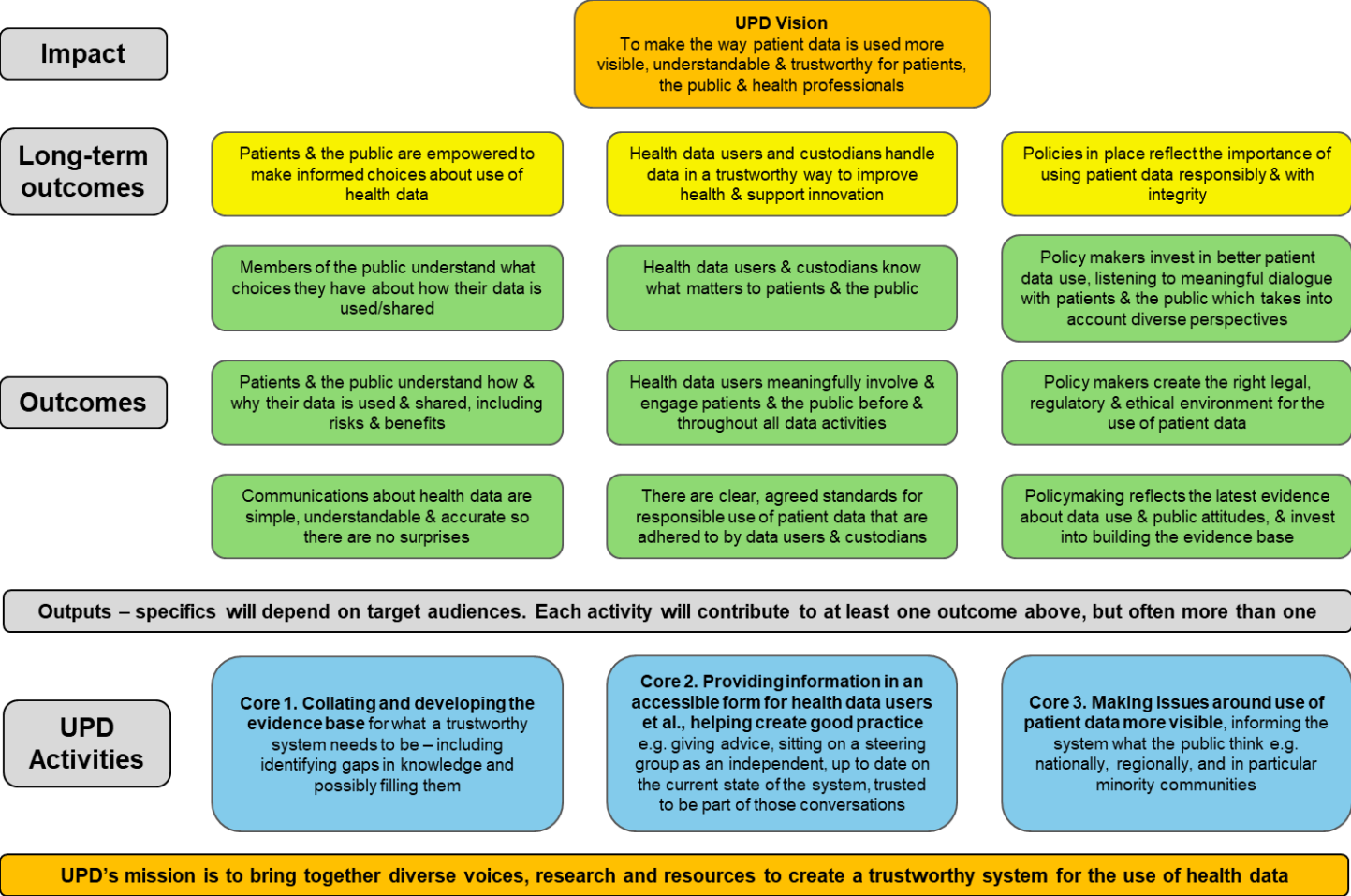


Figure 2: UPD Theory of Change – alternative vision statement (note this is a live, evolving concept so UPD's vision statement is under development)

## 2. About UPD

---

When UPD was initially set up, there were minimal conversations with the public about their health data. Since then, this has dramatically improved, with many health and health research related organisations having ‘patient and public involvement and engagement’ functions. While this is the case, health services are continuing to invest in, and adopt, technologies that rely on patient data, and the importance of health data research has continued to increase particularly since the Covid-19 pandemic. Yet many studies still show that health data literacy remains low. Ensuring that patients and the public understand and support these technical advances within healthcare and health research is imperative if they are to succeed.

Lack of support for the collection and use of patient data beyond individual care is not new. The Health Foundation found that despite many years of dialogue many people feel they know very little about how the NHS uses the data it collects. The findings indicate that for the most part, the public support the use of patient data outside of direct care, but there are still a significant number who do not. For this reason the focus on understanding and trust in how patient data is used is vital for policymakers, commissioners, providers and innovators. Supporting patients and the public to understand how patient data can be used effectively and appropriately to improve health outcomes is clearly a key part of the ongoing agenda of how the NHS and wider health community tackles increasing demands and limited resources.

The Goldacre Review in 2022 draws an early conclusion that to realise the benefits of health data for planning and research we must ‘Build trust by taking concrete action on privacy and transparency: trust cannot be earned through communications and public engagement alone.’

Data custodians and decision-makers still need to understand how the public is feeling, and improve their trustworthiness. People still need to have somewhere to go to, for clear, factual, balanced information.

## 2. About UPD

---

If patients and the public don't have confidence in how their data is used, more people may opt-out of having it used, making the data less representative and reducing the ability for researchers and the NHS to use it effectively. This will have consequences for the effective planning and delivery of health and social care across the UK. A better understanding of how health data is used, and genuine public engagement, will support this confidence. There is increasing interest in how patient data can be used, and the need for the unique services and support provided by UPD is as important today as it was when UPD started in 2016.

However, it is also evident that the landscape of public engagement and attitudes work relating to the use of health data is complex – across government, the NHS, the private sector, the charity sector, and academia. And it isn't always sufficiently coordinated. This means that sometimes work is duplicated, learning is not shared, or work doesn't always make best use of funding available. Greater effort is needed to co-ordinate and connect this work. UPD will need to ensure that its offer adds value to this complex community, by continuing and perhaps convening this shared dialogue on how to ensure the safe and appropriate use of patient data across the whole landscape.





### 3. Evaluation scope and methodology

### 3. Scope and methodology for this evaluation

---

This was a mixed method, summative evaluation of UPD's importance and impact across the UK's patient data landscape (and potentially internationally). Our aim was to provide a foundation for future impact measurement and evaluation, while offering actionable, evidence-based recommendations regarding UPD's future priorities and funding / delivery model.

We set out to review and explore the impact of UPD's work in each of the five key strands, as well as the value this generates across the system, and the mechanisms through which that value is created. This excluded any attempt to explore or quantify financial value.

The evaluation has been informed by:

- 1:1 semi-structured interviews with **17** external stakeholders, many of whom are national leaders in the health and patient data space (see Figure 3).
- An online survey of external stakeholders, which received **40** responses from those working in a wide range of roles and professions across the system (see Figure 4)
- Written feedback from a journalist that had previously worked with UPD and who offered suggestions for increasing UPD's media presence
- A review of website and social media analytics data
- A rapid review of citations and references in published literature
- A review of key organisational documents, including progress and steering group reports, strategy documents, the 2018 UPD evaluation, and the emerging 5 year funding proposition.

