

The MTG Guide to Meaningful Patient Involvement

Objectives

- To identify what is meant by meaningful patient involvement and determine which organisations are involving patients in this way.
- To assess where gaps currently exist within the NHS for meaningful patient involvement.
- To make the case for why patient involvement is important.
- To shine a spotlight on how ICSs are involving patients in their decision making and within formal roles.
- To highlight any best practice, poor practice or regional variation in patient involvement at the ICS level.
- To ensure that the patient voice is represented at every point of the decision-making process.

National

	Current activity	Areas for discussion
NICE	<ul style="list-style-type: none"> Public and Patient Involvement Policy Public and Patient Involvement Team, new committee being set up 	<ul style="list-style-type: none"> Variation in Committees depending on the Chair. Further advice and process is needed to avoid this variation Difference in weighting of evidence and patient feedback
NHS England	<ul style="list-style-type: none"> Patient and public involvement policy 'Involvement Hub' Over 800 Public Patient Voice (PPV) Partners Regional 'Experience for All' programme of work 	<ul style="list-style-type: none"> Several MTG members have indicated that patient involvement with NHS England can feel like a 'tick box exercise' No representation at NHS England Board level
Department of Health and Social Care	<ul style="list-style-type: none"> Department of Health and Social Care have a statutory duty to involve the public and consult them in relation to their health and social care The Department engaged with HSC organisations in the development of their schemes and each body now has a consultation scheme, approved by the Department, in place. The Department also has its own PPI Consultation Scheme 	<ul style="list-style-type: none"> Patient representation within senior decision making in DHSC is limited
NHS Transformation Directorate	<ul style="list-style-type: none"> Data team heavily engaging with Personal and Public Involvement (PPI) 	<ul style="list-style-type: none"> No formal mechanism for patient involvement at this point at senior levels
Clinical Reference Groups	<ul style="list-style-type: none"> Patient representatives are involved in Clinical Reference Groups 	<ul style="list-style-type: none"> Evidence provided by patient representatives not always considered consistently
GIRFT (Getting It Right First Time)		<ul style="list-style-type: none"> No formal role for patients
NHS Supply Chain		<ul style="list-style-type: none"> Unclear if there is any patient involvement on device working groups (DWGs)
Care Quality Commission	<ul style="list-style-type: none"> Public online community 	<ul style="list-style-type: none"> Director of Engagement included in board
Health Education England	<ul style="list-style-type: none"> Patient and carer focus groups in place to provide feedback 	<ul style="list-style-type: none"> Opportunities for patient involvement is limited, as is the ability for patients to feed into decision-making process

Medicines and Healthcare Products Regulatory Agency (MHRA)	<ul style="list-style-type: none"> • Patient Involvement Strategy launched with outline from 2021-2025 	<ul style="list-style-type: none"> • No clear processes yet in place in line with timelines outlined in the Strategy
Accelerated Access Collaborative (AAC)	<ul style="list-style-type: none"> • Accelerated Access Collaborative patient and public involvement strategy launched 	<ul style="list-style-type: none"> • Not yet clear what impact the strategy will have and how patient opinions will be weighted in the decision making process
Academic Health Science Networks (AHSNs)	<ul style="list-style-type: none"> • Many AHSNs have public and patient involvement representatives who work to engage patients and involve them in the work of the AHSNs 	<ul style="list-style-type: none"> • No mandated, or formalised role for patients throughout the AHSN Network
Royal Colleges	<ul style="list-style-type: none"> • The Academy of Royal Colleges has an Academy Patient and Lay Committee (APLC). The APLC highlights issues on healthcare where greater patient and lay perspective is needed. • Several Royal Colleges, including Surgeons and Anaesthetists, have patient involvement groups. 	<ul style="list-style-type: none"> • Royal Colleges are advised but not mandated to ensure patient involvement in their work. • Unclear the impact patient involvement groups have on decision making, and levels of involvement vary across Royal Colleges.

Case Study – Heart Valve Voice Response to NICE Draft Guidelines

In March 2022, Heart Valve Voice worked with clinicians and patients with lived experience to respond to the National Institute for Health and Care Excellence (NICE) draft guidelines for ‘Heart valve disease presenting in adults: investigation and management’. Heart Valve Voice ran a patient consultation to inform their response to the draft guidelines, with 59 patients participating in an interactive webinar and 100 patients participating through online surveys. Heart Valve Voice worked with a patient engagement expert and four patient ambassadors to develop a series of webinars and interview to learn from patients about their experiences of heart valve treatment.

The study found that the top five most important patient issues the NICE guidance panel should consider were collaborative decision making, patient choice, patient involvement, listening to patients and regular follow ups. On Heart Valve Disease diagnosis, 63% of patients were given good information about their valve surveillance, while 35% were given unclear information or no information at all about their surveillance. Of the patients asked, 38% said they felt they were not given all treatment options that were clinically suitable.

The consultation produced three main outcomes, patient wanted earlier detection with more opportunities to detect in primary care, faster referrals, with patient choice at the heart of decisions on surveillance and better access to all clinically appropriate treatment options.

Heart Valve Voice were then sited as influencing changes to the guidance.

