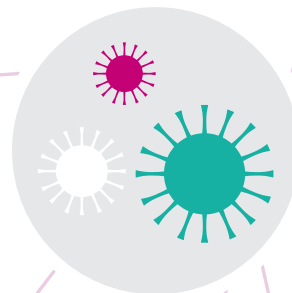


# Delivering Meaningful Patient Involvement:

## The MTG's Guide for Integrated Care Systems



## **Executive Summary**

There is widespread variation in the instance and quality of meaningful patient involvement across the 42 Integrated Care Systems (ICSs) of NHS England.

This variation is seen throughout the structures, policies, and processes of the ICSs, from the omission of patient representatives on decision-making bodies - such as the Integrated Care Boards (ICBs) - to the neglect of clear consultation when decisions are made concerning a patient's care.

From the research and analysis conducted by the MTG during the creation of this report, it is apparent that currently it is where a patient lives that is the biggest determinant to whether they are involved in their care meaningfully, or at all.

## **25 of NHS England's Integrated Care Systems involve a formal patient representative at Board meetings or on sub-committees.<sup>1</sup>**

However, amidst this inconsistency, there are promising instances of best practices scattered throughout the ICSs. These positive examples deserve recognition and dissemination at a national level, offering potential guidelines for others to follow.

The variation between best and worst practice is demonstrated most acutely in the case studies in this report, which highlight how patient involvement should and could be carried out, in comparison with what happens in practice across NHS England's ICSs.

The primary objective of this report is to spotlight these examples of best practice while providing concrete policy recommendations to ICSs, NHS England, and the Department of Health and Social Care, as the bodies centrally responsible for their performance.

The MTG stands firmly behind the conviction that those who receive care and interact with the NHS hold invaluable insights into the delivery of healthcare and how this could be improved. As ICSs continue to materialise and develop, the NHS has the opportunity to ingrain meaningful patient involvement in the structures of local decision making, which has the potential to:

- 1. Improve patient outcomes.**
- 2. Ensure personalised care is prioritised in the establishment of ICSs.**
- 3. Optimise NHS efficiencies.**

## **Recommendations**

### **For Government:**

- The Department of Health and Social Care should publish guidance that requires patient representation on ICBs and the annual reporting of patient involvement and representation in ICB activity.
- The Care Quality Commission should be given more freedom to scrutinise the level of patient involvement being carried out by ICSs and ICBs. This should also take into consideration the structures for accountability and reporting on how patient feedback is considered.

### **For NHS England:**

- NHS England should better incentivise ICBs to involve patients within decision-making structures.
- NHS England should encourage ICS leaders to come together to discuss best practice for patient involvement.
- NHS England should support ICBs to implement their 'Working with People and Communities Strategy' and promote the sharing of best practice nationally.

### **For Integrated Care Systems:**

- ICBs should involve patient representatives on boards and on committees.
- ICBs should ensure that patient feedback loops are properly established and practiced allowing for patient input to formally contribute to the development of policy. Patient feedback should be anonymous and cover all forms of care.
- ICBs should ensure that there is a rolling patient satisfaction survey for patient treatments. These should be used as a management tool to improve services.
- ICBs should include a standing item on their Board meetings to review how effectively they consider the patient voice when making decisions regarding the delivery of care in their local area.
- ICSs and ICBs should first identify Voluntary, Community and Social Enterprises (VCSEs), review how they involve VCSEs, and emphasis should be placed on working collaboratively with community bodies.

## Introduction

The Medical Technology Group (MTG) champions the meaningful involvement of patients within the decision-making structures that impact the delivery of their care across NHS England, its commissioners, providers, and Arms-Length bodies (ALBs).

In 2022, the MTG launched its *Guide to Meaningful Patient Involvement*, which provides an insight into how organisations should involve patients, which organisations do this, and where there is room for improvement.

While integration into decision-making is occurring, more effort is needed for widespread and impactful participation. Inclusive patient input is vital for community-centered NHS services however, the MTG's Guide reveals inconsistent and inadequate involvement, leaving patients feeling unheard or feeling like their consultation has been used as a tick box exercise.

ICSs became statutory bodies during the production of the MTG's *Guide to Meaningful Patient Involvement*, and as such, the MTG was unable to review and recommend meaningful involvement within their decision-making structures. This created an opportunity to develop a greater understanding of how ICSs- now 12 months into their development- involve patients within decision-making structures and how meaningfully this exercise is done.

ICSs were established as statutory bodies with a commitment to delivering integrated health and care services for the well-being of their communities.<sup>2</sup> To ensure success, meaningful patient consultation at all levels is critical, especially in gathering feedback and insights for enhancing service performance and improvement.

During the development of the report, the MTG collected data and evidence from ICSs via Freedom of Information Requests (FOIs) and interviews with ICB Patient and Public Involvement Leads.

