The King's Fund>
Ideas that change health and care

Picker

Understanding integration

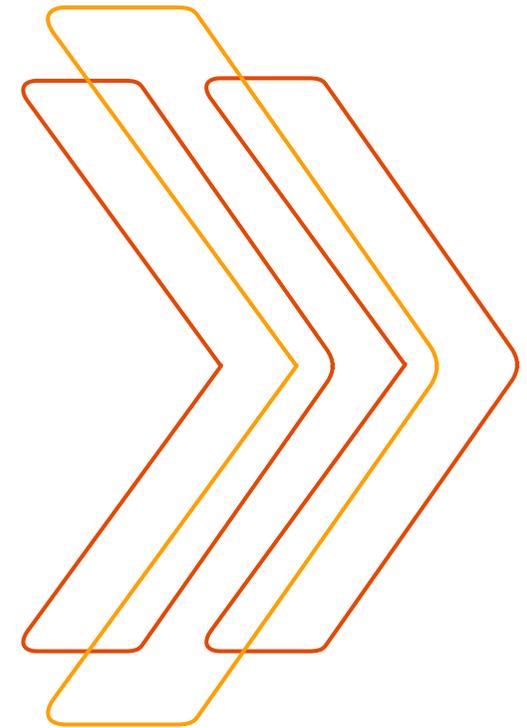## How to listen to and learn from people and communities

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Contents

1 The case for change: bringing services together around people and communities

Integrated care aims to improve people's outcomes and experiences of care by bringing services together around people and communities. This means addressing the fragmentation of services and lack of co-ordination people often experience by providing person-centred, joined-up care.

Those best-placed to understand what they need, what is working and what could be improved are the people using the services. Their lived experience is a powerful tool to improve existing services and identify new and better ways to meet people's needs.

Currently, people's experiences of health and care services are usually collected and understood at the level of individual providers (**Wellings 2019**). This means we know about people's experiences of individual services such as general practice, hospitals or social care, but not about whether these services are working well together to meet people's needs.

As integrated care systems (ICSs) and place-based partnerships develop it will be essential for all local partners, including ICS staff, NHS provider organisations, local authorities and the voluntary, community and social enterprise (VCSE) sector, to come together to develop a better understanding of how patients and users experience integrated care. This is key to improving population

health and developing services that meet the needs of the people and communities they serve. This guide provides practical steps to help embed this way of working into your system.

> *Integration is about everyone – including patients, carers and communities – bringing their experience, skills, and assets to collectively deliver health outcomes that are based on what matters most. It requires collaboration and co-ordination but most of all it requires respect.*
> **Fiona McKenzie**, patient leader

> *Crucial to success will be to listen to patients' experience, tap into community memory and assure that representative patient voice is fully engaged and supported in service commissioning and development.*
> **David Winskill**, patient voice representative

> *Integrated care is an ideal opportunity for us all to get involved and to have a say in our health services. By integrating services across communities we will, hopefully, get rid of the delays and gaps in care.*
> **Carol Munt**, patient partner and advocate

2 Listening and learning together

- All partners in a system should move from only understanding how people experience the care and support they provide to partners listening together to learn how they can provide better joined-up care.

- Multiple public services have a role in delivering better health and wellbeing for their population.

- People do not live their lives in silos; they experience care and support across many different services. We know that for many people, the issues they face are about the lack of co-ordination of services around their needs (**National Voices 2013**). Moreover, gaps in care co-ordination disproportionately affect those with the greatest needs and the poorest outcomes (**Williams *et al* 2020**).

- There is an opportunity now to explore how effectively health and care services are integrated, not only with each other, but also with services such as housing and education to address the wider determinants of health.

Education   Public health

Housing

Transport

Adult social care

Welfare

Local authority

People and communities

Voluntary, community and social enterprise sector

NHS

Primary care

Emergency care

Secondary care

Urgent care

Community services   Mental health

3 What is this guide for?

This guide will support systems to listen to and learn from people and communities about their experiences of integrated care. It offers a practical, evidence-based approach (*see* Appendix) to help partners come together to work with communities to identify what people need, what is working and what could be improved to provide joined-up care.

This guide will support you with

- **Navigating the range of approaches to understanding integrated care**

  There is no perfect way of measuring or understanding people's experience of integrated care. This guide introduces a range of methods, both qualitative and quantitative, that can be adopted depending on what you want to find out and what will work best for different user groups.

