Scottish Data and Intelligence Network Engagement Plan: Report

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Contents

Note 2
Acknowledgements 2
Executive Summary 3
Introduction 7
Existing Work Relevant To Strengthening Public Engagement 9
What Is Public Engagement? 11
Findings and Recommendations 16
List of Acronyms and Terms 20

Note

Whilst this report was commissioned by Public Health Scotland on behalf of the Data Intelligence Network, the findings and recommendations do have wider implications. Public engagement by the DIN does not take place in a vacuum, and nor, given the issues the pandemic raises, will it solely deal with issues related to data and COVID. As the future role of the DIN is considered, it will therefore be important that the findings and recommendations in the report are shared across the public sector, led by Scottish Government.

We would also note that the DIN was and is working in a unique situation. The nature of the global pandemic and necessary speed of response heightened public engagement challenges. Our recommendations are intended to normalise public engagement which would make involving the public whilst reacting at speed less challenging. We also hope that implementing the recommendations will mean the views of the public can be used to inform the response to any future similar public health emergency.

Finally, we would note that the report is written for the DIN and its members. In this iteration it should not be read as a public facing document.

Acknowledgements

We are grateful for the commitment to and enthusiasm for this project from members of the DIN. We would especially like to thank our Steering Group members, our interviewees and attendees at the workshop. As the lead author, I would also like to thank Simon Burall, Kaela Scott and Madeleine Gough at Involve.

Executive Summary

Summary of Recommendations

With a view to realising the ambition of the DIN to widen and deepen public engagement, we have set out five outcomes with associated recommendations.

1. Developing a strategic approach to public engagement

The Portfolio Board should consider refining the objective of the DIN to explicitly include public engagement, transparency, and collaboration. The revised objective should be clear that the DIN seeks to act in a way that will increase public trust in a transparent, accessible and ethical approach by the DIN to the collection and use of data during the pandemic.[1]

Our proposed refined objective (changes in bold) is:

> *to provide a safe, expedient, and ethical access to use data and intelligence from across public services in Scotland* ***in a transparent, participative and collaborative way*** *to effectively manage our response to* ***and recovery from*** *the public health emergency caused by Covid-19* ***in a way that builds public knowledge of access to and trust in data intelligence and its use in a public health emergency.***

The Portfolio Board could usefully develop a theory of change to achieve the objective with clear deliverables and lines of accountability. The theory of change would elaborate how the DIN can move from rhetorical support of engagement to more meaningful support for it.

The Transformation Board should commit to setting out how public engagement will happen as an integral part of inception of DIN challenges. Challenges and decisions must provide clear indicators of where the engagement will have influence.

2. Delivering participation and ensuring transparency

The Portfolio Board should allocate adequate resources to TF2 or its replacement to support a public panel to review the challenges delivered without prior public engagement, both before April 2021 and subsequently. This would:

- enable assumptions to be tested
- inform future decisions
- increase transparency around the decisions made by the DIN
- embed the concept of public engagement.

The public panel could also be asked to review ongoing engagement materials, such as the Daily Dashboard, and suggestions to improve accessibility and ease of public engagement should be implemented by the appropriate DIN member.

[1] This reflects the TF2 Final report, Paragraph 12: "the anticipated outcome (of TF2's work) being public trust in a transparent, accessible and ethical approach by the DIN to the collection and use of data during the pandemic."

The Opportunities for Public Engagement presented in this report should be reviewed by the Portfolio Board and at least one (or a suitable alternative) selected to be operationalised.

3. Ensuring a shared understanding of public engagement

Training in public engagement processes and the spectrum of participation should be offered to all appropriate personnel. The DIN should offer to test the Engagement Tools in the Participation Framework.

To help ensure the necessary cultural change in attitude towards ownership of public engagement, senior leaders should undertake high-level training to build their confidence in commissioning engagement and developing effective engagement strategies.

