National Patient Data Day (NPaDD 2025) – Summarising the impact

Purpose of this paper

This is a short paper for the use MY data Executive Group, written by the Secretariat, summarising some of the metrics, feedback and impact of the first National Patient Data Day (NPaDD) conference.

The paper has been divided into themes, each highlighting a specific aspect of the conference. The contents of this paper will also be used to form the basis of a public document on the impact of NPaDD.

We satisfied the brief that we were given for the conference

The original conference committee, comprising six Members (including three from the Executive Group) and facilitated by the Secretariat, produced the original ideas, concepts and requirements for NPaDD. The Secretariat then took these forward, reporting regularly to the Executive Group.

The original specifications were:

- An overarching theme to underpin the day - celebrating the use of patient data across the UK
- Having key speakers
- Showing how healthcare data has benefitted patients
- Ensuring Members could take part in discussions, not just “be talked at”
- A patient data soapbox session
- A dynamic exhibition and ensuring delegates visited the exhibition stands
- Including commercial companies throughout
- Making sure audience questions and feedback were captured
- Seeing if opinions shifted during the day

The day was designed and described as a celebration of using patient data, across the UK. We used this across all of our conference promotion and in all speaker briefings, as a key point.

We attracted a good range of key speakers and panellists, from across the UK and each session had a Member of use MY data either chairing or speaking. This mix worked well.

For the opening plenary session, the devolved nations panel featured speakers from Wales and Scotland. We had tried to include a speaker from Northern Ireland, however the initial speaker booked had to withdraw. The second speaker booked to replace the first also had to withdraw, shortly before the conference. We did not have time to secure a third speaker. We should have announced this at the start of the session, as it appeared to some delegates that we had decided not to include Northern Ireland.

Our soapbox session was very well received and was very sparky and positive. Alongside the roundtables, this helped to differentiate our event from traditional conferences.

The roundtables were very well received. Feedback indicated that table hosts wanted a little more time to develop discussions with delegates (15 minutes per set of delegates, rather than 10).

> *The mix of representatives from across the patient data 'ecosystem' was a real strength of the event, clearly highlighting both the common challenges and the benefits of addressing them in a more collective and coordinated way*

Ming Tang also stayed to host a round table. As one delegate commented afterwards, “where else could I as a patient get the chance to sit next to Ming Tang and bend her ear?”

We know that 95% of delegates visited the exhibition stalls on Data Street. All the feedback was positive, with suggestions focussed on how it could be improved further, including that more space was needed and more time to speak with the exhibitors.

We had a good mix of delegates, though less of our Members than we had hoped

Following a slow start to registrations, the attendance was strong at around 200 people. There were only nine no-shows, none of which included Members – each of our 39 Members that registered, attended.

The table of registrations is shown below – though requires interpretation. For instance, several of the speakers would also identify as patients, as would the Executive Group, and several of the exhibitors (and speakers) brought their patients on the exhibitors' free tickets.

A better estimate of patients/public would be between 75 and 80, which would equate to just under 40% of delegates.

	Registration Type
39	use MY data Member
21	Patient, relative or carer / Member of the public
8	use MY data Exec Group
29	Speakers
30	Academic / Research organisation
23	Charity
17	Commercial sector / Industry / Pharma
25	Public Sector / Gov / Healthcare Professional
3	NHSE
3	DH
4	use MY data Secretariat / Event Manager
202	

Table showing the breakdown of registration

Engagement from delegates on the day was high

SLIDO statistics demonstrated that delegates played an active role during the day:

- 226 out of 254 SLIDO participants engaged with polls or Q&A (89%)
- 112 out of 254 participants asked a question or voted in Q&A (44%)
- 211 out of 254 SLIDO participants voted in a poll (83%)

Note: some delegates may have been using SLIDO on multiple devices.

