Secure Data Environment patient, public and stakeholder involvement and communications strategy

Incorporating the involvement plan and communications plan

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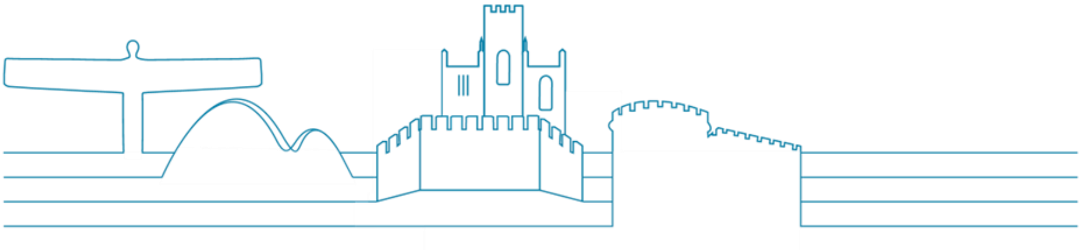

Contents

“Public trust in the Health Service’s ability and willingness to safeguard their privacy is a cornerstone of the NHS. If the public stop trusting that the information they share with their clinician will remain private, then it may become impossible to obtain the level of candour required for effective, safe treatment, posing risks to public health”1

New Economics Foundation, 2010

Who sees what: Exploring public views on personal electronic health records

“The NHS holds an incredibly rich dataset, containing the medical records of more than 65 million patients going back for decades. These detailed records have the potential to help understand the benefits and hazards of different treatments, monitor and improve clinical services and drive life sciences innovation. The same data that could do good work also contains the most private secrets of every citizen in the country. The challenge is this: how do we get lots of analysts doing lifesaving work on the data, whilst also managing the risks when lots of people have access to confidential information?”[2]

Dr Ben Goldacre, 2013

Director of the Bennett Institute for Applied Data Science and author of the Goldacre Report

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[1] Who sees what? Exploring public views on personal electronic health records, Stephen Whitehead, October 2010

[2] Earning the public’s trust on health data, Digital Health, March 2023

1 Secure Data Environments and public involvement

This section sets out background information about Secure Data Environments and high-level context in relation to the North East and North Cumbria for public involvement.

1.1 Introduction

Public involvement consistently confirms the need for use of health and care data to be of benefit to the public.

This strategy and supporting operational plan set out the strategic context which informs tactical actions in relation to patient, public and stakeholder involvement to implement a successful Secure Data Environment (SDE) for the North East and North Cumbria (NENC).

It takes a transparent and open strategic overview to allow readers to consider the historic and situational issues in relation to the legal, regulatory and policy context for SDE and public involvement at a national, regional, sub regional and local level.

The intention is to build upon what has happened previously (nationally, regionally and locally) so that the NENC programme can learn from key insights and relationships that have been gained in developing its joined-up involvement and communications activities which makes best use of expertise and resources.

It's aligned to the Goldacre Review[3], its subsequent independent report[4] the national Data Saves Lives policy[5], both the digital strategy[6] and the involvement strategy[7] of the Integrated Care Board (ICB) for the North East and North Cumbria and the requirements for involvement of the Care Quality Commission[8].

The ICB is responsible for ensuring that high quality and safe health services are accessible to all our communities. It has a wide range of functions including; promoting integration of health and care services, improving people's health and wellbeing, and reducing health inequalities.

The SDE programme for the NENC has commissioned Stand[9], an independent stakeholder, patient and public involvement agency to provide temporary support, expertise and capacity to help develop the involvement approaches.

Throughout this document it should be noted that the term involvement is used as an overarching term for engagement, participation, co-design, co-production etc. The term stakeholder is used to include any stakeholder potentially involved in the

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[3] Goldacre Review, April 2022
[4] Better, broader, safer: using health data for research and analysis, April 2022, www.gov.uk
[5] Data saves lives: reshaping health and social care with data, Department of Health and Social Care, June 2022
[6] North East and North Cumbria ICS Digital Strategy 2020, NENC ICS, December 2020
[7] Communities and People, Involvement and Engagement Framework 2022-2023, North East and North Cumbria Integrated Care System
[8] Care Quality Commission, Engagement and Involvement (healthcare Services), April 2022
[9] Stand

programme including staff, partner organisations, patients, community and voluntary organisations, the public and politicians.

1.2 Context for the North East and North Cumbria

SDEs are a major step forward in addressing public concerns about the safe use of patient data as it means that health and care data will be used in a secure server and only for agreed purposes. It is only in exceptional circumstances that data would leave this environment, and this would be determined by NHS England and agreed through local governance. SDE has been established as a national programme, led and funded by NHS England (NHSE).

The NENC is one of eleven ‘sub-national’ SDEs and is led by the NENC ICB with a range of health, care and academic partners.

The project aim is to establish SDE capability aligned to national standards, regional governance, processes, and data platform to support evidence-based transformation, closely aligning the health and care system and academic partners supporting the NENC Digital Strategy[6].