4. Ensuring collaboration

The DIN should provide a forum for knowledge sharing on engagement activity around data, approaches and outcomes which network members can access – including existing activity. Additionally, to facilitate routine sharing of public engagement activity and approaches, a public engagement database, or similar, should be created. This would provide for processes to easily be searched for in order to provide guidance and inspiration to those seeking to engage the public.[2] Submissions should capture the design of the process and the outcomes. Submitting information to the database should be required as part of the close-out / Sprint Retrospective of any project. Trends in public responses which may provide reassurance in similar circumstances should be identified and may help when decisions are being made at pace, but these should be regularly tested with new audiences.[3]

5. Building public knowledge and trust

The Portfolio Board should agree to the creation of a published overview of the systems of Information Governance across the NHS, NRS and RDS. This will help increase the transparency and the understanding of the DIN and allow the public or those involved in particular projects, to understand how their information is held, by whom, for what purpose, who decides it can be shared and under what circumstances.[4] In so doing, it should consider asking the public for solutions to some of the challenges identified in collection, sharing and matching data. The public should also be invited to share their views about possible reasons for the challenges, and the repercussions of both gaps in data and matching previously separate datasets.

[2] Responsibility for delivery should be made clear alongside timeframes and lines of accountability.
[3] This is to acknowledge that there are some identifiable trends that could assist decision making – especially under pressure of time – but that these should not be assumed to remain accurate over time / different publics.
[4] Based on a finding from the TF2 Final Report - para 23: "What has proved more challenging is understanding the current myriad ways of managing and linking data across public services; there is no published overview of the system which would allow the public or those involved in particular projects, to understand how their information is held, by whom, for what purpose, who decides it can be shared and under what circumstances."

Overview of Findings

Our research has identified that there is a broad understanding of the desirability of engaging the public to determine whether citizens share the view of DIN members on what is appropriate, proportionate or acceptable with regard to the risks and benefits of collecting, linking, storing and accessing data, and an appetite to engage better.

However, there is much more limited understanding of the different ways in which public engagement could support decision making. Furthermore, the lack of an identifiable strategic project management process makes it difficult to recognise when and where public engagement could take place. Members of the network are therefore unable to prioritise thinking strategically about how the public might help make specific decisions more effective. The challenge for the network and its leaders is to provide the strategic framework that will enable the move from rhetorical support of engagement to more meaningful support for it.

When public engagement is undertaken by members of the network, it is predominantly to inform the public about a decision that has already been made, or to consult with them (usually by means of surveys or stakeholder engagement) to test nearly fully finalised policy proposals. This consultation has, in some places, assisted in decision making or reassured those making the decisions that the public support the course of action that has already been chosen. Providing opportunities for the public to have more input into or control of decisions is rare.

We also heard concerns about 'missing' data, especially around protected characteristics. Perceived lost opportunities where data is not joined up were also highlighted. Addressing these gaps is often seen as meeting the public's natural assumptions as to what is done with their data, but this seems to be based on historic and ad hoc consultation or anecdote rather than meaningful public engagement.

Example

Prior to COVID19. the Financial Inclusion team in Glasgow was testing the hypotheses that people were under-claiming grants and benefits. They looked at benefits data and matched it to clothing grants, free school meals etc and identified 5000 families who weren't claiming when they could be doing so.

A citizen's panel for the Tackling Poverty programme were asked if Glasgow City Council (GCC) used the data to give the families the money they were entitled to, would that be an issue? And the response was 'why aren't you doing that already?' An automatic entitlement process was put in in place and there was generally a positive response.

This sort of accidental finding seems to frame attitudes around data matching, including the CHI-UPRN project – where hooking up the data is thought to obviously be a sensible approach and then an assumption that the public would agree.

We perceived a residual paternalism that suggested decisions can be made on behalf of the public where public good is 'obvious'. There is a reluctance to consider that citizens can be skilled up to understand complex ethical judgements and that they might have a different and equally valid understanding of what the public good is. The opportunity presented by public engagement to challenge assumptions and invite consideration of wider implications of data collection and use is not fully appreciated across the network.

