NHS
South West Yorkshire Partnership Teaching
NHS Foundation Trust

Nothing about me, without me

Our guide to involving service users, carers and our communities

With **all of us** in mind.

Contents

What is involvement?

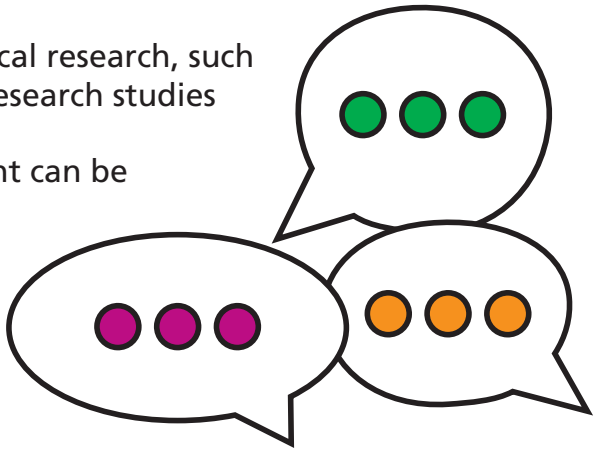
Involvement is about people having a real say in their healthcare and how NHS services are designed. It means:

- Being able to make informed choices about your own care, or the care of your loved ones
- Sharing feedback, helping plan services, and working alongside the NHS to create better care together

This can be as small as deciding what treatment works best for you, or as big as helping shape services for whole communities.

Examples of NHS involvement:

- **Care planning:** Co-produced care plans are created together by service users, carers and staff, working as equal partners to make sure the care provided meets individual needs and is led by the service user
- **Personal care:** Supporting individuals to manage their own health and to be involved in decisions about their treatment, giving them more choice and control over their care. This can include sharing decisions about a procedure or ongoing management of a long-term condition
- **Service design:** Engaging patients, carers, and the public to influence the design, delivery, and evaluation of local health and care services based on their lived experiences
- **Community and public participation:** Encouraging the public to share their views, needs, and wishes to help shape plans and policies. This can include consultations, surveys, and community meetings
- **Co-production:** Working together with service users, carers, and staff to share responsibility for how care is delivered, and services are managed
- **Research:** Involving patients and the public in clinical research, such as participating in trials or providing feedback on research studies
- **Different approaches:** The method of involvement can be a one-off consultation or an ongoing engagement, depending on the nature of the activity and the needs of the people involved



The ladder of involvement

The ladder of involvement is a visual and conceptual tool that illustrates the different ways people can participate in shaping the services they receive. It recognises that involvement is not a one-size-fits-all journey, nor is it necessarily linear.

Each rung of the ladder represents a valuable and valid form of participation, from simply receiving information to full co-production.

DOING WITH
In an equal and reciprocal partnership.

DOING TO
Providing clear, accessible information that supports understanding and confidence.

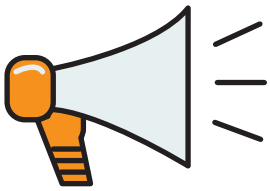
CO-PRODUCTION	Working together as equal partners
CO-DESIGN	Jointly creating solutions and services
ENGAGEMENT	Actively involving stakeholders and users
COMMUNICATION	Clear, open, and accessible dialogue
INFORMATION	Sharing knowledge and data effectively

CONSULTATION
This is the formal/ legal process of asking the public their views on any proposed "*substantial change*" to the way a service is provided or delivered.

Ladder of involvement: stages in brief

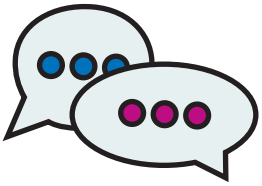
Stage 1. Information

At this foundational level, service users and carers are kept informed about services, changes, and opportunities. This might include newsletters, leaflets, or open day events. It's about transparency and awareness.