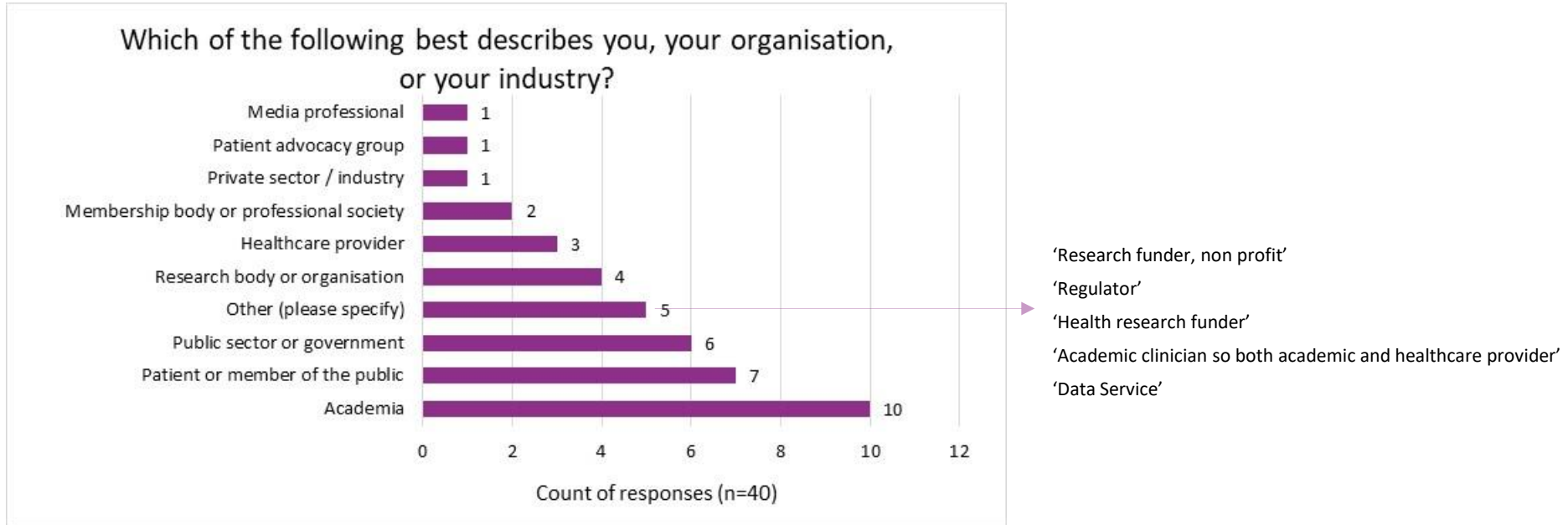
All of this data has been analysed and our findings are presented in Section 4 of this report. Section 5 sets out the possible implications of these findings, for UPD's future funding considerations and for the work that UPD might consider undertaking in the future.

### 3. Scope and methodology for this evaluation

Name	Role	Organisation
Lizzie Remfry	Wellcome Trust Health Data in Practice PhD Student	Queen Mary, University of London
Rachel Edwards	Public Engagement Officer	Research Data Scotland
Matt Howard-Murray	Public Involvement Lead (Research Data Strategy)	Cancer Research UK
Janet Valentine	Executive Director, Innovation and Research Policy	The Association of the British Pharmaceutical Industry
Ellie Munari	Communications and Engagement Manager, NHS Transformation Directorate	NHS England
Sam Smith	Coordinator	MedConfidential
Jeni Tennison	Founder and Executive Director	Connected By Data
Joe Watts	Head of Data Access and Linking Policy	Department of Health and Social Care
Natalie Banner	Director of Ethics	Genomics England
Nicola Byrne	National Data Guardian	Office of the National Data Guardian
Doreen Tembo	Head of Public Involvement and Engagement	Health Data Research UK (HDRUK)
Mike Thorpe	Patient Representative	N/A
Nicola Perrin	Chief Executive	Association of Medical Research Charities
Tariq Kohkhar	Head of Data for Science and Health	Wellcome Trust
Ceri Steele	Patient Representative	N/A
Jacob Lant	Chief Executive	National Voices
Dr Pratibha Veeramani	Consultant Ophthalmologist and INSIGHT Patient and Public Involvement and Engagement (PPIE) Lead	Moorfields Eye Hospital NHS Foundation Trust

**Figure 3: List of stakeholders interviewed for this evaluation**

### 3. Scope and methodology for this evaluation



**Figure 4: Profile of stakeholders who responded to the evaluation survey**



## 4a. Findings – Developing resources

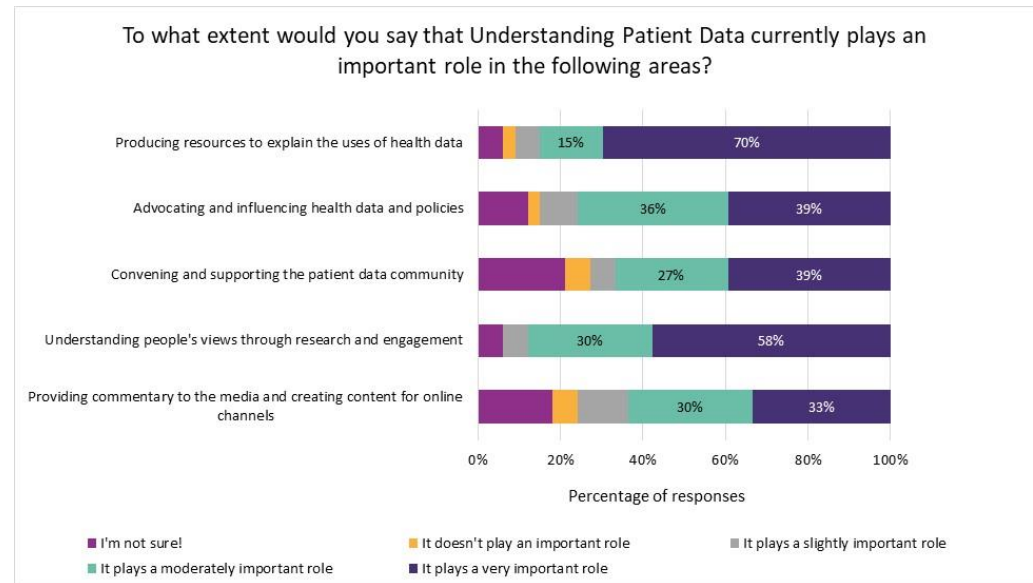
The findings from this evaluation show that the development and publication of resources is considered to be one of the most important, and most impactful (across the wider system) areas of UPD's work. Figure 5 below shows that 85% of survey respondents consider UPD to play a 'very' or 'moderately' important role in relation to producing resources to explain the uses of health data. This was supported by many of the stakeholders we spoke to, who told us that UPD's resources are valued for:

- The clarity of information they contain, including more specifically the language and terminology used, which is pitched at a level that appeals to both researchers and those working in non-research roles
- Their relevance and usefulness, covering a range of topics and contexts
- The different formats used, meaning they can be used in a range of different contexts.

Examples of resources that are used often, and considered to be particularly impactful include:

- The pseudonymisation data graphic
- The Wheel of Health Data
- Terminology explainers
- What Words To Use
- UPD's fair benefit work

UPD's resources are also valued for being well researched and tested with the public, meaning that PPIE professionals in particular don't need to undertake that research themselves, but can focus on making use of / adapting the information in a way that works for their own situation.



**Figure 5: Importance of UPD's different areas of work according to survey respondents (n=40)**

## 4a. Findings – Developing resources

---

Furthermore, UPD's resources incorporate diverse voices, meaning that they reflect both a nationally representative picture as well as the views of groups that are often not heard from in this space. This enables UPD to present a national picture at the same time as recognising key differences between different groups of people.

It is important to note that we didn't, as part of this evaluation, seek to understand stakeholder views specifically on UPD's more recent resources (for example, since UPD's move to the NHS Confederation) compared to those that were developed during the previous hosting arrangement.

*'So the use of data, and particularly things like AI, are coming up time after time in conversation, people are interested in how their patient data is held safely by their NHS Trust. There's been recent breaches. They're interested in how they can access data on apps. They're interested in AI and they're scared about how AI can replace their clinician. You know, there are things there that are not necessarily just research related, and bringing us back to UPD, is that it's helpful for the non research side of where we're providing patient information and want to be a trusted, credible source, and they operate not just in that research space, but also in that health system space, where other parts of our charity are really interested.'* (Matt Howard-Murray, Public Involvement Lead (Research Data Strategy), Cancer Research UK)