The Development Principles and Essential Behaviours described in the DIN Overview indicate an obvious intent to collaborate between DIN partners. Despite this, shared awareness of the activities of others in the network is low. This makes the challenge of strategic consideration of public engagement harder because synergies cannot be identified and existing outcomes are not publicised or easily accessible.

Finally, it became clear as feedback was received on the drafts of the report that the legal requirements of Information Governance will place limitations on what can and cannot be included in public engagement. We have found in the past that complexity can be used as a reason not to take forward engagement. Developing public engagement in the area of data, data ethics and Information Governance should be seen as an iterative process which can be adapted to take account of barriers encountered. Developing a strategic framework would also assist in incorporating these limitations into any engagement processes.

Overall, the quality of engagement and time contributors have given to the project has been very welcome, including significant contributions from senior leadership. This bodes well for the leadership needed to implement the recommendations above.

INTRODUCTION

HOW THIS REPORT CAME ABOUT

Across Scottish Government there is an appetite for, and understanding of the value of, public engagement. The commitment to citizen participation is central to the Scottish Approach to Service Design[5] and the nascent Participation Framework. Processes like the Social Security Experience Panels,[6] the Digital Ethical Nation Public Panel[7] and the Citizens Assembly of Scotland[8] are delivering on this commitment. Scotland is very much at the forefront of including the public in policy development and this should be applauded. That said, it is vital that outcomes match rhetoric. Everything we've learned about public engagement indicates that the people who participate, but then fail to see that their input has been taken account of, lose faith in the wider process of government as well as the specific process they are part of.

Early on in the pandemic, the Scottish Government took a strategic approach to the management of the data required to deal with COVID-19 by establishing the Data Intelligence Network (DIN). The Network brings together expertise from across local authorities, health boards, Directors of Public Health, Health and Social Care Partnerships, Public Health Scotland, Scottish Government, academia and other public bodies.

The current objective of the DIN is:

> *to provide a safe, expedient and ethical access to use data and intelligence from across public services in Scotland to effectively manage our response to the public health emergency caused by Covid-19*

It aims to ensure that the data and intelligence needed is in the hands of the right people, in a form they can use, at the right time.

Recognising the commitment to public participation, the DIN established Task and Finish Group 2 'Communications and Data Ethics' (TF2) and included in its remit agreeing an ethical framework for the DIN, developing scrutiny mechanisms and delivering a strategy for engagement and communication.[9] As part of this work, DIN TF2 has produced two reports: *Report and Recommendations from the Short Life Working Group on Ethics and Engagement for the Data Intelligence Network Task and Finish Group Two* and *The Ethics Framework and Workbook*. An important element of both these reports has focused on how to involve the public in making **decisions about the collection, analysis, use and sharing of data**.

To help design the engagement strategy, Involve was commissioned by Public Health Scotland (PHS) to work with senior leaders across the DIN to develop a draft engagement plan to present to the wider network. It is the beginning of a journey that will require commitment, both in time and money, across the DIN.

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[5] https://www.gov.scot/publications/the-scottish-approach-to-service-design/
[6] https://www.gov.scot/policies/social-security/engagement-on-social-security/
[7] https://blogs.gov.scot/digital/2021/03/22/introducing-the-digital-ethics-peoples-panel/
[8] https://www.citizensassembly.scot/
[9] See Appendix 1 for the full Terms of Reference for TF2.

The approach taken was to carry out semi-structured interviews with leaders across the DIN in order to identify opportunities for engagement. This was followed by a workshop attended by DIN leaders where those opportunities were prioritised and discussed.[10]

We were able to interview over 20 different members of and contributors to the DIN, and we are grateful to them for making the time to speak with us. The individuals we engaged with, either through the interviews or the workshop were identified by our Steering Group as key to the project or with particular insights to share, based on the breadth of collaborators across the DIN.

The Structure of the Report

This report summarises the project, presents our findings and introduces our recommendations. It should be read alongside the *Ethics Framework and Workbook* and the *TF2 Final Report*.

As will be shown, our work with members of the DIN indicates that the direction of travel adopted by the TF2 reports is seen as appropriate and proportionate by those who are aware of them. We therefore summarise the key relevant points from these reports at the beginning of this report.

