

Horizon scanning report: Strategic patient engagement in the healthcare

Background

1. A central aim of our patient engagement strategy is co-production and partnership with patients, this means involving patients in decision making at strategic level. Since 2022 we have been scoping out potential models which would help us best to achieve our aspiration. Initial thinking was focused on the creation of a Patient Council Associate role.
2. At the October 2022 meeting of the Policy and Education Committee (PEC), members were receptive to the concept of involving patients at strategic level but were unsure that the Patient Council Associate model (one patient) was the most appropriate model for GOsC.
3. We reflected on the feedback and began a desk-based research exercise to identify examples of patients involved in decision making in the healthcare sector. We also spoke with counterparts in other health regulators and members of our Patient Involvement Forum to seek their insights.
4. When undertaking the horizon scanning exercise, we kept a number of factors in mind:
 - Organisational culture
 - Needs of patients and how to create a safe environment
 - Equality, diversity and inclusion
 - Recruitment and training:
 - Appointment process
 - Selection criteria
 - Training requirements
 - Term/Number of appointments
 - Remuneration/Budget required
 - Support required from staff and council members.

Benefits of patient involvement for GOsC

5. GOsC has already experienced significant benefits while involving patients in our work through consultations, surveys, focus groups, workshops and ongoing discussions with patients. The views received have been diverse due to the wide range of protected characteristics that the 33-member Patient Involvement Forum possess.
6. Since 2020 members of our Patient Involvement Form helped to shape the language and content of our Equality, Diversity and Inclusion Framework for 2021-24. They have influenced the Guidance for Osteopathic Pre-registration Education as members of the Stakeholder reference group as well as sharing insights for our standards related work around boundaries. The patient voice also

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shaped important consultations including adjunctive therapies guidance and questioning witnesses practice note.

7. Most notably, patients have had a significant impact on our shared decision making project, helping to shape the content and design of the tools as well as the implementation and evaluation of the resources.
8. Our work has also helped to raise our profile with stakeholders in the wider health sector, presenting GOsC with opportunities to discuss patient engagement at the 2021 NCOR Conference, the Annual Scottish Regulation Conference in October 2022 and the PSA Symposium in 2021 and 2023.

A wider healthcare perspective

9. Patient experience of healthcare continues to evolve in the current context of ongoing change. Patients' needs are not always being met by the NHS which means that more patients are coming to osteopaths.
 - a. This is reflected in the recent YouGov Patient and Public Perceptions Survey (2023) we commissioned which showed that, 'More than three-fifths of osteopathic patients surveyed said that, in the past two years, they have seen an osteopath because it was faster than seeking advice/ treatment from a GP (63%)'.
 - b. How does this impact on expectations of patients? Have their needs changed? What is most important now? This changing context may require a set of changing knowledge and skills for osteopaths.
10. It is critical that we take account of this and consider the implications and impact for the delivery of osteopathic care and osteopathic education, standards and CPD. Having patients involved at a strategic level involved in the decision making process like osteopaths offering input from a non-representative but different perspective (like osteopaths do on Council) and could help us build innovative co-produced solutions to potential challenges.
11. External inquiries and reviews have also highlighted a need to focus on involving patients in health regulation. For example, the [Cumberledge Review](#) (2020)¹ noted the need to strengthen the patient voice in the health and regulatory system). This was echoed by the [Pandemic Patient Experience report](#) (2020) from the Patients Association which recommended that the healthcare sector 'maintain the principles and values of patient choice, shared decision making and

¹ [Cumberledge J. First do no harm: the report of the Independent Medicines and Medical Devices Safety Review. July 2020](#)

voice, so that services are shaped by patients, disabled people and others who most need them.’²