There are three main overall objectives for the national SDE programme. Specific references to how involvement will support these objectives are highlighted:

- Unlock the value of data **by bringing together the expertise and knowledge of the regional academic, health, and care communities**, **in partnership with its citizens**, to improve and sustain better health and well-being outcomes in our region.
- Enable an evidence based regional care system to better understand health trends and challenges, **inform decision making and provide intelligence** towards better delivery of healthcare outcomes and improvements (a learning health system).
- Enable **joint collaborations** to focus on local health and care priorities and opportunities for service improvements, innovative treatments and evaluation.

1.3 This document

The intention of this document is to allow any reader without prior knowledge of SDEs to understand the background of key issues in relation to public involvement and communications for the programme. This is important as it provides context and rationale for involvement and communications objectives and subsequent plans to support success.

Footnotes are included where possible to provide supporting information and further reading.

It sets out the legal and policy requirements for involvement for the NHS in relation to SDEs. It includes key background issues and lessons learned in relation to the public’s understanding of the use of NHS data.

It demonstrates a three-stage involvement process for the NENC SDE, which includes:

1. System partner engagement
2. Wider stakeholder engagement
3. Patient and public involvement.

It sets out involvement objectives for the NENC SDE which are aligned to the national Data Saves Lives agenda and support the NENC ICBs Involvement strategy.

Towards the end of the document there is a summary plan on a page of involvement activities and a list of supporting appendices that are referenced in key sections.

2 Why we need to involve

This section provides an overview of how NENC SDE is aligned with and meets the requirements of the Integrated Care Board's Involvement Strategy.

The information in this section then goes on to summarise key, well-established legal and regulatory frameworks for involvement and also for sharing healthcare data.[10]

This information is included to assist readers contextualise the legal, policy and regulatory aspects which are likely to attract questions from the public and stakeholders when carrying out involvement for SDEs.

Including this information also provides assurance for governance purposes and demonstrates how involvement and communications help to identify and mitigate risks in relation to legal and regulatory compliance as well as reputational risk and risk of legal challenge.

2.1 Strategic alignment with the NENC ICB involvement strategy

The Integrated Care Board is the NHS body with overall responsibility for the SDE in the North East and North Cumbria (NENC ICB).

It is the largest in England and is responsible for the health services of more than three million people across urban and rural areas.

Its overarching involvement strategy[11] sets out clear, consistent standards for meaningful involvement which include (in summary):

- Going to where people are
- Supporting people to be meaningfully involved

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[10] Patient health records, Access, sharing and confidentiality, Research Briefing, House of Commons Library, July 2022
[11] Draft Communities and People Involvement + Engagement Framework 2022-23, North East and North Cumbria Integrated Care System, May 2022

- Being open about the challenges and opportunities – being transparent with the people who run and use our services
- Ensuring the recent, relevant lived experience of people using services (and their families and carers) can help to inform service change and improvement
- When people give up their time to share their input provide timely feedback about the impact it has had – you said, we did (or weren't able to because…)
- Use a range of involvement approaches
- Ensure involvement is part of all business case development and implementation
- Take opportunities to innovate – including exploring the creation of a NENC Citizen's Panel
- Make information and opportunities to engage accessible to everyone in our community

For each project, the ICB's involvement strategy requires the following five key questions to be addressed for success:

1. Identify clear objectives that support wider project, programme or organisational goals (setting objectives)
2. Identify the right people and stakeholders and any potential gaps (stakeholder analysis and management)
3. Identify the right messages and methods for the participants (communications support)
4. Identify a realistic set of outputs and activities (tactical plan)
5. What has been learned and has it been fed back to those involved (involvement reporting)

This document and supportive plans are aligned to this approach.

2.2 Providing context in relation to the NHS Duty to Involve

NHS bodies in England such as ICBs have a statutory duty to involve patients (including their carers and representatives) and the public ("by means of providing information, consultation, or in other ways") in:

1. Planning commissioning arrangements.
2. In the development and consideration of proposals for changes services; and
3. Decisions they make.

NHS England's document *Working in partnership with people and communities: statutory guidance*[12], published in July 2022 states that key requirements of ICBs and trusts include that they:

- Assess the need for public involvement and plan and carry out involvement activity
- Clearly document at all stages how involvement activity has informed decision-making and the rationale for decisions
- Have systems to assure themselves that they are meeting their legal duty to involve and report on how they meet it in their annual reports.

This strategy and supportive plans are the evidence of planning and operational activity to discharge these national duties, which in turn is aligned to the ICB's own involvement strategy.

2.3 Providing context in relation to the NHS Constitution

Published in 2012, the principles and values of the NHS in England were set out in the NHS Constitution which states that patients have the right to privacy and confidentiality.[13] The constitution sets out that patients have the right to expect the NHS to keep their confidential information safe and secure, and the right to be informed about how their information is used. Patients also have the right to request that their confidential information is not used beyond their own care and treatment.

2.4 Providing context in relation to Caldicott Guardians

In November 2014, Dame Fiona Caldicott was appointed as the first National Data Guardian (NDG) for health and care, to ensure patient trust in the use of their data and to review the balance between the protection and sharing of this data. The Health and Social Care (National Data Guardian) Act 2018 placed the role on a statutory footing. A Caldicott Guardian is a senior person responsible for protecting the confidentiality of people's health and care information and making sure it is used properly.[14] All NHS organisations and local authorities which provide social services must have a Caldicott Guardian.