- **Promoting a culture of listening and learning together**

  The results of any work in this area will only be as good as the people listening to it. Perhaps more important than the methods adopted is how systems should prioritise this area of work. Too often listening to the voices of people using services is seen as a 'nice to have' rather than a 'must have' (**Wellings 2019**). The guide aims to support local partners in learning together to put the voice and lived experience of people and communities at the heart of what they do.

  The right culture has to be in place to listen and learn from people's feedback (**Wellings 2018**). Our 10 principles will help systems ensure that people's voices are central to how integrated care works and develops.

4 Who is this guide for?

This guide can be used by anyone working within a local health and care system who wants to understand people's experiences of integrated care. It is principally intended for the NHS, local authorities and other local partners to encourage them to work, listen and learn together.

People at different starting points

Too often, work to understand how patients and users experience services is seen as the preserve of patient and public engagement or experience teams, Healthwatch and VCSE organisations. This needs to change so that it becomes everyone's business and is embedded in core activities.

This does not mean that everyone has to be an expert in community engagement and involvement, but it does mean that everyone needs to support this way of working.

The guide recognises that people will be at different starting points with this work, with some already working closely with people and communities, while others will be just starting out.

There is a real opportunity for partners across local authorities, the NHS and the VCSE sector to work together on shared projects, bringing together their shared knowledge and expertise in conducting this type of work, listening and learning together and acting on the results.

The role of leadership in ensuring impact

Drawing on evidence and examples of good practice (*see* Appendix), it is clear that strong leadership is crucial. Leaders create the culture that places people's voices at the heart of systems.

Leaders of systems should lead by example, through prioritising hearing from and working with people and communities.

Existing resources must be used more effectively, and leaders should be driving the work forward, linking it to population health management activity at the system level and to quality improvement activity. There is a real opportunity to bring together the expertise that local authorities, VCSE organisations and the NHS already have in engaging and working with their local populations. Leaders can empower teams to innovate and act on what they learn from people.

In the next section of the guide, we set out 10 principles that can be used to shape the delivery of this work.

5 Ten principles for partners and leaders to work to

Following these 10 guiding principles will help ensure that people and communities are at the heart of how integrated care works and develops.

1 Build a shared purpose for this work across systems	**2** Place this at the heart of your organisations	**3** Set the right culture	**4** Place the work on an equal footing with other data and information	**5** Be clear that this work is everyone's business
6 Build on the resource that exists locally	**7** Ensure you have the right skills, capacity and resource in place	**8** Ask the right questions	**9** Who you hear from matters	**10** Turn understanding into action

5

1 **Build a shared purpose for this work across systems**

There has to be a clear and shared understanding among local partners about what this work is for. Integrated care aims to improve people's outcomes and experiences of care by bringing services together around people and communities. Those best placed to judge whether this is working are people themselves, so they need to be heard.

2 **Place this work at the heart of your organisations**

Too often patient and public engagement or user experience can feel like an add-on rather than being at the heart of health and care organisations. Placing the voice and experience of people and communities at the heart of their work will help partners to understand what people need, what is working, what can be improved and how they can work *together* to deliver what matters to the people they serve.

3 **Set the right culture**

Leaders can set the example in the priority they give to this work, helping to create a culture in which listening to people and communities is valued. They can use this work in their day-to-day meetings and communications with wider staff across their organisations, and beyond, to demonstrate its importance and value. Leaders can also create cultures in which teams are empowered to innovate and act on what they learn from this work.

4 **Place this work on an equal footing with other data and information gathered at a system level**

Too often data drawn from patient and user experience is not given as much importance as other operational data such as admissions to A&E or waiting times. Placing people's voices on an equal footing with other key operational data demonstrates both its importance and how it can add understanding and meaning to other data and information collected rather than being treated separately.

5 **Be clear that this work is everyone's business**

This work cannot be seen as the preserve of patient experience and public engagement teams alone. It should be seen as fundamental to all areas of work across integrated care systems (ICSs), place-based partnerships and the organisations within them. Experts in this area can provide guidance on how best to carry out the work but it will require leaders, programme teams and wider stakeholders to listen to and act on what is learned.

6 **Build on the resource that exists locally**

Local Healthwatch teams, user-experience teams, patient- and public-engagement teams, VCSE sector organisations, patient-participation groups and patient leaders are already engaging with people and communities over a wide range of issues. These are valuable existing resources on which to build work to understand people's experiences of integrated care.

5

7 **Ensure you have the right skills, capacity and resource in place**

This area of work requires expertise in methodologies to engage people and communities, analytical capacity to draw relevant meaning from the work, communication skills to disseminate the work in impactful and actionable ways, and capacity to turn the insight and intelligence gathered into meaningful action. Many of these skills will already exist across systems but will need to be brought together, and added to where necessary, which will require dedicated resourcing and budgets.

