

Pilot Summary Report:

Building the first Public Data Panel in Northern Ireland

November 2022

Frances Burns
Elizabeth Nelson
Deirdre Ferguson
Andrea Thornbury
Maíra Rahme
Carol McHugh
Sian Ogle

Pilot Summary Report:

About Northern Ireland Public Data Panel and This Report

In the fast-paced environment of data innovation, the relationship between data owners, policymakers, technical innovators, researchers and the public, can sometimes become disconnected.

Across various sectors and complex data ecosystems, those seeking to access and use public data are commonly required to show evidence of having engaged with the public. How this is done varies widely and often falls short of expectations of participation and transparency.

In the use of data for public good within the UK landscape, best practice is continually evolving,^{1,2,3,4} recognising gaps in approaches and assumptions between immediate stakeholders, data controllers and wider communities.

To reflect the multiplicity of approaches, the pilot of the Northern Ireland Public Data Panel (NIPDP) has been conducted with an integral cross-sectoral, community centred service design approach particular to Northern Ireland.

The NIPDP pilot marks the beginning of a new chapter in the history of data utility in Northern Ireland. For eight months, the pilot for a Public Data Panel, the first of its kind for Northern Ireland, has been tested and iterated through a comprehensive design thinking process.

Multiple stakeholders have been consulted and involved in this explorative pilot, making it a robust and desirable model for inviting the public to have conversations about Data.

This report reflects on this unique cross-sector collaboration, and the results achieved in the process.

For further information regarding the Northern Ireland Public Data Panel please contact:

Frances Burns - f.burns@qub.ac.uk

Elizabeth Nelson - e.nelson@ulster.ac.uk

The Northern Ireland Trusted Research Environment (NITRE), and the (NIPDP) are part funded via the Data and Connectivity National Core study, led by (HDR UK) in partnership with the Office for National Statistics and funded by UK Research and Innovation (grant ref MC_PC_20058).

1 <https://www.hdr.uk.ac.uk/news/new-principles-published-to-improve-public-confidence-in-access-and-use-of-data-for-health-research-through-trusted-research-environments/>

2 <https://www.gov.uk/government/publications/data-for-the-public-good-government-response>

3 https://understandingpatientdata.org.uk/sites/default/files/2018-04/Data%20for%20public%20good_0.pdf

4 https://www.ark.ac.uk/pdfs/Researchreports/Data_Sharing_Report.pdf

Forward

The reason we need public data panels is because all data technologies are in fact public technologies. This publicness is often masked by the extent to which they rely on private infrastructures, but in fact any data infrastructure or dataset that draws on society, and whose analysis will impact society, is by its nature a public concern. The proposal and pilot which this report recounts offer new possibilities for making, and keeping, data and AI technologies public as they continue to evolve. As such, this is an important experiment which deserves to be taken account of by countries around the world.

The public data panel proposed in the report is a hopeful and forward-thinking contribution because it treats public opinion and the experiences of affected people not as a bug, but as a feature. Too much of current ‘citizen participation’ is merely a rubber stamp on activities of government, industry or researchers: activities which will proceed regardless of the public’s feedback. A panel such as this is instead designed to be noticed, and to have impact on the way data is governed. It constitutes a warning system for Northern Ireland, where creeping opacity of systems, de-linking of public opinion from policy, or biased selection of feedback mechanisms can be surfaced and addressed. It also has the potential to develop into modes of contestation that are currently lacking in our data and AI economy.

Particularly important in this report is the notion that representation is something that is constantly under construction. It must be tried, subjected to critique, reformed, and negotiated. ‘Staying with the trouble’, as one notable researcher, Donna Haraway, has described it. It is only through the proposal contained in this report – that representation must develop along with the publics involved, and must always be open to critique and contestation – that we can move toward a public data economy which is responsive to people’s needs and does not rely on top-down formulations of what is ethical. The ethics of data is always political, and this proposed panel offers a way of making sense of that.

Prof. Linnet Taylor,
*Chair in International Data Governance,
Tilburg University, the Netherlands*

Preface

Our population's health and care data is critical to the continuity of their wellbeing. As we invest and evolve the way in which we collect, use and share information within Health and Social Care in Northern Ireland (HSC), we recognise that holding valued conversation with our population and our people to explain the benefits of data use in care delivery is key to trust, transparency and support for innovation that translates to recognised, measurable public benefit.

Critical to our data journey is our HSC Data Strategy 2022-2030. This strategy describes our ambitious plans to make data more accessible, interoperable and usable in Northern Ireland. Within this strategy is our commitment to public engagement. As we invest in our data infrastructure and capability and accelerate the introduction of regulations that will enable us to deliver data intelligence for patient and public benefit, we will commission and deliver a socialisation programme to help inform and understand our population's attitudes to using their health and care data. From our learning, we will establish the social license to guide the use of their data for the wider good is part of the foundation of this commitment.

Digital Health and Care Northern Ireland (DHCNI) is the data and technology lead to the HSC system in Northern Ireland. The unique cross-sectoral design of the NIPDP reflects our understanding of the value of potential in public data, and the need for wider public discourse in its use, particular to Northern Ireland and its communities.

DHCNI recognises NIPDP as key regional infrastructure and welcomes the findings of this pilot to direct its phase one implementation.

Dr Austin Tanney,
Head of Clinical Information,
Digital Health and Social Care NI

Preface

For a long time, data was seen as too far removed from people's everyday lives; deemed 'too technical, 'too boring' or 'too complex' to be of interest or importance to the 'general public'. While public engagement in research has grown and established itself as an important element of the research process, the same could not have been said of data-focused research until fairly recently. As the use of data in research – and in policymaking and service provision, which data-driven research ultimately seeks to inform – has increased at speed, so too has the recognition of the critical need to engage and involve publics in the decision-making process around the use of their – our - data.

Public engagement and involvement are the cornerstone of what we do at Administrative Data Research Centre Northern Ireland (ADRC NI). Each data point is an experience or life event in the life of real people, who collectively make up the datasets we use for academic research in the public benefit. It is only right that those people are directly involved not only in developing, designing and prioritising the research we conduct, but in helping everyone who collects and uses data to understand what the public means by public good, and directing how, when and why data should be used throughout Northern Ireland.

NIPDP a step forward in our ability to involve publics in data-driven research and innovation. ADRC NI recognises the vital role publics play in conversations about public data, public good, and public decision-making, and welcomes the findings of this pilot and its roadmap for establishing the NIPDP in what we hope is phase one of many.

Prof. Dermot O'Reilly,
*Director,
Administrative Data Research Centre Northern Ireland*

Table of contents

Glossary	9
Executive Summary	13
Background	13
Pilot Objectives	14
Pilot Stakeholders	14
Northern Ireland Trusted Research Environment (NITRE)	14
Administrative Data Research Centre Northern Ireland (ADRC NI)	15
Belfast City Council City Innovation Office	15
Big Motive	15
Stakeholders – Consultative	16
Pilot Delivery and Timelines	16
Lessons Learned and Recommendations	17
Next Steps	18
About the Northern Ireland Public Data Panel Pilot	19
Design Discovery	19
Introduction	19
Interviews	19
Interviewees	19
Interview questions	20
Capacity Building and Awareness-Raising	21
The purpose of a public data panel	21
Onboarding	21
Setting up an independent panel	21
Partnerships	21
Recruitment and retention	22
Incentives	23
Panel size	23
Session design	23
Feedback and reporting	24
Be humble and transparent	24
Prototype/Pilot Panel Design	24
A Service Design Approach	24
Constraints and Limitations	25
Scope	25

Covid-19	25
Incentives	25
Time	25
Resource	25
Recruitment	26
Recruitment	26
Recruitment Profiles	21
Channels	26
Existing networks	26
Social media	26
Tools	27
FAQs page and document	27
Expression of Interest Form	27
Incentives	27
Retention/Dropouts	27
Membership Profiles	27
Pilot panel - Session design	28
Session delivery	28
Session 1	28
Session 2	29
Session results	29
Final survey results	29
Recommendations and next steps	31
The Future of the NIPDP: Next Steps	32
Next Steps	32
References	33
Appendix 1	35
The delivery team	35
Appendix 2	39
Session One	39
Session Two	41

Glossary

Administrative Data Research Centre Northern Ireland (ADRC NI)

ADRC NI is a partnership between Ulster University and Queen's University Belfast. The centre makes it possible for researchers to access information collected by national and local government and other public sector organisations (typically in the delivery of services). ADRC NI is part of the wider Administrative Data Research UK network.