Our work indicated that a shared understanding of public engagement is low. We include a short introduction to the Participation Framework.

After we have provided some context to the findings and recommendations, we will elaborate on some of the opportunities that were identified and discussed during the interviews and the workshop. We will use the Participation Framework to frame our approach.

[10] A full list of interviewees and workshop attendees is available at Appendix 5

Existing Work Relevant To Strengthening Public Engagement

As part of our work we reviewed existing reports from the DIN, a number of areas of which support our findings. We have summarised this here to try to bring all the relevant aspects into one place to make it easier for the reader.

DIN TF2 Final Report

The recommendations in the TF2 report identified new ways in which the public could be involved in key decisions, and how to support the culture change needed to embed public engagement across the DIN.

A citizens' panel for reviewing outputs and outcomes.

A medium-term recommendation from the DIN TF2 report was to:

> "*Scope and test the option of appointing a citizens' panel to review the outputs and outcomes from the DIN*" (para. 41 and 52).

Our research suggests this is an area of significant potential for public engagement. It also emerged from the workshop and was further discussed and developed there. We present this idea as part of the 'Options' section below.

A citizens' panel to support a Data Ethics Commissioner.

The TF2 Final report also recommended that:

> "*a case is set out for the appointment of a Data Ethics Commissioner for Scotland to provide effective scrutiny. This would be a position established by Parliament, with the support and resources required to offer independent advice and scrutiny for the use of data collected and held by public services in Scotland*" (para. 41 and 52).

If this recommendation is taken forward, we would suggest that consideration be given to the Commissioner being supported by a Data Ethics People's Panel.

Supporting culture change

We recognise the Longer-Term Recommendations in the DIN TF2 report and suggest there is obvious overlap here with our recommendations.

> *"The DIN must show leadership to support the investment in skills and capacity to ensure those responsible for offering ethical advice have the seniority, confidence and competence to challenge effectively."*
>
> *"Once the health emergency is removed it will be important to evaluate, review and refresh the ethics framework before moving into business as usual. This is important so that proper consideration can be given to whether or not the moral and ethical dilemmas continue to warrant the same levels of the use of data and intelligence."*[11]

[11] DIN TF2 Final report Summary p3

Transparency, Communications and Engagement[12]

We took on board and would reiterate the DIN TF2 report recommendations in this area.

> *"There should be a culture of proactive publication, both about the DIN itself and the work it is delivering, with public engagement and participation seen as a matter of routine, particularly where the use of data is likely to be seen as contentious by the public. Publications should be in plain language and easily accessible."* (para. 39)

Ethics Framework and Workbook

We support and reiterate the recommendation of the TF2 Final Report which states at para 38: "*The Ethics Framework will have to be evaluated, tested and regularly reviewed – if it does not provide sufficient encouragement or advice to secure ethical considerations by the DIN it should be amended*."

Any public engagement work must be wholly integrated with the ethics workbook. We welcome the recognition of consideration of the public in the ethics workbook and suggest that where public engagement is identified as required, project leads then utilise the recommendations in this report to take forward the public engagement. We strongly recommend that use of the ethics workbook be a documented and shareable process to allow for cross-project and cross-department learning as well as identifying possible instances of shared public engagement methods / processes.

We would also suggest that where public engagement is not deemed necessary whilst using the ethics workbook that these decisions be available for review by a public panel.

Existing Activity

During the interview stage of the research, we asked about existing public engagement activity. The question received a varied response, with some respondents admitting to no knowledge of any engagement activity.[13] We have not had time to work up a detailed map of existing public engagement activity - although we do recommend a review is undertaken

Based on the information we were given in the interviews and some very quick desk-based research we looked at 15 different processes. We have listed these and summarised seven in more detail at Appendix 3. For these seven we have identified their Participation Purpose and the Delivery Cycle stage at which they took place, with a view to their exemplifying different aspects of each. These concepts will be introduced in the next section. Outcome 4 includes our suggestions for improving documentation and communication of engagement processes.

