

**Northern
England
Strategic
Clinical
Networks &
Senate Patient
and Public
Voice Strategy**



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Glossary of Terms

Term	Meaning
NESCN	Northern England Strategic Clinical Network
SCNs	Strategic Clinical Networks
PPV	Patient and Public Voice
CoI	Community of Interest
SDM	Shared Decision Making
SSM	Support Self-Management
CCG	Clinical Commissioning Group
PPE	Patient and Public Engagement
NSUPG	Network Service User Partnership Group
CVD	Cardiovascular Disease
TIA	Transient Ischemic Attack

1. Background

This document sets out the ambition, commitment and plans of the Northern England Strategic Clinical Network (NESCEN) and Senate for patient and public voice (PPV) in 2014/2015.

This strategy is informed by NHS England's vision for participation to ensure that patient, carer and public voices are at the centre of our healthcare services, from planning to delivery.

The Northern England Strategic Clinical Network and Senate wish to ensure that we have wide membership and particularly that the patient, carer and public voice is well represented. To achieve our aims we need to build strong networks and partnerships with patients and carers, voluntary, community groups, commissioners, service providers, healthwatch and other agencies.

'We must put citizen and patient voice absolutely at the heart of every decision we take in purchasing, commissioning and providing services'.

Tim Kelsey
National Director of Patients and Information, NHS England

2. Introduction to Strategic Clinical Networks and Senates

Strategic Clinical Networks (SCNs) bring together those who use, provide and commission a service to make improvements in outcomes for complex patient pathways using an integrated whole system approach. Their purpose is to improve the quality and equity of care for their population, both now and in the future.

SCNs work in partnership with commissioners, including local government, supporting their decision making and strategic planning by working across the boundaries of commissioner, provider and voluntary organisations as a vehicle for improvement for patients, carers and the public. In this way, SCNs aim to support commissioners and service providers to:

- improve people's experience of health care services
- improve health outcomes
- reduce unwarranted variation in health and wellbeing services
- encourage innovation in how services are provided now and in the future
- provide clinical advice and leadership to support decision making and strategic planning.

Established in April 2013, SCNs operate in four key areas:

- Cancer
- Cardiovascular (including renal, diabetes and stroke)
- Maternity, Children and Young People
- Mental Health, Dementia and Neurological Conditions

In addition to the mandated the NESCEN has three work streams that follow the patient's pathway:

- Prevention, Awareness and Early Diagnosis

- Treatment and Patient Experience
- Long Term Conditions, Living with and End of Life Care

Clinical Senates were established to be a source of independent, strategic advice and guidance to commissioners and other stakeholders to assist them to make the best decisions to transform health care. They are comprised a core Clinical Senate Council and a wider Clinical Senate Assembly.

3. Purpose of Patient and Public Voice Strategy

This PPV Strategy has been developed to ensure that the NESCN and Senate:

- place the patient at the centre of everything we do;
- promote a culture of meaningful engagement at all levels of the Networks and Senate;
- support the delivery of our vision, values and objectives;
- is underpinned by partnerships with key stakeholders

How we define Patient and Public Voice

Individual Involvement	Engaging individual patients in their own health and care, through shared decision making and giving them more choice more control over how, when and where they are treated – helping to deliver “ <i>no decision about me without me</i> ”.
Collective Involvement	Engaging patient and carer cohorts (patients with common conditions) to help get services right for them, engaging with the public in decisions about planning, design and reconfiguration of health services, pro-actively as design partners and reactively, through effective consultation and commissioning activities.
Patient Experience	Engagement activities - capture direct feedback from patients, public, carers and wider communities, which is used alongside information on clinical outcomes and other intelligence to inform quality improvements, reshaping of local services and commissioning.

See Appendix A for examples of the above in practice for the NESCN – page 8.