> *"Data about people's experiences of health and social care has huge potential for improving services and discovering more effective treatments and ways to provide care. Those benefits will not be realised without public trust. The Caldicott Guardians are a powerful force for good by making sure that organisations behave in a way that is trustworthy."*[15]

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[12] Working in partnership with people and communities: statutory guidance, NHS England, July 2022, revised October 2022
[13] NHS Constitution for England, Department for Health and Social Care, March 2012, updated January 2021
[14] The UK Caldicott Guardian Council
[15] A Manual for Caldicott Guardians Produced by the UK Caldicott Guardian Council, 2017

Dame Fiona Caldicott, Foreword of the 2017 Caldicott Manual

In December 2022, the current National Data Guardian, Dr Nicola Byrne, published new guidance to help organisations carry out better public benefit evaluations when they are planning to use, or allow access to, data collected during the delivery of direct care for non-direct care purposes such as planning, research, and innovation projects.[16] It sets out the shared vision of improved health outcomes for all through the safe, appropriate and ethical use of data.

> *"This vision relies on earning the public's trust in the use of their data by those who can unlock its potential to deliver improved healthcare services and develop new and improved treatments. Public engagement consistently confirms the need for use of health and care data to be of benefit to the public."*[17]

Dr Nicola Byrne National Data Guardian, December 2022

2.5 Providing context in relation to General Data Protection Regulation

Since 25 May 2018, access to patient health records has been governed by the EU General Data Protection Regulation (GDPR), enacted by the UK Data Protection Act 2018[18] (DPA). The DPA 2018 (UKGDPR) defines 'data concerning health' as personal data relating to the physical or mental health of an individual, including the provision of health care services, which reveal information about their health status.

On 25 May 2018, NHS Digital (now part of NHS England) launched the national data opt-out programme, which allows patients to choose to opt out of their confidential medical information being shared for research and planning purposes.

3 Issues, learning and insights from previous programmes

In line with best practice approaches, a situational review has been conducted that aims to provide a background to key issues, lessons learned and public perceptions around the NHS sharing patient data with third parties.

It explains the previous national programmes which are interrelated with the common theme of safety of NHS data, therefore it is easy to confuse or conflate them.

They are included here in chronological order to help provide clear information, context and to assist in developing a common understanding of each issue as it is likely that questions will arise during public and stakeholder involvement activities.

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[16] What do we mean by public benefit? Evaluating public benefit when health and adult social care data is used for purposes beyond individual care, National Data Guardian, December 2022

[17] New NDG guidance enabling better public benefit evaluations when data is to be used in planning, research and innovation, The UK Caldicott Guardian Council, accessed March 2023

[18] Data Protection Act 2018, Legislation.gov.uk

The review describes national and regional involvement activity to assess public support for initiatives and explores the attitudes of people in NENC in relation to the use of data in research. It provides an overview of the involvement work that has gone on so far in NENC. A summary is included here and the full situational review is available as Appendix one.

3.1 Care.data

In 2012 the Government announced care.data which aimed to automatically extract data from GP surgeries into a central database to be used not only by health care research and NHS managers, but also academic institutions and commercial organisations. Following concerns over the opt-out system in place, a poorly executed communications campaign and patient confidentiality, the scheme was first suspended, then closed.

3.2 Wannacry – the NHS cyber attack

On Friday 12 May 2017 a computer virus known as WannaCry, which encrypts data on infected computers and demands a ransom payment to allow users access, was released worldwide. WannaCry was the largest cyber-attack to affect the NHS in England, although individual trusts had been attacked before 12 May.

It affected 80 NHS Trusts along with 603 primary care and other organisations, at an estimated cost of £92 million. The National Audit Office investigation concluded that none of the 80 NHS Trusts affected by WannaCry had applied an advised Microsoft patch update. This impacted public confidence in the NHS's ability to keep IT systems safe from bad actors who would target the NHS to steal patient data. Critically however, in the North East and North Cumbria, NHS organisations were largely unaffected compared to other parts of the country.

3.3 Google DeepMind

In 2017, the UK's data privacy regulator, the Information Commissioner's Office (ICO) ruled the Royal Free NHS Foundation Trust failed to comply with the Data Protection Act when it provided patient details to Google DeepMind.

The Trust provided personal data of around 1.6 million patients as part of a trial to test an alert, diagnosis and detection system for acute kidney injury. An ICO investigation found several shortcomings in how the data was handled, including that patients were not adequately informed that their data would be used as part of the test. Dame Fiona Caldicott also concluded that data was improperly shared between the Royal Free NHS Foundation Trust and Google DeepMind.

3.4 General Practice Data for Planning and Research (GPDPR)

In 2021 the General Practice Data for Planning and Research (GPDPR) scheme[19] was developed with the intention to gather patient data held by GP surgeries in England and feed it into a central NHS database. Promises that the data would be anonymised were not enough to reassure the public about the privacy risks and millions opted out of the scheme, leading to it being withdrawn.