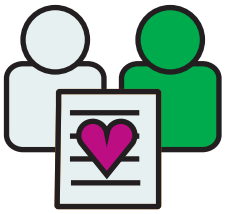
Stage 2. Communication

Service users and carers are invited to share their views through surveys, consultations, or focus groups. It's a two-way dialogue that begins to shape services based on feedback.



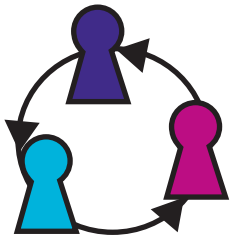
Stage 3. Engagement

Service users and carers actively participate in discussions and activities, such as forums or workshops. Their voices begin to influence service delivery more directly.



Stage 4. Co-design

At this stage, service users and carers collaborate with staff to design specific elements of care or service pathways. Their lived experience becomes a blueprint for innovation.



Stage 5. Co-production

This is the highest level of involvement, where service users and their loved ones work in equal partnership with staff. They co-lead projects, sit on strategic committees, and help shape policy and governance.

Consultation (formal and legal)

Formal consultation must only take place with support from the commissioning system external to the Trust, alongside the Trust's equality team and communications team, and only after approval from the executive management team.

The best way to avoid confusion is to understand consultation (the what) as a "legal/formal process" and the involvement ladder (the how) as the "methods of delivery."

There are case studies, further information and examples for all these approaches and stages available on the intranet.

Ladder of involvement: progression examples

By mapping example actions and potential progression pathways, this tool supports the Trust's commitment to embedding lived experience and involvement at every level of service design, delivery, and governance.

Stage	Description	Example action/ behaviour	Progression to next rung
1. Information	Service users and carers are informed about services and decisions.	Receiving newsletters, leaflets, or attending open days.	Asking questions or providing feedback on the information received.
2. Communication	Service users and carers are asked for their views.	Completing surveys or attending focus groups.	Volunteering to join a working group or advisory panel.
3. Engagement	Service users ad carers take part in activities or discussions.	Attending community forums or service design workshops.	Taking on a peer support or volunteer role.
4. Co-design	Service users and carers are actively involved in shaping services.	Co-designing care plans or contributing to training sessions.	Applying to be part of recruitment panels or governance groups.
5. Co-production	Service users and carers work in equal partnership with staff.	Co-leading projects, being part of strategic planning, or sitting on Trust committees.	Mentoring others, leading involvement initiatives, or influencing policy.
Consultation	A formal public consultation initiated by ICBs/ commissioners with both the community and individuals.	Needed when a service is intending to make a "substantial" change i.e. shutting a service.	This is process that requires support from the equality and communications teams before being initiated.

