



# Service User Involvement Guide.

Working better  
together.



# Foreword

Our mission at Change Grow Live is to help people change the direction of their lives, grow as individuals, and live life to its full potential. Our vision is to develop, deliver, and share a whole person approach that positively changes society. A whole person approach means taking into consideration the full range of biological, behavioural, social, and environmental factors that impact people's health.

We know that listening to the communities we work with and prioritising the voices of people using our services improves outcomes and helps us create better services. Service User Involvement (SUI) means working closely with, listening carefully to, and learning from the people who are impacted by our work. Every voice, every idea, and every piece of feedback enables us to better recognise and meet the needs of the people we work with.

We are all responsible for listening and responding to the people we serve; whether that be in relation to a comment made within a service reception area, or when developing a national project. We hope this guide will inspire

both our people as well as other organisations to work with communities and listen to the voices of people who are seldom heard. This guide has been designed with input from teams across Change Grow Live as a useful resource so we have a shared understanding of what SUI is, why it is important, and how it can inform change.

This guide illustrates a range of ideas to support us in hearing what the people most impacted by the work are saying, create change to our organisation, and make a difference to people's lives. SUI will always be an ongoing process as people's needs will continually change and we need to adapt to meet them.

Sector wide changes have further emphasised the need to listen and respond to the voices of people coming into contact with our services. For example, the Care Quality Commission (CQC), Care Inspectorate Scotland (CIS), and Integrated Care Systems (ICS) are putting SUI at the heart of decision making. A potential consequence of SUI rising up the agenda of public services, is that it becomes superficial, and simply carried out to meet an administrative

requirement. We recognise that SUI can feel like a difficult topic to navigate. We've created this guide with colleagues from across Change Grow Live to support you and to help all of us to recognise and realise the genuine potential of SUI to influence and effect positive change.

In this guide, we have included exercises to help people think about a variety of topics, from how assurance differs from co-production, to understanding the role of SUI within a project. You can think about the questions on your own, however we recommend discussing the questions as part of a team or group so you can share your ideas and thoughts with the people you work with. This guide is not intended to be read in one sitting, and is very much a living document for us to develop together as we embark on this important journey.

Ultimately, by embedding SUI we have the collective potential to amplify the voices of marginalised people and ensure their voices and experiences inform organisational decision making and influence national conversations.

# Identifying and respecting the people we involve

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We recognise that there are important questions regarding how we describe people, and that language can reinforce stigma and negative attitudes towards people. There are a range of ways to refer to the people who use our services for example, stakeholder, expert by experience, or client. We want to be respectful to the people we involve and, where possible, recognise their individual right to self-identification.

For the purposes of this document, we use the phrase 'person using our services' to mean any person that is impacted by the work we do, including people:

- > Who are using or have used services
- > Who needed services but were not offered them
- > Who were offered inappropriate services
- > Who are living with or caring for someone who uses services
- > Who could potentially use our services in the future

For a discussion regarding the use of words for people who come into contact with, or are intended to benefit from our, services, please see [this article](#).

*'From a personal perspective, it gives me a purpose and fills the void left by alcohol. From an altruistic perspective, I enjoy helping others who are in as much need of hope and encouragement as I was myself when I first engaged with Change Grow Live.'* - Neil

All quotes have been anonymised.

