East Midlands Academic Health Science Network
Igniting Innovation

East Midlands Patient and Public Involvement (PPI) Senate
Key Information & Terms of Reference

1. Introduction

1.1. This document forms the Terms of Reference for the East Midlands PPI Senate. It will be subject to periodic review.

2. Purpose

2.1. The Senate is an experienced, informed and independent body which seeks to increase the involvement and participation of patients, carers and members of the public in the development, commissioning and provision of health and social care services. It aims to increase the quality of decision making, leadership and service provision, and will help to establish the East Midlands as a centre of excellence where patients and the public are fully involved.

2.2. To take strategic action so that the East Midlands becomes a leading centre of excellence in PPI in healthcare. Key aspects are:

a. The Senate will have an East Midlands-wide remit, unconstrained by organisational boundaries[1].

b. It will seek out, identify and promote innovative approaches and best practice in patient and public leadership.

c. It will act as an informed critical friend to health and social care organisations in the East Midlands by offering independent challenge and expert advice regarding PPI activities and thus contributing to their governance arrangements.

d. The Senate will work alongside the EMAHSN in delivering the Government's Innovation, Health and Wealth agenda[2] through all aspects of patient and public involvement in health and social care.

2.3. The Senate will identify and spread innovation in response to common but complex challenges to patient and public involvement in all aspects of research, service design and operational delivery[3]. This will be accomplished through promoting and providing leadership in PPI.

[1] This stops the Senate being locked down to just AHSN or just healthcare and paves the way for any emerging independence.
[2] The reference to Innovation Health and Wealth replaces a list of sectors (voluntary sector, industry etc. and instead shows how the Senate fits with AHSN and national priorities. Embedded in there are all the obligations to work in partnership across the sectors.
[3] Such topics might include: seldom listened to communities, lack of opportunities for people to get involved, reimbursement arrangement, sharing professional power; ensuring effective support for PPI reps, making the case for co-production, ensuring that PPI is a must do and running effective consultations.

2.4. To provide expert advice to the East Midlands Academic Health Science Network on patient and public involvement. It will do this by offering constructive and independent advice on how the AHSN can meet its obligations in terms of patient and public involvement.

3. Policy and underpinning values

3.1. The Government adopted principles of "No decision about me without me" and NHS staff are encouraged to "Think like a patient, act like a taxpayer." The NHS Constitution says *"The NHS belongs to the people. It is there to improve our health and wellbeing, supporting us to keep mentally and physically well ,to get better when we are ill, and when we cannot fully recover, to stay as well as we can to the end of our lives."* NHS England says it "Will ensure that public, patient and carer voices are at the centre of our healthcare services, from planning to delivery. Every level of our commissioning system will be informed by insightful methods of listening to those who use and care about our services." The NHS Five Year Forward View shifts the balance power with a "new relationship with patients and communities". Patient and public involvement is thus a 'must do' which needs to pervade NHS and Social Care.

3.2. A principal cause of failure of initiatives is the lack of involvement of the very people the initiative affects. Better decisions are made when a range of experiences and opinions inform them, including the views of, and leadership from, patients and the public.

3.3. The PPI Senate will be inclusive of diversity, responsive, realistic, knowledgeable, relevant and challenging.

3.4. The Senate will promote an approach to PPI that is evidence, informed and values based.

4. Tasks

4.1. To identify the most common challenges in PPI across the region and identify, share, publicise and encourage best practice and the adoption of innovative approaches by health and social care organisations.

4.2. To act as a 'critical friend' to organisations funded to deliver NHS, social care and Public Health in the East Midlands by offering expert advice regarding their PPI activities and thus contributing to their governance arrangements.

4.3. To stimulate collaboration and so improve engagement and co-production of health and social care services across the East Midlands. To work with colleagues who are engaged in the development of patient and public leaders.

4.4. The Senate will have both an internal focus on EMAHSN matters (e.g. ensuring its work programmes address respond to public leadership) and an external focus as set out in section 5 below.

5. Unique contribution

5.1. The Senate will provide an East Midlands wide forum for public members and PPI professionals from the NHS, Third Sector and Social Care to offer leadership, encourage sharing of good practice across these sectors and promote excellence in PPI, through a coordinated approach that engages with academic and business institutions.

5.2. The Senate will not be constrained by geographical, sector or organisational boundaries.

5.3. Senate members will be offered remuneration and, over time and with support, they will be expected to operate at a senior and strategic level in offering leadership within the East Midlands.

5.4. As an independent, cross boundary group with a regional perspective, the Senate will offer expert advice and leadership, and so contribute to local governance arrangements.