Approaches to involve people

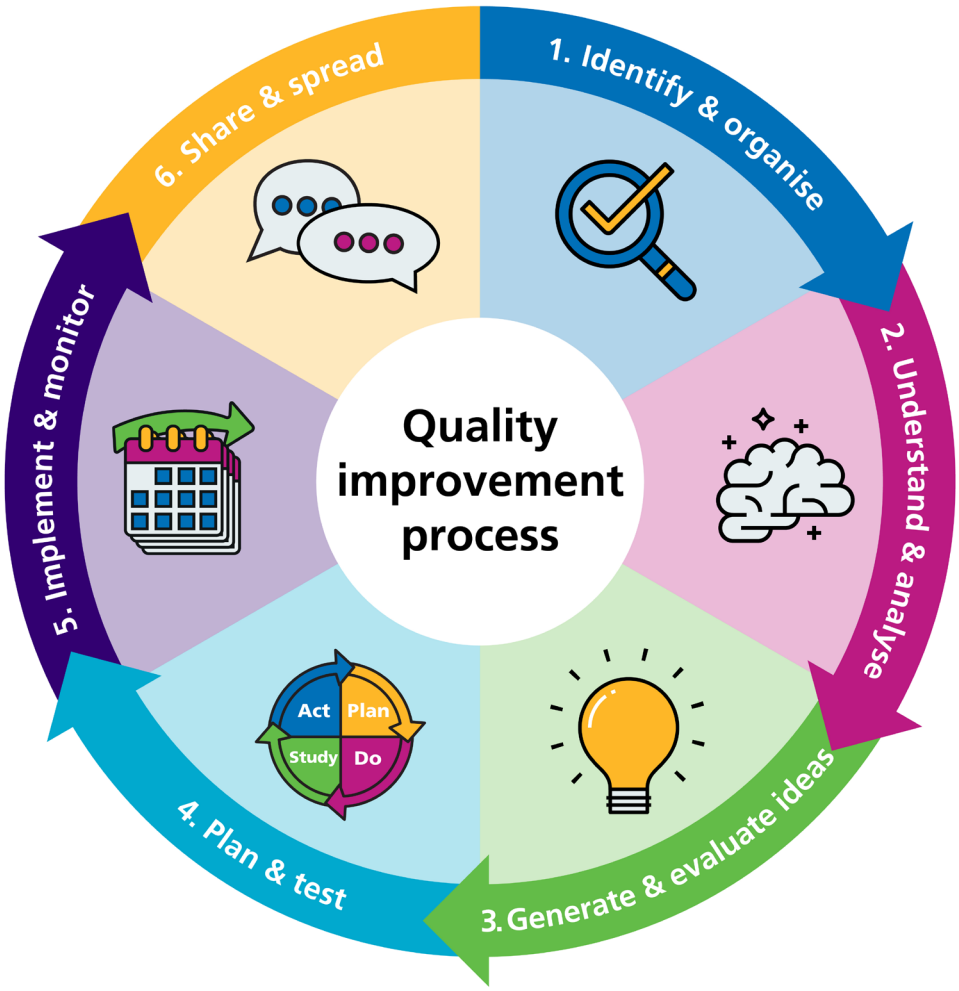
Involvement is an integral part of a quality improvement (QI) process - it's the engine. We know that service change designed **for** people rarely lands as well as change designed **with** them. That's why involvement sits at the heart of QI - it gives us richer insights, sharper problem definition, and solutions that actually stick.

When we meaningfully involve people, residents, patients, communities, carers and staff we tap into lived experience that data alone can't surface. They help us understand not just what is happening, but why it's happening. And in QI, understanding the root cause is half the journey to improvement.

QI gives us the structure and tools, the driver diagrams, the process mapping, the PDSA cycles, but involvement brings the colour, context, and challenge. It keeps us honest. It stops us designing elegant solutions to the wrong problems. And it ensures that the changes we make don't just look good on paper, but work in real life.

Most importantly, involvement builds trust and shared ownership. When people see their insight shaping decisions, they become partners, not bystanders. That gives improvement work longevity, legitimacy, and local leadership, three things that no policy document can create without the relational aspect.

So in QI, involvement isn't just a moral obligation, it's how we make change better, and more sustainable. And it's how we shift from delivering services to people, to improving systems with people.

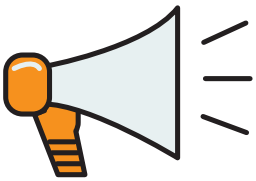


Here are some **suggested approaches** that you could use to involve people, using the involvement ladder:

Stage 1. Information

Service fact sheets

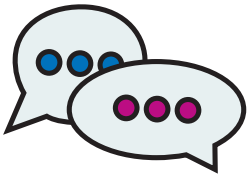
Providing clear, accessible leaflets or digital infographics that explain how a service currently works and sharing data on performance effectively with the community.



Stage 2. Communication

Question and answer webinar

Hosting a live online session where the public can ask questions directly to service leads, ensuring a clear and open two-way dialogue about upcoming changes.