Administrative Data Research Northern Ireland (ADR NI)

The partnership of ADRC NI (see above) and the Northern Ireland Statistics and Research Agency - see below. Part of ADR UK network (see below).

Administrative Data Research United Kingdom (ADR UK)

A partnership between universities, government departments and agencies, national statistics authorities, funders and the wider research community. The group makes it possible for researchers to access information collected by national and local government and other public sector organisations. ADR UK is funded by the Economic and Social Research Council.

Advocates

People who publicly recommend or support an idea, project, community or organisation.

Belfast City Council City Innovation Office (BCC City Innovation Office)

An office within Belfast City Council that aims to make Belfast a centre for innovation. It is a partnership between seven organisations in the city: Belfast City Council, Belfast Harbour, Belfast Metropolitan College, Catalyst, Queen's University Belfast, Ulster University and Invest NI.

Big Motive

An award-winning service design consultancy that helped to design the NIPDP pilot.

Commissioning

Act of granting authority to a person or organisation to conduct a project.

Deliberative workshops

A form of facilitated group discussions that provide participants with the opportunity to consider an issue in depth, challenge each other's opinions and develop their views/arguments to reach an informed position.

Desk top review

Finding and going over all available documentation on a subject.

Devolved jurisdiction

Devolution is about the transfer of power by a central government (like the UK government) to local or regional administrations (like Stormont). The local government is known as a devolved jurisdiction.

Digital Health and Care Northern Ireland (DHCNI)

The group within the Northern Ireland Health and Social Care system who use data and digital technology to try and improve services for patients and working practices for staff.

Economic and Social Research Council (ESRC)

Funder of NIPDP and part of UK Research and Innovation, a non-departmental public body funded by the UK government.

Funder

A body or organisation that provides finance for a project.

Health Data Research United Kingdom (HDR UK)

The national institute for research that uses health data.

Health and Social Care in Northern Ireland (HSC)

Publicly funded health care service in Northern Ireland.

Health and Social Care Public Health Agency (HSC PHA or PHA)

Regional organisation for health protection and health and social wellbeing improvement in Northern Ireland

Health and Social Care Hones Broker Service

- the Trusted Research Environment (TRE - see below) for Health and Social Care (HSC) Northern Ireland (see above)

Local government

Northern Ireland is divided into 11 districts run by the local council. Together these are known as the local government.

NIPDP

Northern Ireland Public Data Panel.

Northern Ireland Statistics & Research Agency (NISRA)

An executive agency within the Department of Finance in Northern Ireland. The organisation is responsible for the collection and publication of statistics related to the economy, population and society of Northern Ireland

Northern Ireland Trusted Research Environment (NITRE)

Part of DHCNI (see above); responsible for strategic data linkage infrastructure for health data and research in Northern Ireland. Funder of NIPDP.

Office for National Statistics (ONS)

The executive office of the UK Statistics Authority, a non-ministerial department which reports directly to the UK Parliament.

Partner (ship)

An agreed association between two or more people or organisations.

Pilot

Taking a working example of an idea and testing it with a small group of people.

Practitioner

Someone who practices a particular activity or profession, e.g. a nurse practitioner.

Prototype

An early example of something that is made to test an idea and see what needs to be changed and improved.

Public involvement

Projects that are undertaken ‘with’ or ‘by’ the public, not ‘to’, ‘about’ or ‘for’ them. It means that people with relevant experience contribute to how projects are designed, carried out and shared.

Publics

The different groups in society that can influence or bring pressure to bear upon a firm’s decision making and have an impact upon its marketing performance.

Public sector

The organisations and services that are funded, owned and operated by the government.

Regional City Deals – Belfast

City Deals are an injection of government money that fund new infrastructure and create partnerships between public and private sector organisations in the region to increase growth.

Smart Cities Programme

Smart cities aim to use data and technology to improve a city's infrastructure, environment and services.

Sponsor

Individual, company, institution or organisation that takes on legal responsibility for starting, managing and funding of project.

Stakeholder

A person, group or company that is interested in, or affected by, an area of work.

Trusted Research Environment (TREs)

Highly secure places where researchers can access information and tools to analyse data in a safe way. This means that data doesn't need to leave a safe location to be sent to researchers.

TREs enable researchers to gain access to data in a safe way. They do so by creating highly secure digital environments that provide access to information and analytical tools in a single place, removing the need for data to leave the safe location to be sent out to researchers.

UK National Core Studies (NCS)

A group of studies that bring together important parts of the UK data set-up in one gateway portal that is used to discover data. The National Core Studies (NCS) work with people interested in medical, biological and social science data research across the whole UK.

The National Core Studies brought together core assets of the UK data infrastructure in the Health Data Research Innovation Gateway, the UK's portal for data discovery. The NCS work in partnership with stakeholders from across the 4 UK nations to organise medical, biological, and social science data on an unprecedented scale.

User-centred design

Design that is based on the opinion and feedback of the people using the service or product. This involves the person using the service or product throughout the design and the development stages.

Design is based upon understanding of users, tasks, and environments; is driven and refined by user evaluation; and addresses the whole user experience. The process involves users throughout the design and development process.

Voluntary, Community and Social Enterprise (VCSE) sector

Sometimes referred to as 'the Third Sector' or 'the Charity Sector'. It is made up of groups that are independent of government and are constitutionally self-governing, usually managed by an unpaid voluntary committee.

Executive Summary

Background

There is an increasing awareness of the potential for data to enhance evidence for public policymaking, and service provision, as well as informing the public. By linking datasets across thematic areas, it is possible to identify trends and areas of concern across a population, and answer questions not previously possible. Many of these data sets exist through delivery of public services, and their use in research is typically secondary.

In late 2020 an Assembly Written Question (AQW) inquired of the then Minister for Health when legislation would progress through the Assembly providing for the secondary use of data, and when and how guidelines would be developed to support this. Several organisations came together to support the Minister's response, detailing the importance of data usage to their organisations and their plans for use of the legislation and subsequent regulations when developed. All of these responses were positive, and highlighted the key importance placed upon the potential of data to help illuminate vital issues within Northern Ireland society. Responses also underscored the importance data could be to the public and communities, specifically in supporting policymaking, service provision and innovation in a democratic and evidence-driven manner. However, how publics and communities would be involved in this process was then uncertain, beyond the existing initiatives run by each organisation on their own.

Northern Ireland is currently the only of the three devolved jurisdictions of the UK (Scotland, Wales and Northern Ireland) that does not have a public panel focused on data use. As the data landscape develops, it is crucial that our public engagement infrastructure and practices do as well. Key to this is acknowledging and understanding the necessarily powerful role that publics play in enhancing and maintaining acceptability of data use, and in normalising the use of data in evidence creation, research, decision-making, and public services.

As each data point is an experience or event in the life of a person, it is vital to involve the views and opinions of different publics if we are to maintain support to access and use this data. The NIPDP aspires to embrace an authentic partnership approach that prioritises co-development with all stakeholders, including the Northern Ireland publics.

In February 2021 a partnership model was established to develop a pilot for the NIPDP. The focus was the validity of, and public support for use of our data resources. Although there is a range of public and patient engagement practises in existence in Northern Ireland, a distinct need was identified for a dedicated public forum on the topic of data and its use for public benefit in a research and innovation setting,

This NIPDP initiative is recognised⁵ as integral to a long-term strategy of public engagement around data innovation; to reflect this, a wide range of stakeholders were engaged to help deliver the pilot.