# Contents

- 02** **Foreword**
- 03** **Identifying and respecting the people we involve**
- 04** **Contents**
- 05** **Summary**
- 06** **Background information**
  - 06 What is 'Service User Involvement' (SUI) and why is it so important?
  - 07 Sector changes and Service User Involvement
- 09** **Using Service User Involvement (SUI) to inform change and improve outcomes**
  - 09 Setting aims and goals of SUI
  - 10 Exercise 1: Ensuring SUI is meaningful
  - 10 Levels to participation
  - 12 Exercise 2: Who is it realistic to involve?
  - 12 How to carry out Service User Involvement and Co-Production
  - 13 Exercise 3: Understanding the role of SUI within a project
  - 14 Approaches to listening
  - 15 Workshops and focus groups
  - 16 Surveys
  - 18 Conversations, groups and meetings
- 19 Webchat
- 20 Care Opinion
- 21 Compliments, complaints and improvement suggestions
- 22 Treatment Outcome Profile Form
- 22 Exercise 4: Recognising what you are already doing
- 23 Co-production: Full involvement in listening and responding
- 23 Co-production in practice
- 25 Feedback loops
- 27 Key principles and ethical considerations
- 29** **Service User Involvement (SUI) at Change Grow Live**
  - 29 Levels to participation at Change Grow Live
  - 31 Central Service User involvement team
  - 32 Local Feedback
  - 33 Regional feedback
  - 34 National feedback
  - 35 Case studies
- 36** **Co-creating what works at Change Grow Live: What happens next?**
  - 37 Additional resources and further reading
  - 38 Useful websites

# Summary

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Service User Involvement (SUI) is about working closely with, listening carefully to, and learning from the people who use, and may use, our services. The chances of services, plans and campaigns working, increases when communities are actively involved in them. As such, over the last decade, local and central services and government have sought to highlight the importance of SUI in commissioning and regulatory frameworks.

We recognise that SUI is something we already do at Change Grow Live, and that it has already directed positive change on a local and national level. This guide has been designed to enhance work that is already happening as well as support people engaging with SUI for the first time. There are many ways of involving and listening to people; this guide describes some of the main methods, their benefits, and key considerations when using them. This guide also outlines some of the ethical issues to consider when working with people, including clarifying the different roles.

We want to encourage people to share their experiences across our organisation. We invite people working and volunteering within Change Grow to help us further develop this guide through [this online form](#).

# Background Information

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## What is 'Service User Involvement' (SUI) and why is it so important?

Service user involvement (SUI) is about working closely with, listening carefully to, and learning from the people who use, and may use, our services.

We have a duty to the people who use our services, and to the communities we work with, to provide the best support we can. We know that the chances of services, plans and campaigns working, increases when communities are actively involved in them and that SUI has a range of potential benefits, including:

- > Ensuring services meet people's needs
- > Improving outcomes for people using services
- > Improving resourcing and prioritisation
- > Giving power back to the people impacted by our work
- > Creating meaningful change by informing local and organisational decision making, as well as national conversations, cultural change, and policy

SUI also benefits our staff and volunteers. SUI means we are more likely to meet people's needs, leading to better and faster treatment outcomes, and greater job satisfaction.

Co-production forms an important part of SUI. Co-production describes the practice of involving people with different expertise - formed from lived experience as well professional experience - in the creation of public policies and services. Co-production recognises the benefit of having a range of people, working together as equals to identify priorities and develop solutions. A significant aspect of co-production is that everyone shapes an agenda, as opposed to people being invited to be involved after an agenda has already been set.

Ultimately, SUI requires us all to communicate and share what we are hearing. Doing SUI successfully means creating meaningful change with the people who use our services and the communities we serve.

## Sector changes and Service User Involvement (SUI)

In recent years, SUI and co-production have come to be seen as essential to both local ways of working and central government. Many different organisations, including our regulators, have embraced this way of working, and many individuals have become vocal advocates for it. For example:

SUI and co-production has recently become a key principle in the [Care Quality Commission's \(CQC\) strategy](#) as they state that:

*'We want to be an advocate for change, with our regulation driven by people's needs and their experiences of health and care services, rather than how providers want to deliver them.'*

The CQC ultimately want SUI feedback to inform their own standards of care and priorities as well as direct future areas of innovation.