[12] The current communications objectives and initial target audiences can be found in Appendix 2

[13] Recommendation 6 includes our suggestions for improving documentation and communication of engagement processes. We suggest any review of existing activity is submitted to the public engagement database.

What Is Public Engagement?

Our research identified that there is little shared understanding of what is meant by 'public engagement' across the DIN. Public engagement can take many forms, but if public trust is to be gained and held, it is vital that from the outset, processes of engagement acknowledge the limits of the influence placed upon it, i.e. where the engagement sits in the participation spectrum (see below) - what is the 'offer' to those who are being engaged? For this to be effective, members of the DIN need to share the same basic understanding of what is meant by public engagement.

It is also important that the definition of 'public' is clear and shared. Whilst, for example, civil society groups and representative organisations are a 'public' they are not 'the public'. We recommend the DIN be clear on what is meant by 'public' in any given engagement process.

This section offers an introduction to clarifying these terms with a view to the DIN being able to develop a shared understanding of 'public engagement'. It relies on the content of the Participation Framework, the Engagement Tools within which we recommend the DIN be involved in testing.

The term engagement is an umbrella term that covers a wide range of potential outreach activities that government might choose to undertake – from social media interactions, to surveys, formal consultation papers, roadshows, workshops, stakeholder working groups, co-producing policies, user-led service design, public meetings and more. These activities can be broadly placed across the Participation Spectrum.

We would challenge DIN members to place engagement previously undertaken on the participation spectrum, and to ask if the public can be more involved in influencing the decisions made and direction of travel within the DIN. Equally important will be identifying where engagement is not appropriate and being transparent about how that conclusion was reached.

The Participation Spectrum[14]

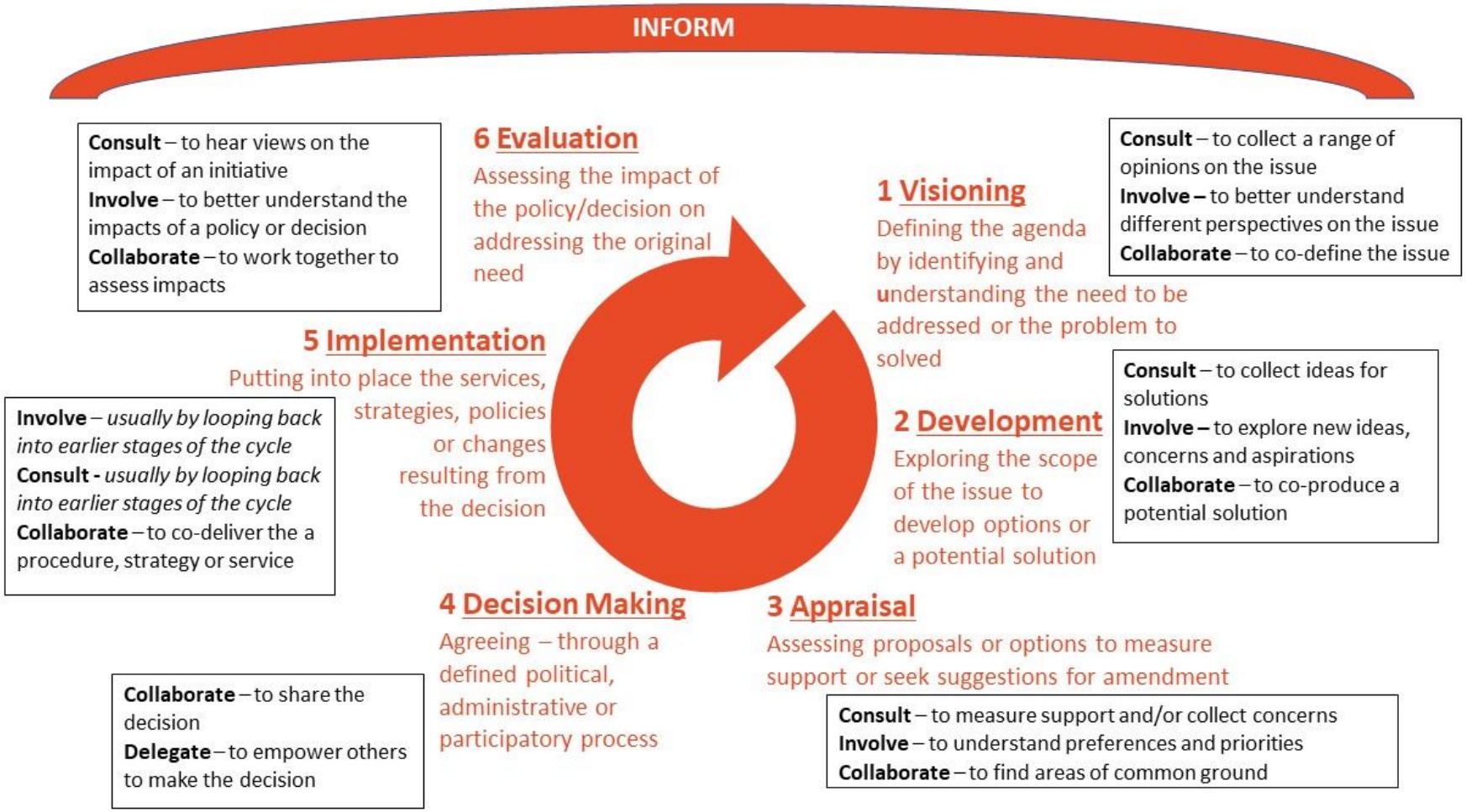
	Activity	Purpose	Promise to participants
INFORM	To provide the public with balanced and objective information	**To inform those with an interest in the outcome (i.e. the public and stakeholder groups)**	• **We will keep you informed** • **We will provide information openly and transparently** • **We will not withhold relevant information**
CONSULT	To obtain feedback on analysis, alternatives, proposals and/or decisions	**To inform those making the decision or developing proposals**	• **We will keep you informed** • **We will listen to and acknowledge your concerns and aspirations** • **We will give serious consideration to your contributions** • **We will be open to your influence** • **We will feedback on how your input has influenced the outcome**