5 <https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-hscni-data-strategy.pdf>

Pilot Objectives

Under principles set out by best practice^{6,7,8} across the UK, this project aimed to pilot a groundwork model for widening the range of perspectives on the use of data and, with publics, create better science and innovation for public benefit, by way of:

- developing public data literacy
- testing public assumptions about data and its use in research
- defining what ‘public good’ means in the context of data utility
- inclusion of the public and their views in the governance and orchestration of service design and delivery
- helping to shape the direction of data use and accessibility for service improvement, data-focused research and policymaking in Northern Ireland.

Pilot Stakeholders

Based on the above rationale this pilot project was established and delivered jointly by the ADRC NI⁹, BCC City Innovation Office and the NITRE as commissioning partner, part of DHSC NI¹⁰. Design consultancy firm Big Motive¹¹ were commissioned to support the pilot design and delivery.

Northern Ireland Trusted Research Environment (NITRE)

NITRE the commissioner for this pilot, is the collective strategic response of the Department of Health, the Northern Ireland Public Health Agency and the Health and Social Care Honest Broker Service to enable connectivity and data provision. Funded from the 2020 HDR UK's, National Core Data and Connectivity National Core Study investment¹³ and overseen by a strategic board from stakeholder organisations, NITRE provides a governance structure, research platform and programme management to ensure the contribution of relevant health and social care data, both to HDR UK's NCS National Core Studies and to answer research questions identified as priority for our population.

6 Aitken, M., Tully, M. P., Porteous, C., Denegri, S., Cunningham-Burley, S., Banner, N., Black, C., Burgess, M., Cross, L., van Delden, J., Ford, E., Fox, S., Fitzpatrick, N., Gallacher, K., Goddard, C., Hassan, L., Jamieson, R., Jones, K. H., Kaarakainen, M., Lugg-Widger, F., McGrail, K., McKenzie, A., Moran, R., Murtagh, M. J., Oswald, M., Paprica, A., Perrin, N., Richards, E. V., Rouse, J., Webb, J. and Willison, D. J. (2020) “Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research”, *International Journal of Population Data Science*, 4(1). doi: 10.23889/ijpds.v4i1.586.

7 Jones, K., Heys, S., Thompson, R., Cross, L. and Ford, D. (2020) “Public Involvement & Engagement in the work of a data safe haven:: a case study of the SAIL Databank”, *International Journal of Population Data Science*, 5(3). doi: 10.23889/ijpds.v5i3.1371.

8 Nelson, E. and Burns, F. (2020) “Impact through Engagement: Co-production of administrative data research and the approach of the Administrative Data Research Centre Northern Ireland”, *International Journal of Population Data Science*, 5(3). doi: 10.23889/ijpds.v5i3.1369.

9 <https://www.adruk.org/about-us/our-partnership/adr-northern-ireland/>

10 <https://www.belfastcity.gov.uk/digitalinnovation>

11 <https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-hscni-data-strategy.pdf>

12 <https://www.bigmotive.com/>

13 <https://www.hdruk.ac.uk/covid-19-data-and-connectivity/>

Administrative Data Research Centre Northern Ireland (ADRC NI)

ADRC NI is a partnership between Ulster University and Queen's University Belfast. Together with NISRA they form ADRC NI. The Centre is part of the wider ADRC UK network, a partnership between universities, government departments and agencies, national statistics authorities, funders and the wider research community. ADRC UK makes it possible for researchers to access information collected by national and local government and others. ADRC NI, BCC City Innovation Office and the NITRE as commissioning partner, part of Digital Health and Care Northern Ireland (DHSC NI).¹¹ Design consultancy firm Big Motive¹² were commissioned to support the pilot design and delivery.

Belfast City Council City Innovation Office (BCC City Innovation Office)

BCC City Innovation Office seeks to provide a unique supportive environment where researchers and innovators from across industry, universities and the public sector can work together to explore how digital innovation can help to address the city's major urban challenges and understand the impact that new technologies can have on urban policy and planning. It is responsible for the delivery of Belfast City Council's Urban Innovation Framework which outlines key underlying supporting 'pillars' needed to maximise urban innovation. One of the key enablers identified is the development of a Citizen Office of Digital Innovation (CODI). This will build the capacity of citizens, equipping them with practical skills, toolkits, and techniques to navigate the challenges and opportunities of a data-rich smart city. CODI aims to facilitate opportunities for collaborative codesign with citizens in areas of data and innovative technologies to support co-creation of solutions to tackle societal challenges across the city that are of interest to them.

Big Motive

NITRE commissioned Big Motive to support the design and development of the NIPDP pilot. Big Motive is an independent design consultancy that focuses on creating digital products and services that improve people's lives. Their team guided the design, test and iteration of different formats and configurations for a public-centred solution, bringing expertise in user-centred design approaches to creating the NIPDP as a service infrastructure to enable public involvement in data decision making.

Stakeholders – Consultative



Pilot Delivery and Timelines

A desk-top review was conducted as part of the pilot, reporting the range of approaches to public panels across the UK and capture learning from practitioners to inform NIPDP future planning. This included¹⁴ representatives from HSC, public panels across the UK, the VCSE sector and academic researchers, who contributed to a consultation on best practices, experiences and learning they could share to inform the design of the pilot and planning for NIPDP. The pilot panel was delivered through a series of deliberative workshops set two weeks apart to allow the team to iterate in between.

June 2021: Define overall pilot outcomes, roadmap, stakeholder groups, align goals

July 2021: Desk-based investigation of existing practice and documented qualitative interviews with practitioners

August 2021: Draft format of the pilot panel

September 2021: Active recruitment of members for a pilot panel

October 2021: Build content for first and second pilot panel

November 2021: Two session pilot panel delivery

December 2021: Surveys, evaluation and Lessons Learned reporting

¹⁴ <https://understandingpatientdata.org.uk/>

Lessons Learned and Recommendations

From both the interviews and the workshops a broad set of recommendations for the future of the NIPDP can be drawn:

- The NIPDP should be established to provide a forum for publics to learn about, discuss, and impact the data landscape in Northern Ireland.
- The NIPDP should ideally be run as a partnership between several different sectors and organisations and should prioritise its independence.
- Participants in the NIPDP should receive some kind of remuneration for their role.
- Organisation of future panels should take cognisance of the different barriers faced by different communities and populations, such as socioeconomic factors and mitigate for these barriers as much as possible.
- Care should be taken to identify appropriate recruitment measures to avoid missing ‘under-served’ local communities and centring inclusion and diversity within recruitment efforts.
- Communication from organisers to members should be clear and consistent, from recruitment to preparation material and follow-up after decision-making, to avoid the appearance or existence of tokenism, and maintain relationships.
- NIPDP should draw on best practice of existing panels, but also adapt its approach as and where necessary to reflect and respond to the particular circumstances of Northern Ireland and its communities.
- NIPDP should be strategically linked to decision-makers so that feedback from members has the best chance of making a positive impact on people’s lives and upholding the goal of democratising data.
- Design of content and delivery should be engaging and interactive, responding to the participant requirements.
- It is crucial to include an awareness-raising or capacity building piece as part of future panels to support full, informed participation.
- There should be transparency so participants can see the impact of their contribution.
- The delivery of NIPDP should be iterative and co-created with its members.

Next Steps

Next steps will include bringing the participants' recommendations to bear when setting up the NIPDP in its next form. This will be known as Phase One and will be funded under the auspices of ADRC NI. It is intended that all future iterations of NIPDP will continue to be co-created with panel members, ensuring as much as possible that Northern Ireland's public engagement infrastructure is itself a product of genuine engagement and involvement.

The learning from the NIPDP pilot has informed the implementation plan for NIPDP and how it can function as key infrastructure enabling public dialogue on issues surrounding the use of data for public benefit. With funding secured, via ADRC NI, phase one commenced in April 2022 to enact the findings of the NIPDP pilot and formally establish the first Northern Ireland Public Data Panel.