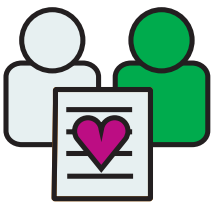


Stage 3. Engagement

Design a survey

Creating a survey is one of the ways that you can gather the views of our communities. This provides guidance, support and resources to ensure you are creating an effective and meaningful survey. Before creating a survey, you want to ensure you have:

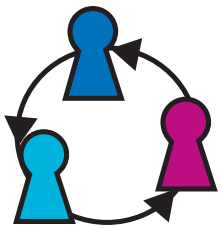
- Defined the goal of your survey and what you want to achieve
- Reviewed existing surveys and insights to understand what you already know and where the gaps are
- Identified your audience and consider different communication needs. Using only one format may exclude many people
- Planned how you will reach your audience and what additional tools or formats you may need
- Considered your timeline carefully. Avoid periods like school holidays or cultural and religious events that may reduce responses



Stage 4. Co-design

Walking the patient journey

An interactive workshop in which staff, carers and service users share their experiences of a pathway of care and work together to identify, prioritise, and implement specific improvements. Or a role that enables a service user or carer to participate as a member of a project group (for example a QI group) or governance group for a specified period.



Stage 5. Co-production

Strategic partnership group

Service users, carers and staff work together from the very beginning as equal partners to design, deliver, and evaluate an entire service, sharing all decision-making power and responsibility.

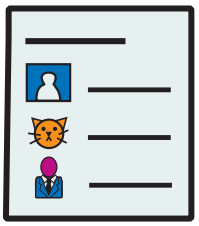
How to involve people: quick guide

Think first

Before involving people, be clear about:

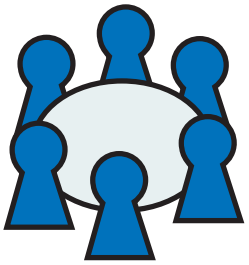
- Who your audience is and what they can influence
- Who is affected by the idea or change
- Who should be involved (service users, carers, staff, volunteers, communities, VCSE groups)
- Whether your group represents local communities – use equality data and include a mix of protected characteristics
- Who has asked to be involved – keep a simple contact list
- What information or support people need to take part confidently

Provide a clear, easier read explanation of:



- What the project or meeting is
- What skills/experience are needed (if any)
- How much time is required and for how long

How to involve people



- Start small: ask for feedback on one issue or invite someone to a short 1:1 conversation
- Explain how their feedback will be used and what decisions it will influence
- Offer support or training if people need help understanding services or NHS processes
- Choose an accessible venue or use digital options, such as online meetings, workshops or focus groups
- Work with local community and voluntary groups to reach people who may not usually take part
- Give plenty of notice (ideally two months)
- Involve people with different experiences to get a broad view
- Hold a pre meeting and always include a briefing and debrief
- Avoid jargon or explain it when necessary
- Provide breaks, refreshments, and good facilitation so everyone can contribute
- Check any access needs or adjustments: large print, interpreters, hearing loops, quiet rooms, written alternatives, etc.
- Make sure people can claim travel expenses easily

Other important considerations

- Be mindful of cultural and religious dates, caring responsibilities, and school holidays
- Ask people for feedback on their experience and use it to improve future involvement
- Consider neurodiversity: offer clear agendas, breaks, quieter spaces, or alternative formats such as written or video responses

Protected characteristics

The groups of people under the Equality Act are split into nine protected characteristics and at the Trust we also include carers as our tenth group. The diagram below shows all ten groups:

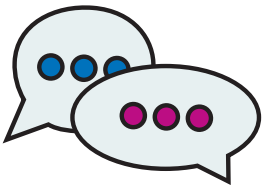
Under the Equality Act the NHS needs to consider treating people fairly and equally to make services inclusive. This aligns with our Trust values.

- **Check who's here:** Use an equality monitoring form to see whose voices are included - and spot who might be missing. Ensure that local communities are represented equally.
- **Listen and learn:** Look at feedback and equality data to find patterns. This helps us understand if some groups are having different experiences.

Equality and inclusion

This means everyone having the same chances to do what they can. Some people may need extra help to get the same chances.