[14]This table has been adapted from The International Association for Public Participation (IAP2) work for inclusion in the Participation Framework https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/Spectrum_8.5x11_Print.pdf

	Activity	Purpose	Promise to participants
INVOLVE	To work directly with participants throughout the policy / decision making process to ensure that their concerns and aspirations are consistently understood and considered	**To enable participants to directly influence the decision / options developed**	• **We will keep you informed** • **We will work with you to ensure that your concerns and aspirations are directly reflected in the outcome / alternatives developed** • **We will feedback on how your input has influenced the outcome**
COLLABORATE	To partner with participants in each aspect of the decision, including defining the issue, developing alternatives and identifying preferred solutions.	**To share the development and decision-making process (as much as possible)**	• **We will look to you for advice and innovation in formulating solutions** • **We will incorporate your advice and recommendations into decision / implementation to the maximum extent possible**
DELEGATE	To place final decision-making in the hands of the participants - to delegate	**To hand over the ability to make decisions and / or take action**	• **We will implement what you decide**

Each of these serve different purposes, produce different types of information and can be useful at different stages of the delivery cycle.

The delivery cycle



Informing the public can and should take place at every stage of the delivery cycle. However, the Scottish Approach encourages wider public engagement that creates a more meaningful relationship between people and government.

The level and form of engagement best suited at a particular point in time will depend on a number of factors including:

1. The overall purpose of the activity and the outcome you hope to deliver.

2. The stage of delivery cycle i.e. activities at the consulting level may be most appropriate when there is a specific proposal (or choice of proposals) that you want feedback on, whereas activities at the 'involve' or 'collaborate' levels tend to work best when you are seeking ideas around which to build a proposal.

3. What is open to public /stakeholder influence i.e. the level of the Participation Offer.

The Participation Framework elaborates on this brief introduction and includes a glossary of methods and tools to identify the right method for the task.