8 **Ask the right questions**

Rather than asking questions about people's experiences of individual services, ask questions focused on partnership working, the co-ordination of services and people's experience of this. How do services work together around people's needs in a way that makes sense to them? What matters to people and what will make a difference to their lives?

9 **Who you hear from matters**

There is real potential to address health inequalities by ensuring that those who have poorer health outcomes are engaged with and listened to. We know that gaps in care co-ordination disproportionately affect those with the greatest needs and poorest outcomes (**Williams** *et al* **2020**). Take into account diversity and inclusion, ensuring that voices are heard from all parts of the community – not just those who speak loudest or those the system has traditionally found easiest to engage with.

10 **Turn understanding into action**

Finally, and most importantly, this work will mean nothing if nothing is done as a result. There is no point carrying out any of this work if what is learnt is not acted on. This is a real opportunity for local partners to come together and work differently to develop co-ordinated services focused on the needs of their communities.

6 A roadmap to understanding people's experiences of integrated care

Joined-up listening – joined-up care

This guide will take you through the roadmap opposite, as a suggested order of steps to support teams through the process of understanding people's and communities' experiences of integrated care.

What is the aim of the project?

⌄

Who needs to be involved?

⌄

What do we want to find out?

⌄

What is already known?

⌄

Who do we need to hear from?

⌄

Which approaches are most appropriate?

⌄

How do we collect and interpret what we hear?

⌄

How do we turn data into action?

⌄

Where are we now?

6

What is the aim of the project?

When planning this work it can be helpful to think about which stage of the planning cycle the overarching question you are looking to answer relates to.

- **Where are we starting from?** Identifying what is working for people, what needs improving, what needs are not being met, and the gaps in provision.

- **Where do we want to be?** Working with people on changes that will make a difference to their lives.

- **How will we get there?** Co-designing new services, interventions or pathways with people who use services. Framing the work with the community is much more likely to result in effective and sustainable solutions.

- **How will we know we are there?** Measuring and understanding whether what you are doing is effective.

Where are we starting from?

Where do we want to be?

How will we get there?

How will we know we are there?

6 Who needs to be involved?

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⌄

Where are we now?

Start with people and communities and work backwards, ensuring their voice is central to developing and improving services. Efforts need to be made to bring the voices of all people and communities to the design of this work, not only those who the system has traditionally found easiest to engage with.

Which services are people coming into contact with? Ensure these services are engaged in the work from the start.

While the work itself may be carried out by user experience and engagement teams, different teams, services, organisations and sectors need to be involved from the start.

It is important to think about how to engage those who are involved in shaping, improving and delivering joined-up health and care services – those who will be acting on the findings of the work – at this early stage to ensure it is meaningful to them.

The evidence is clear that involving people from the start in the design of the work means they are far more likely to act on what comes back (**de Silva 2013**).

6

Groups to consider including in your work

- Voluntary, community and social enterprise organisations
- System leaders across local authorities and the NHS
- Community champions
- Service change
- Have you considered including representation from the following groups?
- People and communities
- Programme leads across NHS and local authorities
- Carers
- Pathway redesign
- Patient and user representatives
- Analysts
- Frontline staff
- Quality improvement

6

A key question early on is, 'what is the right level for this work?'

Think about the relationship between the system, place and provider footprints to determine where this work will:

- have the most impact

- engage people and communities meaningfully in a conversation about services and pathways

- make sense to frontline staff

- help staff from multiple services work together to decide on the actions and collectively.

ICS

Place

Providers and provider collaboratives

Primary care networks/ neighbourhoods

Deciding the level of this work in West Yorkshire and Harrogate ICS

Principles

West Yorkshire and Harrogate Health and Care Partnership has been exploring what engagement activities should take place at different levels.

The ICS covers six places, each with its own plans. System leaders here have considered where this work will have the most impact, and are applying the **principle of subsidiarity** to their work. The partnership will only work at ICS level where there are economies of scale and where it makes sense to do things once.

Principle of subsidiarity
Decisions should be made as close as possible to local communities, based on what makes sense to communities and staff, and activities should only be led at scale where there is good reason to do so.

6 What do we want to find out?

What is the aim of the project?

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⌄

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How do we turn data into action?

⌄

Where are we now?

With the overarching aims of the project in place, you can start to pin down more detailed objectives: do you want to **understand** user perspectives, opening up new issues and learning what matters to people in order to make improvements; to **monitor** progress, particularly when seeking to understand whether changes are resulting in improved care; or to **measure**, particularly when services are to be compared or evaluated?