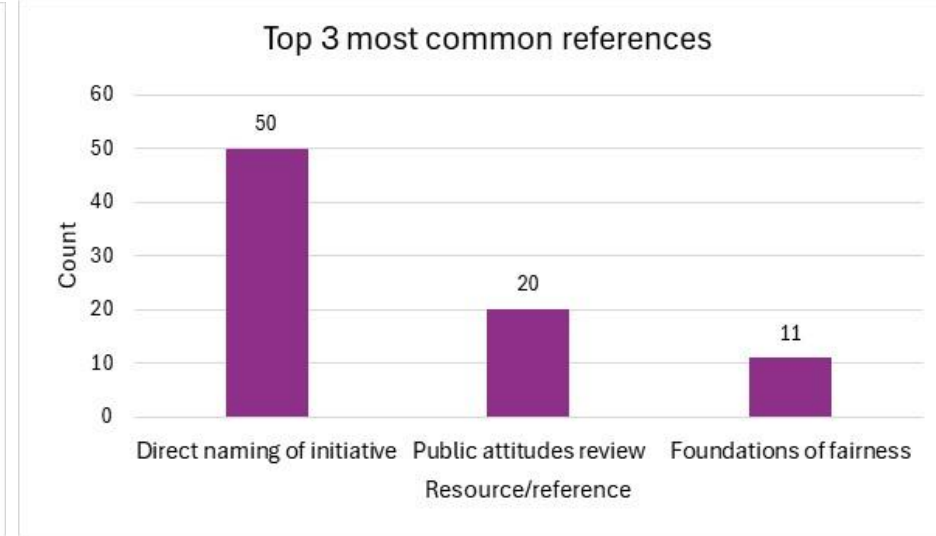
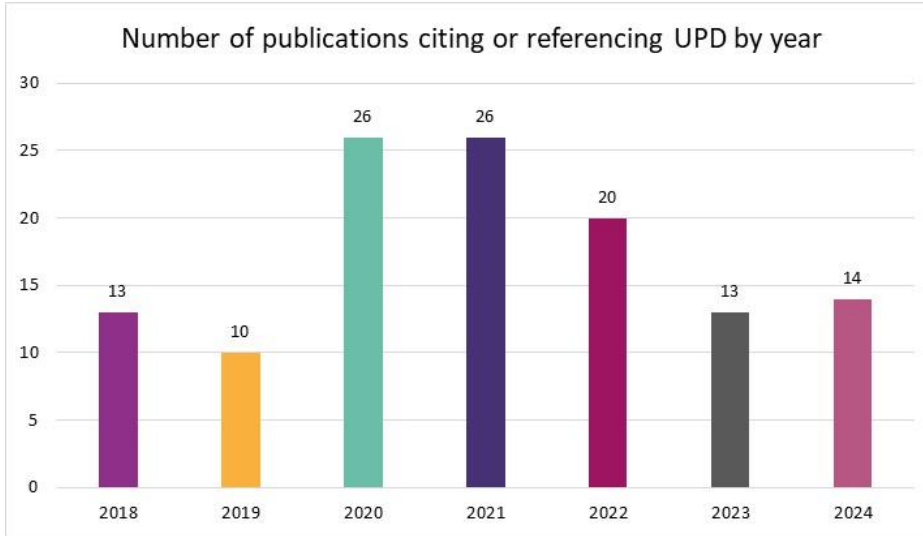
*'They [UPD] are the go-to for explaining what de-identified data is.'* (Ellie Munari, Communications and Engagement Manager, NHS Transformation Directorate, NHS England)

*'The What Words To Use resource is fantastic and is a rare resource setting out how things should be described.'* (Rachel Edwards, Public Engagement Officer, Research Data Scotland)

Website data shows that the website pages concerning UPD's research and resources are among the top six pages receiving the highest number of views (excluding the home page).

A rapid review of published literature identified 122 unique publications between 2018 and 2024 which referenced UPD and / or UPD resources / content in some way (Figure 6). Nearly half of these were from 2020 and 2021, a period during which the Covid-19

## 4a. Findings – Developing resources



**Figure 6: Frequency of UPD references in published literature 2018 to 2024**      **Figure 7: The top 3 most common references regarding UPD's work**

pandemic raised awareness of, and optimism for, the potential for health data to support public health. The pandemic also drove an increase in debate and scepticism around health data, particularly with the NHS contact tracing app sparking conversations around monitoring, confidentiality and personal choice.

The majority of the publications identified in the review referenced UPD by directly naming it (Figure 7), consistently using UPD as a specific example of good practice in:

- Articulating the need for NHS and research institutions to be trustworthy and to communicate values such as patient benefit
- UPD acting as a champion for responsible uses of data, and
- Effectively communicating the benefits that can be realised through data.



## 4a. Findings – Developing resources

---

This was followed by references to UPD's review of public attitudes to patient data use in the UK, referred to in one paper as an 'excellent compendium' of studies. Papers mentioned and / or discussed the summary themes highlighted in that research, including public support of data sharing for public benefit, concerns around commercial access to data, and as evidence of the significant work being done on data sharing more generally.

The Foundations of Fairness report was the next most commonly identified piece of UPD's work. It was potentially one of the most popular and high-profile resources due to collaboration with NHS England, as well as being based on a topic that garners significant widespread interest and debate (such as perceptions around third-party involvement in and use of NHS data).

References to UPD dropped slightly in 2022, despite the team publishing a series of large projects that year, including the Primary Care Professionals' Attitudes to Data Use report, the Guide to Large Datasets, the Diverse Voices on Data / Closing Gaps in Patient Data for Black and South Asian communities reports, and the Easy Read / Coproduction guides.

References dropped further again in 2023 and 2024. It is possible that part of this can be explained by the transition that UPD went through in moving from Wellcome to the NHS Confederation. None of UPD's newer resources (that is, those by the current team) have made their way into the literature as yet, but it may be that more time is needed for these to be referenced in published literature.

Alongside this, the stakeholders we interviewed felt that UPD's independence and positioning in the system (which is explored further in Section 4c of this report) meant that it would be well placed to be a credible source of health data resources in the future. And while there were no strong views among stakeholders on specific resources that would be useful in the future, it is likely that resources which explore the potential impacts of new digital technologies on public trust (such as the role of AI) and the use of patient data in new and / or growing areas of research interest and application (such as genomics), will be important for UPD to consider in the coming years.

## 4a. Findings – Research and public engagement

---

UPD's research and public engagement activity is very much embedded in (and seen by external stakeholders as part of) the content and resources UPD generates. We explore this idea further in Section 4b later in this report. This makes it difficult to separate out UPD's impact in relation to this area of work. However, stakeholders did point to some specific examples where they felt UPD's work had had quite significant influence:

- Supporting the Welsh Government with their public deliberation exercises, and
- Using UPD content, such as its information on genomics, as pre-read materials for workshops and events, helping to ensure consistent messaging to participants.

*'The Welsh Government RDD team has been developing policy options around the potential use of routine data to enhance the identification and approach of potential participants for research studies. Having chosen a supplier to deliver a deliberative public engagement approach, we needed support to develop the materials being presented to the public in an accessible and engaging way. UPD joined our oversight group to provide advice on designing the exercise and agreed to help shape and present the key information across the three initial explainer sessions. The ability to draw on their expertise and existing materials was invaluable. Having Understanding Patient Data delivering the information materials in an objective way allowed us to present key information without any perceived bias from policy officials or organisations with vested interest, and lent credibility to the exercise.'*

*(Representative from the Welsh Government)*

*'Understanding Patient Data does some critical work in progressing the use of routine health care data for research. Their work has guided much of the research I do and in my role as Chief Clinical Data Officer for HDRUK....significantly impacted our work by...educating the public, patients and PPIE reps about the benefits of using routine healthcare data. Acting as an arms length trusted brand to independently guide clinicians and academics in the best way to do practice.'*

*(Survey respondent)*

## 4a. Findings – Advocating and influencing policy and practice

---

We found promising evidence from this evaluation that UPD generates impact through its work to advocate for the patient data community, and to influence both national policy and practice, particularly in relation to patient and public involvement and engagement (PPIE). Stakeholders we interviewed reflected that there has been a noticeable increase in the number of organisations that are undertaking meaningful PPIE work in relation to patient data, with UPD's work and influence being seen as a contributory factor. There is evidence that UPD has made a noticeable contribution towards 'getting the principle that patient engagement is important, into people's heads'.

UPD's 'insider – outsider' position (explored further in Sections 4b and 4c of this report) is seen as incredibly helpful for other organisations across the patient data ecosystem, including by bringing others into more central policy discussions. For example, UPD was able to set up a positive meeting between the Department of Health and Social Care and Connected By Data to help share Connected By Data's research outcomes. UPD is seen as being able to bring 'outside' voices into 'inside' conversations in constructive ways. Alongside this, a senior NHS England stakeholder commented that their large scale public engagement exercise would not have been undertaken without UPD's influence, both indirectly through its public-facing outputs, and directly through its knowledge of the system and close working relationships with policy leads and decision makers. This was particularly in relation to the governance of secure data environments, the roll out of the single care record, and the future 'opt-out' landscape.

*'UPD were a forerunner of public engagement on data, and that has been a major catalyst for the current focus on public engagement being a critical enabler to data transformation, through building and maintaining patient trust. That has been a key building block for the large-scale public engagement currently being delivered by DHSC and NHSE, which is supported through about £2m of funding. That financial commitment might never have happened if it hadn't been for UPD's previous work and making the continued case for public involvement'. (Joe Watts, Head of Data Access and Linking Policy, Department of Health and Social Care)*