Regional Bodies

Integrated Care Systems	<ul style="list-style-type: none"> NHSE/I are carrying out work on involving people and communities in ICS's Guidance issued on how to work with people and communities 	<ul style="list-style-type: none"> No formal role for patients and no involvement at Integrated Care Board level Variation already occurring in how ICSs are involving patients within the ICS decision making structure
Health and Wellbeing Boards	<ul style="list-style-type: none"> The King's Fund found that the majority of Health and Wellbeing Boards state that they do have public and patient involvement representatives on the Board 	<ul style="list-style-type: none"> No clear, formalised roles for patients exists across the Health and Wellbeing Boards, national and regional variation exist
Primary Care Networks		<ul style="list-style-type: none"> Lack of clarity about the role which patients can play within Primary Care Networks
HealthWatch	<ul style="list-style-type: none"> Mechanism exists for patients to seek support and raise concerns. Healthwatch engages with, and gathers feedback from, people using health and care services at both local and national level. There are more than 150 Healthwatch teams across England Patient Participation Groups across the country 	<ul style="list-style-type: none"> Lack of power and accountability for HealthWatch to action

Case Study – Integrated Strokes Delivery Network

Pam Irving sits on the user voice panel for the North East and North Cumbria ISDN (Integrated Stroke Delivery Network), one of a network of 20 regional bodies throughout England responsible for services across the whole stroke pathway.

ISDN's have public and patient voice groups in each area which input into service delivery. As a volunteer, Pam attends virtual meetings once a month to speak about the patient experience with other patients. Pam recently worked on the roll out of telemedicine in the North East, with the members of the panel interested to hear how telemedicine would impact the quality of life of patients who had had a stroke. Sitting on the panel, Pam said she feels listened to by the other panellists and believes they want to understand the patients viewpoint.

Pam's work has also seen her engage with the North West Ambulance Service, who were interested in reducing the response time for stroke patients.

Pam's background is in IT, where she regularly spoke to large groups of people, and presenting information was part of her everyday life. Since suffering from a stroke at 51 and being told about Different Stroke in hospital, Pam has become a volunteer ambassador on a number of panels. She believes patient volunteers on boards and committees need to have a certain type of experience to be able to voice their concerns in front of audiences who do not share the same experiences as themselves.

Local Bodies

<p>NHS Foundation Trust Boards</p>	<ul style="list-style-type: none"> • Patient can apply to join a Foundation Trust Board 	<ul style="list-style-type: none"> • Opaque reporting structures mean that it is difficult to assess overall coverage and take advantage of opportunities to be on the Trust Board • No representation required in meetings
<p>NHS Hospital Trust Patient Survey</p>	<ul style="list-style-type: none"> • There are surveys for patient feedback, the Friends and Family test and in certain cases PROMS 	<ul style="list-style-type: none"> • Restrictive questions give little in-depth feedback for patients.
<p>Community Diagnostic Centres</p>		<ul style="list-style-type: none"> • Regional variation in patient involvement • No formal mechanism to involve patients
<p>Local Authorities</p>	<ul style="list-style-type: none"> • Local government has a strong history of building relationships with the public and generating important insight into how people experience the services it delivers 	<ul style="list-style-type: none"> • No clear patient involvement structures in place across many Local Authorities
<p>General Practice (GPs)</p>	<ul style="list-style-type: none"> • Patient participation groups (PPGs) are groups of volunteers that work in partnership with GP practices. These facilitate discussions with the patient population to help the practice provide proactive services that reflect the needs of its local population. It is a contractual requirement for practices to establish a PPG and ensure efforts are made to ensure it is representative of the practice population 	<ul style="list-style-type: none"> • Variation in quality of these forums and how feedback is addressed. They are often seen as a tick box exercise
<p>Pharmacies</p>	<ul style="list-style-type: none"> • Many pharmacies involve patients in the decision making process around their own care, in line with shared decision making tools 	<ul style="list-style-type: none"> • Lack of clarity over who is involved in decisions at each pharmacy leading to regional variation and a lack of patient involvement at decision making levels

Best practice examples

What does good look like?

1) Good advertising for patient roles

- Advice for organisations regarding patient recruitment
- Wide reach of adverts for new roles that become available
- Proactive outreach to relevant patient groups working in a specific disease area and to underrepresented groups
- Where appropriate ensure recruitment is extended to include carers of patients

2) Good support for patient representatives

- Appropriate training and mentoring offered to patient representatives, ensuring competency for role and understanding of commitment
- A point of contact within the committee for day to day involvement with the group
- A point of contact beyond a specific committee to raise any concerns if necessary
- Always use accessible language
- Training for committee members and chairs to ensure appropriate engagement with patient representatives
- A clear outline of reimbursement and personal support available for patient representatives

3) Meaningful roles

- Clarity over the role for the patient on the relevant Board or Committee
- Guidelines on how patient representatives will be treated and heard during consultation process
- Agreement on how the patient view will be weighted in final decision making
- Include the voice of carers where appropriate

4) Accountability for delivery and action

- Clear outline of how patient input will be taken into consideration
- Timeline for agreed actions
- Clear disclosure of type and depth of patient involvement to be included in finalised reports and strategies

5) Consistent feedback and learning

- Mechanisms in place to ensure that learning from patient involvement work is carried forward and enhanced in future activity
- Follow up activity to be undertaken so patient representatives are aware of outcomes
- A consistent approach to patient involvement to be actively cultivated within organisations

Recommendations

- 1. All organisations to produce guidelines on advertising and recruitment practices for patient roles**
- 2. Organisations to subscribe to producing guidance packs for patient representatives outlining their role on board/ committee, training available, points of contact, and glossaries of key terminology**
- 3. Organisations to produce internal guidance outlining the role of patient representatives in their work**
- 4. A defined feedback loop to be implemented in all organisations, with a clearly defined route for patient feedback and for organisations to update representatives on decision making**
- 5. The impact of patient input on decision making to be clearly disclosed on all finalised reports and strategies**
- 6. Organisations to set a clear guideline outlining expectations for patient involvement within strategy documents, ensuring patient involvement across all organisational decision making processes**
- 7. Patient involvement to be included at ICS Board level, to ensure that the patient voice is heard within ICS decision-making structures**