From this evidence, the MTG can draw attention to the definitive variation in meaningful patient involvement across NHS England's commissioning bodies and can confidently recommend that more be done to involve patients in all aspects of decision making, from wider ICB decisions, to those concerning their own care.

The themes of this report highlight the aforementioned lack of consistency across ICSs and ICBs, building on the 2022 *Guide to Meaningful Patient Involvement*.

ICSs are an exciting opportunity in many ways. If done properly, the development of ICSs can ensure a framework of patient involvement that becomes standard practice in the long-term.

The MTG believes it is important patients are involved in the development of ICSs to:

**1.**

**Ensure services deliver for the needs of the local population they serve.**

**2.**

**Guarantee better outcomes for patients via personalised and tailored care.**

**3.**

**Protect the right of the patient to access the recommended and approved treatments anywhere across the NHS.**

## **Integrated Care Systems**

### **What is an Integrated Care System?**

Integrated Care Systems are partnerships of organisations that come together to plan and deliver joined up health and care services, to improve the lives of people who live and work in their area.<sup>3</sup> Following the passing of the Health and Care Act (2022) in July 2022, 42 ICSs were established across England.<sup>4</sup>

### **What is an Integrated Care Partnership?**

An Integrated Care Partnership (ICP) is a statutory committee sitting within an ICS that brings together a broad range of system partners, including Local Government and Authorities, NHS providers and commissioners, and the Voluntary, Community and Social Enterprise sector (VCSE).

An ICP is responsible for developing a health and care strategy for the local area, outlining how services will be delivered to meet the needs of the population.<sup>5</sup> Local authorities and place-based partnerships also support in the delivery of care providing essential services for local populations and offering support to local care partners.<sup>6</sup>

### **What are Integrated Care Boards?**

Integrated Care Boards (ICBs) are the statutory body responsible for developing the plan in which the ICSs will meet the health needs of their local population. ICBs are also responsible for setting the budget and provisions of health services in the ICS area.<sup>7</sup>

It is clear that some ICSs are more developed in the ways in which they involve patients in their organisational structure, taking a leading role in the meaningful involvement of patients.

This best practice is varied, with some ICSs opting for dedicated committees and working groups that consult the ICB, and others utilising specialist focus group engagement or the use of Citizen's Panels in decision making. The most advanced ICSs are in the process of implementing distinct patient strategies that categorise how and why patients are involved within the structures of the system.

These methods all have their strengths; however, the central concern remains the ICSs that have no plans or practice to involve patients.



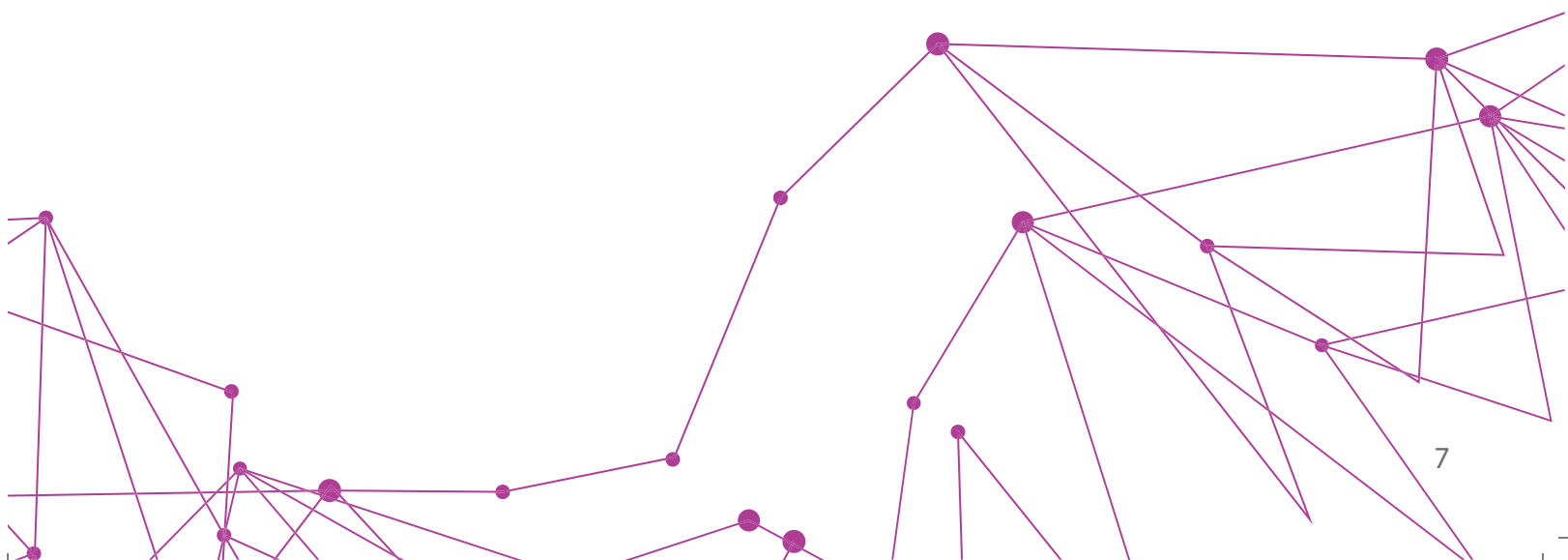
## Areas for Focus

It is clear from the research conducted throughout this report that the structure of each ICB has been developed and constructed differently, subsequently impacting the level and extent of patient involvement on each individual Board. There is no statutory requirement for an ICB to have any patients on their board.

