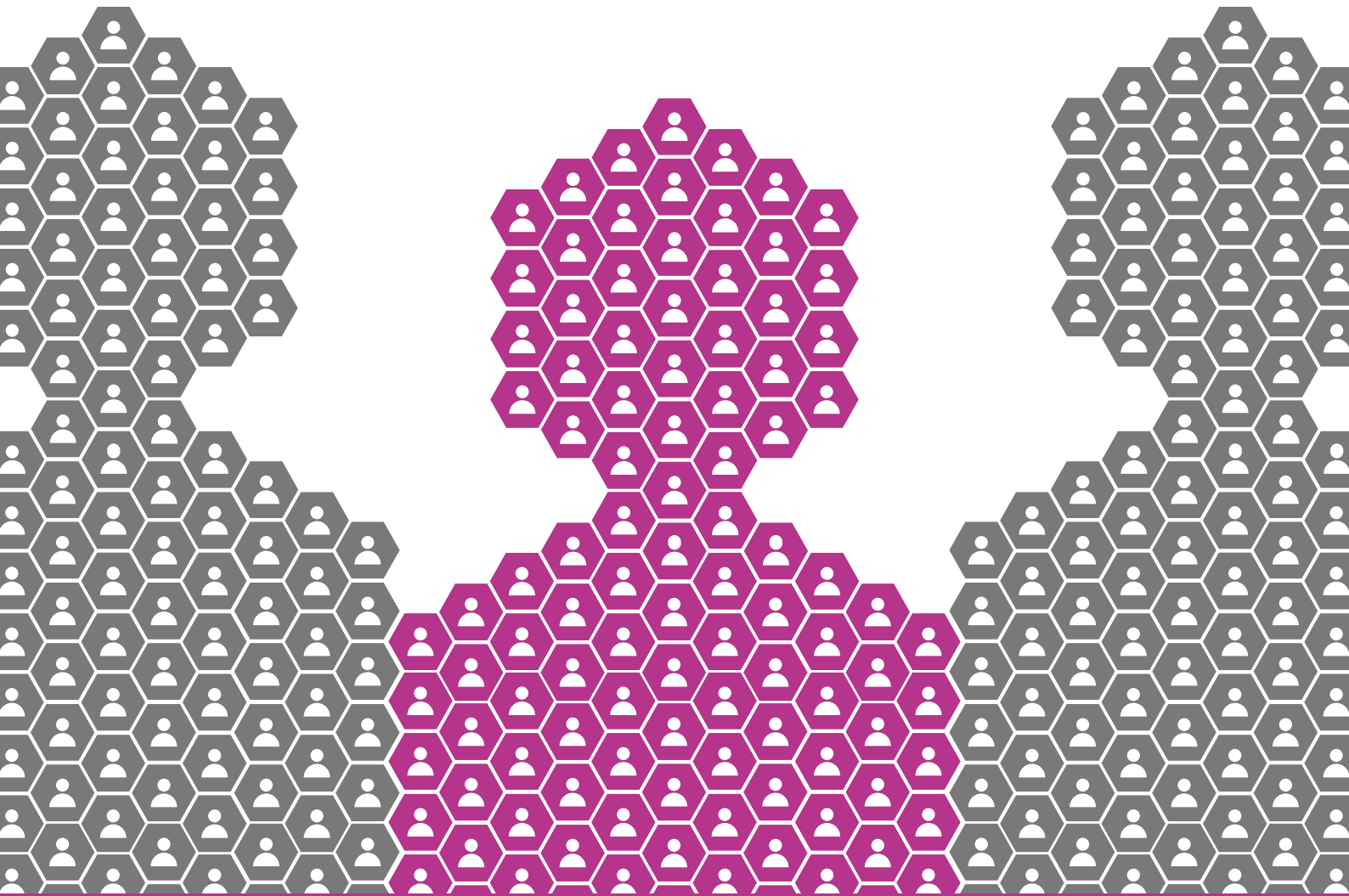


The MTG's Forum of Meaningful Patient Involvement



Introduction

The patient voice is at the heart of the work of the Medical Technology Group (MTG). With 44 patient group members, the MTG offers a unique perspective to the NHS and other relevant organisations to hear and engage with the collective voice of patients from across different condition areas.