3.5 The Goldacre Review

Professor Ben Goldacre was asked by the Secretary of State for Health and Social Care in 2021 to conduct a major review into the safe use of health data. The result was the 'Better, broader, safer: using health data for research and analysis report'[20], better known as the Goldacre Review. The report makes 185 recommendations that would benefit patients and the healthcare sector including the development of secure data environments for the efficient and safe use of health data for research and development.

The report was aimed at policy makers in the NHS and Government, research funders and those who use the data for service planning, public health management and medical research.

> *"It's not just enough to tell people to trust the good work you're doing with data. You have to take practical steps and prove to them what systems and platforms you've got to protect their privacy. You need to show rather than claim."21*

Professor Ben Goldacre, Digital Health, March 2023

3.6 Data Saves Lives strategy

In June 2022, the UK Government published a strategy, Data Saves Lives[22], setting out the Secretary of State for Health and Social Care's vision for the use of patient data in "Patient health records: Access, sharing and confidentiality bring benefits to all parts of health and social care" and to "demonstrate that the health and care system is a trustworthy data custodian".

The principles set out in the Data Saves Lives strategy are:

1. Improving trust in the health and care system's use of data
2. Giving health and care professionals the information, they need to provide the best care

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[19] General Practice Data for Planning and Research (GPDPR), NHS Digital, last edited November 2022

[20] Better, broader, safer: using health data for research and analysis, April 2022, www.gov.uk

[21] Earning the public's trust on health data, digital Health, March 2023

[22] New data strategy to drive innovation and improve efficiency - GOV.UK, Department of Health and Social Care, June 2022

3. Improving data for adult social care
4. Supporting local decision-makers with data
5. Empowering researchers with the data they need to develop life-changing treatments and diagnostics
6. Working with partners to develop innovations that improve health and care
7. Developing the right technical infrastructure

A key component in giving patients greater confidence than ever that their personal information is safe is the establishment of SDEs to become the default for NHS and adult social care organisations to provide access to de-identified data for research and development.

Consequently, patient and public involvement has been placed at the heart of the SDE programme. The overarching aim is to ensure that the public have confidence that their data is being handled properly, that they have a good understanding of how it is being used, and that they have greater access to that data. Data Saves Lives states five ways that trust will be built on:

- Keep data safe and secure
- Be open about how data is used
- Ensure fair terms from data partnership
- Give the public a bigger say in how data is used
- Improve the public's access to their own data

3.7 Insights gained from previous involvement

This section identifies key themes along with areas for further exploration which provide a solid basis to develop a pipeline of issues to discuss with stakeholders and the public.

3.7.1 Insights around barriers

- Public understanding - people didn't want their data used for profit by anyone other than the NHS. There is a low public awareness of robust ethics practices in academia, so people would need reassurance how their data is being used
- People needed reassurance that those legitimately using their data were suitably qualified and experienced to ensure the data was correctly handled and managed.
- There is a need for education and dialogue through public engagement - poor planning for public engagement was a root cause of the failure of care.data. Misinformation (incorrect or misleading information) also needs to be considered, for example, when people thought that the Covid-19 app wasn't

trustworthy because it was run by a private sector provider and not fully understanding that personal information was fully protected

- Choice and control - people are concerned about why third parties want their data, the security of which affects public perceptions.

3.7.2 Insights around enablers

- Trust - the Department of Health and Social Care found as part of their ‘Data Saves Lives’ initiative that 59% of people trust the NHS to use personal data ethically, more than any other organisation surveyed. However, this should not be taken for granted as it is conditional.
- Public benefit - the benefit does not have to be specific, but being clear and specific about secondary uses with tangible examples is likely to gain more public support. Also highlighting the opportunity cost of not sharing the data may be beneficial.
- Relationships - patient/professional relationships will be key to this programme being successful. This could also help in the shared decision-making agenda

3.7.3 Key themes from previous involvement

In terms of collating key themes, the following were identified in the review:

- Meaningful public engagement
    - **Reciprocity:** Citizens recognised the benefits of sharing data for improving health and social care for themselves and others in the community. Citizens said they would like to have access to data held about them, both to see what is said about them and to add additional information like organ donor preferences.
    - **Fairness:** Citizens expected communication and making decisions about data sharing (including information about what data they are happy to share) to be accessible to all regardless of class, education and literacy, disability, ethnicity or capacity. They expected an even higher level of care for data sharing about potentially sensitive or stigmatising issues like mental health, reproductive health and sexuality.
    - **Agency:** Citizens said they want a say in how data about them is used, by whom and for what purposes. Control of information use and access was not only an individual issue. Citizens expected to be involved in the oversight and governance of information sharing and the Great North Care Record.
    - **Privacy:** Citizens expect their privacy to be maintained, except where they have specifically agreed to share personal information. They recognise privacy as central to preservation of 6 an individual’s sense

    of self (identity) and that it should not be violated. Citizens wanted to know that data about them is secure and that their choices and preferences are upheld.

    - **Transparency and Trust:** Citizens expected to be informed about how data about them is or may be used. They wanted to be able to access further information on Great North Care Record and data sharing as and when they needed it. Citizens expected institutions handling data about them to act in a trustworthy manner. They said healthcare institutions are the most trusted. Research institutions were felt to require more information to give clarity and lead to greater trust. Concerns were raised over agencies such as police. Commercial and for-profit organisations the least trusted.