The FOIs submitted to each ICS reveal vast variation across the country, with each ICB taking a different approach to involving patients and local communities in their decision-making structures. Maturity has also had an impact on the level of patient involvement seen in decision-making structures, with variation often stemming from the stage of an ICBs development.

Upon review, five clear areas for future focus are apparent across the patient involvement strategies of the 42 ICSs:

- 1 Regional variation in patient involvement.**
- 2 The development of an ICSs *'Working with People and Communities'* strategy.**
- 3 The meaningful involvement of patients at ICB meetings.**
- 4 The inclusion of voluntary, community and social enterprises.**
- 5 The effective utilisation of Citizen Panels and patient surveys.**



## 1. Regional variation in patient involvement

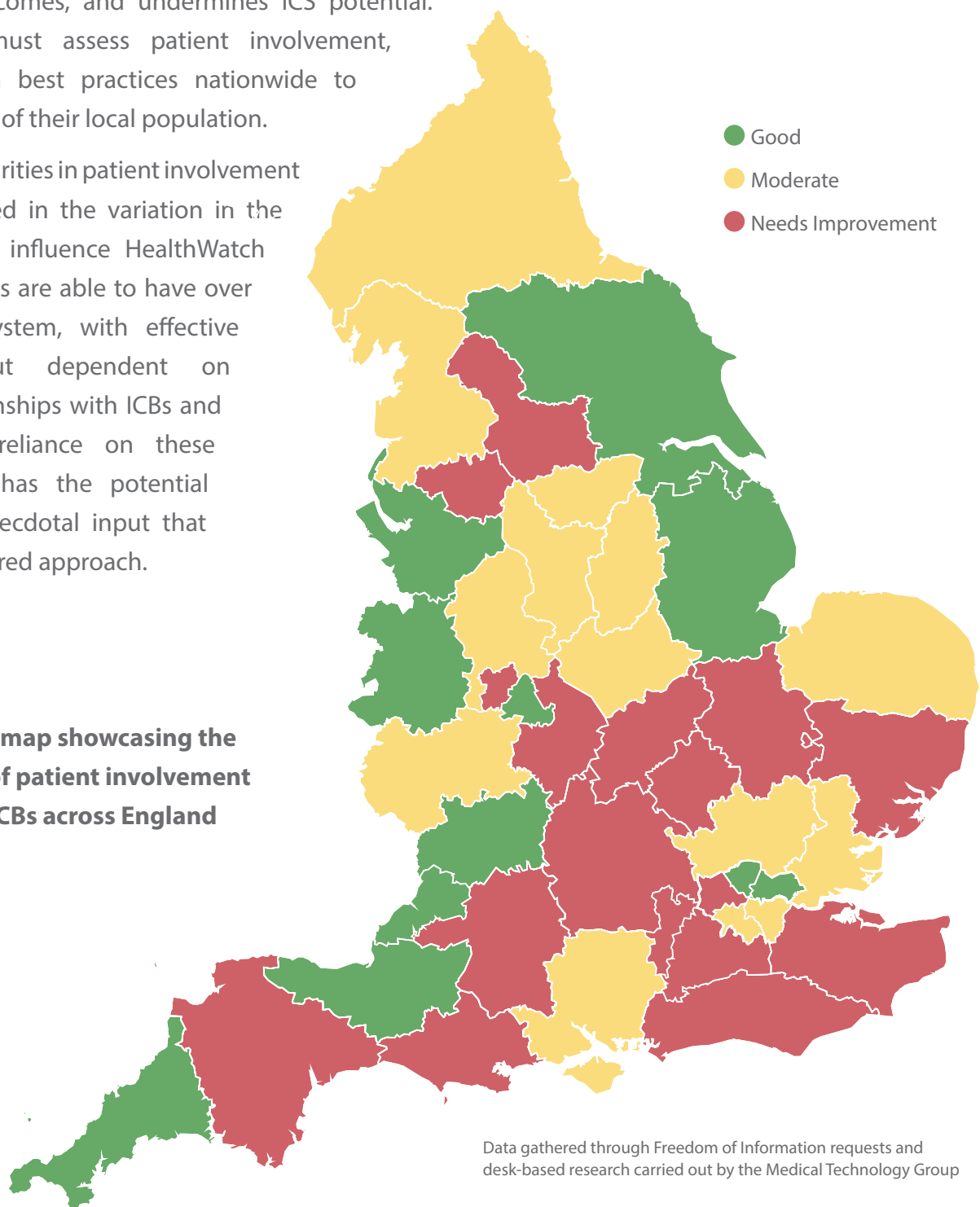
Through FOIs, the MTG has found that while some ICSs have looked to involve patients through representatives from HealthWatch, or Voluntary, Community and Social Enterprise Groups (VCSE), many have no formal representative at all.