4. Our Visions, Aims and Objectives for Patient and Public Voice

Our vision is to listen to and involve patients, public and carers so we can understand how we can best serve their needs and fulfil our commitment to ‘put patients at the heart of everything we do’. We will achieve this by:

- Listening to patient’s views: we can learn about their needs and experiences acknowledging differing viewpoints and identify specific areas for improvement.
- Involving patient, the public and carers in service design, delivery and research: we can ensure that our services and research are designed and adapted to respond better to the needs of individual patients and patient groups.
- Using technology such as Twitter, websites and other forms of social media to support our work.
- Ensuring PPV is the responsibility and role for all staff: we can ensure effective local PPI is carried out.
- Working in partnership with patient, the public and carers: we keep patients’ needs at the forefront of every decision we make.
- Measuring how we are doing: we can see how our improvement plans and activities are progressing.

Our aim is to ensure that NESCN will continue to engage with and include patients, public and carers in a meaningful way to help deliver, develop and improve services.

A diagram of the NESCN PPV structure can be found at Appendix B – page 9.

5. Engagement Bank (Your NHS, Your Voice)

Fundamental to this approach is the development of the “Engagement Bank” called Your NHS, Your Voice. Our intention is to build on current relationships with local people and organisations, not to duplicate their work but to be systematic about how we involve the public in decision making.

To do this we aim to develop an engagement bank called Your NHS, Your Voice. This bank will have many people who have experience of Patient, Public, Engagement and Involvement and whom we can call on to inform our work plans. Organisational PPV Leads will endorse and support the network to engage with key members of the public via their links and connections. This could involve taking part in a range of activities which may include:

- Getting involved in project groups
- Attendance at events and meetings where certain healthcare challenges are being debated
- Surveys or e-mails to seek opinion for specific projects

This engagement needs to be a partnership and a two way relationship. Therefore as well as asking people to get involved in our work we will also keep them informed with a NESCN newsletter three times a year and through social media. This will include feedback on the impact of PPV within our work plans and will be a vehicle for members to raise any issues and comments to the team.

The engagement bank database will be managed by the network.

6. Representation on Groups

The Network Oversight Group, Steering and Advisory Groups and the Senate will have agreed PPV representation at meetings. Engagement will be through regular communication on network projects. Members will be invited to engage on emerging and existing work, to ensure a wide range of perspectives and involvement. See Appendix C – page 10, 11.

7. Values and Standards

A future objective of the SCN and Senate is to develop an internal set of standards. These standards will be the aspirations on which all of our work will be based. This may be based on a number of models already in use such as Macmillan, 9 Outcomes and the NICE quality standards for PPI (QS15).

8. Governance

Northern England Strategic Clinical Networks and Senate’s Accountability and Governance Framework ensures that the views of patients, carers and the public routinely influence policy making and strategic decisions.

9. Reimbursement of Expenses

Northern England Strategic Clinical Network and Senate are determined that no-one should be out of pocket as a result of their participation in engagement activity. We will follow the

NHS England policy with regards reimbursement for all patients, carers and members of the public involved in our work. See Appendix D – page 12.