- Avoidance of misinformation
- Public benefit as the principal motivation
- Proactive transparency
- Time to plan and carry out meaningful involvement
- Non-exploitative, people don’t like the idea of themselves, or the NHS being taken advantage of by private enterprise.

4 Involvement and communications strategy

The previous sections provide the strategic context which has allowed the development of main elements of the involvement and communications for the NENC SDE programme. This section sets out the key elements of the NENC SDE strategy.

4.1 Setting involvement objectives

The NENC SDE programme’s involvement objectives are aligned to both the overall national programme standards and the NENC ICB’s Involvement strategy which specifically asks to identify clear objectives that support the wider project, programme or organisational goals.

Involvement objectives for NENC SDE are to:

- Create the conditions to develop partner, stakeholder, patient and public two-way relationships and trust in the SDE programme.
- Demonstrate listening, learning, and understanding including ideas and early warnings on issues from involvement activities to shape the programme implementation.
- Enhance patient and public support and enthusiasm for use of NHS health data to drive research and development.

- Ensure the public voice is a part of the governance structure.

4.2 Stakeholder analysis and management

The relationship between the programme and its stakeholders is critical to the success of any programme of change, and especially in complex environments such as integrated care systems in which the SDE project resides. Proactive consideration of how stakeholders are identified, assessed, and then managed is a fundamental part of programme management success.

The Good Governance Institute (GGI) Stakeholder Engagement Maturity Matrix[23] outlines nine key elements of communicating, engaging, and building relationships with core organisations and individuals.

It's a practical tool that enables boards and communications teams to identify their current level of progress against each key competency, to determine where they want to get to in the next 12 months and how to get there.

The matrix outlines nine core elements in relation to being at a baseline; a basic level; early progress in development; firm progress in development; maturity/results being achieved; and exemplar.

A self-assessment has been carried out on where the SDE programme sits in relation to stakeholder maturity which is owned by the programme team. It will assist in keeping focus on how stakeholder management is an ongoing process and not a one-off activity. This assessment and plan are included in Appendix two.

4.3 Stakeholder strategy

Building on the stakeholder maturity self-assessment, the programme can develop a deep understanding of who stakeholders are, how they relate to the programme so that relationships can be developed. Relationships create the conditions to establish mutual understanding and trust, which helps support the exchange of views to gather invaluable insights to help with a successful project outcome.

Working with the programme team, a process of mapping, analysing and categorising stakeholders has been carried out to support involvement strategy development, this is also included as Appendix two.

Proven approaches have been used to map and group stakeholders according to three actions needed to deliver the objectives of the SDE programme – these actions are involve, engage and inform. From the stakeholder mapping, a three-phase approach to stakeholders has been identified, these are:

1. System partner engagement
2. Wider stakeholder engagement

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[23] GGI Stakeholder Engagement Maturity Matrix, Good Governance Institute, May 2022

3. Patient and public involvement activities

It is important to recognise that are not neat binary groups and there will be overlap, however phasing helps with programme management of capacity and resources.

4.4 System partner engagement

This involves targeting key professionals in target partner organisations e.g. NHS, local authorities, primary care and universities. The SDE programme will test clarity on SDE positioning, programme development and messages.

The stakeholders who would be targeted include (grouped into priorities):

Priority one	Priority two
Key ICB leaders in local place teams Universities Local Medical Committees Primary care and GP alliances Healthwatch Local authorities – social care and public health initially Provider collaborative and NHS providers	Directly interested Voluntary and Community Sector Organisations (VCSOs) Health and care research networks Clinical networks Secondary care NHS trusts

4.5 Wider stakeholder management

This involves targeting key people and organisations in wider stakeholder organisations for example, patient groups, wider VCSOs, elected members and the industry. The SDE programme can build on previous work to further test clarity on SDE positioning and messages. The stakeholders who would be targeted include (grouped into priorities):

Priority one	Priority two
Patient participation groups – GP groups, hospital organised groups VCSOs targeting health groups, especially long-term health conditions Communities with health inequalities	Elected members and MPs Health and Wellbeing Boards Health overview and scrutiny Industry

4.6 Patient and public involvement

This involves targeting key communities of interest which have been identified from equality impact assessments, patient groups and the wider public. This is to ensure that key communities of interest are targeted are included in involvement activities.

4.7 Classification and sequencing

Combining the information gathered has informed the strategic stakeholder approach set out below and helps to show sequencing of activities with different stakeholder groups.

Relationship	Classification for SDE
Involve: Key players - groups and people who are critical to the project and those who need to be ***involved*** to meet the organisation’s statutory duties.	System partners Patient and public involvement activities
Engage: Important partners - to be ***engaged.*** We would like to have input from these partners.	System partners Patient and public involvement activities
Inform: Wider stakeholders - from whom input is welcome but not required. These groups will be kept ***informed.***	Wider stakeholder engagement

5 Links with national and regional networks

This section explains how the NENC SDE is linked in with networks national and regional and how it intends to develop, grow and support networks in the North East and Yorkshire (NEY) and NENC.