- > Care Inspectorate Scotland (CIS) has made SUI a priority and states in its [Improvement Strategy](#) that *'the involvement of people who experience care and support will help to direct improvement support to where it matters most for people and the communities they live in.'*
- > The benefit of SUI was also a factor in the restructuring of Clinical Commissioning Groups (CCGs) into Integrated care systems (ICSs). Councillor David Fothergill, chairman of the Local Government Association's Community Wellbeing Board commented that:

*'Integrating health and care has the power to transform how, and how well we deliver these services to residents. Integrated Care Systems will allow local authorities and the NHS to pool their wealth of skills and local knowledge to ensure people are receiving appropriate, timely and effective care.'*

[Dame Carol Black's 2021 independent review](#) for the government, set out a range of recommendations on drug treatment and recovery, including SUI needs being recognised as essential when making commissioning decisions:

*'Increased funding will not improve services unless the commissioning process is strengthened [...] This process will be enhanced by co-production with people with live experience of addiction, and so the national Commissioning Quality Standard should sit comfortably alongside the quality standard for recovery support services which is currently being developed by the College of Lived Experience Recovery Organisations (LEROS).'*

The sector changes outlined above present a growing movement where the views of marginalised people and communities are recognised as integral to setting future agendas. Co-production relates to any of the four areas: co-planning, co-design, co-delivery, and co-evaluation. Full co-production is where people using services are involved in all four areas. The more we involve people using services at each of these stages, the more likely we are to be s achieve better outcomes.



# Using Service User Involvement (SUI) to inform change and improve outcomes

## Setting aims and goals of SUI

Service User Involvement (SUI) and feedback can be used to collect a range of information for different purposes. Sometimes feedback is used for assurance reasons (making sure that we are doing what we should be doing) and sometimes it is used to make changes which benefit in some way (using SUI to adapt to changing needs and innovating in our work).

### SUI for assurance purposes

- > SUI can provide a level of assurance about the quality of our work.
- > Involves measuring satisfaction, getting feedback on good and bad experiences
- > Led by the regulatory environment and compliance
- > Can be reactive to the needs of regulators
- > Benefits the organisation

### SUI for organisational change

- > Involves service users creating ideas for improving CGL and, where appropriate, their active involvement in making change happen
- > Led by people using our services
- > Can be responsive to the needs of people using our services and communities
- > Allows for innovation and can be less reactive to the regulatory environment
- > Benefits people using services, the sector and wider policy via evidence- based agenda setting

## Exercise 1: Ensuring SUI is meaningful

We need to ensure that SUI is done for the right reasons and with a sense of purpose. We want SUI to be genuine and meaningful.

For this exercise, we would like you to consider the different people using our services. How do you use their feedback to gain assurance or develop a new project or change, and why do you work in the way you do?

## Levels to participation

Harry Shier's 'Pathways to Participation Model', shown on the next page, illustrates the different levels of participation with regard to SUI and what is required to achieve it. It considers an organisation's readiness and capacity to involve people using services in meaningful participation. The level of participation will depend on a range of factors, including what decisions are being made, how much time there is to develop a project as well as how participants feel about being involved.

For people to feel empowered, they should be able to choose how and when they get involved; from simply giving their views when receiving support to attending an organised event or meeting. Some people may seek to become involved with a development/project on an ongoing basis. In Billie Oliver and Bob Pitt's book, 'Engaging Communities and Service Users' they explain that 'for some people, at the stage where they do not feel comfortable, confident, or motivated to participate, consultation may be the preferred and more appropriate level of engagement. At other times, different approaches, such as advocacy or mentoring, might be the appropriate method of engaging people.'

There are three levels of commitment at each level:

- > Openings: refers to an interest and readiness and desire to work to support fair involvement
- > Opportunities: describes the procedures and activities within the practice of an organisation that are necessary to support participation
- > Obligations: describes the infrastructure of policy that is built in within the organisation to enable democratic participation to become the norm.