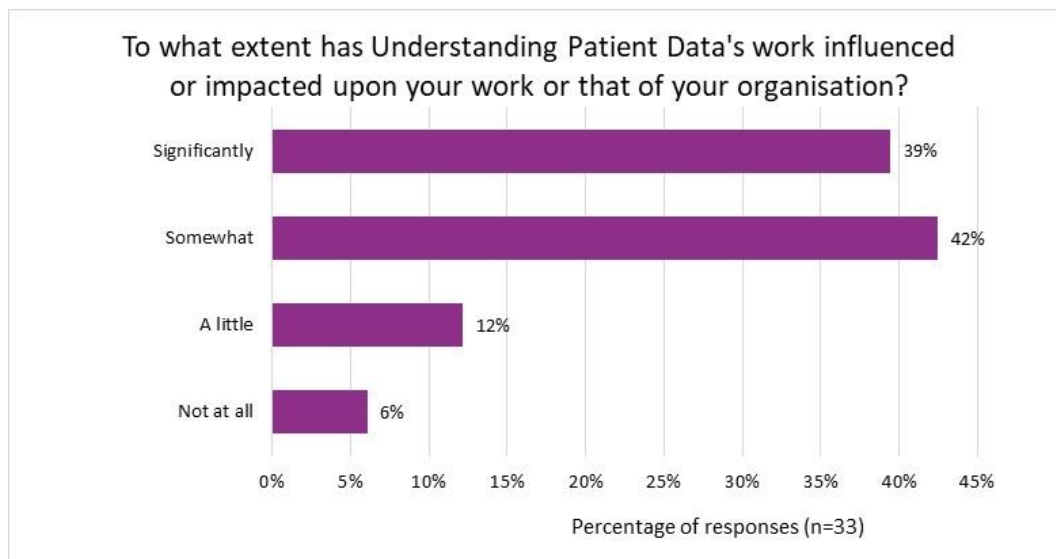
*'They are a very useful insidery kind of organisation, for helping the outsiders also to be more effective and bringing outside messages into the system in ways that they otherwise wouldn't hear. I think it's really important to have that somebody, who can bring some of those messages in, in a way that's going to be heard.'*  
(Jeni Tennison, Founder and Executive Director, Connected By Data)

## 4a. Findings – Advocating and influencing policy and practice

*‘They [UPD] aren’t running big public campaigns, and aren’t directly creating policy, and they’re happy to occupy that quite niche space. From my perspective, I think that that’s where they best fit.’*

*(Ellie Munari, Communications and Engagement Manager, NHS Transformation Directorate, NHS England)*

The stakeholder survey findings also support a high degree of influence through UPD’s work, with 81% of respondents saying that UPD has impacted their work (or that of their organisation) ‘significantly’ or ‘somewhat’ (Figure 8).



**Figure 8: Extent of UPD’s influence on individuals and organisations according to survey respondents (n=33)**

Some stakeholders that we interviewed also noted that they felt that there had been a noticeable increase in the number of organisations delivering meaningful public engagement work, which they believed was at least in part attributable to UPD’s resources and influence in this area.

## 4a. Findings – Advocating and influencing policy and practice

---

UPD's work has also led to a shift in the language that individuals and organisations use, with the 'What Words To Use' publication being particularly influential. Examples frequently mentioned by stakeholders who participated in the evaluation include:

- Foundations of Fairness was shared by Wellcome colleagues with the Aapti Institute in India, an organisation that operates 'at the intersection between technology and society' and which found it valuable as a reference point for discussions with central Government, to demonstrate similarities in how people think about patient data
- The UK Government's National Data Guardian will frequently refer people to UPD, as a source of information to guide their own practice / approach, and also to help problem solve particular issues, and;
- UPD research and publications were used by Cancer Research UK's health policy team to help inform their own organisation's position on various data policy issues.

*'I think a lot of the language that we use in the sector is really guided by UPD research and their resources. So the fact that, for example, now when we are talking to the public, we never say direct care, we say individual care, because UPD's research proved that that's what resonates more with people and they didn't understand what direct care means.'*  
(Ellie Munari, Communications and Engagement Manager, NHS Transformation Directorate, NHS England)

*'In the early days, we didn't have any of that [resources that explain patient data terminology]. So we were trying to have conversations with the public about things like pseudonymised or anonymised data. How do you explain that? I'm not a technical expert, and we were writing explainers and we were getting it horribly wrong. So they [UPD] put a real foundation level in there of trying to explain some of those concepts, you know, anonymised data, the different use cases for data, the legal basis for processing data, all that sort of stuff, they'd be really good at just creating that baseline of how organisations should talk about it.'*

(Jacob Lant, Chief Executive, National Voices)

## 4a. Findings – Advocating and influencing policy and practice

---

Furthermore, stakeholders mentioned a number of specific examples where they felt UPD's influence on practice in relation to health data had been particularly notable. These included:

- UK Biobank – where UPD's research influenced their approach to gathering data and directly supported the shift towards a Trusted Research Environment (rather than access to data via downloads), including providing a rationale for this to their board and funders
- Cancer Research UK – where UPD's resources are used to inform their public involvement work and have shaped internal policy in this area
- NHS England – supporting clear external messaging in relation to the NHS Federated Data Platform, its purpose and intended uses, and to build trust among healthcare professionals and the wider public.

## 4a. Findings – Developing the patient data community

---

This area of UPD's work is defined as those activities that 'support those who work with or care about patient data, through convening and partnership projects, building a network of advocates and disseminating good practice.' This includes:

- Providing 1:1 support, such as through conversations with individuals and people who contact UPD for advice
- Speaking at events, as a keynote speaker or as part of panels
- Representing the patient data community through publications and involvement in meetings and forums, and
- Undertaking partnership projects.

This area of work is generally seen as important (66% of survey respondents rated it as 'very important' or 'moderately important') and of considerable value:

*'I have read the UPD reports with interest as they help to provide evidence to support the work that we do. UPD also supported and promoted our recruitment drive to gain new volunteer members.'* (Survey respondent)

*UPD resources are very useful for sharing with team members as explainers. Nicola H sits on our public engagement steering group, providing really helpful direction and feedback. And Nicola chairs the PPECAP meetings, which my team jointly own internally.* (Survey respondent)

*UPD has significantly impacted our work...UPD provides really clear resources, which are useful for sharing and learning, as well as developing our own materials and ensuring we get things right. UPD provides a constructive and clear voice in meetings, enabling an efficient working environment, with expert input.*

*(Representative from the Department of Health and Social Care)*

## 4a. Findings – Developing the patient data community

---

Stakeholders also tended to support the idea that UPD could play more of an overarching ‘convening role’ across the patient data community. There was some concern that this may overlap with some of the work being undertaken by other groups, for example PEDRI (Public Engagement in Data Research Initiative), the NIHR / Health Research Authority Shared Commitment for Public Involvement Group, and the UK Health Data Research Alliance, although their scopes vary and don’t cover UPD’s remit specifically.

Notwithstanding this, some stakeholders were concerned that key people may struggle to commit to being part of another forum or group. However, UPD could leverage its reputation, positioning and expertise in relation to patient data specifically, to convene a ‘light touch’ community of practice space for PPIE practitioners working on health data issues. This could involve creating spaces for shared learning, discussion of challenges, and dissemination of best practices. It could also help to inform emerging gaps and needs across the system and topics for future UPD research and / or resources.

*‘I think they could also play a really interesting role in coordinating all the different engagement that's happening, even if they're not directly involved. I feel we need to get a wrapper on all these different pockets of engagement that are happening and make sure there's no overlap and duplication.’*

*(Ellie Munari, Communications and Engagement Manager, NHS Transformation Directorate, NHS England)*



## 4a. Findings – Media commentary and content reach

---

### The UPD website

Website analytics (collected since UPD moved to the NHS Confederation in April 2023) show fairly consistent traffic to the UPD website with occasional spikes associated with the publication of research reports, or following publicity at events. Examples include UPD's patient and public involvement and engagement (PPIE) award at the Health Data Research UK conference in March this year, and a joint blog about the Federated Data Platform in November 2023. Traffic comes primarily from the UK, followed most commonly by the United States of America, Australia and New Zealand. The website also receives small pockets of traffic globally, including across Europe, Africa, Asia and South America.

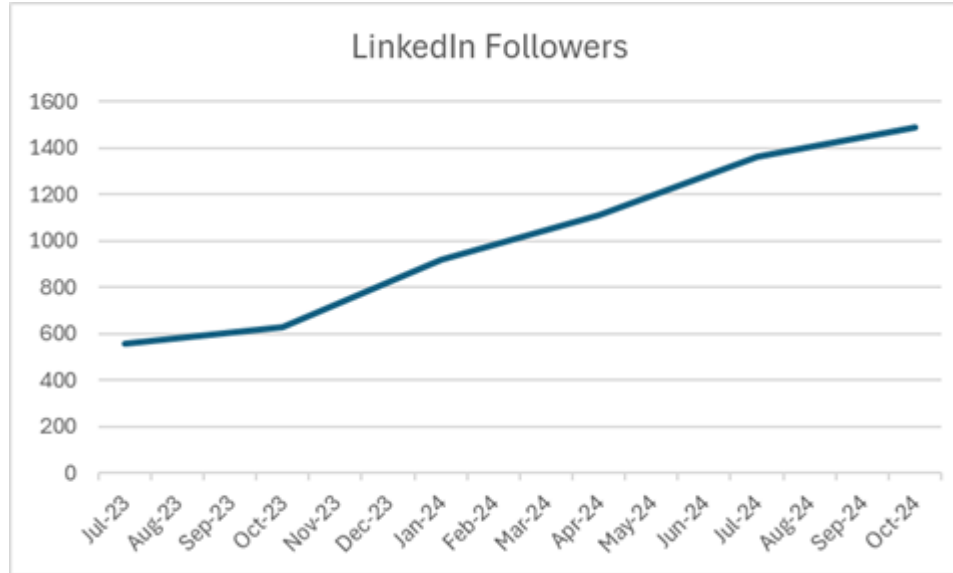
The highest viewed pages are 'how is data kept safe?', 'Why is it important to use patient data?', and 'What are the risks around patient data?'. The 'How do people feel about the use of data?' content has also started to receive an increasing number of views in recent months. A number of other website pages have been referenced in the academic literature, including the FAQ page and some blog posts. This reinforces the need ensure that all website content is kept up to date (as opposed to the creation of new content) which can be difficult to do within the current resources available to the team.