Functioning under the auspices of ADRC NI in post-pilot phase one, September 2022- March 2026, NIPDP will test and refine delivery of the panel whilst also exploring, with panel members, how to design future delivery to enable a Northern Ireland-wide view in innovative use for data specific to this region and its people. Funding for subsequent phases will be identified across the project timeline.

This approach reflects that while NITRE, ADRC NI and BCC City Innovation Office are advocates for involvement of the public in decisions around use of their data, evidenced by their funding and sponsorship of the NIPDP initiative to date, this conversation is necessarily wider and not limited to them.

About the Northern Ireland Public Data Panel Pilot

Design Discovery

Introduction

Discovery is a preliminary phase in the design process that consists of investigating the problem and gathering insight and learning to inform the design process. Desk-based research was conducted to map out existing research and resources. Furthermore, 14 representative practitioners from established panels across the UK and from the VCSE sector were interviewed on the subjects of best practices, experiences and learning they could share to inform the design of the pilot.

Interviews

Interviewees

1. Senior Policy Officer, Understanding Patient Data UK¹⁴
2. Public Engagement and Involvement Manager, Health Data Research UK¹⁵
3. Programme Manager, Northern Ireland Public Health Agency Research & Development Division¹⁶
4. Policy and Public Affairs Manager, British Heart Foundation NI¹⁷
5. Senior Policy and Public Affairs Officer, Barnardos NI¹⁸
6. Professor of Genomics, stratified and personalised medicine, Ulster University¹⁹
7. Member, Health and Social Care Northern Ireland Honest Broker Service Governing Board²⁰
8. Associate Director for public partnerships, National Institute for Health Research²¹
9. Public Engagement and Knowledge Exchange Manager, Scottish Centre for Administrative Data Research (SCADR)²²
10. Head of Charity Services, Employers for Childcare²³

¹⁵ <https://www.hdruk.org/about-us/patient-and-public-involvement-and-engagement/#:~:text=Patient%20and%20Public%20Engagement%E2%80%8B,from%20patients%20and%20the%20public.>

¹⁶ <https://research.hscni.net>

¹⁷ <https://www.bhf.org.uk>

¹⁸ <https://www.barnardos.org.uk/>

¹⁹ <https://www.ulster.ac.uk/faculties/life-and-health-sciences/biomedical-sciences/subjects/stratified-medicine>

²⁰ <https://hscbusiness.hscni.net/services/2843.htm>

²¹ <https://www.nihr.ac.uk/>

²² <https://www.scadr.ac.uk/>

11. Chief Executive, Northern Ireland Council for Voluntary Action²⁴
12. Head of Information Management, Northern Ireland Council for Voluntary Action²⁴
13. Professor and Data Governance Lead, SAIL Databank, Wales²⁵
14. Director, Northern Ireland Cancer Registry²⁶

Interview Questions

A discussion guide was developed to include questions such as:

- From your knowledge, what best practices or key examples could you share of well-run panels?
- How do you premise and maintain independence in the set-up and management of a panel?
- What has been the most challenging aspect of setting up and running a public panel, and how would you approach it differently now?
- What are the main issues affecting recruitment, retention and attrition, we should be aware of?
- Other than financial incentives what attracts people to engage in panels and stay?
- Can you suggest a recruitment method that would allow us to recruit inclusively?
- Where would you say to concentrate efforts in terms of staff skills or competencies for resourcing a panel?
- What have you found are the best mechanisms and formats for giving information back to the members on the impact and value of their work?

A full audio transcript of each practitioner interview was recorded and saved with consent of each interviewee.

23 <https://www.employersforchildcare.org/>

24 <https://www.nicva.org/>

25 <https://saildatabank.com/>

26 <https://www.qub.ac.uk/research-centres/nicr/>

Learnings and Recommendations from Practitioner Interviews

Capacity building and awareness-raising

Panels have a crucial role in helping people understand and interrogate the use of data for the public good. Practitioners pointed out that the range of data knowledge amongst members usually varies immensely. It is crucial to include an awareness-raising or capacity-building piece as part of the pilot and future panels. This may take the form of one-day training, and/or prepared materials that are delivered in advance, with lead-in time to prepare for the session.

The purpose of a public data panel

The function of the panel should be a forum for dialogue, advising on the use of data and on efforts to build public trust and acceptance. The panel will be linked to data driven decision making processes, across sectors to maximise its impact and in recognition of its unique contribution.

Onboarding

Practitioners recommended involving rights-based organisations from the start, helping the panel recruiters connect with communities. This approach will help reach different ethnicities, genders, ages and geographic distribution across Northern Ireland. Communication should be transparent and accessible, with the role of panel member clearly defined. In the words of one practitioner: “Plain language is the holy grail”.

Setting up an independent panel

A range of recommendations were reported by practitioners for building and maintaining independence as core values for NIPDP. These spoke to the set-up and management of a panel, as well as the structure, guidance for participants, and mindset needed.

- **Structure:** A panel should outline and describe roles and responsibilities very clearly from the start
- **Guidance:** Establish ways of working and rules for engagement, give participants an in-depth induction, and emphasize their role as critical friends
- **Mindset:** Many practitioners emphasized that no panel is perfect, and perfect should not be the enemy of good
- **Independence:** Establishing a panel based on co-production, independent of any one body is the desired model.

Partnerships

It was clear from practitioner responses that a consortium or partnership model would be best placed to ‘host’ a public panel. In the words of one practitioner *“If it could be for health, and policy and academic research, then that’s quite a nice position to be in, it feeds into everyone’s work, and some committee would oversee it: ‘We’re running this panel together, and we all have interests’. Actually, quite nicely,*

with a panel like that one could feel their influence in lots of areas of public policy and practice. (...) If it could be that, this would be the best panel in the UK. It really would.”

Recruitment and retention

Recruitment and retention are the most pressing challenge, raising questions on representation and how to reach a truly diverse audience. Practitioners noted that while best practices are still in the process of being distilled, relevant recommendations can be made to inform the recruitment for the NIPDP.

Key considerations are clarity in who needs to be represented on the panel, and why, and what skills you may like them to have. Practitioners noted the importance of avoiding a public panel that is composed of data experts, or the informed public only: members of the diverse publics are crucial. Some groups recognised as ‘under-served’ might be considered especially difficult to reach. Make use of partner organisations across established networks that could be useful in engaging with those groups.

In the words of one practitioner: *“One of the things that someone said to me once and I really held on to it is that we always use this term ‘hard to reach’. Actually, if you reach them in the way that is suitable for them, then you’ve reached them and it wasn’t actually difficult, you were just using the wrong ways”.*

Some panel participants might find it challenging to engage due to simple barriers, for example access or transport issues. Practitioners noted that panel organisers need to always be mindful that members have other responsibilities, dependencies and challenges. One practitioner noted that in their experience *“Our sessions are during the day, so they put off younger people”*. The time of day, format, and duration of session and travel times should always be considered to alleviate such pain points wherever possible.

In recruitment drives, newspapers and radio were reported to get a significant volume of responses. Partnerships with organisations like healthy living centres and other community consortia have also been successful for some. Recruitment, design or consultancy specialists have also been used for recruitment but are not as connected to communities.

Other approaches include social media, advert on the website, mention in radio interviews, posters on supermarket notice boards or GP practises, and partnering up with community leaders who can help create trusting connections. Facebook was recognised as useful for engaging directly with potential members, whereas Twitter was a more useful route for engaging with partner organisations.

Another recommendation was to maintain an ongoing recruitment stream. Panel members may drop out or become unavailable for a particular session for a variety of reasons. Recruitment is not one finite stage of the process, but a recurring, ongoing activity. Importantly, a panel should always make it easy for members to opt-out (e.g. by making it clear what the procedure is if they no longer wish to attend the sessions) and make it easy for new members to opt-in (e.g. by giving the understanding on what has been covered, so they can get on with other focused work).

A key point from practitioners was to let go of the idea that a panel is representative of the whole society. There will always be underrepresented groups. Recognising and reporting the representation you do and do not have is vital.