Patient involvement in an ICB may not be obligatory, but the MTG deems it crucial for decision-making. Neglecting patient input risks missed opportunities for personalised care, improved care and outcomes, and undermines ICS potential.

Thus, ICSs must assess patient involvement, learning from best practices nationwide to suit the needs of their local population.

Regional disparities in patient involvement can be realised in the variation in the level of local influence HealthWatch representatives are able to have over their local system, with effective patient input dependent on strong relationships with ICBs and Chairs. Over-reliance on these relationships has the potential to lead to anecdotal input that lacks a structured approach.

**Heat map showcasing the level of patient involvement in ICBs across England**



Data gathered through Freedom of Information requests and desk-based research carried out by the Medical Technology Group





## 2. The development of an ICSs 'Working with People and Communities' strategy

When ICBs became statutory bodies, they were expected to develop a system-wide strategy for engaging with people and communities.<sup>8</sup> This strategy was intended to ensure ICBs have plans in place to gather information about the experience and aspirations of people who use care and support and its approach to using these insights to inform decision-making and quality governance.<sup>9</sup>

## Five ICBs are yet to publish 'Working with People and Communities' strategies.<sup>10</sup>

Alongside the number of ICBs that are yet to publish their 'Working with People and Communities' strategies, MTG research has also revealed that, of the ICBs that do have strategies in place, many still lack clear examples of patient representation on their Boards. During interviews, ICBs have said this is due to the fact that NHS guidance does not require this level of representation.

The MTG would like to see all 42 ICBs publish their 'Working with People and Communities' strategies by March 2024. These strategies should include clear steps on how patients can be involved in local decision-making structures and must be supported by an implementation plan that can hold ICBs accountable to commitments made.

As the lack of patient representation comes following a lack of NHS guidance, the MTG would also recommend that the publication of NHS England guidance requires patient representation on Integrated Care Boards, both supporting and enforcing commitments to meaningfully involving patients.

### Case Study: Kent and Medway Integrated Care Board

Kent and Medway ICB have created an Involving People and Communities Advisory Group, made up of subject matter experts, who discuss matters relating to the voices of people and communities.

The People and Communities Advisory Group will be able to review, scrutinise (excluding activities reserved to council scrutiny committees), and refer matters to decision-making groups within the ICBs governance structures.

The group oversees the delivery of the ICB's 'People and Communities Strategy' to ensure the voice of patients and communities is heard across the system. The ICB's four health and care partnerships are encouraged to have similar governance arrangements, all of which will report to the Group on a quarterly basis.

Kent and Medway's Advisory Group have only met once, but plan to hold regular meetings throughout 2023 and 2024.

The creation of the Advisory Group showcases Kent and Medway's promise to deliver on the commitments outlined in their 'People and Communities Strategy'. The Group will play a key role in the success of the Strategy and hold the ICB to account on its delivery. The MTG would like to see all ICBs set up Advisory Groups to create clear lines of accountability for the implementation of People and Community Strategies.

\*Case study gathered via FOI response

### 3. The meaningful involvement of patients at ICB meetings

In the absence of having formal involvement in board meetings, many ICBs involve patients by taking questions ahead of meetings and answering these as part of the running agenda. These questions are submitted by patients through the ICBs website.

However, whilst it is clear that ICBs are working to better understand the patient experience, there is concern surrounding the lack of clarity on how many questions are answered in each meeting and how next steps are communicated to patients once they have been answered. There is also a lack of clarity on whether changes and improvements are made as a result.

Moving forwards, the MTG would like ICBs to ensure that feedback loops are properly established and practiced so patient input formally contributes to the development of policy and is not used as a tick-box exercise for ICB reporting. It would also be encouraging for ICBs to clarify how they advertise the opportunity of submitting questions to patients using their services.

In the long term, the MTG believes that consulting patients on the delivery of their care will ensure services are set up in a way which meets the needs of those who use it. The system therefore benefits with the potential of reduced hospital readmissions, or unplanned admissions, as services and treatments are better aligned and prioritised.

#### Case Study: Cornwall and Isles of Scilly

Cornwall and the Isle of Scilly ICB respond to patient and staff stories during Board meetings. The ICB's 'Health and care vignettes' are a standing item on the agenda as part of the ICBs 'your story, shapes our future' programme which sees the ICB share stories of local people and staff to showcase the 'lived experiences' of the health and care system.<sup>11</sup>

In April 2023, the 'Health and care vignettes' included a patient story on a patient who faced access and communication challenges due to hearing loss. Each story presented to the Board is accompanied by a film clip providing a first-hand account of the patient or staff members experience.