Asking yourself some questions about what you know, and don't know, about the following can help shape the aims of the work.

- What are the priorities of people and communities?

- What can we learn from service and population health data?

- What are the system- and place-wide priorities?

- What are the internal stakeholder priorities?

6

What are the priorities for people and communities?

Start by identifying the issues and challenges that only people and communities can bring to light. Engaging with people and communities can ensure issues and concerns that systems, services, and programmes would not detect are not missed. This presents an opportunity to work with specific population groups and tackle inequalities: hearing what is meaningful and what matters, and shaping work around those insights.

Doing so relies on close working with VCSE organisations, patient leaders and user representatives to make sure that issues important to the communities served are being raised and fed into the system, with further work carried out where necessary.

To be effective, this should be about having conversations with people and communities that are open and start with what matters to people rather than what the system thinks is important. Equally important is to remain realistic and be honest about what will be done with the work.

CASE STUDY:
The Healthwatch network

The Healthwatch network carried out a nationwide conversation with communities, asking them how they wanted the NHS to improve (**Healthwatch 2019**). People told the team that convenient ways of getting to and from health and care services were important to them. Travel was identified as a key issue, above other priorities like choice over where to be treated. By listening to and learning from communities, a gap in care was identified and this allowed for more focus in local plans on improving the links between health and care services. The gap was identified because the conversation was kept open to ensure it started with what mattered to people and communities what the system thought was important.

6

What can we learn from service and population health data?

Exploring data at place, service and system level, as well as national data, can also inform what you need to find out, the questions you ask and which groups you should speak to. This can be effective where existing indicators and population health analytics point to a problem or poor outcome for a particular group. Ask yourself the following questions.

- What patterns do you observe as an output of population health analytics but need to understand in more detail to explain why they might be occurring? Working with people and communities will shed light on what you are seeing in the data.

- Where might talking to people provide insight into what you are seeing, especially around existing health inequalities?

- How might you involve people and carers in designing solutions for the issues identified?

Sources of this kind of information include service utilisation data, readmissions and delayed transfers of care, and outcome data.

This type of work should be seen as filling an intelligence gap. The data sources will only take you so far, and will only tell you that something is happening, not why it is happening. Speaking to people and communities will provide that insight and understanding. For example, if there is a group of people who are readmitting to A&E regularly then the logical next step is to go and find out why by asking them and their support networks what is happening.

What are the system and place-wide priorities?

User insight can help to inform, achieve and understand progress against system-wide priorities, including:

- ICS, integrated care provider (ICP) and place objectives, including those set out in systems' strategic plans

- creating a narrative about the needs, assets and health and wellbeing priorities of the local population

- setting out what integration should achieve

- asking people and communities whether these goals have been achieved.

This approach can explore what 'good' would look like for people, and can also provide information for systems on whether their existing improvement efforts are working, giving them real insight and understanding into how well, or otherwise, integrated care is being delivered.

As new programmes of work are set up across systems and partners, this is about ensuring work with people and communities is embedded from the outset.

6

What are the internal stakeholder priorities?

What do internal stakeholders think they need to understand? What are the intelligence gaps they have? Do they know how well services are working for people and communities?

Engaging with these stakeholders and enabling them to help shape which areas you explore will be crucial, both for securing support and buy-in and to ensure that the right questions are being asked from the outset.

Engaging with these groups can help you understand:

- the care pathway (How is it provided? Who is involved in providing it? How does it work? What issues have been raised previously?)

- the nature of the service-user group (demographic and socio-demographic characteristics, any challenges that would have a bearing on methods used – eg, dementia or other disability, whether carers would be involved in the research, etc)

- which methods are best suited to this group (derived from answers to the questions above alongside consideration of research aims).

6 What is already known?

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Where are we now?

Once you have decided what you want to find out, it is important to understand what is already known.

The work to inform this guide (*see* Appendix) demonstrated that there is already a huge amount of work being done with people and communities across both local authorities and NHS services, as well as in the VCSE sector. Before undertaking a new piece of work, it is important to ensure it builds on what is already known. What do you already know from the wide variety of work that is already carried out with people and communities across your system?

- **People's experiences in the area of interest** – by looking into existing insight data, you can avoid potential duplication of findings and identify gaps in understanding. There is a wealth of existing experience data. Looking at national and local findings is a good place to start.