Examples of strategic patient engagement in healthcare sector

Overview

12. In 2023, we began reviewing secondary source literature including research papers, articles and websites of NHS Arm’s Length Bodies, health charities, patient engagement experts and other health regulators seeking out examples of patients involved at governance level in healthcare sector.
13. While conducting this desk-based research we used search terms (on their own and in combination) which included: patient*, partner*, strategic, governance, leader, healthcare, involvement, group, advisor, engagement, board, collaboration, representative, decision making, chair, NHS, health regulator, co-production.
14. The horizon scanning process highlighted that patient involvement at strategic level is sporadic and models are bespoke to each organisation. However, the models that have been successful and continue to yield meaningful results have the following hallmarks:
 - Patients acting as critical friends rather than representing personal healthcare condition or interest
 - Effective culture for power sharing in place with equal value placed on both lived and learned experience
 - Robust recruitment processes, clarity of role/responsibilities and dedicated training
 - Specific efforts made to ensure that seldom heard groups are included
 - Accessibility needs are prioritised – (eg changes to language including the avoidance of acronyms)
 - Psychologically informed engagement based on empathy and understanding that vulnerability has a place
 - Dedicated budget on a parity with other committee members (remuneration)
 - Dedicated and proportionate staff resource to facilitate ongoing support for patients and management of administrative processes
 - Ongoing evaluation for organisational learning and quality improvement.
15. Based on this learning we identified four types of operational models in which patients have made important contributions to health organisations helping to shape policy and strategy:

² [Patients Association, Pandemic Patient Experience UK: Patient experience of health, care and other support during the COVID-19 pandemic. September 2020](#)

- a. Advisory panels/groups (made up of staff/registrants/service users)
- b. Patient leaders/Patient experts
- c. Patients as full lay members
- d. Patients as co-opted board members (similar to council associate role)

Model 1: Advisory panels/groups

Social Work England: National Advisory Forum

16. **Background:** Social Work England's [National Advisory Forum](#) (NAF) was established in March 2020 with 10 founding members. The group is now comprised of 18 members which includes practising social workers, social work academics, student social workers and six members with lived experience of social work. The members serve an initial term of three years.

- a. **Lived experience members:** The six members include a community campaigner and co-production advisor within the health and social care sector, and several members who are involved in healthcare professional training in the higher education sector as experts by experience.

17. **Purpose:** The Forum acts as a critical friend to Social Work England (SWE) bringing lived and learned experience to the regulator, as well as acting as the main driver of co-production across the organisation. The NAF makes recommendations to SWE senior and executive leadership teams about the regulator's impact on the social work sector.

- a. The group meets approximately six times a year and is co-chaired by a Social Work England staff member and a member of the group on a rotating basis.
- b. The Forum is moving towards a co-governance model and developed co-production training which has been delivered to senior leadership and rolled out across the organisation. They are currently building relationships with the board which involves a buddy system and joint workshops.

18. **Training and recruitment:** Members are recruited via a formal selection process which includes three rounds of recruitment.

19. **Resources:** Forum members can claim expenses and receive involvement payments (for example, per full day spent on engagement activities they will receive £160). Operational support for the Forum is led by SWE's Regional Engagement team and in particular the Participation Officer.

- a. The forum involves 75% of the Participation Officer's role. The officer is supported by a Regional Engagement Lead (a social worker based in the South West).

- b. Overarching support is provided by the Head of Strategic Engagement who led on the establishment of the Forum.

Patient Participation Groups in GP Practices (NHS England)

20. **Background:** Patient Participation Groups (PPGs) consist of patients acting as a link with the people a GP Practice serves and as a critical friend taking an active role in developing local health services.

- a. When looking at the structure that underpins groups ‘...there is no particular requirement, nor description in statute, of what constitutes a PPG, what it can do, how it should be organised, and whether it should be a face-to-face group or a virtual group, or both...’(Wilkie, 2016)³
- b. As a result, ‘Every PPG is unique, based on the relationship with practice staff and evolving to meet local needs.’⁴

21. **Purpose:** The purpose of a PPG is to facilitate patients and the GP practice’s staff working together to share ideas to help improve the services offered at the practice. PPGs also influence the GP practice/wider NHS to improve commissioning offering an avenue for patients to have a say in how services are planned, developed and evaluated.

22. **Membership:** Groups comprise of a Chairperson, Secretary, Treasurer (if fundraising is involved), Carer(s), Group members (patients from across the surgery representing the practice population), GP Practice Manager and Nurse.