### Social media channels

In relation to social media, UPD's X (formerly Twitter) and LinkedIn accounts have around 5,600 and 1,500 followers respectively. The latter has been more recent (the LinkedIn account was created in April 2023) and is the result of a concerted effort by the team since that time to attract new followers (Figure 9). In both cases, most interactions happen when UPD's posts relate to more controversial issues / topics / events (such as a data breach that is receiving wider media coverage) or following the publication of more significant research reports. While effectively managing and making the most of this online presence likely requires a level of dedicated resource in the UPD team (something which is currently limited alongside other areas of work), social media does appear to have some value in relation to increasing UPD's reach into the wider system, including those who may be less familiar with UPD's work.

## 4a. Findings – Media commentary and content reach

The UPD team also sends out periodic newsletters to promote new (and generally more significant) content. This currently goes to around 160 subscribers and receives a small increase in the number of subscriptions each quarter (typically via the UPD website).



**Figure 9: Number of followers for UPD's LinkedIn account since July 2023**

UPD has received some prominent media coverage in recent years, largely through quotes and references in trade publications and academic journals, some of which are then covered in more mainstream media. Examples include:

- 'The human side of health data', published in Nature Medicine (July 2020)
- An article in the Health Service Journal (February 2020) setting out the risks of the NHS sharing patient data unlawfully.

## 4a. Findings – Media commentary and content reach

---

- A response by the Association of the British Pharmaceutical Industry on UPD securing future funding (December 2022): ‘Understanding Patient Data (UPD) has played an influential role in the health policy landscape, communicating the views of patients and the public and championing the trustworthy use of health data.’
- A news article on the Digital Health website (‘We need to bring the public with us on NHS data’) following an event on data infrastructure and architecture in the health space (September 2023)
- A news article in the British Medical Journal (BMJ), ‘Sell access to NHS data to boost health innovation, say Blair and Hague’ (January 2024)
- As part of NHS England’s announcement of its large-scale public engagement exercise on the use of health data (September 2023)
- An editorial in the BMJ (co-author) in February 2024, and
- A compilation of expert reactions to an announcement by the new Secretary of State for Health and Social Care (October 2024) about the Government’s policy direction for consented cohorts, OpenSAFELY pilots and exploring a single digital health record.

Feedback from a journalist that previously worked with UPD included some suggestions for increasing UPDs reach into both scientific and more mainstream publications and media channels. These included:

- Proactive engagement with health journalists (1:1 and / or through media engagement events) so that they better understand UPD’s aims, scope of work, and potential to offer expert opinions on different topics, and who can then work collaboratively with UPD to identify potential stories and effective routes into the media.
- Providing named expert opinions (and quotes) for stories that are already being researched. This could include opinion(s) from the core UPD team and / or bringing in relevant people from UPD’s steering group, which represents many different aspects and perspectives of the health data landscape.

## 4a. Findings – Media commentary and content reach

---

Stakeholder feedback also supports the view that UPD's content is useful, especially as an independent and neutral view that can simplify quite complex issues and concepts. Stakeholders generally view UPD's tone with regard to its external communications as helpful and correct for the context, although there is an appetite among some for a more active external communications function, especially in relation to proactively responding to media coverage that may not present an accurate view of the evidence concerning public attitudes about patient and / or health data.

*'How is this approach safer than what's happened in the past? Why is what the government and the NHS are trying to do is a good thing? These are both quite complex things to communicate to the public, and UPD's position as both an advocate for better data use, while being an independent critical voice allows them to present a balanced, trusted assessment to the public and wider stakeholders is quite unique. On top of this their [UPD's] work to deliver specific tools and explainers are also helpful, explaining complex things clearly in a way that the general public understand, and that civil servants and technical experts can struggle with.'*

*(Joe Watts, Head of Data Access and Linking Policy, Department of Health and Social Care)*

## 4a. Findings – Impact story

### **Department of Health and Social Care – shaping a large scale public engagement exercise on health data**

Following the publication of the Data Saves Lives strategy in 2022, NHS England embarked on a £2 million programme of large-scale public engagement, to help inform future data policy, and to continue to build public understanding and trust in the use of health data.

As a member of the group overseeing this programme of engagement, UPD has been able to work closely with DHSC and NHS England to shape the priorities and discussion topics for the exercise, and to help bring in the latest insights and evidence about what is important to the public when it comes to the use of their health data, and how particularly complex issues around health data can be most effectively communicated and understood.

UPD reviewed and commented on the different materials being used as part of the public deliberations, and existing UPD resources have provided inspiration for their design, including ideas around the appropriate language to use, and using UPD's diagrams and visuals to help convey quite complex terms and principles in a simple way.

This has made a major contribution to the effectiveness of NHS England's public engagement around health data to date, helping to ensure those discussions make sense to a very wide audience, and improving the quality and depth of evidence that is now available to inform future policy and decision making at a national level.

UPD's expertise and resources also regularly inform NHS England's programme-specific engagement with stakeholders, the public, and patients, alongside these wider and larger public deliberations.

## 4a. Findings – Impact story

### The NHS Federated Data Platform – supporting proactive and open communications to build public trust

The NHS Federated Data Platform (FDP) is a technology solution that aims to bring together NHS operational data, currently stored in separate systems, so that the health and social care system can make better use of all the data routinely collected as part of the provision of healthcare services. Federation – in this context – is a process that uses software to connect many existing systems so that they can function as one. The aim is that better use of its own data will help the NHS to improve how it arranges and delivers care. A contract for the provision of the Federated Data Platform was awarded by NHS England in 2023 and roll-out is now well underway.

UPD, in collaboration with other organisations working to support the voice of patients and members of the public in relation to health data, was actively involved in critiquing NHS England's external communications about the platform. This included encouraging them to address openly (and up front) both the potential benefits of the FDP and the potential risks, and the opt-out position, especially from the perspective of patients and the public. Risks such as the concerns patients may have about who will be able to see their data, worries that their data may be exploited for profit, and a need to fully understand the privacy protections that will be in place. UPD advised on topics that needed to be covered and appropriate language choices. UPD's positioning as an independent authority on health data, and deep understanding of the concerns that the public might have when it comes to large data projects like this, were crucial for the development of communications that would build public trust. UPD also suggested the creation of a portal for people to ask questions and provide feedback, which was acted upon, a technique which has also been used on a greater scale for the NHS 10 year plan a year on. This informal critique then became a more formal Check and Challenge programme, bringing voices from the civil society sector into the programme's roll out.

The FDP has the potential to generate enormous public benefit. UPD's input will help improve public and professional understanding, and potentially support, therefore putting it in a better position to succeed over the longer term.

## 4a. Findings – Impact story

### **Welsh Government's public deliberations: using data to identify and approach people for research**

The Welsh Government's ambition is to realise Wales' unique health data offer to become a high class destination for life sciences research and development. This relies on increasing the linkage and breadth of data available to securely access and analyse, as well as supporting faster and more effective clinical trials enabled by a data-driven service.

The current legal position across the UK is that individuals generally can't be contacted about taking part in research without having given their consent to be contacted beforehand. Whilst Wales makes use of registers to do this, there is a reliance on people actively signing up, and there were concerns that this might not meet public expectations about being alerted to relevant options, as well as not making use of the large and diverse population.

A group of experts was established to provide direction and challenge to the project. UPD was part of this group, and provided input at a strategic level (critiquing decisions on which issues should be tested and how), in addition to input at a practical level (reviewing materials, providing advice to the supplier, delivering presentations at the deliberation sessions and answering participants' questions).

UPD's resources were also used to help explain concepts such as identifiability and secure data environments.

Welsh Government and the supplier greatly appreciated the ability to draw upon UPD's objective resources and voice as it allowed them to present key information without perceived biases in an accessible and engaging way. This supported with building a positive relationship with the participants and making the exercise credible, which is essential for taking the recommendations forward into policy development.

## 4a. Findings – Impact story

### **Data Saves Lives: adapting and sharing the UK's approach to patient data in European Union member states**

Data Saves Lives is a multi-stakeholder initiative with the aim of raising wider patient and public awareness about the importance of health data, improving understanding of how it is used and established a trusted environment for dialogue about responsible use and good practices across Europe. It is led by the European Patients' Forum (EPF) and supported initially by the European Institute for Innovation through Health Data (i~HD), and has now been running for five years.