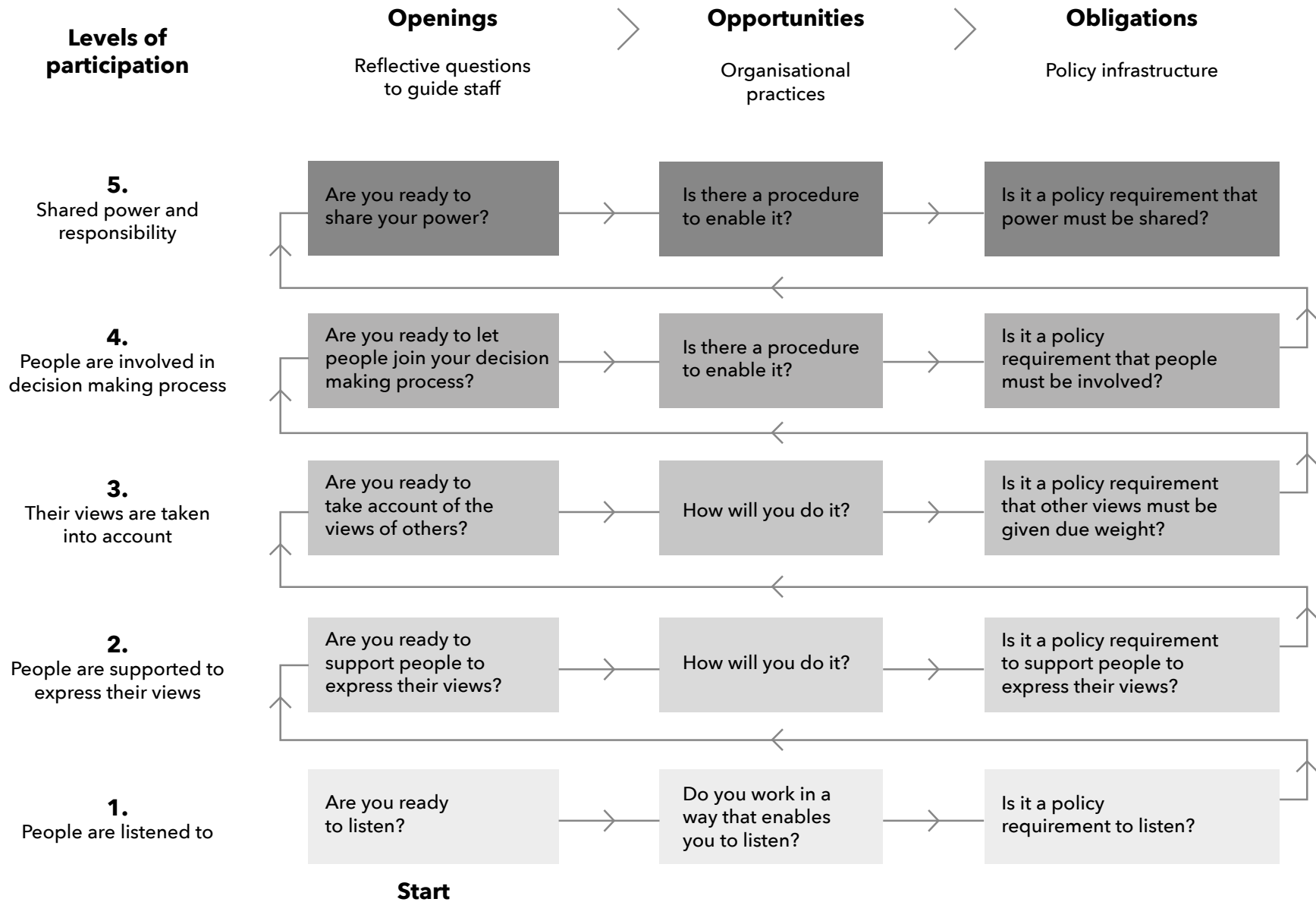


Diagram 1: Pathways to Participation Model

## Exercise 2: Who is it realistic to involve?

Consider the diversity of the people you want to involve. How realistic is it to ask them to be involved in assurance or developmental SUI at different times of their journey?

Think about how you currently involve people and if there might be anything you can do differently or ways in which you can encourage people to participate.

## How to carry out Service User Involvement and Co-Production

In this section, we explain the variety of methods to listen and involve people using services. The different approaches have different considerations and benefits depending on specific contexts in which they are used.