- **How lived experience data is used and listened to in your organisation** – think about how work with people and communities is used to inform decisions and acted on for change. Are there any barriers to overcome? When have decisions been made based on what people and communities have told you? Why was this? Equally, when this did not happen, why not?

6

Where to look for existing insight:

- local authority citizen insight work

- work from national organisations on specific issues, ie, Healthwatch England, National Voices and research organisations

- the Friends and Family Test

- complaints

- national survey programme (**NHS England undated**)

- local patient participation groups (PPGs)

- VCSE organisations

- local Healthwatch

- Healthwatch health and care experience profiles

- joint strategic needs assessment (JSNA)

- previous local patient and public engagement.

CASE STUDY:
Using a balanced scorecard in Leeds

In Leeds, the Health and Care Partnership Executive Group has adopted a balanced scorecard approach to ensure everyone experiences high-quality, person-centred care when moving across the health and care system. Its work showcases the different sources of existing patient and user intel used to inform system improvement:

People's Voice	Multi-agency and multidisciplinary case file audit
Compliments and complaints analysis	**Metrics**

- following and hearing real-time stories from people's health care journeys, month-by-month, using written and video narratives

- multi-agency and multidisciplinary case file audit

- analysis of compliments and complaints through the Leeds city-wide complaints group

- use of metrics across partners to capture quantitative measures of people's experiences of integrated care (building on Friends and Family Test and the Adult Social Care Outcomes Framework).

CASE STUDY:
Insight network in Derbyshire

One way of understanding what is already known is by bringing together and working with those already engaging with people and communities across a system.

Joined Up Care Derbyshire has established an insight network to streamline how data is gathered and used across the health and care system. The system insight group brings together approximately 50 different system partners with the vision of developing a culture of being insight-led and linking different sources of insight together when making decisions.

Patient-experience team

Engagement team

Communication and engagement representatives

Clinical commissioning groups (CCGs)

Healthwatch

Voluntary, community and social enterprise sector

Local authority

Insight network

Strategy leads

Experience/ engagement representatives

NHS provider and service level

Social care

Quality leads

Patient participation groups (PPGs)

Public health

Patient advice and liaison service (PALS)

6 Who do you need to hear from?

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Where are we now?

Think carefully about who you need to hear from. Your project aims and objectives should be your starting point.

- If you want to find about the preferences of the whole population, then the sample (ie, the group you will be doing the work) needs to reflect this.

- If you are interested in specific pathways of care, then focus on the groups experiencing them.

- To focus on specific population groups, use relevant sociodemographic criteria.

Think about population groups that tend to be under-represented in existing engagement activity. For example, are the views of people from ethnic minority groups sufficiently well understood? For some of these communities, community-led approaches or working with VCSE organisations might be more appropriate than more traditional methods, such as surveys or workshops.

It is important to work with people from the relevant communities to ensure the methods adopted will be appropriate. Ways that work for some communities will not work with others.

Some people may require additional support or rely on proxy respondents like carers. Carers know what is working and what could be improved, while having their own support needs, so it is important to give them a voice.

6 Which approaches are most appropriate?

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Where are we now?

No single method offers a 'silver bullet' for understanding the experiences of all groups in all different settings. Instead, you will need to think about the range of different approaches you might take. The key questions to work through to inform your methodology are: what are your overall aims and objectives and how will the information be used?