5.1 National SDE involvement community of practice

NHS England national SDE team have established a community of practice. The working group has subject matter experts from all sub-national secure data environments for research (SNSDEs), the national SDE team and representatives from NHS England. The purpose of the working group is to:

- Foster collaboration to solve delivery challenges
- Enable SDE teams to remain updated about NHSE strategy and policy
- Facilitate a consistent approach to design, standards, and operational policies across SDEs, ensuring interoperability in the medium term

- Enable SDEs that are at a more advanced stage of delivery to work together on common delivery issues, while sharing these delivery blueprints with other teams
- Provide networking opportunities

The first monthly meeting took place in February 2023 and this network is embryonic and expected to grow. The terms of reference are included in Appendix three.

It is assumed that the national team will develop at scale resources to support SDE programmes locally to ensure consistency. They are also looking to develop a ‘network identity’ and key messages for sub-national SDEs are to follow.

The group is also looking at opportunities for engagement and involvement which can be carried out at a national level.

5.2 Links with North East and Yorkshire NHS England region SDE programmes

NENC SDE programme has reached out to Patient and Public Involvement and Engagement (PPIE) leads across the other sub-national SDE programmes in North East and Yorkshire (NEY) and facilitated a NEY PPIE network meeting. There was broad agreement to share where possible and broad recognition that all the NEY programmes were in different places. Relationships will develop in the coming months and this strategy will be shared.

5.3 Links with NENC research PPIE infrastructure

The NENC research community through the National Institute for Health and Care Research (NIHR) has a well-established Patient and Public Involvement and Engagement (PPIE) network, with a history of collaboration on projects across research active organisations. The network is called Creating Connections[24], which is administered by the Research Design Service and run by the members. There are three levels of involvement in the network:

1. Core group who deliver joint projects (mainly PPIE staff from NIHR platforms). The core group arranges EDI and PPIE training regionally and collaborates on community engagement projects and bids for engagement funding.
2. PPIE community who meet up to six times a year online to share what they are working on, ask for support or advice, update on new initiatives in PPIE nationally. Anyone who has PPIE as part of their role (staff and volunteers), can join these calls. Members are from NIHR platforms, universities, NHS trusts, voluntary sector, public volunteers and any other research active organisation.

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[24] Creating Connections, NIHR, accessed April 2023

3. Mailing list. Anyone interested in PPIE can be on the mailing list to: get updates on national and local initiatives or new guidance/standards; hear about training opportunities and events; hear about consultations; share opportunities for involvement or engagement. The mailing list can also be used to ask questions of members and to access public members of research active organisations.

The National Institute for Health and Care Research (NIHR) infrastructure (platforms) in NENC have collaborated to fund a role within Voluntary Organisations Network North East (VONNE) to link researchers and community (VCSO) organisations locally. This role and Creating Connections liaise regularly with Cumbria Council for Voluntary Service (Cumbria CVS) to cover North Cumbria.

All of the NIHR platforms have an expectation to engage with the public. Many have full time PPIE staff who deliver engagement projects with under-served communities across the NENC, for example, young people, people with learning disabilities, care home residents, new mothers, ethnic minorities, disadvantaged communities, rural populations. The majority of platforms have their own public panels/advisory groups, public champions or public representatives on committees. The volunteers who work with the platforms have significant community networks themselves, so information and opportunities to get involved are shared widely.

Another way of advertising and recruiting the public for research involvement or consultation activities is through Voice[25], which is hosted by Newcastle University. They are an online platform specifically created for this purpose.

5.4 Nationally led review by IPSOS and Imperial College Partners

NHS England funded IPSOS and Imperial College Partners (ICP) to work with 11 SDEs including NENC to undertake an analysis of existing PPIE outputs and conduct stakeholder interviews.

The objective was informing future public engagement plans, at both the sub-national level and at a national level. The review set an ambition to carry out deliberative citizen engagement as described by the International Association of Public Participation[26] using the international spectrum of participation, this is included as Appendix four.

A workshop with the NENC SDE and the IPSOS/ICP took place in February 2023 to sense check findings and confirmed the opportunity and appetite for SNSDE to build upon the strong legacy of insight previously gained from public engagement in the region.

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[25] Voice, accessed April 2023

[26] International Association for Public Participation (IAP2)

The key topics identified to become a pipeline of topic areas for involvement are included in Section 6.1.

The final IPSOS/ICP report is included as Appendix five.

5.5 Public members in governance

In line with good governance, a number of public members will be recruited to support the work of SDE programme. Their key purpose is to provide a broader public perspective to the work of the programme.

They will sit on the various governance groups and working groups to provide a public perspective on the issues being considered. Their role will be codified in the group's terms of reference, and it will be in relation to public members' broad understanding of what matters most for people using health and care services. They will contribute what they think patients, people who use services, carers, or communities might want to ask or comment on in relation to the issues under discussion.

Public members offer a different point of view from other people on a committee who are likely to be healthcare professionals such as clinicians, researchers or managers, and academics.