Incentives

The most common incentives to engage and retain participants in panels are monetary incentives. At a minimum, lunch and travel expenses should be covered for an all-day session. Some initiatives do not offer cash. One practitioner stated, *“if you don’t pay people for their time, you won’t get the person you want”*. It was commented that an average monetary incentive offered is £20 an hour, to which travel expenses are added. One panel has chosen to incentivise by session, rather than hourly - they pay £50 per session. Some variations of the monetary incentive model include a scale, which goes up the more sessions you attend, or small grants that are given out in lotteries. Other forms of incentive used are the incentivisation through gift lotteries, such as hoodies and iPad draws, or a charitable contribution. Offers of Civic Dollars, which is context and location specific, was also noted.

The risk of not offering payment is biased participation. A majority of white, retired, middle-class panel members. These are the people who have the free time and can afford to participate voluntarily and solely out of interest. Some panels have reported having participants who are a part of multiple panels, and who therefore become ‘experts’ in how to respond to questions, rather than representing their lived experience.

Lastly, some members of the public might not be able to take payment if they are also public servants or offering time within their working hours. These members can then choose to offer a charity donation, or be invited to a conference, event or meal as a way to say thank you.

Panel size

A reasonable number of participants is somewhere between seven and 20. Holding a panel with too many people is a common mistake, and it can hinder your conversations and exchanges. *“If you have too many people you never get anywhere”*. From other panel experiences, it was reported that 20 is the largest number you would wish to host on one panel.

Session design

Several principles were distilled out of the practitioner interviews:

- Make it feel accessible and welcoming
- Use accessible language
- Help the panel understand the outcome of their participation and feel that it is meaningful
- Ice breakers may help break down any barriers, particularly in virtual panels
- For a long-running panel, set up a Buddy system that allows panel members to check in with each other or a member of staff to debrief their experience
- Stick to the scheduled amount of time. People are more likely to engage if it is concise, well planned and organised.

Feedback and reporting

Involvement is hard to measure but impacts of the panel should be documented and reported back. Regular updates on the impact of member's contribution can be valuable for retention. Formats for feedback should be agreed with panel members.

Members like to be kept up to date through written and verbal updates, so alongside publishing reports, meetings can be set up just to acknowledge panel's contributions and share back on how they are shaping the data world. Using a simple three-part framework such as "this is what you told us, these are the recommendations, and this is the impact" will help members see that their contribution has led to something valuable. Final observations and recommendations included producing lay summaries and making sure materials are visually appealing and succinct. Having the materials readily available on the website can also make it easier to access it than reaching out to the Panel team.

Be humble and transparent

Setting up a new panel means putting effort into building strong relationships and recognising that it takes investment from both facilitators and panel members to build trust. Panel facilitators should always be open and transparent and maintaining continuous communication.

Finally, and perhaps most importantly, recognise that you do not know what the public thinks. The whole point of the exercise is to create the space for them to share that and allow yourself to be informed by them.

Prototype/Pilot Panel Design

A Service Design Approach

This project utilised a robust service design approach, strengthened by the following principles:

- **Service design is agile:** Service design is an effective tool for driving change. Therefore, we promoted iterative rounds of design, including recurring meetings with the team to continuously learn and design a pilot most suitable for the Northern Ireland context. This iterative approach provided us with a framework for deliberate and marked progress while minimising the risk of over-designing in the wrong direction.
- **Designing out complexity:** Services often require complex systems to deliver simple experiences to users. We began with understanding and visualising the complexity of the current landscape of panels and understanding existing best practise to inform our design. Doing this at the start helped us raise and discuss emerging issues and priorities to address complexity at an early stage.
- **Service design is visual:** Visual tools and diagrams to explore how multiple aspects and inputs to the pilot could be orchestrated to create a seamless experience for users. Working with the delivery team to design and document the full service, focusing on the development of user journeys, process maps and other visuals was an important tool to ensure focus and buy-in across the different partners.

- **Service design is human-centred:** One approach for the pilot was to investigate which approach would best serve the members of the public who chose to join a panel. All stages of participant's involvement was followed with bite-sized comprehension checks and engagement evaluations'. In the end, a comprehensive survey was sent out, ensuring that the delivery of recommendations is informed not by assumptions, but what the participants have to say about their experience.
- **Service design is collaborative:** Co-creation is a prominent feature of human-centred design. Collaboration is a core principle at Big Motive and working with the different stakeholders in this project proved once again that when it comes to the design of services, co-creation can lead to powerful breakthroughs. Regular meetings were held and they made best use of the diversity of strengths and competencies of each team member to build a robust and successful pilot.

Constraints and Limitations

Scope

The scope of this project was limited to the subject matter of two sample panel sessions, rather than the exercise of establishing a pool of participants involved in different workstreams. Therefore, the scope of the results is limited to this sampling.

Covid-19

Due to the restrictions imposed by the COVID-19 pandemic during the pilot period, the pilot was restricted to the virtual/online environment, limiting not only the recruitment but also the participation of members.

Incentives

Due to this being a publicly funded project, incentives were not a part of the original scope, but the discovery interviews indicated that recruitment would not be as successful if people were not compensated accordingly for their time. Therefore, a short-term incentive solution was established through Big Motive as a private organisation.

Time

The pilot was established, researched, designed, delivered and assessed within a seven-month period. Most pressingly, the time constraints had a direct impact on the recruitment process, given that the recruitment time-window was compressed and time bound.

Resource

Despite the immense dedication of each member to the establishment of the NIPDP, no particular stakeholder had the ability to be fully dedicated to it full-time.

Recruitment

The compressed recruitment time-window and the limitations to the online setting had a direct impact in the diversity of profiles recruited. It was not fully compromised, but the panel could have benefited from selecting multiple, even more diverse profiles from within a larger pool of applicants.

Recruitment

Recruitment Profiles

The makeup of the panel membership is key and working to ensure diversity and inclusion within the NIPDP will be paramount. Therefore, the pilot membership aimed at representing that diversity through a range of ages, genders, ethnicities and socioeconomic backgrounds.

Three main profiles were identified for recruitment:

1. Patient and Public Involvement (PPI)-experienced participants
2. Members with data knowledge
3. Members with no data/PPI Experience

Channels

Existing networks

To recruit PPI participants, support was sought from existing public panels, public engagement in research initiatives, and PPI initiatives from across the UK. Other organisations working with data and technology were also contacted, with a focus on attracting members with data knowledge. These two groups were contacted directly by stakeholders from the panel via email. All stakeholders used the same email draft.

Social media

A rigorous social media recruitment drive was crucial for the success of the pilot public panel. Recruitment was focused around the identified profiles.

To safeguard equality of opportunity for applicants, as well as ensure we had participants with no data/PPI experience, a broad recruitment effort was put in place through several social media platforms including Facebook, specific Facebook Groups, Twitter, Instagram, Reddit, Nextdoor, friends & family and a paid ad on LinkedIn with a budget of £200 targeting people within Northern Ireland.

To ensure we were onboarding individuals appropriately, screening by the Big Motive team was carried out on all those prospects who registered their interest in the pilot.

Tools

FAQs page and document

An FAQs page was set up under the Big Motive website to answer potential answers participants might have as they consider signing up.

<https://www.bigmotive.com/pilot-public-panel-on-data-faqs/>

The page contained 18 questions and answers and directed people towards the Expression of Interest form should they choose to join. The questions were also set up as a PDF document to be circulated by the stakeholders as a part of the invitation emails.

Expression of Interest form

The Expression of Interest form was set up on Typeform and collected the minimum amount of data possible to help the team assess the suitability of the applicant.

Questions included name, email address, location, knowledge of data, membership in other panels and their reasons for expressing interest in joining a pilot public panel. <https://form.typeform.com/to/fiCEHHFr>

Incentives

A phased recruitment rollout was tested, with the first phase not mentioning incentives, and the second phase offering a £40 voucher for those who participated in both sessions. Four applications were received in the first phase and 13 were received in the second phase.