It was established originally because the European Patients' Forum and its members became aware, through a presentation at the European Federation of Pharmaceutical Industries and Associations (EFPIA) Patient Think Tank in Brussels, of the Understanding Patient Data initiative in the UK, which started a couple of years earlier. It was evident that countries in the EU were facing many similar problems to those experienced in the UK; low awareness of how patient data is used, varying levels of public support, and a lack of clear, simple information about concepts such as data sharing, the data journey and the safeguards in place.

*'Hearing about 'Understanding Patient Data' was a "aha moment" for us – we recognised the gaps across Europe regarding patients' understanding and trust in responsible health data sharing, and a group of us came together to work out how we could address these, inspired by the impact of UPD in the UK'* said Nicola Bedlington, Secretary General of EPF when Data Saves Lives was set up.

The team at EPF had many conversations with the team at UPD to understand what they did and consider how best to adapt it for a broader European context. This led to the creation of Data Saves Lives as a Platform, with educational materials, communication campaigns, and training sessions, not only at the EU level but also in several member states such as Germany and the Netherlands.

Data Saves Lives and Understanding Patient Data continue to have a close relationship, sharing policy analysis and materials relating to the EU's new European Health Data Space.



## 4b. Findings – UPD's 'cycle' of impact

---

While UPD generates quite tangible and notable impacts through each of its five areas of work, for individual professionals / practitioners, organisations, and across the wider patient data landscape, those impacts are most pronounced (and more likely to happen) as a result of the combination of activities which span those areas of work. One way of representing this could be as a continuous 'cycle', which begins with relationship building (to identify needs and gaps across the system), moves on to gathering evidence about public attitudes and / or how best to address a particular need or gap, and then, supported by the co-creation of resources, UPD exerts influence directly and indirectly in relation to how people operate when it comes to patient data (Figure 10).

This notion fits with the perceptions and views of those external to UPD (as found through this evaluation), and the experiences of the UPD team, including how their work is planned and delivered.

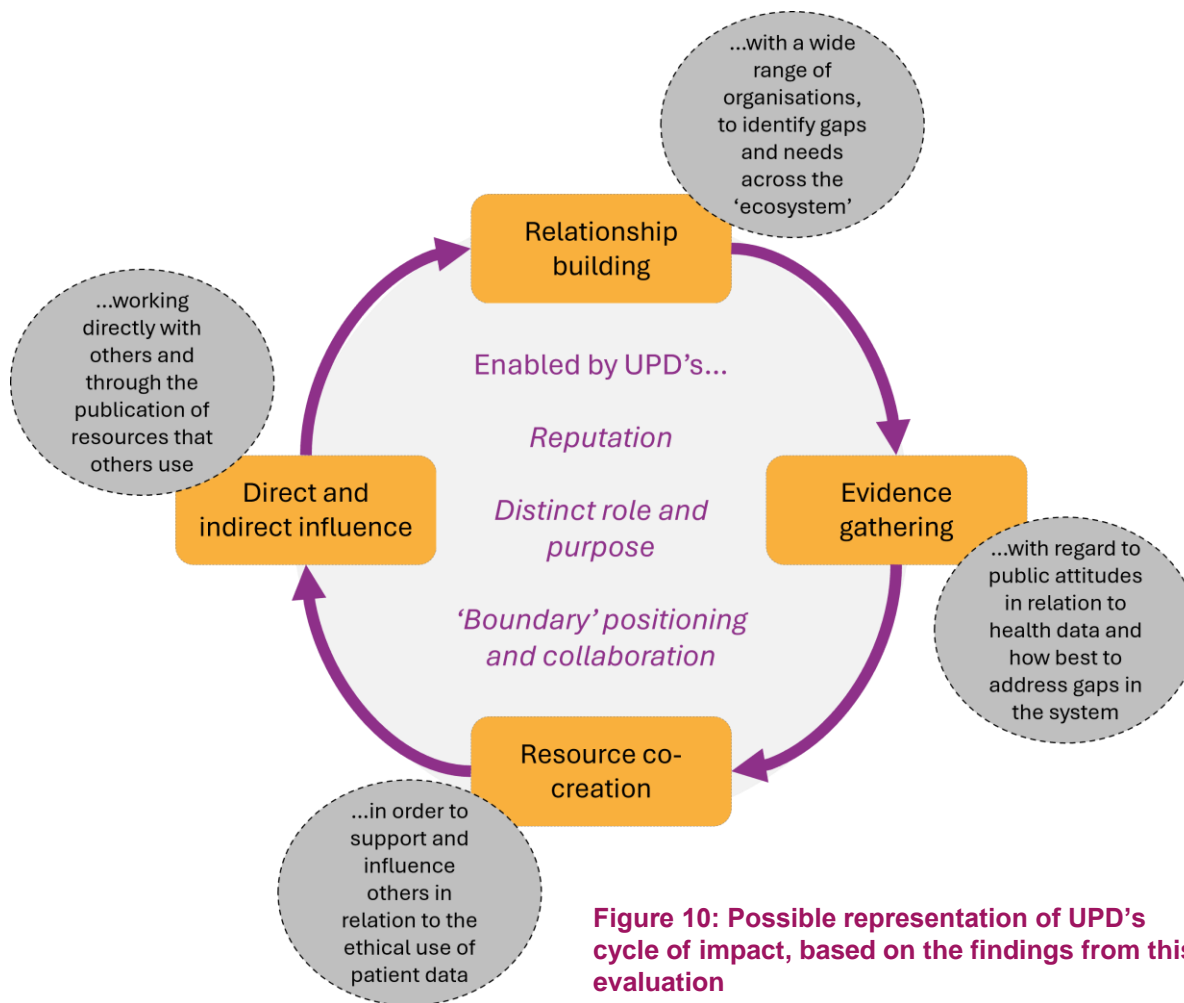
We believe that this cycle can happen as a result of UPD's:

- Reputation and brand recognition among those working in a wide range of roles and contexts across the patient data landscape
- Distinct role and purpose
- 'Boundary' positioning, and
- Engagement and communications activity, and reach into a wide range of relevant forums and groups.

### Reputation and branding

UPD benefits from a very strong brand recognition. It supports, is trusted by, and has 'the ear of' researchers, clinicians, policy professionals, regulators, and members of the public. It is widely cited as an important and notable initiative. UPD is also viewed as 'neutral' regarding the use of patient data. That is, people see UPD as being concerned with supporting constructive debate and discussion, rather than taking a particular view one way or another.

## 4b. Findings – UPDs ‘cycle’ of impact



**Figure 10: Possible representation of UPD's cycle of impact, based on the findings from this evaluation**

## 4b. Findings – UPD’s ‘cycle’ of impact

---

Linked to this, UPD is viewed as highly independent, although this does mean different things to different stakeholders. Some mean independent from Government or the NHS (and therefore being able to take a stance which may go against current policy). Others mean independent in a more general sense, such as being able to focus on gathering the evidence and using that to produce relevant and useful information for others to use, or being an informed ‘critical friend’ on particular issues. Stakeholders see the UPD team as transparent and operating with integrity.

We also found that UPD’s current hosting arrangement (NHS Confederation) is not seen as either a particular benefit, or concern for UPD’s work and reputation. However, were UPD to be hosted by an NHS body or central Government, this could be seen as a move away from the level of independence UPD currently has.

*‘Nicola knows what the inside are trying to do, which helps her talk to the inside, but she’s not a champion or cheerleader, she is there to shape and scrutinise.’*

*(Joe Watts, Head of Data Access and Linking Policy, Department of Health and Social Care)*

*‘They are known for being trustworthy, clarity of message and being collaborative. Being affiliated with the NHS Confed (and the NHS) might be important for some people, as it’s a trustworthy brand. But being hosted by NHS Confed isn’t something that people think about, or I think really influences UPDs work.’*

*(Rachel Edwards, Public Engagement Officer, Research Data Scotland)*

*‘Having an organisation that explains very complicated regulations and policies and things is actually very crucial. And especially making sure that that voice is a neutral voice that’s respected is really crucial. So I think UPD fulfills a very, very important need.’*

*(Doreen Tembo, Head of Public Involvement and Engagement, Health Data Research UK)*

## 4b. Findings – UPD's 'cycle' of impact

---

### Distinct role and purpose

UPD is seen as holding a distinctive role in the patient data landscape. It doesn't hold a particular view about the use of patient data that some other organisations hold, it doesn't represent particular groups, it doesn't perform a formal Government advisory function (such as the National Data Guardian), and it doesn't focus solely on working with particular sections of the patient data community (such as PPIE professionals or researchers). UPD is also considered different because of its focus on all uses of health data (not just health data for research), including data governance, and bringing in the patient voice to the debate. However, it is able to hold strong, trusted relationships with many of those other organisations which means it can tackle issues in a more balanced and evidence-based way.