To be inclusive in your involvement activity, you will need to consider how you involve people equally by reviewing any additional needs they may have and what reasonable adjustments you can put in place. For example:



Language inclusivity

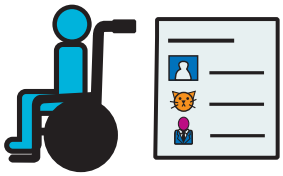
Do any of the people speak a different language? Is English not their first language? You may need to book an interpreter to work alongside you in the involvement activity to translate and explain what you are aiming to do.

Deaf inclusivity

Are any of the people hard of hearing? Do you need to provide a hearing loop in the room for hearing aid users, or do you need to get a BSL interpreter in the room also to translate?

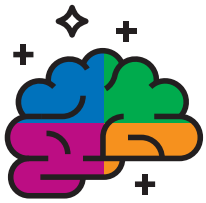
Blind inclusivity

Are any of the people involved short sighted or have partial sight loss and require information in large print?



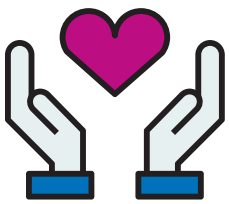
Disability

Do any of the people involved have a disability? You may need to consider access and what additional support they may need to understand and get involved e.g. easy read or their support worker to attend with them



Neurodivergent approach

To include neurodivergent people (like those with autism, ADHD, or sensory differences), it's important to offer different ways to take part - such as written, visual, or verbal - avoid sensory overload, give clear agendas with few last-minute changes, allow extra time to process, use plain language, and always ask what support someone needs instead of guessing.



Trauma informed approach

Formal consultation must only take place with support from the commissioning system external to the Trust, alongside the Trust's equality team and communications team, and only after approval from the executive management team.

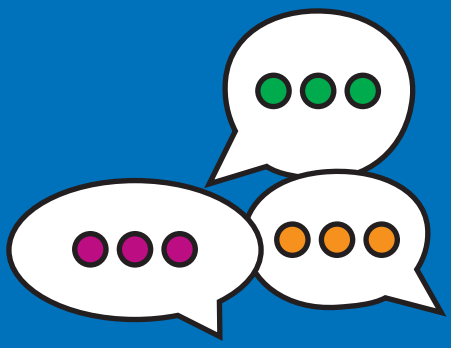
Carer inclusivity

Do any of the people attending have caring responsibilities? Consider offering flexible involvement options such as shorter sessions, online participation, or written feedback, and schedule around caring routines where possible.

Reporting and feedback

Reporting

When carrying out any involvement activities, you must report on it. This means capturing what approaches you have used, who you involved, timescales you worked to, what insight you received and what themes and recommendations the insight gave you. This all provides a valuable audit trail of the work.



Feedback

It is very important to feedback what your findings are and what actions you have taken, plus give a further opportunity to thank those people who were involved and the time they gave up.

A simple email with a one page summary or an infographic poster with outcomes of your survey or a 'you told us, we listened' approach where you can explain what actions you have taken against the findings you have captured. For fuller involvement activities a report of findings can be shared.

Examples of how to feedback to those involved:

- You said, we did poster
- Infographic
- Digital display on TV screen in waiting room area
- Report that is published online – hard copy available to print off
- Email, text or telephone call – whatever preference people asked for
- Running another focus group to update on progress
- EIA reports: log any involvement activity into the action plan of your EIA to showcase your work and update actions

Need help?

The equality and involvement team can support you to plan meaningful and inclusive involvement activities.

Even if your service isn't clinical, you should still involve service users, carers and communities, especially when developing strategies or changes that affect people across the Trust.

Contact us on: InvolvingPeople@swyt.nhs.uk

Training

The equality and involvement team provide a range of training for staff, so they gain a better understanding of their role and responsibilities.