Retention/Dropouts

The form received a total of 17 applications. After the deadline, each applicant was contacted individually with a welcome message outlining dates and times for the two pilot sessions.

Closer to the date of the first engagement, a second message was sent with Zoom login details, Principles for Engagement and the NDA agreement. A calendar invite was also sent out, keeping the invitees list private and confidential.

Of the 17 invited members, nine attended the first pilot session, and three excused themselves for health, work or personal reasons. The second session saw a drop out of two more members, and a third dropout who was present at the start but lost their internet connection quite early on. A total of six members concluded both pilot sessions successfully.

Membership Profiles

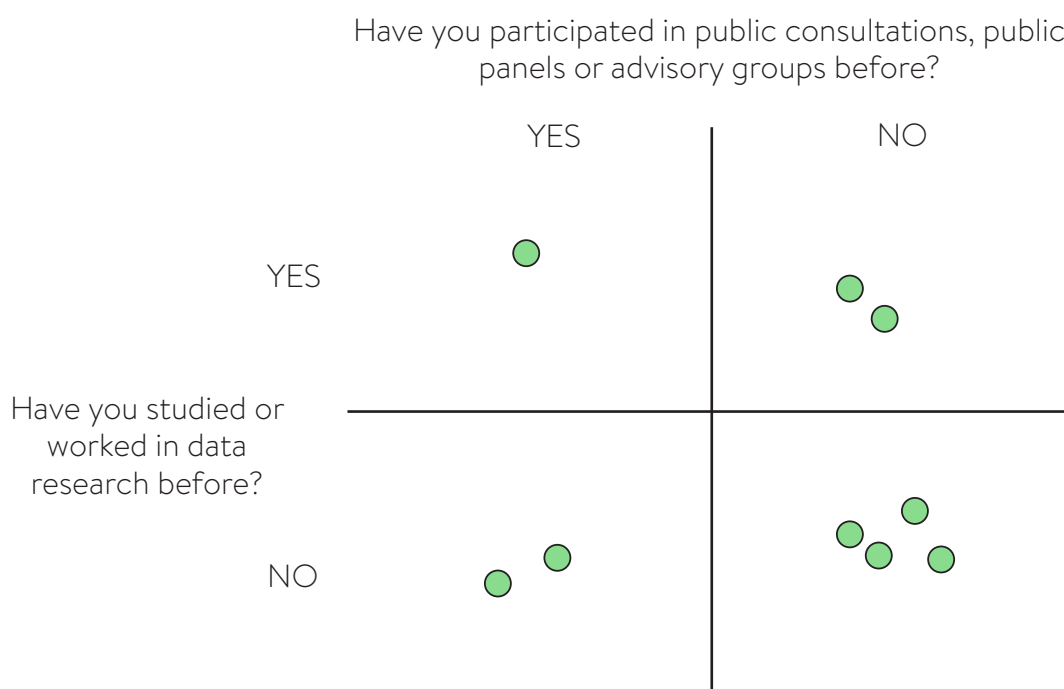
The profiles of the participating members were organised in three categories:

Primary residence: four participants from country Antrim, four from Down and one from Tyrone

Have you studied or worked in data research before: three yes, six no.

Have you participated in public consultations, public panels or advisory groups before: three yes, six no.

There was a gender and age ratio balance: five male, four women with ages ranging between 24 and 54.



Visualising the backgrounds of our pilot participants. Note this indicates nine participants, which was the original number for session one. This dropped to six in session two.

Pilot Panel - Session Design

Two pilot panel sessions were collaboratively designed, drawing on topics of relevance from stakeholder experience and of published panels from other practitioners. These sessions used two types of building blocks: explanatory activities, and participatory activities. The explanatory activities had the purpose of orientating the members around their participation in the panel, the flow of the session and the capacity building pieces. The participatory activities were designed to facilitate and stimulate discussions and conversation in small groups and in plenary sessions.

The session agenda can be found within appendix.

Session Delivery

Session 1

The first session included a section on the data landscape. Three case studies were presented for discussion. Individual qualitative responses were collected using the [Mentimeter](#) tool, and the Zoom Poll function was used for gathering quantitative data around case studies, the quickfire questions and their participation in the panel.

Session 2

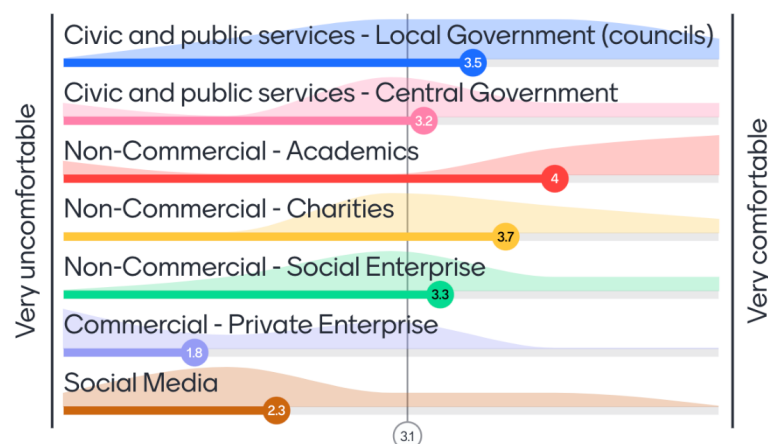
The second session focused on public trust and dynamic consent and included a deeper reflection about the quickfire results from the previous session. For Session 2 the discussion was kept in the main plenary room, instead of breakout rooms. The small number of participants (six) made this viable, and every member had a chance to participate and speak about the different prompts.

Session Results

Though the Pilot sessions were set up as a prototype, one of the great strengths of this pilot was that it used real world case studies and relevant data-related questions to engage the participants.

It was found that despite not having any strong opposition to data sharing and usage within the cohort, there was a wide variety of opinions on the detail of data use in the discussion. In general, the members expressed that their opinions on data sharing are very dependent on who is collecting the data, where it is stored and how it is used, eg: *“Sharing my anonymised and aggregated data for researcher on air pollution would be acceptable. Individual and identifiable not so”*.

How comfortable do you feel about our personal data being shared with...



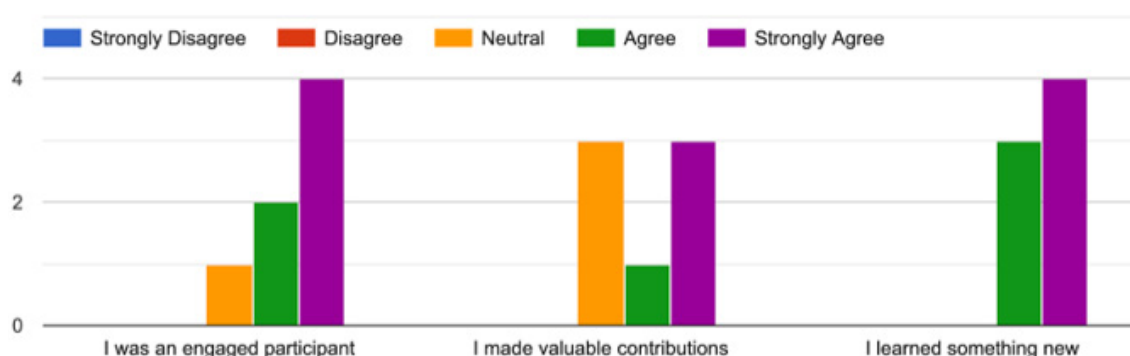
Results from a Mentimeter poll, session 1, indicating participants' comfort with their data being shared with various entities (0 = Very uncomfortable, 5 = Very Comfortable)

Final Survey Results

The final survey had a total of eight responses, seven who were present at both sessions and one absent. The survey investigated members' satisfaction with their own participation, the recruitment and setup for the panel, the delivery of the sessions, and their future engagement with the Panel.