For work that is more exploratory, or is trying to answer the question 'why', then qualitative methods, such as interviews or group discussions, are more appropriate. Qualitative methodologies tend to use smaller samples but provide more in-depth understanding and allow participants to guide where the conversation goes.
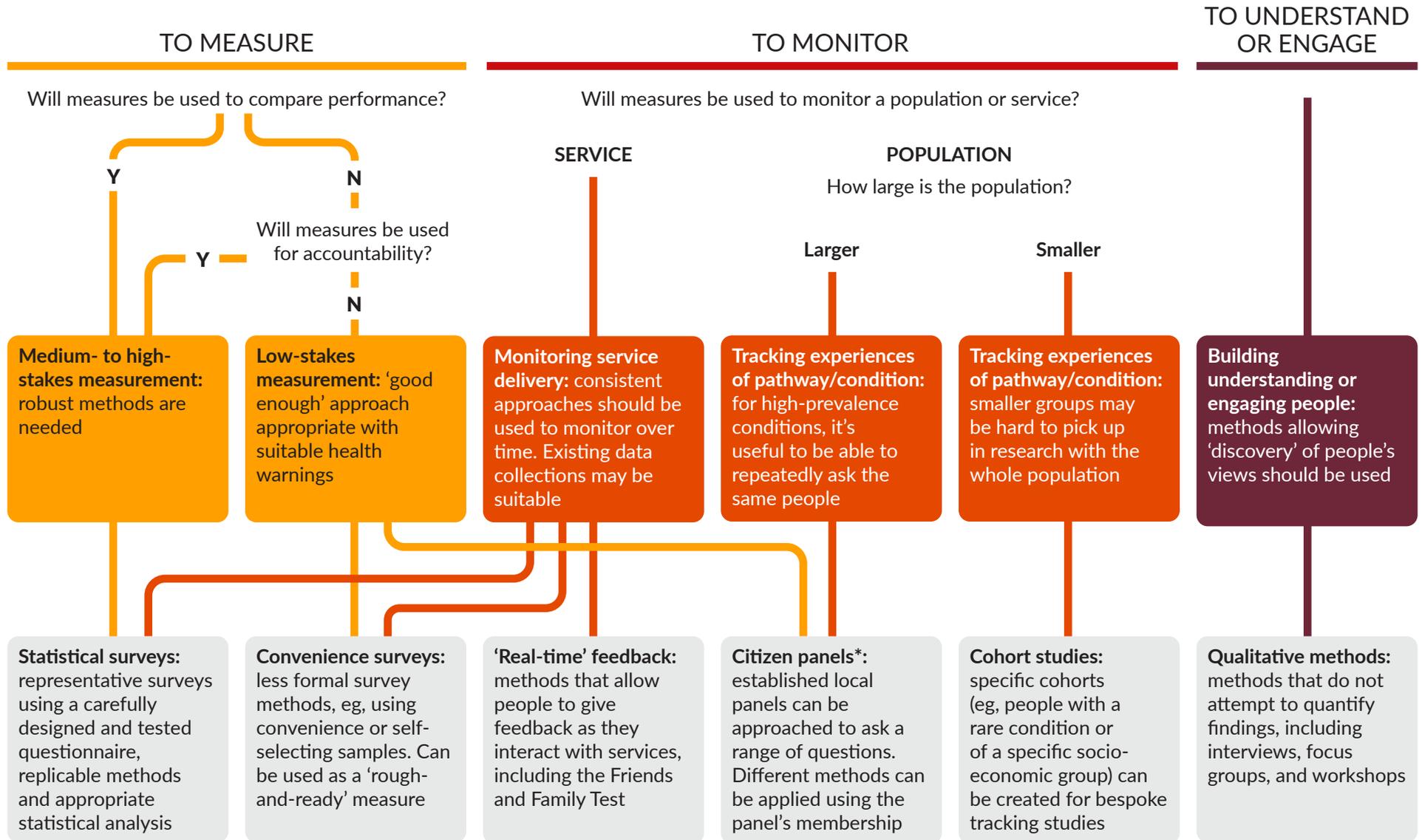
Quantitative methods such as surveys, are better placed to answer questions like how many and how often. They will require a larger sample and provide numerical data that can measure how well you are doing. They can also allow understanding of variation across areas or between groups.

Using different quantitative and qualitative methods in combination can help build a more comprehensive picture of people's experiences of integrated care.

Before deciding on your approach, spend time working with stakeholders ensuring there is a shared understanding of what the work is looking to achieve. The decision tree on the following page can help you with this process.

Which approaches are most appropriate and when?

TO MEASURE **TO MONITOR** **TO UNDERSTAND OR ENGAGE**

Will measures be used to compare performance?

Will measures be used to monitor a population or service?

Y **N**

SERVICE **POPULATION**

Will measures be used for accountability?

How large is the population?

Y

N

Larger **Smaller**

Medium- to high-stakes measurement: robust methods are needed

Low-stakes measurement: 'good enough' approach appropriate with suitable health warnings

Monitoring service delivery: consistent approaches should be used to monitor over time. Existing data collections may be suitable

Tracking experiences of pathway/condition: for high-prevalence conditions, it's useful to be able to repeatedly ask the same people

Tracking experiences of pathway/condition: smaller groups may be hard to pick up in research with the whole population

Building understanding or engaging people: methods allowing 'discovery' of people's views should be used

Statistical surveys: representative surveys using a carefully designed and tested questionnaire, replicable methods and appropriate statistical analysis

Convenience surveys: less formal survey methods, eg, using convenience or self-selecting samples. Can be used as a 'rough-and-ready' measure

'Real-time' feedback: methods that allow people to give feedback as they interact with services, including the Friends and Family Test

Citizen panels*: established local panels can be approached to ask a range of questions. Different methods can be applied using the panel's membership

Cohort studies: specific cohorts (eg, people with a rare condition or of a specific socio-economic group) can be created for bespoke tracking studies

Qualitative methods: methods that do not attempt to quantify findings, including interviews, focus groups, and workshops

* for more information on setting up and using a citizen panel contact england.systempartnerships@nhs.net

6

Developing and designing questions for quantitative methods

Surveys can be used to understand people's experiences of integrated care by asking a sample a set of pre-prepared questions.