In 2022, the MTG produced its *Guide to Meaningful Patient Involvement*, which looked to identify what is meant by meaningful patient involvement, and where this is in practice within the healthcare system. During the development of the Guide, the MTG surveyed the work of national, local, and regional bodies to assess the level of patients involved across the NHS landscape. The Guide included recommendations on how to improve patient involvement and ensure the patient voice is given due weight in decision-making.

In 2023, the MTG developed its Meaningful Patient Involvement work further, developing its *'Delivering Meaningful Patient Involvement: The MTG's Guide for Integrated Care Systems'*. The report focuses on how ICSs involve patients within decision-making structures and how meaningfully this exercise is done. The MTG found variation throughout the structures, policies, and processes of ICSs, from the omission of patient representatives on decision-making bodies, to the absence of clear consultation when decisions are made concerning a patient's care.

The MTG believes that those who receive care and interact with the NHS hold invaluable insights into the delivery of healthcare and how this could be improved. To support this ambition, patient group members of the MTG have engaged in a consultation to share their experiences in their involvement with committees and working groups set up by the NHS and other relevant organisations, including NICE, the Care Quality Commission, HealthWatch, Integrated Care Systems (ICS) or Royal Colleges.

The consultation highlighted several areas where improvements can be made in the effort to improve the patient experience within committees and working groups. This feedback has been collated below to support the NHS and other organisations to make patient involvement more effective, not only to improve service delivery across the health sector, but also the patient experience in engaging with working groups and committees. The key themes of the patient forum include:

- 1. Comprehensive Training for Patients**
- 2. Support Mechanisms and Resources for Patients**
- 3. Advertisement and Promotion of Patient Involvement**
- 4. Understanding a Range of Patient Experiences**
- 5. The Feedback Loop**
- 6. Involving Patients in Decision-Making**

"Embracing best practices in healthcare delivery holds immense potential to enhance patient experiences and outcomes. This doesn't necessitate a complete overhaul, but rather a commitment to ensuring equal access to top-notch care. Too often, patients are left out of crucial decisions regarding their own care, regional service offerings, and national-level policies. The MTG, composed of patient advocates, industry representatives, and researchers, is dedicated to amplifying the patient voice. Our report, 'Delivering Meaningful Patient Involvement: The MTG's Guide for Integrated Care Systems', spotlights exemplary practices for nationwide replication, for the eradication of the postcode lottery in patient engagement. The MTG remains committed to advocating for genuine patient involvement, aiming to set new standards of care delivery across the NHS."

– Barbara Harpham, Chair of the Medical Technology Group

"Patient and public involvement should be considered of utmost importance within relevant NHS structures. By hearing from those with lived experience, healthcare professionals are provided with a crucial insight that they would otherwise lack, and this can only be positive in terms of designing more effective support. Having structures in place which effectively represent patients and carers within the decision-making processes are empowering for the individuals that take part as well as providing significant benefits from an organisational perspective. It's vital that we stop looking at patient involvement as a 'nice thing to have', or a box to be ticked, but as a highly desirable practice which brings real benefits to all those concerned."

- Austin Willett, Chief Executive of Different Strokes

Comprehensive Training for Patients

The provision and quality of training and support offered to patients varies in level depending on the organisation. MTG patient groups revealed that the training provided by organisations to enable patients to actively engage was varied, with some training not adequately preparing patients.

Several patient groups suggested that the training provided by decision-making organisations is more about 'paying lip service' to the patient voice rather than being of genuine benefit.

The lack of support has resulted in patients feeling unprepared to sit on committees or working groups, hindering the patient's ability to express their opinions and meaningfully contribute to discussions. Consequently, to empower patients to take part in decision-making processes, patient groups are having to supplement the information offered by public organisations with their own training tools.

The MTG believes more responsibility and action must be taken by organisations to work collaboratively with patient groups to ensure patients sitting on committees and working groups are properly prepared.

Support Mechanisms and Resources for Patients Who Are Taking Part in Committees and Working Groups

When asked what organisations can do to better support patients in their role on committees and working groups, MTG patient group members noted the importance of providing sufficient supportive materials and resources.