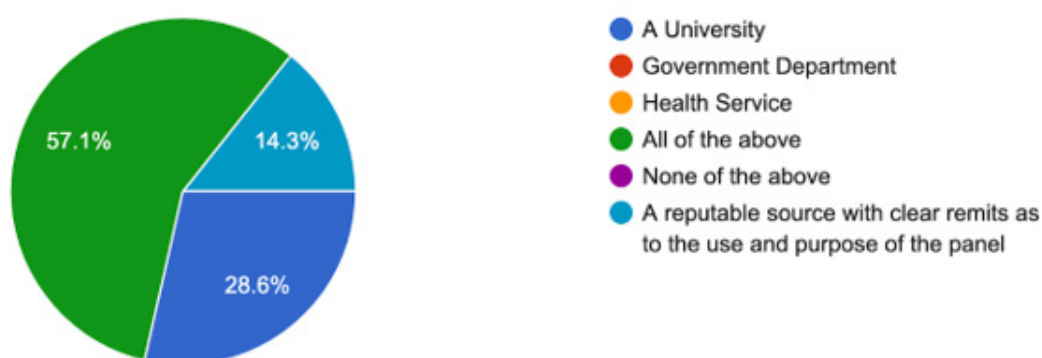
Most participants reported they felt satisfied with their engagement and learned something new.

How would you rate your participation?



Results from the seven respondents to the final poll

As for future panel sessions, five out of seven respondents reported that they would be willing to participate in a session every two months, preferably on a weekday, with a slight preference for mornings. Four reported they would prefer the session to be kept under two hours, two were open to it being three hours and one person chose an hour only. No participant picked the full-day option.



How the seven respondents to the final survey felt about who should issue an invitation to any future NIPDP

When asked who should issue the invitation for future panels, four respondents indicated that it should be from a university, government department and health service, combined. Two selected *“a university”* only, and one respondent selected ‘other’ and described *“a reputable source with clear remits as to the use and purpose of the panel”*.

Regarding incentives, the expectations for remuneration for participation were varied, with a couple of people indicating that the incentives offered for the pilot were appropriate (£20 per session). Other responses included: *“At least minimum wage per hour”*, *“£20 per hour”* and *“No remuneration for virtual but covering expenses to attend actual meeting”*.

Recommendations and next steps

Despite its small size, this pilot clearly reflects an interest from participants in the use of data, how it can impact and benefit them, and how they, in turn, can impact the data landscape and data-driven decision-making. As well as working through practical real-world case studies of how data is currently or could potentially be used in research, services and policymaking, participants were in the unique position of being able to make recommendations on how a future panel should be set up, based on their own real-world experiences. This is valuable knowledge for the future establishment of the NIPDP.

From both the interviews and the workshops a broad set of recommendations for the future of the NIPDP can be drawn:

- A Northern Ireland Public Data Panel should be established to provide a forum for publics to learn about, discuss, and impact the data landscape in Northern Ireland.
- The NIPDP should ideally be run as a partnership between several different sectors and organisations and should prioritise its independence.
- Participants in the NIPDP should receive some kind of remuneration for their role.
- Organisation of future panels should take cognisance of the different barriers faced by different communities and populations, such as socioeconomic factors and mitigate for these barriers as much as possible.
- Care should be taken to identify appropriate recruitment measures to avoid missing ‘under-served’ local communities and centring inclusion and diversity within recruitment efforts.
- Communication from organisers to members should be clear and consistent, from recruitment to preparation material and follow-up after decision-making, to avoid the appearance or existence of tokenism, and maintain relationships.
- NIPDP should draw on best practice of existing panels, but also adapt its approach as and where necessary to reflect and respond to the particular circumstances of Northern Ireland and its communities.
- NIPDP should be strategically linked to decision-makers so that feedback from members has the best chance of making a positive impact on people’s lives and upholding the goal of democratising data.
- Design of content and delivery should be engaging and interactive, responding to the participant requirements.
- It is crucial to include an awareness-raising or capacity building piece as part of future panels to support full, informed participation.
- There should be transparency so participants can see the impact of their contribution.
- The delivery of NIPDP should be iterative and cocreated with its members.

The future of the NIPDP: Next Steps

Next Steps

Next steps will include bringing the participants' recommendations to bear when setting up the NIPDP in its next form, within phase one. It is intended that all future iterations of NIPDP will continue to be co-created with panel members, ensuring as much as possible that Northern Ireland's public engagement infrastructure is itself a product of genuine engagement and involvement.

The learning from the NIPDP pilot has informed the implementation plan for NIPDP and how it can function as key infrastructure enabling public dialogue on issues surrounding the use of data for public benefit. With funding secured, via ADRC NI, phase one commenced in April 2022 to enact the findings of the NIPDP pilot and formally establish the first Northern Ireland Public Data Panel.

In post-pilot phase one, the NIPDP will test and refine delivery of the panel whilst also exploring, with panel members, how to design future delivery to enable a Northern Ireland-wide view in innovative use for data specific to this region and its people. Funding for subsequent phases will be identified across the project timeline.

This approach reflects that while NITRE, ADRC NI and BCC City Innovation Office are advocates for involvement of the public in decisions around use of their data, evidenced by their funding and sponsorship of the NIPDP initiative to date, this conversation is necessarily wider and not limited to them.

References

- 1 <https://www.hdruk.ac.uk/news/new-principles-published-to-improve-public-confidence-in-access-and-use-of-data-for-health-research-through-trusted-research-environments/>
- 2 <https://www.gov.uk/government/publications/data-for-the-public-good-government-response>
- 3 https://understandingpatientdata.org.uk/sites/default/files/2018-04/Data%20for%20public%20good_0.pdf
- 4 https://www.ark.ac.uk/pdfs/Researchreports/Data_Sharing_Report.pdf
- 5 <https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-hscni-data-strategy.pdf>
- 6 Aitken, M., Tully, M. P., Porteous, C., Denegri, S., Cunningham-Burley, S., Banner, N., Black, C., Burgess, M., Cross, L., van Delden, J., Ford, E., Fox, S., Fitzpatrick, N., Gallacher, K., Goddard, C., Hassan, L., Jamieson, R., Jones, K. H., Kaarakainen, M., Lugg-Widger, F., McGrail, K., McKenzie, A., Moran, R., Murtagh, M. J., Oswald, M., Paprica, A., Perrin, N., Richards, E. V., Rouse, J., Webb, J. and Willison, D. J. (2020) “Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research”, *International Journal of Population Data Science*, 4(1). doi: 10.23889/ijpds.v4i1.586.
- 7 Jones, K., Heys, S., Thompson, R., Cross, L. and Ford, D. (2020) “Public Involvement & Engagement in the work of a data safe haven:: a case study of the SAIL Databank”, *International Journal of Population Data Science*, 5(3). doi: 10.23889/ijpds.v5i3.1371.
- 8 Nelson, E. and Burns, F. (2020) “Impact through Engagement: Co-production of administrative data research and the approach of the Administrative Data Research Centre Northern Ireland”, *International Journal of Population Data Science*, 5(3). doi: 10.23889/ijpds.v5i3.1369.
- 9 <https://www.adruk.org/about-us/our-partnership/adr-northern-ireland/>
- 10 <https://www.belfastcity.gov.uk/digitalinnovation>
- 11 <https://www.health-ni.gov.uk/sites/default/files/publications/health/doh-hscni-data-strategy.pdf>
- 12 <https://www.bigmotive.com/>
- 13 <https://www.hdruk.ac.uk/covid-19-data-and-connectivity/>
- 14 <https://understandingpatientdata.org.uk/>
- 15 <https://www.hdruk.org/about-us/patient-and-public-involvement-and-engagement/#:~:text=Patient%20and%20Public%20Engagement%E2%80%8B,from%20patients%20and%20the%20public.>

References

- 16 <https://research.hscni.net>
- 17 <https://www.bhf.org.uk>
- 18 <https://www.barnardos.org.uk/>
- 19 <https://www.ulster.ac.uk/faculties/life-and-health-sciences/biomedical-sciences/subjects/stratified-medicine>
- 20 <https://hscbusiness.hscni.net/services/2843.htm>
- 21 <https://www.nihr.ac.uk/>
- 22 <https://www.scadr.ac.uk/>
- 23 <https://www.employersforchildcare.org/>
- 24 <https://www.nicva.org/>
- 25 <https://saildatabank.com/>
- 26 <https://www.qub.ac.uk/research-centres/nicr/>
- 27 <https://www.qub.ac.uk/sites/NICOLA/>
- 28 <https://matrixni.org/belfast-joins-odi-open-data-network/>
- 29 <https://smartbelfast.city/>

Appendix 1

The Delivery Team

The core team was composed of seven members from cross-sectoral organisations.