Developing a new survey

There is currently no national survey to measure people's experience of integrated care for you to draw on. Designing a new survey offers the opportunity to explore the aspects of integrated care that users deem most important and design questions around those aspects.

Using our question bank

The question bank accompanying this guide offers a catalogue of questions that have been previously used in surveys which can be used as a starting point for developing or adapting questionnaires to understand people's experiences of integrated care. Work should be done with the target group to ensure the questions are understood and capture what matters to people.

More information about designing questionnaires can be found on the NHS England website (**NHS England 2018c**).

The importance of qualitative approaches to engage and understand

Qualitative approaches are key to gaining deeper insight into what matters to people and understand why they hold certain views of their care

Group discussions	A semi-structured discussion of a particular topic in a group setting. A moderator is present to manage the discussion. Interaction in the group is used to facilitate and elicit further discussion and views
Interviews	A discussion with a person to elicit information about a particular topic
Patient or user stories/case studies	Provides an individual account of people's experience as a narrative
Health and care experience profiles	An engagement methodology, developed by Healthwatch, for local systems to understand how joined-up services work for people with particular health and care experience profiles. Find out more on the Healthwatch England website (**Healthwatch 2021**)
Ethnography	Following someone throughout their pathway of care and observing interactions for an extended period of time
Peer-led research	A participatory methodology in which people with lived experiences take part in designing and conducting the research

Further information can be found on the NHS England website (**NHS England 2018a**).

6

CASE STUDY:
Mental health services in Cambridgeshire and Peterborough

Healthwatch Cambridgeshire and Healthwatch Peterborough piloted using health and care experience profiles: a qualitative research methodology designed by Healthwatch England to assess how local systems were providing joined-up care.

The team engaged young people who have transitioned or are transitioning from children's mental health services to adult mental health services to understand their experiences.

Expected care	A review of local models, policies and services; and of national guidance and The NHS Long Term Plan commitments: to identify current best practice and potential gaps in knowledge
Actual experience	A comparative review of experience against this literature via existing insight reports and surveys, and various qualitative methods including one-to-one chats and discussion groups. Themes identified from research included issues accessing services or finding information and advice about services and support.
Conclusion	Several recommendations came from people and their families, providing insights unavailable through quantitative research alone. These included the need for a more holistic and patient-centred approach to service delivery, and are being fed back into the local system.

Further information can be found on the NHS England website (**NHS England 2018a**).

6 How do we collect and interpret what we hear?

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How do we turn data into action?

⌄

Where are we now?

Collecting and analysing data, acting on findings and implementing actions will require skilled staff with protected time to oversee and co-ordinate the work, and a dedicated budget.

Thought needs to be given to whether the work can be carried out in-house or whether external support should be brought in to carry out the project.

There may be partners across the system, for example, local Healthwatch teams, VCSE organisations or a range of market or social research companies, which specialise in understanding people's experiences (**NHS England 2018b**).

Regardless of the approach taken, budget and resourcing will need to be made available for this work. This is not a 'nice to have' but a 'must have' and to be done properly it will require time and investment.

Find out more about gathering insights on the NHS England website (**NHS England 2016**).

6

How do we turn data into action?

What is the aim of the project?
⌄
Who needs to be involved?
⌄
What do we want to find out?
⌄
What is already known?
⌄
Who do we need to hear from?
⌄
Which approaches are most appropriate?
⌄
How do we collect and interpret what we hear?
⌄
How do we turn data into action?
⌄
Where are we now?

Too often work of this kind is carried out but the findings are not acted on. There is a significant opportunity here for partners across a system or place to listen to and learn from the people they serve but it will mean nothing if nothing is done.

Relevant stakeholders should be engaged in drawing up a change plan to respond to the project's findings.

It is important to get leadership buy-in to the work from the beginning, so that the findings have more chance of making a difference. For example, involving senior stakeholders from across different organisations from the outset means they will be aware of the research and primed to receive findings. One of the most important aspects of this work is ensuring people know they can act on what they hear, something that needs to come from leaders.

The project team will need to make use of different communications channels to ensure that relevant stakeholders are aware of findings at all levels within relevant organisations.