6. Exclusions

6.1 The PPI Senate is not:

a. A substitute for organisations carrying out their own PPI activities and ensuring that the voice of patients is heard in each of their decision-making fora.

b. A way for managers or clinicians to avoid taking responsibility for their decisions in this domain. The Senate aims to have influence but does not have the authority to insist on any particular course of action.

c. An attempt to replicate or replace existing PPI activity.

d. The same as the East Midlands Clinical Senate, which is "a source of independent, strategic advice and guidance to commissioners and other stakeholders to assist them to make the best decisions about healthcare for the populations they represent." While the Clinical Senate includes patient members, the majority are senior clinicians. In contrast, all full members of the PPI Senate will be patients, carers or the public. The PPI Senate will work with the Clinical Senate and other infrastructure organisations wherever possible.

7. Representation

7.1 There will be up to 15 members on the Senate, from diverse backgrounds, linked with a range of organisations including some independent members.

7.2 Senate members will serve for varying terms of office (1-3 years) in order to refresh the group over time without disrupting efficient working.

7.3 While the membership of the PPI Senate aims to be diverse, there will not be a formal alignment of individual members to specific constituencies.

8. Member Recruitment

8.1. All members of the PPI Senate will be patients, carers or members of the public, with EMAHSN proving support functions.

8.2. Senate members will be 'organisationally agile' – familiar with public sector organisations, able to critically evaluate strategy, and sensitive to the challenges of achieving positive change.

8.3. Members will have an established track record of PPI activities. Wherever possible they will hold a strategic role in an East Midlands organisation - perhaps as the PPI voice on the Board or in a similar position of responsibility or influence. Evidence that the previous or current work of the applicant has benefited the organisation will be shown in a letter of commendation from an executive in that organisation.

8.4. Members will have some knowledge and experience of an EMAHSN workstream subject area.

8.5. Members will display personal and professional integrity, summed up by the acronym **OSCAR**:

- **O**wn – the member will carry a sense of corporate responsibility for the activities and decisions of the PPI Senate
- **S**hare – the member will listen and talk to partner organisations and others beyond the PPI Senate to widen its reach and impact
- **C**ontribute – the member will take an active and constructive part in the activities of the PPI Senate
- **A**ttend – the member will attend meetings and participate in follow up activities whenever possible
- **R**espect – the member will treat others with dignity and respect.

8.6. Individual mentoring and wider development opportunities will be available to Senate members where required. This may include support in preparation for individual meetings. In addition, support for the development of the Board will be provided by EMAHSN.

8.7. Two Co-chairpersons will be elected by Senate members themselves, serving 2 years to refresh the group over time without disrupting efficient working.

9. Meeting arrangements

9.1 The PPI Senate will hold up to 6 formal meetings with an option of up to 3 development sessions. Meeting will last up to 4 hours a year and may rotate around the region, so members will need to be willing to travel within the East Midlands. The Senate will approve and monitor a rolling three year action plan.

9.2 Senate members will be invited to express an interest in taking on the role of co-chairs and obtain nominations by their peers. The chairs will be elected by the Senate.

10. Administrative support

10.1 EMAHSN will provide administrative support to the work of the Senate, recruit members, prepare for meetings and take minutes.

11. Budget and Remuneration

11.1 EMAHSN has made adequate financial provision to recruit to and operate the PPI Senate through its Patient and Public Leadership Enabling Workstream.

11.2 Each Senate member will be offered a participation fee of £150.00 per meeting plus receipted expenses (matching the NIHR participation rate). As Senate meeting are half a day, it is expected that the Senate will undertake follow up activities outside of meetings. Additional activities and participation payments will be communicated.

11.3 Payments will be made in response to a claim from members and will be completed by bank transfer approximately a month after each meeting. **All claims must be submitted within 3 months of undertaking the activity**.

12. Agenda

12.2 The Senate will agree its agenda, activities and impact measures with the EMAHSN and will regular review this.

12.2 Time will be devoted to Senate members building effective working relationships and establishing a positive working culture. Activities will be set out in a regularly updated work-plan. The Senate will seek requests from health and social care (including Public Health organisations) in the region who wish to seek advice or other input from the Senate about how they address challenges through a co-production approach. Individual topics will be explored in each meeting to identify, adopt and spread good practice.

13. Reviewing membership

13.1 Members who consistently breach the OSCAR behaviours set out in 8.5 will be asked to step down from the role.

13.2 In order to ensure the PPI Senate is effective a level of commitment is required form all Senate members in terms of attendance at meetings and undertaking activities outside of meetings. Illness, caring responsibilities and personal circumstances, will affect involvement. When such issues occur, members should inform either Co-Chair and/or PPLL so that apologies for meetings and planned activities can be re-arranged in a timely manner.

13.3 Where members are not actively participating in meeting/activities and no explanations has been provided to either Co-Chairs and/or the PPLL, a meeting involving all parties will be arranged to discuss solutions.

13.4 Where participation continues to remain low and there is no explanation or resolution, the suggestion to step down will be made.

14. Review date and where to go for more information:

14.1 For further information email EMAHSN Patient and Public Leadership Lead. shahnaz.aziz@nottingham.ac.uk

13.2 Version3 updated Shahnaz Aziz April 2017. Review date: 27 Feb 2018