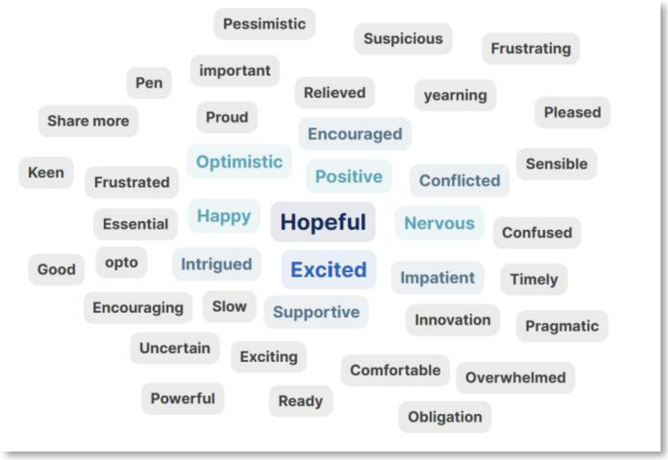
The number of questions asked across the three plenary sessions was:

Plenary 1	60 mins	How do we achieve a National Health Data Service for the UK now that we have a national Health Data Research Service?	82 questions
Plenary 2	45 mins	The media, the public, patient data and us - how can each one of us influence the media to publish stories that celebrate using our patient data?	64 questions
Plenary 3	45 mins	Me, my data and (A)I	32 questions

The questions are available in a separate spreadsheet.

All SLIDO questions were moderated – none were rejected.

Our principle of positive engagement, and that of the conference being a celebration of using patient data, seemed to be echoed by the audience when polled by the National Data Guardian. The results of the question “What’s one word to describe how you feel about the NHS using your data for activities like research, planning and innovation?” are seen in this World Cloud:



We attracted a good level of sponsorship, which covered our costs

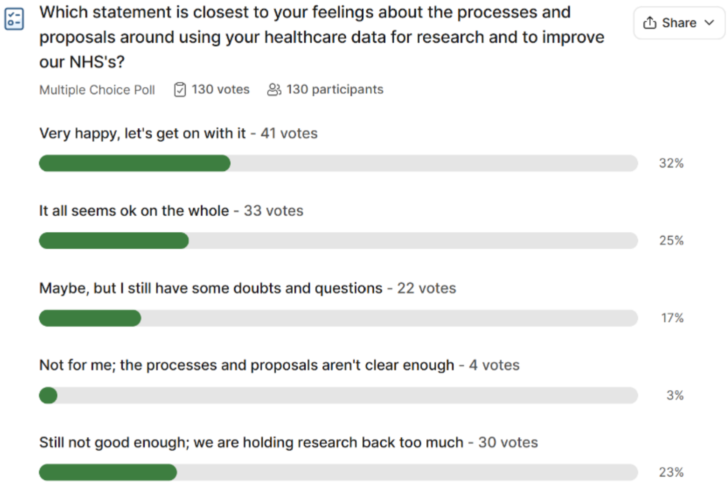
Our sponsorship income covered the costs of running the conference and we have generated a small surplus. The details of the financial breakdown are shown in a separate paper.

The strength of feedback from the event has been hugely impressive, and positive

Direct feedback from delegates on the day was very positive. Plaudits for the first National Patient Data Day event in Leeds have continued to come in.

Several comments from delegates noted that they had the unusual chance to engage directly with national leaders.

At the end of the day, there were some quantifiable changes to the attitudes of the delegates that attended, who were asked the same question at the start and end of the day, with the results:



Which statement is closest to your feelings about the processes and proposals around using your healthcare data for research and to improve our NHS's?

Multiple Choice Poll 130 votes 130 participants

Very happy, let's get on with it - 41 votes 32%

It all seems ok on the whole - 33 votes 25%

Maybe, but I still have some doubts and questions - 22 votes 17%

Not for me; the processes and proposals aren't clear enough - 4 votes 3%

Still not good enough; we are holding research back too much - 30 votes 23%

> *The exhibition stalls were great to hear from some organisations, I think it might be nice to also host some project stalls in the same way to be able to chat to and learn from some project leads across engagement/research/policy/comms*

Which statement is closest to your feelings about the processes and proposals around using your healthcare data for research and to improve our NHS's?