23. **Training and recruitment:** No training is required, and the roles are entirely voluntary.

24. **Resources:** In terms of resources, there is no requirement that PPGs be funded and so while all GP practices in England are required to have a patient participation group some are more active than others.

- a. Patient-led groups within general practices are supported by an umbrella organisation, the [National Association for Patient Participation](#) which:
 - i. helps GP practices to establish new groups
 - ii. helps develop and sustain existing groups
 - iii. enables PPG networking
 - iv. shares good practice
 - v. promotes and secures patient participation in national policy development and research.

³ [Wilkie, P. Patient participation groups in general practice: building better partnerships. 2016](#)

⁴ [National Association for Patient Participation. A guide for Patient Participation Groups](#)

Model 2: Patient leaders/Patient Experts

Health and Care Professions Council Partners

25. **Background:** [Health and Care Professions Care Partners](#) are independent contractors that provide expertise to support HCPC with decision making. They help ensure that HCPC has appropriate professional and lay (public) input into their work.
- a. The broad term 'Partners' includes a variety of different roles that can be filled by people with different experience and qualifications. The type of partner role reserved for patients and members of the public is as [Service User Expert Advisors for HCPC's quality assurance of education](#).
26. **Purpose:** Service User Expert Advisors provide specialist expertise and advice through HCPC's assessment of institutions and education and training programmes. They support Lead Visitors in making informed decisions related to service user and carer involvement in the education and training of HCPC professions. Lead Visitors are registrants who assess institutions and education and training programmes to ensure they meet HCPC standards.
27. **Training and recruitment:** HCPC Partners are recruited through a formal application process against a competency framework. Service User Expert Advisors must undergo mandatory training. Partners use the [Learning Hub](#) - HCPC's online platform for delivering learning – to undertake a variety of e-learning modules.
28. **Resources:** Partners are paid daily rates and have their travel and expenses remunerated.
- a. There is a Partner team made up of HCPC staff who are the point of contact and provide ongoing support.
 - b. Partners have access to a dedicated Partner Portal hosted on the HCPC website.

NHS Patient Safety Partners

29. **Background:** Recommendations from the [Berwick review into patient safety](#) that stated 'patients and their carers should be present, powerful and involved at all levels of healthcare organisations from wards to the boards of trusts'⁵ was a driving factor for the creation of the NHS [Patient Safety Partners](#) role.
- a. Patient Safety Partners (PSPs) involvement in organisational safety relates to the role that patients, carers and other lay people can play in supporting and

⁵ [Department of Health. Berwick Review into Patient Safety. Recommendations to Improve Patient Safety in the NHS in England. 2013](#)

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contributing to a healthcare organisation's governance and management processes for patient safety.

- b. They work in partnership with staff to influence and improve the governance and leadership of safety within an NHS organisation.
- c. Examples of NHS Patient Safety Partners include the [Wessex Patient Safety Collaborative Initiative](#) and [NHS Mid and South Essex Integrated Care System](#).

30. Purpose: Patient Safety Partners provide challenge and insight to NHS trusts and Integrated Care Systems. PSPs can act as 'knowledge brokers' using their lived experience to help inform learning and holistic safety solutions that cross organisational boundaries. They provide a different perspective on patient safety, one that is not influenced by organisational bias or historical systems.

- a. Roles for PSPs can involve membership of safety and quality committees whose responsibilities include:
 - working with organisation boards to consider how to improve safety
 - participation in investigation oversight groups.
 - involvement in patient safety improvement projects

31. Training and recruitment: A formal recruitment process is in place with a clear role description and an interview process.

- a. All new PSPs have a planned induction which includes meeting relevant staff and other PSPs.
- b. Training needs are identified which include both personal development as well as training in relevant elements of the patient safety syllabus.
- c. Where possible PSPs are trained alongside staff.

32. Resources: PSPs are reimbursed for out-of-pocket expenses incurred while working for the NHS (travel and subsistence). In some circumstances they may be offered payment.