This section is intended to help you decide what is right for your specific goals and project. For example, we know that what works best in central Birmingham is likely to be different to what works best in Cambridge. It can also be useful to blend a range of methods in your local service in order to truly understand experiences and emerging needs.

*'I've been on and off involved for different reasons over the last few years. Involvement with CGL is certainly much better than addiction is'*

## **Exercise 3: Understanding the role of SUI within a project**

It is worth taking time to think about the following considerations before embarking on a project with people using our services or other members of the public.

- > What is the role of the person using our services? Consider where the project sits in terms of the level of participation ([see diagram 3](#))
- > Why do you want people involved in your project? What will their perspective add?
- > Who do you want to be involved in the project? Where will you find them?
- > What are your expectations of the people you are involving? What contributions will be expected of them? Are your demands on their time realistic?
- > What skills do the people you are involving need? Do they need particular communication skills or to have previous experience? Are you providing training?
- > What support might the people you are involving need? Will they be exposed to sensitive information or triggering content?
- > Are there any concepts, expressions, or words that participants might need help to understand?
- > Have you involved people using our services in setting the project agenda and answering the questions above?
- > What is the facilitator's/organiser's/host's purpose/offer?

# Approaches to listening

There are many ways people who use services can be involved. You can develop your own methods to listen to people using our services and we encourage you to share your ideas and methods with others in our organisation.

The kind of information you collect can often be categorised as either 'quantitative' or 'qualitative.' The table below describes how quantitative and qualitative methods differ from one another. We also introduce the phrase 'mixed methods' which refers to using both methods at the same time.

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## Quantitative approaches

- > Numbers based - countable or measurable
- > Data tells us how many, how much or how often
- > Fixed and universal 'fact'
- > Gathered by counting or measuring things
- > Analysed by statistical analysis
- > Can involve more responses
- > Easy to analyse and draw conclusions

## Qualitative approaches

- > Words and language based - descriptive
- > Data tells us why or how things might be happening
- > Dynamic and open to interpretation
- > Gathered through observation or interviews
- > Analysed by grouping the data into categories or themes
- > Supports development of new ideas
- > Helps with understanding people's motivations, thoughts, and behaviours
- > Can provide detailed answers

## Mixed methods

- > Uses both quantitative and qualitative approaches to reach a conclusion
  - > A mixed method approach makes the most of the advantages of the quantitative and qualitative methods, while offsetting the drawbacks of each
-

## Workshops and focus groups

**Type of method:** Qualitative

### How do they work?

Focus groups generally involve a small group of 6-12 carefully selected people who are asked a series of questions about a specific topic. The topic is generally identified by someone outside of the group, who also develops the questions. Focus groups should be led by a facilitator using a topic guide to steer the session and keep it on track. Workshops are similar in that they involve a small group of people talking about a specific topic. However, workshops tend to be more collaborative and participatory in nature. Rather than being questioned by a facilitator, the participants might work in teams and engage in exercises and activities to create something. They might be asked to prioritise ideas and generate new ideas and solutions to a problem.

### Things to consider

The recruitment, design, and facilitation of workshops and focus groups is extremely important in order to avoid biases, group think (where individuals can make **irrational and non-optimal decisions** as a group) can become dominated by a small number of participants or may lose focus.

Recruitment, especially of people from seldom heard groups and communities that do not yet use our services, can be challenging. You might consider working with partner organisations to engage such groups. Incentives can be offered, but they should be carefully considered so that they motivate the right behaviour and do not bias results.

### Benefits

Workshops and focus groups can be a great way of gathering the views and opinions of people using services. Focus groups are an effective method for answering a question quickly. Workshops can even be designed to help prioritise actions and involve people using services in the planning, delivery, and evaluation of our work.