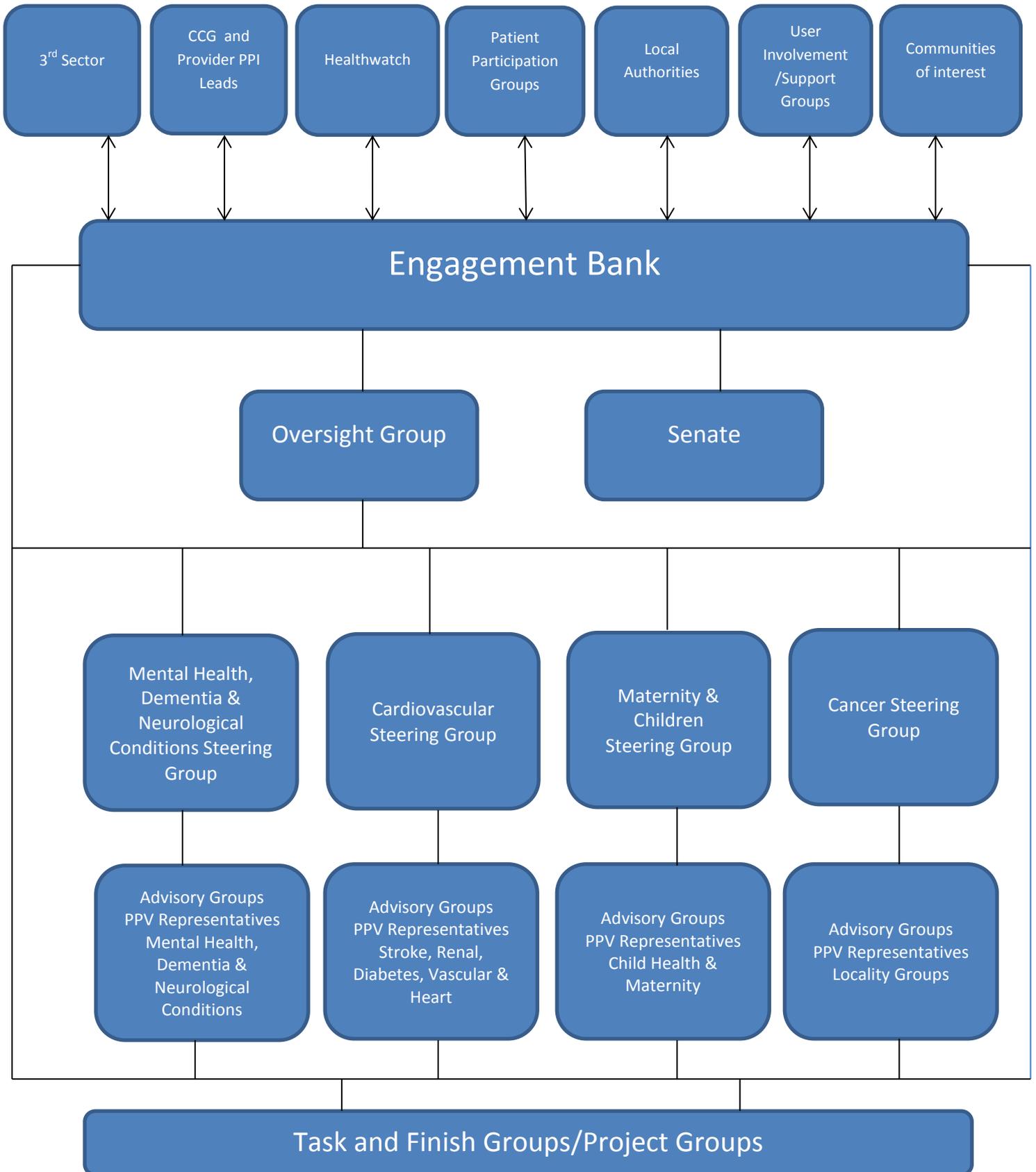
10. Monitoring and Evaluation

Patient, carer and public voice activities will be monitored at least annually and evaluated to ensure that it is contributing towards better care for patients, carers and the public.

APPENDIX A – Examples of Patient and Public Voice

<p>Individual Involvement “no decision about me without me”</p>	<p>The SCN is currently working in partnership with the Institute of Health and Society’s Shared Decision Making Community of Interest on shared decision making, support for self-management and care planning. The Community of Interest (CoI) brings practitioners, third sector, the public, patients and academics together.</p> <p>The CoI has a Twitter presence which complements the events and email communications.</p>
<p>Collective Involvement Ensuring that patient voice is heard and involved in our decision making</p>	<p>Developing a People Bank with members from</p> <ul style="list-style-type: none"> • CCG PPI Leads • Healthwatch PPI Leads • Voluntary Sector PPI Leads • Self Help and Support Group Chairs • PPI Locality Chairs • Providers PPI Leads <p>Current PPI groups include</p> <ul style="list-style-type: none"> • NSUPG (Cancer) • 3rd Sector Coalition (CVD) • Local patient and carer groups to be developed for Maternity/Child Health and Mental Health Dementia/Neurosciences <p>PPI membership is identified as core for each of the following Network and Senate groups</p> <ul style="list-style-type: none"> • Senate Council • SCN Oversight Group • Network Steering Groups • Network Advisory Groups
<p>Patient Experience Gathering insight and feedback to enable us to understand how to improve patient experience.</p>	<p>Health outcomes matter to patients and the public. The NHS Outcomes Framework sets out the outcomes and indicators to encourage improvements. The indicators are grouped around five domains. SCN works with the Patient Experience Lead Teams at a local, regional and national level. Meet regularly to share best practice and discuss PPI work. This includes gathering information and intelligence from the following methods (this is not an exhaustive list):</p> <ul style="list-style-type: none"> • Family and Friends Test • National Cancer Patient Experience Survey • National Chemotherapy Patient Experience Survey • National Palliative Care Patient Experience Survey • Stroke Association Patient Survey on TIA (mini strokes) • Patient Experience of Diabetes Services (PEDS) • Community Mental Health Survey 2013 • Maternity Survey 2013 • Care Quality Commission Survey • Feedback websites such as CareConnect or PatientOpinion • Patient Stories • Local patient surveys and feedback