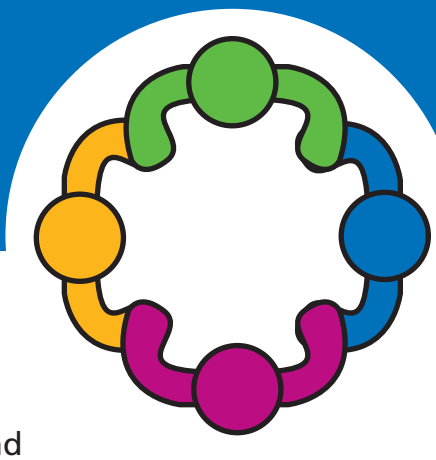
You can access the latest information and book training on the intranet:

- Equality, diversity and inclusion mandatory training
- Equality impact assessment (EIA) development session
- Enhanced equality, diversity and inclusion training
- Cultural awareness and humility training
- Connecting people training
- Staff carers awareness training

The following resources are available on the intranet:

- Equality monitoring form and easy read equality monitoring form
- Equality films
- Research bank
- Shared co-production principles
- Engagement plan and timeline
- CHATpads

Connecting People programme



What is the programme?

The equality and involvement team run the Connecting People programme, where staff and members of the public are trained to be a community connector.

What does the training involve?

The training consists of two online sessions where you will learn about the Trust, how the NHS works, how to meet our legal duties for involvement and equality and methods and approaches to involvement.

How do I enrol?

You can email the team on InvolvingPeople@swyt.nhs.uk to register your interest and also check the intranet for advertised upcoming courses.

What happens after you have completed training?

Once you have completed the training, connectors are registered on our database and have a profile so that we can work with them to target specific involvement activities by understanding their reach, e.g. works within a community of young people in Wakefield or works within a community in Calderdale with older people.

What do connectors do?

Connectors can help others to have a say in the design and development of services by connecting with them on your behalf – they can meet with people individually, run focus groups, complete surveys or even design artwork to feedback on issues/designs that involvement activities require.

Connectors are paid for their involvement so as a service, you will need to allocate a budget for them to be involved and take on the project on your behalf by connecting with a wider community reach, than you may be able to do in service.

Young connectors

The Trust has a young connectors programme which is focused on training young people who wish to be a community connector, aged 14-25 years.

Other ways to get involved with the Trust

There are lots of other ways to get involved to have your say and influence:

Join our Foundation Trust

Become a governor

Raise money for us

Volunteer

Help shape the future of our services

Train as a connector

Useful links:

Equality and involvement resources

Health inequalities toolkit

If you require a copy of this information in any other format or language please contact the Trust.

إذا كنت تحتاج إلى نسخة من هذه المعلومات بأي تنسيق أو لغة أخرى، فيرجى الاتصال بـ Trust.(Arabic)

اگر شما به یک نسخه از این اطلاعات در هر قالب(فرمت) یا زبان دیگری نیاز دارید، لطفاً با بنیاد (Trust) تماس بگیرید.(Farsi)

Ha a jelen információk másolatát más formátumban vagy nyelven szeretné megkapni, akkor kérjük, hogy lépjen kapcsolatba a trösszttel. (Hungarian)

ئەگەر ڕوونووسی ئەم زانیارییانەت بە هەر زمان یان فۆرماتێکی دیکە پێویستە تکایە لەگەڵ ئیمە پێوەندی بگرە.(Kurdish Sorani)

Jeśli potrzebują Państwo uzyskać kopię niniejszej informacji w innym formacie lub języku, prosimy o kontakt z Funduszem Zdrowia. (Polish)

Se necessitar de uma cópia destas informações em qualquer outro formato ou idioma, entre em contato com a Fundação. (Portuguese)

جے تہانوں ایس جانکاری دی اک کاپی دی کسے ہور فارمیٹ یا بولی وچ لوڑ اے تے مہربانی کر کے ٹرسٹ نال رابطہ کرو۔ (Punjabi Pakistani)

Dacă aveți nevoie de o copie a acestor informații în orice alt format sau limbă, vă rugăm să contactați Trustul nostru. (Romanian)

اگر آپ کو اس معلومات کی ایک کاپی کی کسی دوسرے فارمیٹ یا زبان میں ضرورت ہو تو براہِ مہربانی ٹرسٹ سے رابطہ کریں۔(Urdu)

Codesigned in 2026

JOB NO 5617 APR26