*'In my mind I always split them [patient focused organisations in the health data landscape] into two categories. Some of them are national patient groups that focus on patients but also have an interest in data and digital and how that impacts people. And then you have specific advocacy groups, who focus on specific perspectives relating to the use of patient data. But I think UPD occupy a really unique space, because they're quite a neutral body. They're independent from the NHS and from DHSC, but they're really focused on the patient perspective when it comes to data. And I think the health data landscape is incredibly complicated.'*

*(Ellie Munari, Communications and Engagement Manager, NHS Transformation Directorate, NHS England)*

UPD's distinctive role means that it can hold relationships with many different key stakeholders and groups, supporting both a better understanding of the different perspectives, and providing a platform from which to influence practice among those working at different points along the patient data 'journey' (from when data is collected through to both primary and secondary uses). It also means that it can provide clear and honest communications. UPD is not, by virtue of its central purpose, held to a particular view.

## 4b. Findings – UPD’s ‘cycle’ of impact

---

### Working across boundaries and collaboration

By virtue of UPD’s distinct role and purpose within the patient data landscape, we found strong evidence that its impact is very often driven by an ability to work across the different boundaries that exist in the system, and to effectively navigate different (and sometimes quite polarised) perspectives and positions. Figure 11 illustrates how this plays out in practice, bringing together UPD’s independence, neutrality, use of evidence, and overall knowledge and expertise. UPD’s work on trying to develop a shared language is seen as instrumental in bringing people together, promoting the importance of public engagement, and moving the patient data ‘debate’ forward in a positive way.

*‘The NDG has a formalised role in legislation which allows her to have influence and sway which is important. But the more informal, cross-organisational space that UPD sits in is different and complementary. They come at the same problems from different perspectives, with the NDG having a focus on legal protections, and ensuring people’s confidential information is kept safe and used properly. I see UPD having a unique role in championing how the ‘system’ communicates and explains what changes are happening, and to ensure the public are involved in those changes.’*

*(Joe Watts, Head of Data Access and Linking Policy, Department of Health and Social Care)*

*‘Their resources and work has a language standardising and socialisation effect, notably with PPIE professionals.’*

*(Matt Howard-Murray, Public Involvement Lead (Research Data Strategy), Cancer Research UK)*

*‘Transparency and integrity resonates through the team, and the values of the individual shine through. UPD leaders have consistently demonstrated these values – they are extremely collaborative by nature.’*

*(Natalie Banner, Director of Ethics, Genomics England)*

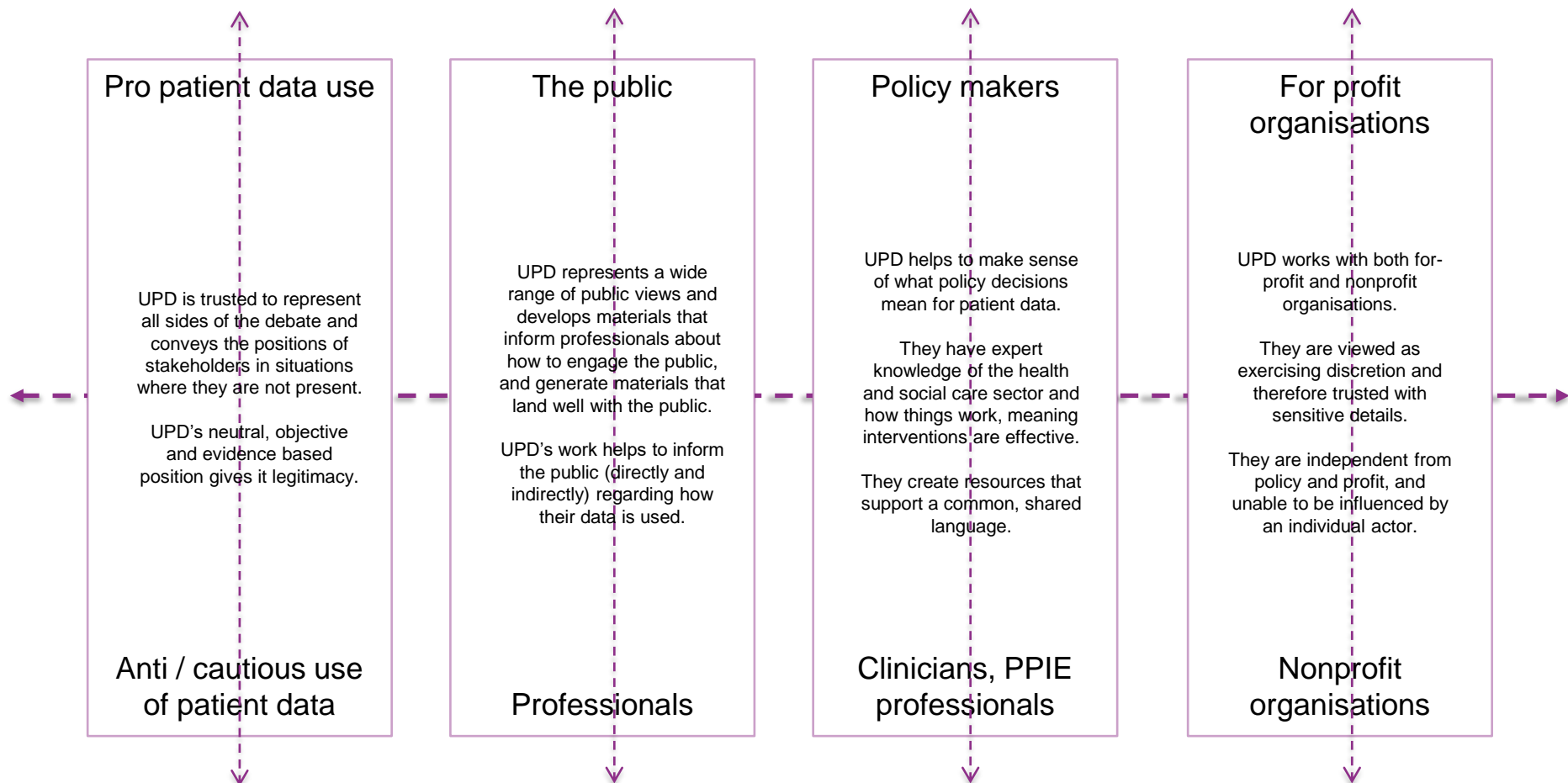


Figure 11: A representation of UPD as a 'boundary spanning' organisation

## 4c. Findings – UPD’s influence and value at a system level

---

We found some promising evidence that UPD’s work generates influence and value at a whole system level. This is because UPD:

- Is seen to represent the views of the public and, through its resources, to help keep them informed about how their data is used
- Connects and provides relevant and useful information for professionals
- Holds system-wide knowledge and expertise that doesn’t exist elsewhere, and;
- Helps to increase the value of other investments.

### Representing the views of, and informing, the public

UPD’s research and resources are seen by others working in a variety of roles across the patient data landscape as being useful because they reflect the views of the public, and can be used in turn to support other public engagement work and build greater understanding among different groups. The Spectrum of Identifiability graphic is particularly valued and routinely used, as a clear and simple visualisation of the differences between personal data, pseudonymisation and anonymisation – concepts that can be difficult for those outside of the system to understand, but which are central to building public trust. And while UPD has a strong focus on the patient voice, it understands some of the nuances when it comes to practical applications and can convey these effectively in the content it creates. UPD has actively shaped large scale public engagement work by central Government and associated communications.

*‘[Our UPD representative] challenges in a really professional and helpful way. Her comments will stimulate discussion by patients and publics, and she is in a position to answer the questions that the patients and the public have. She cuts through some of the technical stuff better than NHS staff do.’*

*(Ellie Munari, Communications and Engagement Manager, NHS Transformation Directorate, NHS England)*

## 4c. Findings – UPD’s influence and value at a system level

### Connecting and informing professionals

The UPD website is seen as an important library of resources among professionals from a range of different backgrounds. Stakeholders often spoke of referring to the UPD website before starting a project, and more generally, to keep up to date with what is happening in the patient data space (particularly in relation to PPIE). Some also mentioned that UPD was identified as an important resource when they started in their role.

Professionals view UPD as the ‘go to’ for explaining what de-identified data is, what words to use when engaging others, understanding and explaining trusted / secure research environments, and concepts such as ‘big data’. UPD’s resources are clear and they make sense to the public, meaning that they can be used in a wide range of contexts.

In addition to this, survey responses show that professionals most often engage with UPD through UPD’s resources and research, browsing the UPD website, and working more directly with the UPD team. This may include both formal and informal conversations, convening small discussion groups, and offering one-off advice and guidance on particular issues. There is also a sense among stakeholders that UPD’s work has led to a greater level of NHS / clinical engagement in patient data discussions compared to five years ago.