For more information about using workshops or focus groups please contact the central service user involvement team:

**Chris.barnes@cgl.org.uk or Mark.Pryke@cgl.org.uk**

# Surveys

**Type of method:** Qualitative/Quantitative depending on the data being collected

## How do they work?

Surveys can take the form of a structured interview (where a person is asked the questions by someone else recording their answers) or a questionnaire (where the service user fills out the survey on their own).

## Things to consider

It is crucial to plan how you are going to carry out your survey, as well as consider who your survey is for, and how you intend to use the data. While random sampling is generally used to select participants, response rates can bias the results of a survey. The 'social desirability bias' can lead people to respond in a way that they think makes them 'look better.' For example, a respondent might report that they engage in more healthy behaviours than they do in real life.

You must also consider the design of your survey. For example, when writing the survey, you must think about who the survey is speaking to and what you might be assuming when asking questions. Poorly constructed and administered surveys can undermine the validity of any data they generate. Ultimately, you must consider if your survey allows people to answer in a way that accurately reflects how they feel or what they think.

## Benefits

Survey research is especially useful when you are aiming to investigate the characteristics, behaviours or opinions of a large group or groups of people. They can also be used to quickly gain general details about the population of interest to help prepare for a more focused, in-depth study using time-intensive methods.

## Change Grow Live Surveys

- > **The Children and Young Persons (CYP) pulse survey** asks Children and young people to provide feedback about the service they have received. The answers can be used to gain assurance around current service delivery and provide insight into areas which can be developed to improve CYP experience. The survey also helps us to know more about the children or



young person leaving the response, for example whether they are new to service, how old they are, and which services they use. The survey can be accessed via [this link](#) or the QR code below which can be sent to people using our services or even embedded within posters and leaflets:

Alternatively, paper copies of the CYP SU pulse survey can be completed and uploaded to the online survey. Responses are standardised and collated every fortnight and are available to anyone within Change Grow Live. For more information about using the SU pulse survey please contact the central service user involvement team:

**Chris.barnes@cgl.org.uk or Mark.Pryke@cgl.org.uk**

- > **The Service User Pulse Survey** asks people using services what they think about the service they receive. The answers can be used to gain assurance around current service delivery and provide insight into areas which can be developed to improve SU experience. The survey also helps us to know more about the person leaving the response, for example whether they are new to service, how old they are and which services they use. The survey can be accessed through the following [this link](#) or the QR code below which can be sent to people using our services or even embedded within posters and leaflets:

Alternatively, paper copies of the SU pulse survey can be completed and uploaded to the online survey. Responses are standardised and collated every fortnight and are available to anyone within the organisation. For more information about using the SU pulse survey please contact the central service user involvement team:

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# Conversations, groups, and meetings

**Type of method:** Qualitative

## How do they work?

Groups and forums create spaces where people using services can be consulted on new developments, have their say, and hear about training and opportunities. Conversations between staff, volunteers and service users happen everyday and provide a useful opportunity to listen and respond to what people using our services are asking us.

## Things to consider

We know that while these groups and meetings are of huge importance, they can sometimes be attended by a small number of regular service users or volunteers. By sharing examples to show how we respond or ask for people using service to help us to develop a response to feedback we show that their voice matters and this encourages others to attend and share additional feedback in the future.

## Benefits

Face to face local or regional service user meetings provide effective ways to gather feedback around topics which matter to those accessing services and for people using services to become actively involved in shaping our work. We also know that some people are more willing or comfortable sharing their experiences with their peers.

## Webchat

**Type of method:** Qualitative/Quantitative depending on the data being collected

### How do they work?

Across CGL, we have several webchat services. These online platforms can be used to gather feedback and explore the experiences of people accessing or thinking about accessing services.

Current work is underway to improve the recording of information via webchat to enable Change Grow Live to understand and then respond to unmet needs.

### Things to consider

There is a [case study](#) later in this guide that shows how web chat can be helpful to identify new and emerging trends that aren't yet appearing in other data.