Following the presentation provided by a local HealthWatch representative, the Board heard the immediate next steps which had been taken.

Cornwall and Isle of Scilly ICB had shared the story with the relevant hospital trust and Cornwall Council. The Royal Cornwall Hospital Trust confirmed that improving access and communications for patients, particularly those who are hearing impaired, is one of their priorities and that the film would be used as part of their disability awareness training.

Cornwall and Isle of Scilly ICB also reflect on the ways in which the ICS can improve accessibility standards across the system. The ICB shared ideas which can be implemented moving forward to improve outcomes for patients, this includes working with Hearing Loss Cornwall, a charity specialising in supporting people with hearing loss, to feedback practical ways the ICS could improve accessibility. Following these suggestions, Board members were asked to provide feedback on the next steps.

The MTG believes that all ICBs should include patient stories at the start of Board meetings, with clarity on how the process behind this is organised. Learnings can be taken from the work of Cornwall and Isle of Scilly ICB to outline clear next steps to continue driving forward improvements in the system and improve the patient experience.



#### 4. The inclusion of Voluntary, Community and Social Enterprises

Voluntary, Community and Social Enterprises (VCSE) are organisations ranging from large social enterprises to more informal grassroots organisations.

VCSEs hold expertise in areas across the health and social care sector, and are used across ICSs and ICBs, sitting as voting and non-voting participants on committees and decision-making bodies. They offer the unique opportunity to ensure community voices are heard. As attendees at ICB meetings the VCSE representative, while often sitting as a non-voting participant, can center discussions around the community. Following a review of ICB meeting minutes, the MTG found that the VCSE representative would regularly highlight the importance of shaping delivery around the VCSE sector and community approaches to care delivery.

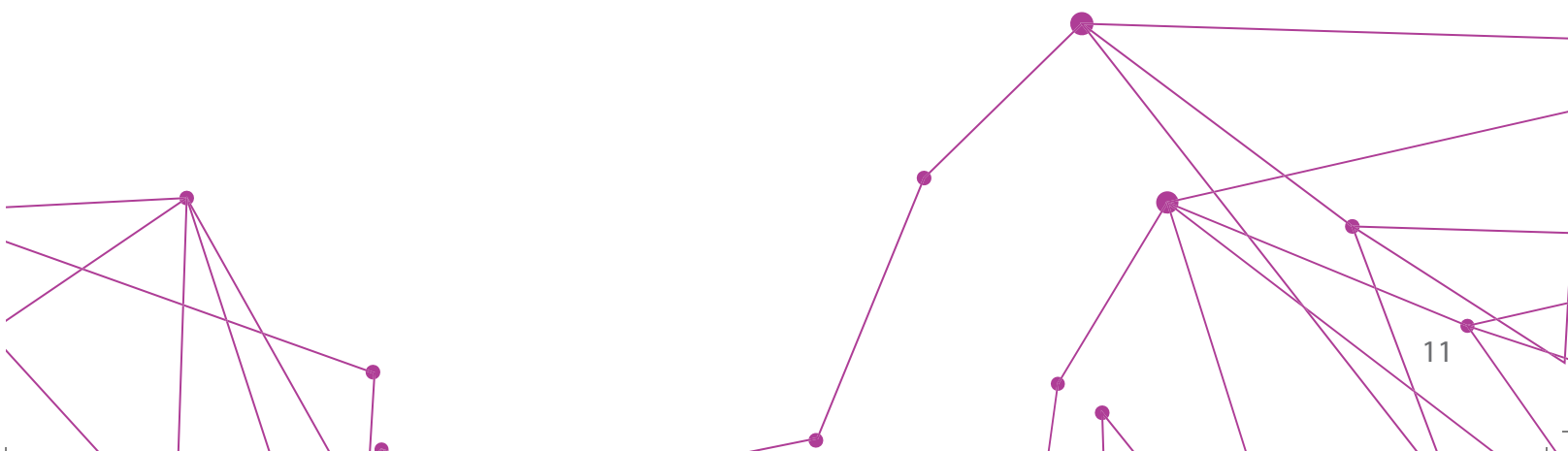
However, whilst the inclusion of VCSEs in decision-making structures is positive, through FOI analysis, it is clear that they are used at the discretion of an ICB, to varying levels nationally. An example of this is the contrast between the Humber and North Yorkshire ICB, which uses VCSEs as patient representation during Board meetings, and Cheshire and Merseyside ICB, which includes a VCSE representative on every Board sub-committee.

The variation in the use of VCSE's is a known issue, with NHS England publishing guidance to address the practical barriers to their integration in ICS operations in May 2023.