- a. Responsibility for recruiting, selecting and supporting PSPs is delegated to NHS staff. Staff also receive training in patient involvement in patient safety.
- b. All PSPs have an annual appraisal at which clear objectives are agreed. A mentor/buddy system is in place and support is provided from senior leadership in the organisation.

Model 3: Full lay members

NHS England Patient and Public Voice Partners (members of committees and working groups)

33. **Background:** [Patient and Public Voice \(PPV\) partners](#) include patients, service users, carers, families and other members of the public. PPV partner is an umbrella term that encompasses a variety of positions. For the purpose of this paper, we are outlining the governance roles only.

- a. PPV partners can be recruited to governance committees/roles and are involved in strategic and accountable leadership and decision making activity. They can also be members of groups that make recommendations to committees that have delegated authority of the NHS England Board.
- b. The importance the NHS places on involving PPVs at strategic level was outlined in the [Five Year Forward View, NHS England, October 2014](#).

*'We need to ensure that patients and the public are an integral part of our governance, decision making forums, service improvement, re-design and assurance. It is vital that the patient and public voice (PPV) is embedded in all of our commissioning process.'*⁶

34. **Purpose:** The [NHS England Patient and Public Voice Partners Policy](#) (Page 8) outlines the following purpose for partners:

*'PPV partners bring unique perspectives and insights into the work of the NHS, through their lived experience as a patient/carer or as a member of a community with particular health and care needs. They challenge thinking, help innovate and improve what NHS England does, ultimately making services more responsive to people's needs, improving access to services as well as improving health outcomes.'*⁷

- a. In governance roles PPV partners are expected to demonstrate strategic and accountable leadership. They are involved in shared decision making in NHS England's committees and priority programmes, or can be involved in making recommendations to committees that have delegated authority from the board.
- b. Please see below an example of a strategic PPV role:

'Following an application and interview process, Mary Smith was selected to become a PPV representative on the Individual Funding Review panels. These panels make decisions about whether treatment should be made available for a patient when the general policy is not to fund it. Her input to this panel contributes to decisions that have an impact on budget resources.'

⁶ [NHS England. Five Year Forward View. October 2014](#)

⁷ [Public Participation team, NHS England. Patient and Public Voice Partners Policy. July 2017](#)

It is an accountable and leadership role.' ([NHS England Patient and Public Voice Partners Policy Page 11](#))

35. **Training and recruitment:** Strategic PPV roles have recruitment processes that entail interviews, references and mandatory training. The lead contact within the NHS who recruits the PPV needs to ensure that any PPV partner roles have a clear role description indicating the nature of the role, any skills and experience required, how long the role will last and any mandatory training associated with the role.
36. **Resources:** PPV partners receive involvement payments. Individual teams in NHS England have responsibility for engaging and supporting PPV partners in their work.

Maternity Voices Partnership: Service user as Chair (NHS England)

37. **Background:** Maternity Voices Partnerships (MVPs) were recommended by the 'Better Births report (2016) as a forum for co-production with women and families to implement better births.⁸ The [Three year delivery plan for Maternity and Neonatal services](#) set the ambition that Maternity and Neonatal Voices Partnerships have strategic influence and are embedded in decision-making.⁹
38. **Purpose:** An MVP is a NHS working group that reviews and contributes to the development of maternity services within a local area. It brings together the staff who commission and provide maternity services with the women, birthing people and families who use those services. The MVP is coordinated by a service user chair or leadership team, who are independent lay people. All members of the partnership take responsibility for the development and delivery of an agreed workplan.
39. **Training:** MVPs are supported by [National Maternity Voices](#) the association of Maternity Voices Partnership (MVP) independent lay chairs in England. National Maternity Voices offer multidisciplinary training packages as well as bespoke training for MVP chairs. This training is designed to support collaborative working and help ensure MVPs are as effective as possible. The MVP chair must act in accordance with the Nolan Principles of Conduct in Public Life when carrying out their role.
40. **Resources:** For the role of Maternity Voices Partnership (MVP) chair to be accessible to people from all backgrounds the role is a paid post. They also receive administrative and IT support.