Multiple Choice Poll 105 votes 105 participants

Very happy, let's get on with it - 47 votes 45%

It all seems ok on the whole - 12 votes 11%

Maybe, but I still have some doubts and questions - 17 votes 16%

Not for me; the processes and proposals aren't clear enough - 2 votes 2%

Still not good enough; we are holding research back too much - 27 votes 26%

Interpretations are difficult, but the absolute number and the percentage of people in the first response both increased, and delegates who responded “ok on the whole” on the first poll, shifted perspective to “get on with it” at the end of the day. The middle ground (maybe & not for me) remained largely the same.

Very happy, let’s get on with it	32% increased to 45%
It all seems ok on the whole	25% dropped to 11%
Maybe, but I still have some doubts and questions	17% marginal change to 16%
Not for me, the processes and proposals aren’t clear enough	3% marginal change to 2%
Still not good enough, we are holding research back	23% dropped to 16%

(130 delegates voted at the start, 105 at the end)

People have been talking widely about the event and are taking action because of it
Examples of practical, immediate impact of the conference:

a) At the event, one of our Members, Antony Chuter, talked to us about his work on a project with Dundee University, about AI and trusted research environments. He offered to take away the questions from the AI plenary session, to analyse and come up with themes.

   He is going to share those themes with use MY data, but he will be using these to help Dundee University in their collaboration cafés with the public.

b) Notably, the ABPI chose the event to launch their data case studies. We have worked with the ABPI over many months to help them formulate their thoughts about developing positive case studies with their members, culminating in the first set of case studies being launched at NPaDD.

   We have already followed up with the ABPI about running education sessions for our Members to look in more depth at these, and other potential case studies, with the relevant ABPI member organisation.

c) Roger Halliday, the CEO of Research Data Scotland, wrote to us to say "I got so many important and inspirational stories of what people would like to see for the use of data and will be using them in discussions with data controllers to help to unlock the data they have and put it to use for the benefit of patients".

d) The National Cancer Audit Collaborating Centre (NATCAN) wrote to say "The exhibitors stand helped to facilitate some interesting discussion with the conference delegates and the two-minute soap box competition, provided a great platform for my colleague Olivia, to speak (very quickly!) about the goals of our work".

   NATCAN run ten national cancer audits have their own, each with their own PPI Forums. They want to work with us the development of a 'cross-NATCAN' group of PPI representatives.

   "I can see there could [be] great benefit [of] useMYdata's impressive expertise in patient data feeding into the PPI group and the work of NATCAN more broadly/"

e) One of our sponsors, Promptly Health, published a blog, championing their sponsorship, and stating their belief that "patient voices must be central to every conversation about real-world data", and that "building trust isn't just a goal — it's a continuous commitment".

   They ended by saying "we're proud to stand with the community in supporting safe, transparent, and impactful use of health data".

f) One patient delegate noted that the event had broadened her "considerations about publication and journalism. I had not previously considered these aspects and the possible outcomes from their interaction, such as bias of both selection and presentation of information to the public". This patient is on at least two other PPIE groups.

g) One Member use MY data told the Secretariat afterwards that she was "brimful of ideas to deliver patient-centred with parity learning" and was keen to be involved in the planning of NPaDD 2026.

Membership
As a direct result of NPaDD we have eight new Members and three Associate Members.

Communications
As a direct result of NPaDD our LinkedIn followers have increased significantly.

NPaDD has given us the opportunity to capture on film, influential figures in the patient data world and the resulting film will have wide usage and a long shelf life, beyond NPaDD.

Reflections on operational aspects and impact for use MY data

What didn't go as well as we had hoped?