Involving user groups and communities as active participants in deciding what should happen in response to the research findings is key to ensuring the project achieves its aims.

6

CASE STUDY:
Permission to innovate in Wigan

Wigan Council has put listening to and learning from people in its community at the centre of what it does. The council has spent a great deal of time and effort in creating the right culture to allow staff to listen and act on what they heard from the people and communities they serve.

Leaders at the council recognised that for this to work it had to be everyone's business not the sole preserve of engagement or experience teams. They put in place training for all staff to have different conversations with the communities they serve.

As part of the Wigan Deal, genuine partnerships with the community were developed where open and honest conversations were had to find out what matters to people and what would make a difference to their lives (**Naylor and Wellings 2019**).

A range of different methods and tools, both quantitative and qualitative, were used to hear from users including surveys, citizen reference groups, mystery shopping, complaints and stories.

Leaders in the council recognised that staff needed to feel they had permission to innovate when acting on what they heard from the community – giving staff confidence to try new things and taking a different attitude to risk.

Behind all this was a belief that for services to work for users the first step was to listen to what matters to those users and then to keep listening.

6

Where are we now?

What is the aim of the project?

⌄

Who needs to be involved?

⌄

What do we want to find out?

⌄

What is already known?

⌄

Who do we need to hear from?

⌄

Which approaches are most appropriate?

⌄

How do we collect and interpret what we hear?

⌄

How do we turn data into action?

⌄

Where are we now?

Once the work is finished, it is important to dedicate time to come together and review the process. Some questions to ask yourself and your team are outlined below.

- Where are you now? Have you met the aims of the work, and did you find out what you wanted to?

- Do you need to know more? Are there gaps in understanding or people who were not heard from? Would other methods tell us more? Consider continuing the engagement around the area of interest.

- Have you shared what was learnt with all relevant groups? It is important to share with partners who are in positions to take action, but also with the people and communities involved and let people know what has happened as a result of their contribution.

- Has the work been listened to and acted on in the short term? Has there been an improvement to services in the longer term? Consider what it was about your approach that enabled this to happen, or what might work better in the future.

- What next? Understanding people's experiences should be an ongoing process, not a one-off activity.

7

An opportunity to do things differently

The advent of ICSs and place-based working offers a real opportunity to ensure people and communities are at the heart of health and care. This guide provides a framework for how this can happen, but at the heart of this work has to be the recognition that the voices of people and communities matter and need to be heard.

Done well, this work can bring partners together around a shared purpose, one that is set by the people and communities they serve. It can be used to measure progress towards that purpose and offer real clarity and insight on what is needed to get there.

It won't always be easy. There is no perfect way of doing this work and it will require partners to learn together about what works. It also requires partners to listen to people and communities together rather than in silos. Joined-up care will only happen if there is joined-up listening.

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Appendix: Work to inform the content of this guide

The work completed to inform the content and structure of the how to guide included the following.

- **A literature review**
  We conducted a review of relevant literature to explore what is already known about understanding integration from the perspective of people who use services. The review covered the relative strengths and weaknesses of the different methods and approaches previously used to understand and measure integration, and highlighted the key lessons about turning data into action.

- **Stakeholder interviews**
  We conducted interviews with a range of different stakeholders from across the NHS and local government as well as experts in understanding and measuring patient and user experience.

- **Engagement with integrated care systems**
  We worked with four ICSs to explore how they could better understand and measures integration from the perspective of people and communities. We spoke to a range of stakeholders in each system including patient and public engagement leads, local Healthwatches and system leaders and senior clincians.

The four systems that participated were:
- Bristol, North Somerset and South Gloucestershire ICS
- Integrated Care System for Devon
- Joined Up Care Derbyshire
- South West London Health and Care Partnership.

We presented the results of the initial work back to the sites and sought input from them on what they needed from this guide.

- **Workshops**
  The King's Fund and Picker hosted three workshops to test a draft of this guide with stakeholders:
  - sites leads at ICS level
  - patient leaders
  - representatives from the third sector and national bodies and social research experts.

The workshops had a semi-structured format, with suggested topics for the participants to review and discuss. The draft of the guide was shared with participants in advance of the workshops. The King's Fund and Picker colleagues reviewed and made change to the guide in light of the feedback from the three workshops.

The King's Fund is an independent charity working to improve health and care in England. We help to shape policy and practice through research and analysis; develop individuals, teams and organisations; promote understanding of the health and social care system; and bring people together to learn, share knowledge and debate. Our vision is that the best possible health and care is available to all.

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