As well as sufficient training, patient groups said organisations could do more to provide support mechanisms for patients, especially in consideration of disabilities and/or language barriers. Ensuring there is an equitable opportunity for all patients to sit on committees and working groups is crucial, as without the breadth and depth of patient insight, organisations lose the ability to provide breadth and depth to ongoing policy. Patient groups also highlighted the difference between a patient having lived experience and their ability to properly represent others through this, with the latter vital for meaningful involvement, but in need of support and understanding around the policy and context of decisions to be achieved.

Financial support to attend committees and working groups was also highlighted as a barrier to meaningful involvement. While patient groups acknowledged that funding was often a barrier to patient involvement, the cost-effectiveness of patient involvement to NHS decision-making was stressed.

The MTG believes it is essential that the long-term benefits of patient involvement are showcased to increase funding and improve support for patients wanting to meaningfully contribute to decision-making across the Government and NHS.

Advertisement and Promotion of Patient Involvement

There is consensus among MTG patient groups that more must be done to advertise and promote patient participation beyond general advertisements on social media.

It was noted that recently organisations have been doing more to engage with patients, particularly through the forum of patient groups and charities. Following engagement, patient groups send regular newsletters to advertise any committee roles they have been made aware of by relevant organisations.

In addition, it was suggested that organisations fail to meet their target audiences due to the use of medical jargon, which is often misunderstood.

The MTG recommends the use of clear and understandable language in their engagement with patients, alongside the clear establishment of expectations for patient participation, particularly within advertisements. In the long-term, the MTG believe this will result in the recruitment of a diverse range of patients.

Understanding a Range of Patient Experiences

When discussing the advertisement and promotion of patients, the MTG patient groups noted that 'expert patients' are often recruited to sit on committees and working groups due to the inaccessibility of the most appropriate individuals.

An expert patient refers to an individual who has personal experience dealing with a specific medical condition. These individuals typically possess an in-depth understanding of their condition, its management, and the patient experience. Their expertise is grounded in their firsthand experiences and can be instrumental in improving healthcare practices, patient care, and awareness of specific medical issues. However, the frequent recruitment of these patients not only results in a failure to represent the average patient experience, but also results in a lack of diversity.

Patient groups did praise the ongoing consideration to improve the recruitment of patients from a diverse range of cultural and socio-economic backgrounds. However, the extent to which this is being achieved was questioned.

While the 'expert patient' is extremely valuable in sharing and disseminating the patient experience within committees and working groups, failure to recruit a range of diverse patients limits the extent to meaningful involvement across the health service. This runs the risk of patient involvement becoming a tick-box exercise.

The MTG believes it is essential that the NHS and other organisations increase the diversity of patient involvement to ensure the average patient experience is wholly represented across decision-making.

The Feedback Loop

MTG patient groups felt the feedback loop on how organisations were taking forward information provided by patients during committees was inconsistent.

Feedback from organisations was described as minimal, often given verbally, or presented in the form of a summary at the end of the meeting. The National Institute of Health and Care Excellence (NICE) were praised for their feedback, providing a clear chart with the feedback given from patients.

The MTG recommends the improvement of patient feedback loops and would like to reiterate the importance of improvements to ensure patients know what the output of their input has been.

Involving Patients in Decision-Making

Feedback from MTG patient groups pointed to a good awareness of the need to involve patients within the decision-making structures of the NHS and other relevant organisations.

While the deliverables of patient involvement were in question, the desire to involve patients and hear their voice was viewed as genuine.

Such awareness is crucial to the meaningful involvement of patients, demonstrating that if the feedback provided in this consultation is taken on board, the NHS and other relevant organisations will truly benefit from the value of the patient voice.

The importance of co-creation of policies and procedures was also highlighted, creating forums for better patient involvement alongside patients and patient groups. This co-creation can exist to understand the patient experience, or create circumstances to ensure this is more meaningful moving forwards, for example, creating pre-engagement working groups to understand the landscape ahead of policy-related engagement.