They will also play a key role in the further development and monitoring of the involvement strategy and work plan. The involvement lead will be the key link person for public members. Public members have a role description, will receive an induction and be renumerated in-line with NIHR guidance as referenced in Section 5.3

5.6 Clinical leaders and advocates

Clinical leaders are identified via the NENC ICB and will be supported by a range of SDE clinical advocates. Through engagement with NENC Local Medical Committees (LMCs) it's expected that a job description and objectives will be developed in line with British Medical Association recommendations. A key part of the advocate role will be to support the involvement strategy particularly in relation to stakeholder and partner involvement and supporting public activities. This element of the strategy will develop in the early part of 2023/24.

6 Involvement topics and tactics

This section sets out the key topics for discussions and the different ways these can be discussed (tactics). To take a planned approach key topics are set out in a 'pipeline' so they are transparent and can be planned in a priority order for discussions with different stakeholders.

6.1 Topic areas for involvement

Key topics are identified from work with IPSOS/ICP are contained in the table below and are ranked in relation to primary and secondary priorities for NENC and priority for the National team. These topics should be positioned in consideration with the insights gained from previous involvement covered in Section 3.7.

Topic pipeline		
	Theme / topic / issue	**Spectrum of participation level:**
Short-term priority in NENC	**NENC programme issues** Testing SDE narrative and build understanding Understanding opportunities and challenges from each stakeholder group perspective to develop narrative and inform SDE design Testing NENC communications materials, branding, toolkits, narratives and visual story telling Testing research clinical audit service evaluation and DAC scope Testing involvement planning Developing and defining public participation Other emerging issues as they are identified	Involve, Inform, Consult, Empower
	Actors involved in accessing data *Who* will use it and *why*	Involve, Inform, Empower
	Commercial model Access and underpinning principles	Involve, Inform, Consult, Empower
	Access criteria and safeguards What conditions or criteria the public want to set, the public's role in access decisions	Empower
National priority	**Process for individual opt-out** How this is applied	Empower

Medium-term priority in NENC	**Types of secondary data use** Including for what purpose	Inform, Collaborate, Empower
	The use of non-NHS data for secondary purposes for example, *how* and *why* Local Authority, environmental or other data such as police, fire could be linked	Involve

6.2 Activities for involvement

This table shows the range of tactics that will be used to involve different stakeholders at different times. To note this will evolve as the programme develops.

Activities for involvement		
Stakeholder group	**Tactics**	**NENC SDE Involvement objective**
System and partner engagement	● A planned series of webinars targeting different stakeholder groups ● Map and attend existing networks and meetings to provide updates ● Plan to develop focus groups on key topics ● Plan to develop surveys on key topics ● Recruit GP advocates	● Create the conditions to develop partner, stakeholder, patient and public two-way relationships and trust in the SDE programme ● Demonstrate listening, learning, and understanding including ideas and early warnings on issues from involvement activities to shape the programme implementation
Wider stakeholder involvement	● Map opportunities and provide updates to elected members and MPs via ICB and place leads e.g. Health and Well-being boards, regular MP updates	● Create the conditions to develop partner, stakeholder, patient and public two-way relationships and trust in the SDE programme ● Demonstrate listening, learning, and understanding including ideas and early warnings on issues from involvement activities to shape the programme implementation
Patient and public involvement	● Develop deliberative approaches e.g. Citizens assembly ● Plan recruitment to involvement activities ● Plan to develop focus groups on key topics ● Plan to develop surveys on key topics ● Recruit public members in governance	● Enhance patient and public support and enthusiasm for use of NHS health and care data to drive research and development ● Create the conditions to develop partner, stakeholder, patient and public two-way relationships and trust in the SDE programme

6.3 Reporting and metrics

It’s important to regularly report on involvement activities and to measure and monitor activities to show what has been learned, how it has influenced the programme and feeding it back to those who have been involved so their time, opinions and inputs are recognised.

The following will be used:

- Rolling three-month involvement action plan
- An involvement and communications dashboard for programme management purposes
- Each key involvement activity has plan for delivery and reporting
- Quarterly report of activities, output and outcomes for governance assurance

7 Strategic communications support

This section describes how communications will support the involvement strategy as well as the delivery of the wider SDE programme.

7.1 Communications operational arrangements

The SDE programme is supported by the NENC Academic Health Science Network (AHSN) for communications.

The communications plan (in Appendix six) provides direction on key messages, methods and tactics for the SDE programme to communicate with a range of stakeholders. The plan applies to the current phase of the programme and runs throughout 2023/24. Subsequent plans will be developed as the programme progresses into later phases. It is not expected that mass public communications will take place in 2023, however there will be phased and intense involvement and relevant supportive communications activities to support this.

The scope of the communications plan covers this initial start-up phase and is moving into testing and forming its own governance structure.