In short, very little. However, the little is also the most major…

Accessibility

There were serious difficulties with accessibility within the venue, which had a significant impact. The venue is marketed as accessible, however this was not the case. We have formally complained to the General Manager of the Queens Hotel. A follow-up meeting is set for Wednesday, 16 July, at which Alison, Chris and Georgina will represent use MY data.

An immediate decision is that for any future venue booking, we will use an independent, expert, organisation to assess the venue's accessibility.

A comment from a delegate:
"If you are hoping to engage real patients/former patients/the public then thought needs to be in play as to how anyone with a disability, visible or not, can be accommodated at the venue".

One Member arrived and asked for a subtitling/captioning facility, as he was hard of hearing. This had not been requested at the registration stage and although we tried to set up the facility, despite several attempts it was not possible. We did arrange for this Member to sit at the very front for the talks, which he said this did really help and aided him in following all of the plenary speakers.

In future, we need to ensure that we capture this type of accessibility need, at the registration stage.

Exhibition space / lunch space

The physical position of the pillars in Data Street made things feel tight. More space was needed.

There were queues for the lunch, which we had anticipated might be an issue. However, it was worse than anticipated. Chris and others managed the queue, letting people know what was happening and helping them move along, once they had their food. For the number of delegates, we needed more food stations. Regrettably this was not possible in this venue.

A selection of feedback from delegates from the post-event surveys

"Could there be a follow up Q&A to answer the questions that were not covered? There were so many put through SLIDO the engagement was amazing and it was such a shame that so many went unanswered."

"As an Associate member I hope you will explore Richard's ideas for making the organisation and its Members more useful for the rest of us."

"The day was very long, especially for Data Street stallholders."

"A hard copy programme would have been useful."

"Perhaps have a conference aim or a goal for 2025/6 or similar. Something to catch people's interest and something they could contribute to in some way?"

"Could there be a follow up Q&A to answer the questions that were not covered? There were so many put through SLIDO the engagement was amazing and it was such a shame that so many went unanswered."

And finally,
"I am not sure how it could be bettered; for an inaugural event you have a set a very high bar. The one thing that was missing was highlighted by something to which Richard alluded - examples of or from patients who are using the data or helping others to use it. Maybe that will be for next year?"

Appendix: Online feedback published openly on LinkedIn (as at 3 July)

Patient data is more than numbers it’s stories, struggles, and survival. Yesterday reminded me why our voices must lead, not follow.

I had the privilege of attending the inaugural National Patient Data Day (hashtag#NPaDD2025) in Leeds, hosted by @useMYdata and it absolutely delivered.

The day brought together NHS leaders, researchers, policymakers, and most importantly, patients and carers the people who live with the outcomes of these systems every single day.

As a two-time cancer survivor, Flatiron UK PVP member, and long-time patient advocate, I didn’t just show up to listen. I came to challenge, connect, and co-create.

My key reflections:
- True co-design is still rare — but entirely possible. When patients shape the room before decisions are made, everything shifts.
- Transparency fuels understanding not just access. We need plain language, feedback loops, and systems that centre informed consent and dignity.
- The public narrative around data needs a rewrite. Too often, media headlines focus on fear. We need to collectively shape a more accurate, hopeful story about what ethical data use really looks like.
- People want to get it right. There’s growing appetite for collaboration — but we must keep pushing for accountability, not just consultation.

👏🏾 A huge well done to Helen Bulbeck and Linda Galbraith for their powerful presentation on the impact of Flatiron Health work improving and extending lives by learning from every cancer patient’s experience.

I left inspired, grounded, and more committed than ever.

If we want to rebuild trust in health systems, patients can’t just be invited into the room — we must help design the room.