This guidance offers support to ICS leaders, NHS providers, local authorities, and VCSE organisations on how to address and overcome the barriers to VCSE integration. NHS England found that the barriers and challenges can be broken down into three areas:

- Commissioning and strategic planning, including the role of the VCSE sector in service design and delivery.
- Sharing data, intelligence, and insight, including using VCSE data to inform population health management and social prescribing.
- Funding, sustainability, and investment in the VCSE sector.

To overcome these barriers, NHS England has produced a series of solutions which can be brought forward to improve integration and ensure VCSE's are involved across the health and care service. These solutions are also supported using case study examples of best practice found in ICSs and Health and Care Partnerships across the country.



The MTG believes a number of these solutions should be introduced as a matter of priority. This includes:

- Giving VCSE organisations advance notice/opportunity for involvement in planning service design and delivery to ensure systems are created to meet the needs of the communities they serve.
- The creation of a commissioning framework to outline expectations and recommendations for working with the VCSE, including an understanding of the needs of VCSE organisations, their value within the system, how they can be supported, and approaches to investment. As outlined by NHS England, the MTG believes the framework should be developed in collaboration with VCSE organisations and agreed and signed up to by VCSE and system leaders.
- ICSs should work in partnership with VCSE's to design a pathway to meet the needs of patients, including mechanisms and responsibilities for delivery and funding.
- The MTG believes all ICSs and ICBs should have a system in place to clearly feedback on the information and recommendations given by the VCSE.

### **Case Study: Devon ICS**

In September 2020, NHS England issued the Community Mental Health Framework and invited submission of plans to secure funding at a local level to support implementation. Core to the framework was that the transformation should be a system response, with an expectation that NHS providers would work collectively with VCSE organisations.

When Devon ICS submitted their proposal to NHS England, they stated in the document (approved by Devon CCG) that they would work with the VCSE sector as an equal partner. In the plan they outlined that a fair proportion of the funding would be invested in the VCSE sector.

The CCG initiated discussions by keeping key VCSE organisations informed of developments at an early stage, cultivating alignment and an open dialogue. Collaboration took center stage, with the CCG and VCSE groups jointly designing service delivery alongside mental health providers, service users, and carers. This led to the establishment of the Devon Mental Health Alliance, uniting national and local organisations to enhance community mental health services. The CCG approach balanced ambitious goals with flexibility, adapting procurement processes to bolster equal partnerships, with VCSE organisations while adhering to regulations.

The initiative also prioritised building enduring relationships, allocating a substantial portion of transformation funding to VCSE organisations over three years. Looking ahead, the CCG envisaged expanding their collaborative model to other regions, advocating integrated care partnerships and a broader system response for mental health. Throughout, the CCG highlighted an evolving mindset, learning from comparable initiatives and adapting conventional procedures to foster meaningful and cooperative partnerships with VCSE organisations.

The above case study was drawn out by The King's Fund and presented in NHS England's framework for addressing practical barriers to integration of VCSE organisations in integrated care systems.

\*Case study gathered via FOI response



## 5. The effective utilisation of Citizen Panels and Patient Surveys

ICBs also use Citizen Panels (CPs) to assess public preferences and opinions. Across the country, these panels are in the early stages of development. A CP is made up of citizens, patients and carers who act as the voice of the local population, and engage with the work of the ICS to suggest meaningful changes to the delivery of care.

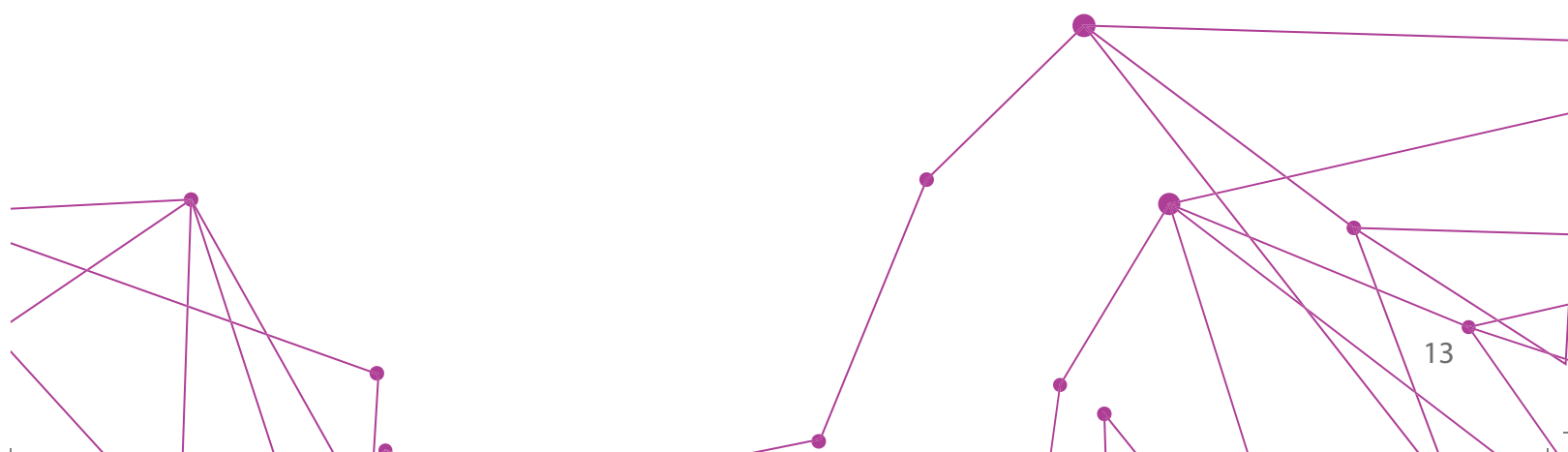
In guidance published by NHS England in 2021, they proposed that system leaders should consider a system wide approach to engagement through shared methods and principles. This is seen in the use of CPs, local health champions, and working with people with lived experience.<sup>13</sup> CPs provide an excellent opportunity for ICSs to develop a greater understanding of the experiences of local communities and importantly those from underserved communities.