Findings and Recommendations

With a view to realising the ambition of the DIN to widen and deepen public engagement, we have set out five outcomes with associated recommendations. In this section we provide more detail of our findings about public engagement across the DIN and link them to the outcomes and recommendations.

1. Developing a strategic approach to engagement

Finding

Leaders across the DIN engaged with the process of our work and expressed their support for public engagement. However, public engagement is absent in the DIN's overarching objective. The seeming relegation of public engagement to a second tier level may be contributing to the challenge of moving from rhetorical support of engagement to a more meaningful foundation.

Recommendations

The Portfolio Board should consider refining the objective of the DIN to explicitly include public engagement, transparency, and collaboration. The revised objective should be clear that the DIN seeks to act in a way that will increase public trust in a transparent, accessible and ethical approach by the DIN to the collection and use of data during the pandemic.[15]

Our proposed refined objective (changes in bold) is:

> *to provide a safe, expedient, and ethical access to use data and intelligence from across public services in Scotland* ***in a transparent, participative and collaborative way*** *to effectively manage our response to* ***and recovery from*** *the public health emergency caused by Covid-19* ***in a way that builds public knowledge of access to and trust in data intelligence and its use in a public health emergency.***

The Portfolio Board could usefully develop a theory of change to achieve the objective with clear deliverables and lines of accountability. The theory of change would elaborate how the DIN can move from rhetorical support of engagement to more meaningful support for it.

The Transformation Board should commit to setting out how public engagement will happen as an integral part of inception of DIN challenges. Challenges and decisions must provide clear indicators of where the engagement will have influence.

[15] This reflects the TF2 Final report, Paragraph 12: "the anticipated outcome (of TF2's work) being public trust in a transparent, accessible and ethical approach by the DIN to the collection and use of data during the pandemic."

2. Delivering participation and ensuring transparency

Findings

Public engagement is inconsistent and underused. During the initial stages of the covid crisis it was felt that engagement would delay action – and that the trade-off between public health and public engagement was weighted towards public health. In the early months, this prioritisation was obviously correct. However, decision-making continues to tend towards the paternalistic even after the initial emergency has receded and the public continue to be excluded from critical decisions.

Public engagement is under resourced. Further to the observation that insights about public perspectives are under shared, the teams who deliver that public engagement are also under-resourced and often siloed. This limits both the extent of possible engagement and its communication. Better resourcing would enable increased knowledge of what is being done and how it could be integrated into other processes and decision-making cycles.

Recommendations

The Portfolio Board should allocate adequate resources to TF2 or its replacement to support a public panel to review the challenges delivered made without prior public engagement, both before April 2021 and subsequently. This would:

- enable assumptions to be tested
- inform future decisions
- increase transparency around the decisions made by the DIN
- embed the concept of public engagement.

The public panel could also be asked to review ongoing engagement materials, such as the Daily Dashboard, and suggestions to improve accessibility and ease of public engagement should be implemented by the appropriate DIN member.

The Opportunities for Public Engagement presented as a discussion paper appended to this report should be reviewed by the Portfolio Board and at least one (or a suitable alternative) selected to be operationalised.

3. Ensuring a shared understanding of public engagement

Findings

Public engagement is limited in purpose and scope. When public engagement is undertaken by members of the network, it is predominantly to inform the public about a decision that has already been made, or to consult with them (usually by means of surveys or stakeholder engagement) to test proposals. This consultation has, in some places, assisted in decision making or reassured those making the decisions that the public support the course of action that has already been chosen. Often engaging with civil society or members of professional bodies external to government is considered to be public engagement. Providing opportunities for the general public to have more input into or control of decisions is rare. If public engagement is to be meaningful, assist in decision making and influence behaviour it must be broader in its purpose and scope.

There is an appetite to engage but less clarity on how and when to do so. There was a high level of commitment both to our work and to engaging the public in the work of the DIN. The idea that public engagement is necessary is supported. What is less clear is an understanding of what the public might be tasked to consider and how. Whilst we were able to identify some opportunities for engagement, DIN members found it harder to imagine how the public might be engaged in specific 'challenges' or decisions.