Thank you to everyone I met today. As always it’s lovely to see some old faces and made new connection. But also got to connect with the flatiron team in general. Let’s keep building better — together. Mark Duman MRPharmS Yvonne Adebola Chris Carrigan

What’s one bold step you’ll take to centre patient voices this year?

hashtag#PatientAdvocacy hashtag#useMYdata hashtag#NPaDD2025 hashtag#HealthDataEquity hashtag#PatientLedInnovation hashtag#MariaLawalAdvocates hashtag#FlatironUK hashtag#CoDesignInHealthcare

Maria Lawal, Patient Advocate

This is more than a conference — it's a timely reminder that the future of health data in the UK depends not only on infrastructure, technology, and governance, but also on public trust, openness and collaboration.

DARE UK

It was wonderful to attend use MY data's first National Patient Data Day (hashtag#NPaDD) in Leeds yesterday.

Lots of thought-provoking discussion about:

- what does meaningful public and patient involvement and engagement look like?
- how to acknowledge the crucial role of healthcare data in supporting research and development without straying into hype.
- the ever present challenge of language - how to strike a balance between avoiding technical jargon whilst not appearing to be condescending.

And excellent examples of best practice, include those from colleagues at Leeds Teaching Hospitals NHS Trust and the National Pathology Imaging Co-operative (NPIC).

Great to see the launch of the NHS Health Data Use Case Study Library by James Squires and colleagues at The Association of the British Pharmaceutical Industry (ABPI) (link in the comments).

I'm looking forward to the second edition of the hashtag#NPaDD!

Phil Waywell, CDO, Y&H SDE

It was inspiring to hear how data and technology, when combined with insights from patients and communities with lived experience, has the potential to be federated through collaboration in a seamless way to transform how we prevent and treat diseases.

This is especially critical in the rare disease space, where the journey from diagnosis to affordable treatment is often long and complex.
Madhu Madhusudan, LifeArc

Great day talking with patients and experts at the National Patient Data Day. Great things happen when we work together to create health data solutions that solve real world problems whilst being designed with public transparency and trust at its heart

Lorna Branton, Head of Strategy & Communications, Data for R&D, NHS England

Great to be at the inaugural National Patient Data Day organised by use MY data today! Loving speaking to lots of patients and other people working with health data, and in particular hearing Rory Cellan-Jones speaking about the positive coverage of Our Future Health UK on the panel chaired by Anna Steere of Understanding Patient Data hashtag#NPaDD

Nicola Hamilton, Head of Data Operations, Our Future Health

A brilliant start to the use My Data National Patient Data Day. With engaging plenary talks from Nicola Byrne the National Data Guardian and Ming Tang Chief Digital and Information Officer at NHS England
Followed by a challenging and engaging panel with the plenary speakers and Alex Newberry Head of Research Involvement, Governance and Informatics at Health and Care Research Wales and Roger Halliday Chief Executive Research Data Scotland.

Doreen Tembo, Head of Public Involvement & Engagement and Strategic Lead, HDR UK

We’re here at the first ever National Patient Data Day to celebrate the power of patient data to improve care, drive research, and inform change across the NHS.

At the National Oesophago-Gastric Cancer Audit (NOGCA), we’re proud to use patient data to shine a light on variation in cancer care, support local quality improvement, and ensure more patients receive timely, effective treatment.

Thank you to the patients and carers who make this work possible.

Nat OG Cancer Audit, NATCAN

Our thanks to all involved for an excellent inaugural Patient Data Day hosted by use MY data. Congrats to Chris Carrigan Richard Stephens and all the team.

Thanks also to fellow panellists LifeArc's Rebecca Cosgriff and Jo Gumbs from Ocular Melanoma UK, for an insightful and productive session addressing the question 'Can we create a UK-wide data environment fit for international rare disease research?'.

For rare cancers like salivary gland cancer, international collaborations are hugely important. It was great to share the work done by EURACAN and the European Reference Networks around the IDEA4RC Project and learn of other wonderful projects showcasing similar collaboration.

It was also fantastic to catch up with friends from National Cancer Research Institute (NCRI) days.