However, through FOIs, the MTG found that the effectiveness of CPs often depends on the level of engagement and buy in from senior leaders in ICBs, most notably the Chairs.

The MTG believes it is important that all ICBs use CPs to gather feedback from local communities on a range of topics. These activities help to improve efficiencies in the NHS and ensure that services are designed to deliver care which meets the needs of patients. The MTG believes it is important that ICBs provide feedback to panelists to display how learnings from this activity have been taken forward, with clear lines of accountability to outline how the ICB will do this.

Much like CPs, patient surveys are used across ICBs to varying degrees. These surveys are used to gather feedback from the public on a range of topics, including confidence and trust in healthcare professionals, satisfaction with care delivery, and suitability of appointment times. In NHS England's 'Working in partnership with people and communities' guidance, they encourage ICBs to ask for individuals opinions on ideas or options to gather views and ensure they are considered appropriately.<sup>14</sup>

Surveys are a valuable tool to allow ICBs to understand the patient experience. The MTG believes they can be better utilised by ICBs to support the development of new ways of working. It is important that surveys are not used as a tick box exercise by ICBs, instead dedicated time should be set aside to deliver feedback to patients on the ways in which their concerns or recommendations have been taken forward, and how changes have been made to services. ICBs should outline clear methodologies for the way they will gather information from patients and deliver changes based on the feedback they receive. For this reason, surveys should be anonymous to allow patients to feel comfortable to give an honest review of their experiences.



## Case Study: Cheshire and Merseyside ICS

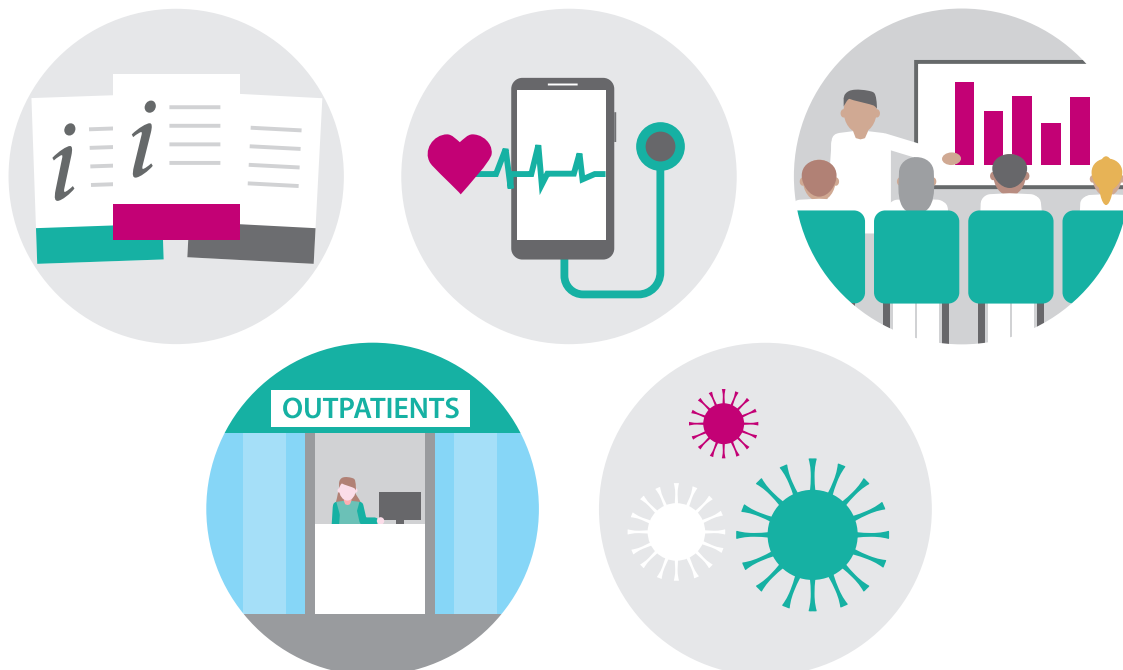
Cheshire and Merseyside ICB is currently in the process of 'testing' various approaches to its CP, aiming to ensure patients are involved properly within decision-making.