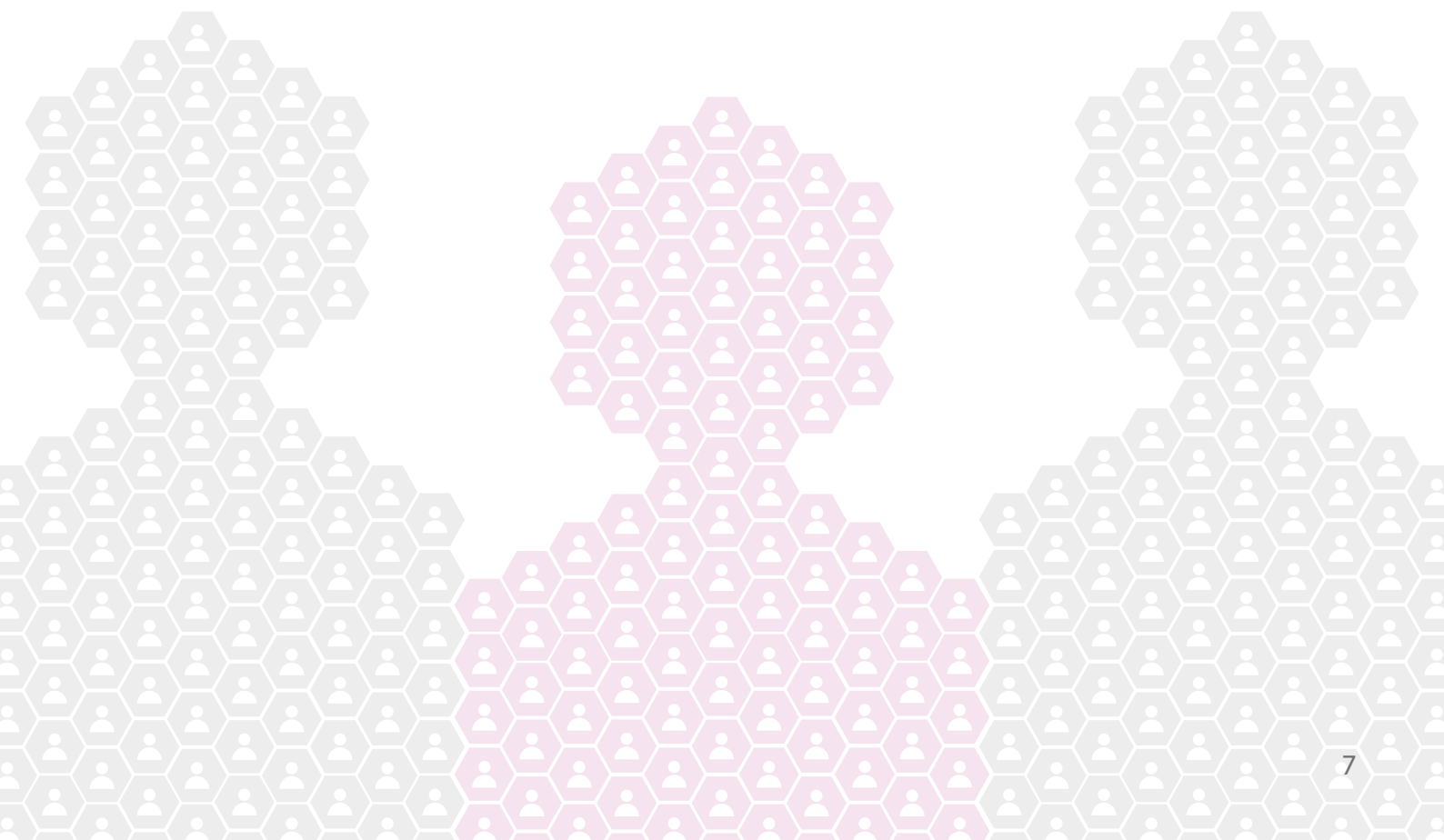
The MTG is proud to support and advocate for the improved involvement of patients across decision-making structures. Over the last 12 months, the MTG has supported the following organisations in their awareness and improvement of patient involvement, and looks forward to supporting others moving forward:

1. *National Institute of Health and Care Excellence (NICE)*
2. *Department of Health and Social Care's Medical Technologies Directorate*
3. *NHS Supply Chain*
4. *HealthWatch*
5. *Medicines and Healthcare Regulations Authority (MHRA)*

Appendix

This information was gathered through a consultation and interviews with patient group members of the Medical Technology Group, these include:

- **Arrythmia Alliance**
- **Prostate Cancer UK**
- **FEmISA**
- **Leg Club**
- **Different Strokes**
- **Parkinson's UK**
- **Heart Research UK**
- **The Patients Association**
- **Heart Valve Voice**



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