Frances Burns - Programme Lead, Northern Ireland Trusted Research Environment (NITRE)

Frances is lead for the Northern Ireland Trust Research Environment (NITRE)¹¹, a strategic group from the Department of Health, the Northern Ireland Public Health Agency and the Health and Social Care Honest Broker Service to enable connectivity, and data provisioning from within Health and Social Care Northern Ireland. She also works with Health Data Research UK (HDR UK) connecting Northern Ireland Health and Social Care data to support and accelerate research and enabling streamlined data access and analysis. Previous to her current roles Frances was the Programme Lead for the Administrative Data Centre Northern Ireland (ADRC NI)⁹ and previously managed the establishment of the Northern Ireland Cohort for the Longitudinal Study of Ageing (NICOLA)²⁷, Northern Ireland largest public health research project with over 8,500 participants.

Frances hold a PhD in factors affecting impact of publicly funded research and innovation.

Elizabeth Nelson - Public Engagement, Communications & Impact Manager, ADRC NI (ADR Northern Ireland)

As lead for engagement and impact within ADRC NI⁹, Elizabeth's remit includes developing partnerships with voluntary, community and social enterprise (VCSE) sector groups as well as policymakers and prioritises involving key stakeholders in data research for public benefit. Her work focuses on centring the different types of knowledge possessed by different publics within the administrative data research of the ADRC NI, and in identifying and supporting innovative sites of both engagement and impact. She has extensive experience in engaging with vulnerable and disadvantaged communities and enhancing the participation of these groups in politics, research and policymaking.

²⁷ <https://www.qub.ac.uk/sites/NICOLA/>

Andrea Thornbury - Project Manager,
City Innovation Office, Belfast City Council

Andrea's remit includes the role of Data Specialist in the City Innovation team, working towards the development of a city data strategy and developing a well-maintained network of public officials, developers, companies and citizens to leverage data infrastructure to improve quality of life and address city challenges. As manager of the Belfast Hub her work fosters innovation in areas of historic urban interest in eight cities across Europe. Andrea has previously worked at NICVA24 managing the Detail Data project, harnessing open data for public good and establishing ODI Belfast²⁸, the first Open Data Node on the Island of Ireland.

Deirdre Ferguson - Innovation Broker,
City Innovation Office, Belfast City Council

Deirdre's career spans public, private and community sectors where she has worked in community development, regeneration, training and development, retail and the pharmaceutical industry. More recently Deirdre has played a fundamental role in establishing Belfast City Council's City Innovation team and developing the 'Smart Belfast' programme²⁹ which aims to harness digital innovation to address urban challenges and nurture economic growth. In her role as City Innovation Broker Deirdre has led on and supported a range of open innovation projects, inspiring colleagues and city partners to work collaboratively to explore the potential of data and digital technologies to address societal challenges. She has supported the development of the Digital Innovation Pillar of the Belfast Region's City Deal which will bring £120 million into the region over the next ten years and is working with team members to develop a Smart District to support the trialling, testing and deployment of digital solutions to accelerate innovation.

28 <https://matrixni.org/belfast-joins-odi-open-data-network/>

29 <https://smartbelfast.city/>

Rebecca Walsh - Service Design Director,
Big Motive

Rebecca is Service Design Director at Big Motive and a Chartered Mechanical Engineer (IMechE). She holds an MEng (Hons) Aerospace Engineering from Queen's University Belfast and brings ten years of experience in user-centred design and service innovation to her role at Big Motive.

Beginning her career in Bombardier Aerospace working exclusively in aerodynamic design, Rebecca joined Bombardier's innovation team to work on future aircraft design. She also worked on business efficiency and lean/transformation programmes, collaborating with teams across four global locations.

Rebecca is responsible for the delivery of high-quality experience design projects for a range of Big Motive's clients. Using her wealth of knowledge and expertise, she also delivers an interactive design-led module for the MBA programme at Queen's University.

Maíra Rahme - Strategist and Facilitator,
Big Motive

Maíra holds a Bachelor in Design from ESPM in Brazil, and an MSc in Sustainability from BTH in Sweden, where she conducted research with a focus on Complexity and Behavioural Sciences. An accomplished Service Designer and Strategist, Maíra is a confident and competent designer who is able to develop designs based on evidence of user needs and organisational outcomes. Her expertise in agile working and leadership, combined with her communication, community collaboration, strategic thinking and user focus enables her to design end-to-end solutions and recommendations that work. Maíra's current focus with Big Motive is to design and deliver Human-Centred Design & Experience Design solutions for clients such as the Department of Health, and Health and Social Care NI.

Carol McHugh - *Researcher and Participant Recruiter, Big Motive*

Carol holds a BSc (Hons) Communication, Advertising & Marketing from Ulster University.

She works alongside the creative team to ensure that all projects are supported by solid research and testing, having successfully recruited hundreds of participants to participate in quantitative and qualitative research for many of Big Motive's clients including the Information Commissioner Office (ICO), Department of Health, Allstate Insurance, The Public Health Authority, Danske Bank, Power NI, Coca Cola, Pobal and An Bord Pleanala.

In this project, Carol had a central role in managing and scheduling the Interviews with Industry Leaders, as well as recruiting the participants for the Pilot.

In previous roles, Carol has worked with a wide range of blue-chip clients including Jameson Whiskey, BT, Lidl and Tourism Northern Ireland.

Appendix 2

Session One

Participatory activities highlighted:

Part 1: Arrivals and welcome
Arrivals
Welcome
Introductions
Purpose of the session
Format/agenda
Recording and NDA
Rules for engagement
Part 2: Onboarding
Ice Breaker
Panel member introductions
Public Data Panels - what are they?
Teamed Icebreakers in Breakout Rooms
Part 3: The Data World
Quick introduction to data: Data Facts.
<i>Quick Fire Qs: What does data mean to you?</i>
Case Study 1
<i>Reflection Question about Case Study 1</i>
Case Study 2
<i>Reflection Question about Case Study 2</i>
Case Study 3
<i>Reflection Question about Case Study 3</i>
More context around Case Study 3
<i>Has your opinion changed?</i>

Part 4: What is Data?

Capacity building piece on Data

Part 5: Discussion

Review and Revisit Quick Fire Questions

Breakouts Part 1: Case Study Discussion

Breakouts Part 2: Your Data

Session Review

Outline what we covered during the session

Did you learn anything you didn't already know about data?

Did your perspective on use of data change in any way?

Do you see value in a Public Data Panel for Northern Ireland?

Next Steps:

Online evaluation

Agenda

Channel for communications

Voucher information

End

Session Two

Participatory activities highlighted:

Part 1: Arrivals and Welcome
Arrivals
Welcome
Purpose of the session
Format/agenda
Refresh on NDA
Refresh the rules for engagement
Part 2: Ice Breaker and Recap
Ice Breaker
Team Ice Breaker in Breakout Rooms
Recap of Session 1
Part 3: Quickfire Discussion
Show graphs on quickfire results
<i>Discussion about two quickfire question results that displayed change in responses in session 1.</i>
Part 4: Public Trust Discussion
Menti: 2 Questions about Public trust
<i>Plenary discussion about Questions</i>
Introduction to Consent
<i>Discussion about Consent</i>
Quick Evaluation and Check-out
Spiral journal
Closing
Voucher information and next steps
End