Public engagement is seen as risky. Despite the enthusiasm to engage, nervousness around the ability of the public to understand complex issues around data and concerns that their response might require the trajectory of a policy process to be changed or even vetoed, remains. This was expressed as the public being inexpert or misled by media framing and miscommunication. This lack of trust will need to be addressed if meaningful engagement is to take place. The public need to believe that their views matter and will be acted upon.

Recommendations

Training in public engagement processes and the spectrum of participation should be offered to all appropriate personnel. The DIN should offer to test the Engagement Tools in the Participation Framework.

To help ensure the necessary cultural change in attitude towards ownership of public engagement, **senior leaders should undertake high-level training to build their confidence in commissioning engagement and developing effective engagement strategies.**

4. Ensuring collaboration

Finding

Insights about public perspectives are under-shared. Significant evidence and data exist already about public perspectives and have been used to support previous decisions. However, there is limited knowledge across the network that these insights exist, where they are held, let alone what they are. This means that either that decisions are taken without taking into account existing evidence, or public engagement is duplicated wasting time and public money.

Recommendation

The DIN should provide a forum for knowledge sharing on engagement activity around data, approaches and outcomes which network members can access – including existing activity. Additionally, to facilitate routine sharing of public engagement activity and approaches, **a public engagement database, or similar, should be created.** This would provide for processes to easily be searched for in order to provide guidance and inspiration to those seeking to engage the public.[16] Submissions should capture the design of the process and the outcomes. Submitting information to the database should be required as part of the close-out / Sprint Retrospective of any project. **Trends in public responses which may provide reassurance in similar circumstances should be identified and may help when decisions are being made at pace, but these should be regularly tested with new audiences.**[17]

5. Building public knowledge and trust

Finding

Data collection is incomplete and not joined up. We heard concerns about 'missing' data, especially around protected characteristics. Perceived lost opportunities where data is not joined up were also highlighted. Addressing these gaps is often seen as meeting the public's natural assumptions as to what is done with their data, but this seems to be based on historic and ad hoc consultation or anecdote rather than meaningful public engagement. The risk here is that by not being fully transparent and asking the public either why data is missing or if data should be matched, the possibility is opened up that public data is being used in ways the public do not expect. Asking the public about how to fill data collection gaps, the implications of data being collected or not, and the repercussions of matching data could offer different insights.

Recommendation

The Portfolio Board should agree to the creation of a published overview of the systems of Information Governance across the NHS, NRS and RDS. This will help increase the transparency and the understanding of the DIN and allow the public or those involved in particular projects, to understand how their information is held, by whom, for what purpose, who decides it can be shared and under what circumstances.[18] In so doing, it should consider asking the public for solutions to some of the challenges identified in collection, sharing and matching data. **The public should also be invited to share their views about possible reasons for the challenges, and the repercussions of both gaps in data and matching previously separate datasets.**

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[16] Responsibility for delivery should be made clear alongside timeframes and lines of accountability.

[17] This is to acknowledge that there are some identifiable trends that could assist decision making – especially under pressure of time – but that these should not be assumed to remain accurate over time / different publics

[18] Based on a finding from the TF2 Final Report - para 23: "What has proved more challenging is understanding the current myriad ways of managing and linking data across public services; there is no published overview of the system which would allow the public or those involved in particular projects, to understand how their information is held, by whom, for what purpose, who decides it can be shared and under what circumstances."

List of Acronyms and Terms

DIN – Data Intelligence Network
NMO – DIN Network Management Office
TF2 – Task and Finish Group 2

CHI – Community Health Index
GCC – Glasgow City Council
HIS – Healthcare Improvement Scotland
NHS – National Health Service
NRS – National Records of Scotland
PHS – Public Health Scotland
RDS – Research Data Scotland
UPRN – Unique Property Reference Number

Challenge – DIN terminology for project
Daily Dashboard – the public facing presentation of health data related to the pandemic
Portfolio Board – Provides leadership to DIN
Transformation Board – Agrees, supports and progresses challenges