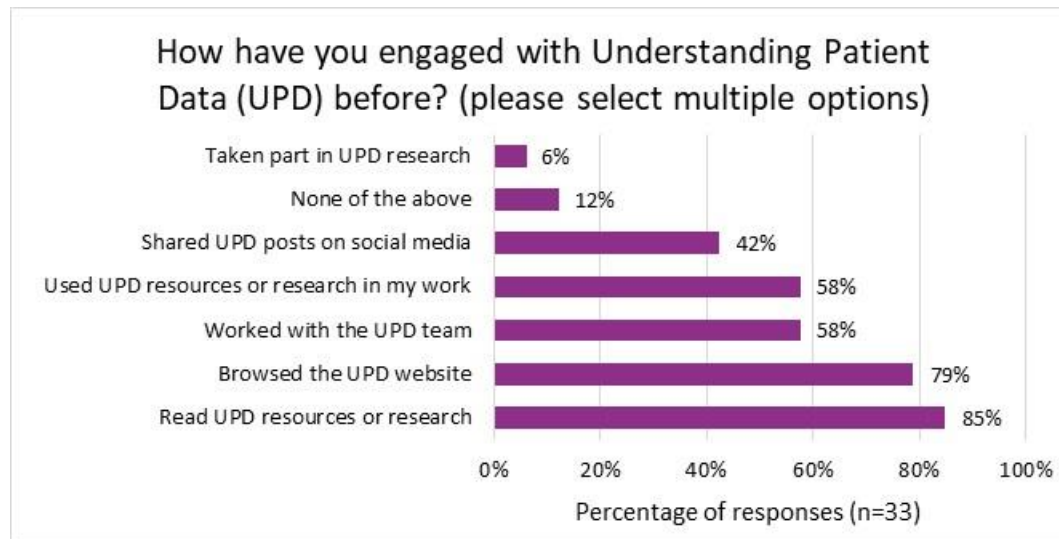


Figure 12: Ways of engagement with UPD among survey respondents (n=33)



## 4c. Findings – UPD's influence and value at a system level

---

### Knowledge and expertise

Stakeholders see the UPD team as having an in-depth view of what is happening across the sector, how the interactions between different organisations and key actors work, and holding a deep understanding of different perspectives and practical challenges (through both explicit and implicit (tacit) knowledge). They are also seen as being able to translate quite complex and sometimes abstract concepts, into tangible outputs that people can use.

However, given the small size of the team, much of this knowledge and expertise lies with a few individuals, and this may impact UPD's ability to deal with any future staff changes, especially in terms of maintaining a consistent approach, and building and sustaining momentum.

### Increasing the value of other investments

It is widely recognised by external stakeholders that UPD's work adds value to investments (and potentially saves money) elsewhere in the system. UPD does this by:

- Removing the need for others to undertake public attitude work on those things already covered by UPD (in particular terminology explainers and use of language that the public will understand)
- Creating resources that are relevant and easy to use / adopt in a range of contexts, particularly with regard to how patient data is used in different contexts, what is important for the public to understand, and how to explain more complex topics (such as UPDs work on Secure Data Environments) in a simple and effective way.
- 'Joining the dots' and helping others to understand the wider patient data landscape, including current and emerging issues, the views and attitudes of particular groups, and explaining health data policy and practice.
- Freeing up time by knowing that UPD will represent the interests (and amplify the voices) of a wide range of system players at key meetings and forums.

Note, however, that no-one who we interviewed as part of this evaluation was able to quantify what the scale of any financial savings might be elsewhere in the system.

## 4c. Findings – UPD’s influence and value at a system level

---

*‘[UPD]...absolutely increases the value of other investments – if UPD didn’t exist, stimulus packs for NHS England’s large scale public engagement exercise wouldn’t have been as good as they were. It would’ve been more work and the resources wouldn’t have been as good because we used so many UPD materials and knew they had already been tests and designed with people. We can then build on this work and these conversations since we know how to talk to people about deidentified data...’*

*(Ellie Munari, Communications and Engagement Manager, NHS Transformation Directorate, NHS England)*

*‘UPD needs to exist – it’s a vital part of the infrastructure.’*

*(Sam Smith, Coordinator, MedConfidential)*

*‘The work UPD have done is valuable. It’s provided a baseline for ‘what good looks like’ when engaging the public in health research, and it provides a general understanding of the public’s expectations and priorities. It does make everyone’s job easier, letting teams working in health research focus on work that’s unique to their priorities rather than having to start from scratch on public engagement. Speaking with colleagues in government and funders, many would agree that if UPD didn’t exist, you’d probably end up creating something like it again, for the efficiency it offers the field as a whole.’*

*(Tariq Kohkhar, Head of Data for Science and Health, Wellcome Trust)*

...



## 5. Implications of these findings

## 5. Implications of these findings

---

The findings from this evaluation provide a number of considerations for UPD as it moves beyond the current funding period, and which could strengthen both its standing, and the value it generates across the patient data landscape. These are set out below.

### Securing future funding

- Continue to highlight the risk of UPD not being there, with particular reference to its unique role and positioning within the patient data landscape, and why this means it is well placed to promote constructive and evidence-based debate on a wide range of topics / current issues.
- Alongside the above, build greater recognition among funders of why shorter term funding can cause uncertainty among those looking to UPD to support their work, and may result in UPD being more 'reactive' to the issues of the day, rather than being able to take a long term view of what a trustworthy patient data system needs to be.
- Continue to explore a diverse funding portfolio, while recognising that general public sector or nonprofit funding is likely to be perceived best among external stakeholders.

### Creating a 'community of practice'

- Consider facilitating some sort of 'community of practice' for public / patient involvement practitioners working on health data issues. This could involve creating spaces for shared learning, coordinating work, discussion of challenges, and dissemination of best practices, rather than just providing one-off resources. This would need to include consideration of how such a forum would be different from potentially similar or overlapping convening / community of practice work by other organisations (including, for example, PEDRI, Connected by Data, and the National Institute of Health Research), such as being more focused on particular topics and by playing a more direct advocacy and public engagement function. Longer term funding would also support UPD to look further ahead, identify emerging issues earlier, and use a forum like this to begin identifying and understanding the potential knowledge and evidence gaps. A community of practice could also provide opportunities for income generation (depending on its defined purpose and function) outside of UPD's core funding agreements.

## 5. Implications of these findings

---

### Resources

- Consider developing resources tailored more for use by pharmaceutical / life sciences organisations, within the boundaries of UPD's mission, and in a way that supports UPD's independence and neutrality. This may include demonstrating how positive health outcomes can emerge from both profit making and non profit / statutory organisations, and the importance of bringing the public along.

### Research and public engagement work

- Explore the potential to increase in-house research capacity, thereby reducing the need to commission some external research, raise funding, and to further capitalise on UPD's internal knowledge and expertise.

### Communications

- Consider, as part of any future funding agreements, an increased external communications capacity, which could support more proactive messaging around emerging issues and help to manage uncertainty and risk as new technologies and patient data initiatives are developed. This could be supported by the inclusion of more prominent voices from those with subject matter expertise and / or experience of the political / health policy environment.

### Overall priorities

- Consider the potential to increase visibility and reach in those areas where UPD's presence is less well known. This could be in front-line health settings, through work across the whole care spectrum (including, for example, with primary care and in less specialist clinical areas by making information available in GP practices and engaging with Caldicott Guardians in hospitals), and increasing the use of social media to disseminate existing materials and videos.
- Explore the potential to increase UPD's expertise in relation to technology infrastructure and capabilities (including future innovations) to produce more resources covering the whole 'data pipeline' and the potential risks and issues that will need to be taken into account.

## 5. Implications of these findings

---

- Consider if (and how) UPD should increase its international presence, building on the reputation it has already built in other parts of the world. This may help to bring in additional learning from other countries and practice examples that can be brought into local debate and influence.
- Should there be a further reduction in the size of UPD's overall funding, consider whether UPD's impact could be maintained by concentrating research efforts and policy advocacy on a smaller number of specific, high-impact areas of health data use rather than trying to cover the full breadth of issues that need to be tackled in some way across the patient data landscape, without risking UPD's positioning and distinctive role in the system. While there is no evidence from this evaluation to suggest that this type of shift is necessary at this stage (or indeed that it would be feasible within the context of any future reduction in the team's capacity), it may be a way of continuing to have a positive impact on the system while staying true to UPD's values and positioning.
- For the longer-term strategic direction, review the extent to which an entirely separate entity (for example a charitable organisation) might help or hinder UPD's aims and programme of work, as opposed to continuing to be a hosted initiative.

John Newman, Director

Email: [john@apteligen.co.uk](mailto:john@apteligen.co.uk)

Tel: 07789 896022



[www.apteligen.co.uk](http://www.apteligen.co.uk)

Egale 1  
80 St Albans Road  
Watford  
WD17 1DL

Sam Mackay, Director

Email: [sam@apteligen.co.uk](mailto:sam@apteligen.co.uk)

Tel: 07866 463434