Model 4: Co-opted Council board member

⁸ [The National Maternity Review. Better Births: Improving outcomes of maternity services in England: A Five Year Forward View for maternity care. 2016](#)

⁹ [NHS England. Three year delivery Plan for Maternity and Neonatal services March 2023](#)

The West Yorkshire and Harrogate Health and Care Partnership Board co-opted members

41. **Background:** The [West Yorkshire and Harrogate Health and Care Partnership Board Partnership Board](#) is a key element of the leadership and governance arrangements for the West Yorkshire and Harrogate Health and Care Partnership. It is responsible for setting strategic direction of the partnership and provides oversight for all Partnership business, and acts as a forum to make decisions.
42. **Purpose:** The Partnership Board includes two co-opted members, who act as independent critical friends to the Board, rather than representing a personal healthcare condition or interest.
- a. Co-opted members provide strategic, impartial input into the board's decision making.
 - b. In particular, they champion the public, service user, patient and carer perspective, providing assurance that people's needs are at the centre of the Board's decisions.
 - c. Co-opted members are able to participate on all issues but do not have a vote.
43. **Membership:** The co-opted members include an autism advisor with NHS England who is an expert by experience with Inclusion North, and a member of Bradford's Patient Network who established the People's Board which involved the public in NHS Bradford District and Craven Clinical commissioning groups.

Horizon scanning: Additional points to consider

Creating the right environment

44. The horizon scanning exercise demonstrated that for patient involvement to work at strategic level, a dynamic needs to exist, that allows the patient voice to flourish. This requires power sharing, a commitment to openness and transparency, as well as good leadership. In the initial stages of creating the right environment patients are likely to require learning and support, focused on developing confidence and capability – particularly 'process' skills.
45. Before involving patients at a strategic level, good practice recommends that senior leaders should consider if they are ready to provide an effective culture to support patients. Tokenistic attempts to involve patients in governance are likely to be detrimental overall.

Representativeness

46. At the October 2022 PEC meeting and again at the June 2023 meeting when considering the proposal for patient involvement at strategic level an issue that

was raised by committee members was the extent to which patients can be said to “represent” others. This is a common debate that appeared during the horizon scanning process. However, the horizon scanning exercise has showed that patient involvement is not about having a representative sample, but the impact having a different perspective in the room can yield.

Professionalisation

47. A common issue which emerged during horizon scanning that was highlighted at the October PEC meeting was whether long-term involvement causes patients to become professionalised and lose sense of the experiences as a patient.

48. Findings from the horizon scanning exercise suggested that:

- a. Limiting people’s involvement on the grounds that they have developed expertise is wasteful. Some may want to increase their level of involvement roles as their knowledge and confidence grows.
- b. Developing expertise through training rarely means that people lose sense of the experiences as a patient. Many of patients who participated in governance roles live with chronic health conditions, experienced traumatic illnesses that they were still recovering from, and/or are carers for family members who have ongoing health conditions. As a result they hadn’t lost their outsider perspective.
- c. Ongoing involvement allowed organisations and patient to build trust, continuity and relationships and gave patients time to grown into the role. It became apparent that experience and long-term involvement are likely to make patient representatives more effective and efficient.

References

1. [Cumberlege J. First do no harm: the report of the Independent Medicines and Medical Devices Safety Review. July 2020](#)
2. [Patients Association, Pandemic Patient Experience UK: Patient experience of health, care and other support during the COVID-19 pandemic. September 2020](#)
3. [Wilkie, P. Patient participation groups in general practice: building better partnerships. 2016](#)
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5. [Department of Health. Berwick Review into Patient Safety. Recommendations to Improve Patient Safety in the NHS in England. 2013](#)
6. [NHS England. Five Year Forward View. October 2014](#)
7. [Public Participation team, NHS England. Patient and Public Voice Partners Policy. July 2017](#)
8. [The National Maternity Review. Better Births: Improving outcomes of maternity services in England: A Five Year Forward View for maternity care. 2016](#)
9. [NHS England. Three year delivery Plan for Maternity and Neonatal services. March 2023](#)