We're looking forwards to next year already!

Salivary Gland Cancer UK

Busy workload + eight week old baby = missed National Patient Data Day in Leeds hosted by use MY data. I hear it was great, thanks for the verbal and LinkedIn summaries Rebecca Cosgriff, Mark Avery and Lorna Branton. Also really enjoyed this blog from Rory Cellan-Jones. Why don't we shout more about the good news stories from using health data? How can we expect anyone to have an informed view when they only hear the downsides and scare stories?

Chris Russell, Leader in healthcare & data transformations, & RWE research

I had a fantastic time at the first hashtag#NationalPatientDataDay in Leeds yesterday. Lots of interesting discussions about the need to centre patients’ views in health data research. Such an important topic at the current time as the NHDRS develops.

Catherine Bowden, Associate Researcher at the University of Manchester

Yesterday we were at the first ever National Patient Data Day hashtag#NPaDD where it was good to see so many important topics being covered, including unifying patient data across the UK and how to make that happen, building public trust in how data is handled, the role of the media, AI, and so much more!

The day also included an excellent session on establishing a data environment to support research for rare disease.

And, importantly, patients were at the heart of it all.

Congratulations to use MY data on delivering the excellent event!!

Rare Disease Research UK

Awesome initiative 😎 so glad we made it this year!

Francisco Ramitres, Global Sales & Partnerships, Promptly Health

Amazing!!

Giulia Brunetti Condez, Promptly Health

It was a real pleasure to attend the event, and a privilege to present.

It was such an inspiring day, with so many interesting and talented speakers, and you could only imagine all the hard work that had taken place to achieve such a seamless event.

I look forward to the next one!

Linda Galbraith

As a mum of 2 little people I'm constantly asking if they "have their listening ears on".

Today, I had the opportunity to do just that - to actively listen and reflect on what both Promptly Health and key stakeholders in health research in general can improve when it comes to patient engagement and the transparent use of patient data in research.

Alongside approx. 200 other participants at the use MY data inaugural National Patient Day event, I listened and heard an abundance of positive engagement messages around the use of data.

I heard key opportunities such as:

📢 Focussing communication on the "public good" in any project using public data, particularly for commercial companies.
📰 Overcoming the often negative bias created by the media by better promoting the benefits, the success stories and the positive value derived from accessing NHS data; celebrate the good more!
GBThe potential in a truly national approach, with representatives from Scotland and Wales stressing the importance of common standards, policies and ways of working.
📈The power of AI to not only transform research, with a powerful example from Moorfields Eye Hospital, London and Google DeepMind. https://lnkd.in/ec7yFwPe

🙌Thank you Bella Starling for being a brilliant co-host for our round table discussion.

And congratulations Chris Carrigan, Georgina Bursby and team for a successful day!

Michelle W, Health Analytics, Promptly Health

It was one of the best-run events I have ever been to - and you made it so,

Richard S

Well done on making yesterday such a success Georgina, and sorry that I wasn't able to say hello in person or catch up later in the day with Chris. I got so many important and inspirational stories of what people would like to see for the use of data and will be using them in discussions with data controllers to help to unlock the data they have and put it to use for the benefit of patients. Well done again.

Professor Roger Halliday (He/him), Chief Executive Officer, Research Data Scotland

…well done for organising such a great day! I really enjoyed it and learned a lot.

Ben Cromarty, delegate

Thank you for organising the event, we really enjoyed it. The speakers were great, and it was lovely that patient voices were at the heart of the event.

Frances, UK Biobank

"It really was a superb team effort and well, well worth it. We will be able to build on it for some time to come.

Particular thanks to Richard for having the idea, to Chris and Alison for doing so much preparatory work and also for finding Georgina who was a true professional…."

EG member

"The feedback I got as people were leaving, was really positive, having made a number of connections. I even got asked if this was going to be annual event!..."

EG member