7.2 Communications materials

Initially materials to support the professional and public engagement will be the immediate focus. This will include the development of:

- Key messages
- Slide decks
- Videos/animations
- Social media
- Website updates
- Briefings

- Newsletter content

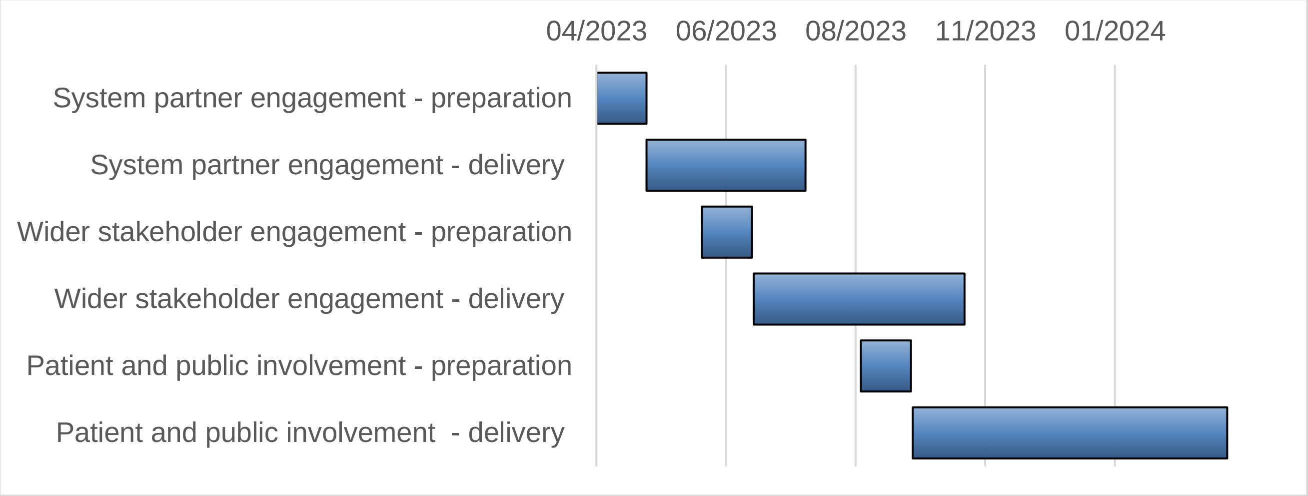
Discrete communications plans will be developed for specific campaigns such as public member recruitment, GP advocate recruitment, primary care engagement and academic engagement activity.

Work on developing the branding and programme identity will be a key focus for this year which will need linking with direction of the national SDE programme and works for the North East and North Cumbria population. The branding work will be developed in collaboration with the ICB communications team and will be co-produced with public members and patient focus groups.

8 High level strategic timeline

This section sets out the high-level timeframe for key phases of activities to assist with program planning. It should be noted that some activities may take place at different times, for example some initial public focus groups in the earlier phases with patient groups.

- System partner engagement April to July 2023
- Wider stakeholder engagement July to October 23
- Patient and public involvement October 23 to March 24



9 Next steps

This section sets out the key actions to implement this strategy. These are:

- Agreement of this strategy through ICB governance routes
- Endorsement on the topics for the pipelines of issues
- Development of a three-month rolling involvement plan
- Implementation of the plan to recruit public members
- Development of the plan to recruit GP advocates

- Consideration of operational resources to support the involvement plan including people and access to software e.g. survey licence, stakeholder management system
- Detailed patient and public analysis including equality impact activity to identify key communities of interest to supplement stakeholder analysis
- Further work with the national team to determine resources and support for citizens assemblies (in relation to IPSOS/ICP work).

10 Involvement strategy plan on a page

NENC SDE PPIE objectives	Stakeholders	Planned activities	Topics pipeline	Timescales	Metrics and KPIs
Create the conditions to develop partner, stakeholder, patient and public two-way relationships and trust in the SDE programme	System and partner engagement	Webinars Attendance at networks and meetings Focus groups and surveys Recruitment of public members Recruitment of GP advocates	Understanding opportunities and challenges, testing narrative, communications materials, toolkits, narratives and visual storytelling, DAC scope, involvement planning, scope of PPIE Other emerging issues as they are identified	April to July 2023	Rolling three-month involvement action plan and monitoring Specific plan for each activity Feedback reports on activities Insight repository SDE involvement dashboard Quarterly report of activities, output and outcomes for governance assurance
Demonstrate listening, learning, and understanding including ideas and early warnings on issues from involvement activities to shape the programme	Wider stakeholder engagement	Updates to elected members and MPs Health and Well-being boards Health overview and scrutiny	Access criteria and safeguards What conditions or criteria the public want to set, the public's role in access decisions	July to October 23	
Enhance patient and public support and enthusiasm for use of NHS health data to drive research and development	Patient and public involvement	Develop deliberative approaches e.g. Citizens assembly Recruitment Focus groups on key topics Surveys	Actors involved in accessing data Who will use it and why	October 23 to March 24	
Ensure the public voice is a part of the governance structure		Recruit SDE clinical advocates and public members for governance	Commercial model Access and underpinning principles	April to July 2023	

11 Appendices

Appendix	Title
Appendix one	Situational review for NENC SDE
Appendix two	Stakeholder self-assessment against the GGI Stakeholder Maturity Matrix and plan
Appendix three	National PPIE and comms working group terms of reference
Appendix four	IAPP Spectrum of participation
Appendix five	IPSOS NENC SDE Discovery phase report
Appendix six	SDE Communications plan 2023