APPENDIX B – PPV Structure



Role Descriptor for Members of the Northern England Strategic Clinical Network and Senate

What is the role of PPV members on the group?

The patient and public voice representation brings important views, perspective and challenge into the group – this role is essential in championing a service user, patient and carer/family viewpoint, ensuring that the needs of the patient/carer are met through the outcomes of the programme.

The role of the public and patient voice is:

- to champion the diversity of patient and public views (not to only represent their own experience).
- to champion and advocate for increasing patient and public awareness of the programme outcomes and achievements.
- to review programme plans and documentation.
- to comply with the Standards of Conduct, and to respect the confidential nature of discussions when it is made clear by the Chair that this is a requirement.
- to report back to the organisations to which they represent as well as Network & Senate.
- to prepare for meetings by reading all pre-circulated papers and forwarding comments where necessary.
- to ensure the views and experience of hard to reach groups are sought and represented.

What skills and experience are required for this role?

- Experience of speaking in groups.
- Able to represent the views and needs of patient, the public and carers.
- Interacting with multiple stakeholders at various levels.
- Ability to understand and evaluate a range of information and evidence.
- Experience of working in partnership with healthcare organisations or programmes.
- Can display sound judgement and an ability to be objective.
- Able to listen and respect the views of others.
- Have an awareness of, and commitment to, equality and diversity.
- Understand the need for confidentiality.

What is the duration of the time commitment?

- 2 years with 1 year review.
- Minimum term of 1 year preferred.

What is the time commitment for this role?

Must be able to attend meetings during working hours and at different locations across the network areas.

Standards of conduct and conflict of interest

All group members will be asked to subscribe to an agreed code of conduct and confidentiality agreement, and to declare any potential conflicts of interest.

Support for PPV members

- A named link will be provided. This person will be able to support PPI members with background or context material that they may require.
- If necessary pre-meeting briefings will be provided either by email, post or telephone call.
- Meeting documents will be emailed and/or provided in an accessible form as requested by the PPI member. This will include printed versions and (if requested) A4 paper, postage stamps and envelopes for submitting written responses.
- For individual patient/carer patient members – NHS England will reimburse out of pocket expenses and provide a named contact for expense claims to and discuss any queries that arise. Expenses usually cover travel and any accommodation or subsistence requirements that arise, but would also seek to address any barriers to participation, for example covering the costs of a carer that may need to accompany PPI representatives. Please get in touch with your named contact to discuss any support requirements that you might have.
- Out of pocket expenses incurred as part of the work will be reimbursed in line with NHS England's Patient and Public participation expenses policy.



NON STAFF EXPENSES FORM

Meeting Title	
Meeting Date	
Supplier Name	
Address Line 1	
Address Line 2	
Address Line 3	
Address Line 4	
Post code	
Phone Number	
Email Address	

Description	Total
Provide clear details of the goods / services provided including receipts where appropriate	

Bank Name		
Sort Code		
Account Number		

Signed		Authorised	
			For NHS England use only