Their Cheshire and Merseyside CP is focused on reducing health inequalities in the region, and will include a diverse range of participants from the local area, with the ICB aiming to recruit up to 1,000 people living and working in the region.

CP Members will participate in four surveys annually, focused on issues such as GP services and hospitals, and will have access to the NHS Peer Leadership Development Programme (NPLDP). The NPLDP looks to provide people with lived experience the opportunity to learn more about the benefits of personalised care, how to develop peer support, and how the 'voice' of people with lived experience can shape and influence how health and care services are developed and delivered.<sup>15</sup>

Members of the Cheshire and Merseyside CP who partake in the NPLDP will also be invited to be members of a Lived Experience Network with opportunities to participate in formal roles at Integrated Care Board level and input into decision-making structures.

Cheshire and Merseyside ICB's Citizen's Panel allows the ICB to gather data on the patient experience on a large scale, supporting patients to use their 'voice' to share their opinion on issues. The Panel can support the ICB to deliver tailored care to communities within the ICSs.





## Examples of Best Practice

### **Derby and Derbyshire Integrated Care System**

Joined Up Care Derbyshire (JUCD) introduced a new initiative called the Patient and Public Partner (PPP) role.

PPP are lay members who want to be involved in improving health and care services who have extensive experience across the health and social care landscape. They can provide feedback and insight into existing services and contribute to quality improvement efforts, improve communication between patients and healthcare providers, help health care providers embrace potential changes with a view on the patients perspective, and ensure patients are full participants in decisions that affect them.

In Derbyshire there are 37 active PPPs across various Boards, Committees and workstreams covering condition areas and commissioning.

In 2022, there were 13 PPPs we wanted to gather feedback from the to understand what their experience had been like from recruitment to present day and look at what worked well and what could be improved. Although experiences were very positive, it was clear that there was room for improvement, particularly around standardising the process, and ensuring people have the same level of support regardless of the workstream they are involved in.

In response, we developed a guide to patient and public partners to help promote the role and provide a detailed explanation of the role, the recruitment process, expectations, and a role description template. We shared this with the current PPPs as a draft to ensure it actively reflected their thoughts.

We also identified from the initial feedback that PPPs had very different experiences of their induction process and ongoing support. An 'induction plan and checklist' was developed and provided to all workstream leads during the recruitment process to help standardise the process. A draft version is being trialled with workstream areas and before this is finalised, feedback will be gathered from the leads and PPPs to see if any further amendments are required.

JUCD is also looking to create a Peer Support Network to provide the opportunity for PPPs across the system to come together and meet one another, the first meeting was held in January 2023.

This exercise has allowed Derby and Derbyshire ICB to gather feedback from lay members of the public on specific areas and gather patient feedback to create services which meet the needs of patients.

### Nottingham and Nottinghamshire Integrated Care Board

The Nottingham and Nottinghamshire Integrated Care Board (ICB) Engagement Team supported the successful funding application by the community group Empowerment for Heya, for the 2022 East Midlands Academic Health Science Network Public Involvement Fund. Heya is a group for all Arab Women in Nottingham and Nottinghamshire who have recently moved to the UK and lack personal and social networks, resulting in social isolation.

The group was successfully awarded funding to host and provide workshops for their community group in four key areas; registering with a GP/GP access, accessing healthcare services in the UK, maternity and breastfeeding/chestfeeding and first aid.

It was noted that additional sessions would also be beneficial for the group, including healthy lifestyles, mental health, menopause, children's vaccinations, and CPR training.

To date the engagement team have coordinated and attended three workshop sessions for Heya.

These sessions focussed on healthy lifestyles, pregnancy, breastfeeding/chestfeeding, and mental health. Further sessions are being coordinated for Heya and are planned to take place.

This exercise allowed Nottingham's ICB engagement team to hear feedback activity from women who may not have known how to provide feedback otherwise. The workshops also allowed the team to understand other condition areas impacting the women, and the team were able to adapt their work to meet the needs of the patients. This has allowed Nottingham and Nottinghamshire ICB to adapt services to ensure they are more suited to meet the needs of patients.





## **Recommendations**

### **For Government:**

- The Department of Health and Social Care should publish guidance that requires patient representation on ICBs and the annual reporting of patient involvement and representation in ICB activity.
- The Care Quality Commission should be given more freedom to scrutinise the level of patient involvement being carried out by ICSs and ICBs. This should also take into consideration the structures for accountability and reporting on how patient feedback is considered.

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