*'I need to connect with others ... so I can give a bit back and share my story' - Change Grow Live Service User, 2022*

# Care Opinion

**Type of method:** Qualitative/Quantitative depending on the data being collected

## How do they work?

Care Opinion provides ways for people using services to share their experiences of UK health and care services anonymously. Published stories are made available on Care Opinion's independent platform. Care Opinion connects those stories to the different people across the organisation which enables us to respond by making changes to the services we provide in response to the feedback received.

In addition to improving services, stories can be shared with commissioners and communities to personalise the experiences of the people we support, showcase the experiences of the people we support and encourage others who could benefit from accessing services to do so. Care Opinion automatically generates reports and visualisations which can be used to gain assurance around service delivery or provide insight into future developments to improve services/support.

## Benefits

The scope and accessibility of Care Opinion means it holds enormous potential. Currently, Change Grow Live has 577 published stories which have been read 20,900 times in the last 12 months. Access to these stories can be found [here](#). The Care Opinion platform can analyse data/stories and can generate reports/visual depictions of the information which can support services. For more about how it can feel to leave a story behind, please watch [this video](#) or for more information please see this [guide](#).

## Accessing Care Opinion

Change Grow Live Services can start using Care Opinion free of charge and all training is included within our ongoing organisational subscription to this service.

For more information, please contact the central service user involvement team: **Chris.barnes@cgl.org.uk** or **Mark.Pryke@cgl.org.uk**.

## Compliments, complaints, and improvement suggestions

**Type of method:** Qualitative/Quantitative depending on the data being collected

### How do they work?

Compliments, complaints, and suggestions can be provided to services from people with experience of the service. Within Change Grow Live, this feedback is captured and recorded within our case management system and the data is available within Tableau. This helps anyone across the organisation to see the compliments, complaints and suggestions made by people using services across the country.

### Things to consider

For more information on Change Grow Live's approach to complaints and compliments please see [our policy](#) and access to the Tableau dashboard for all services can be accessed [here](#).

### Benefits

Whilst able to provide assurance around service delivery, the compliments and complaints Tableau dashboard allows emergent themes within the feedback to be identified. This development can support services to identify specific areas where changes will have positive outcomes for people using the service.

### Accessing compliments, complaints, and improvements suggestions

Local, regional, and national data leads and staff members with access to [Tableau online](#). For more information, please see our [guidance](#).

# Treatment Outcome Profile Form

**Type of method:** Quantitative

## How do they work?

All of our Adult and Children and Young People drug treatment services (for people receiving structured treatment) use this feedback method. Information is captured every 24 weeks and is available to view in [Tableau here](#).

## Things to consider

Additional background information can be obtained by colleagues at Change Grow Live on the SUI Tableau dashboard.

## Benefits

This feedback method provides measures of satisfaction and involvement within decision making which can be compared across services and time. This method has been used to gain assurance around service delivery during inspections and identify changes in the experiences of people using our services which can then be explored using one of the many qualitative feedback methods previously mentioned.

## Accessing Treatment Outcome Profile Form

Local, regional, and national data leads will be able to support gathering SU feedback from the treatment outcome profile form. In addition, this data can be viewed by any staff member with access to [Tableau](#).

## Exercise 4: Recognising what you are already doing

Consider how you hear the views of people using services in your area.

Make a list of all the ways that people using services provide their views (formally and informally). How is the information gathered and acted upon?

## Co-production: Full involvement in listening and responding

Our ambition at Change Grow Live is to develop ways in which people using our services can have an active voice and be involved in co-producing services and activities. The aim of co-production (sometimes referred to as Patient and Public Involvement or PPI) is to involve people using services and the public as partners.

Co-production aims to create a culture that values all expertise and knowledge, particularly the expertise and knowledge of the people that are most affected by the problem and solution. Co-production can be used to inform better ways of working, improve the overall quality of a project, and enable better outcomes.

Full co-production is recognised to involve four phases: co-design, co-planning, co-evaluation, co-delivery. Any of the four can be used on their own or in conjunction with the other three. It is for teams to decide how they involve people and what level of co-production they can accommodate within a project.

### Four phases of co-production

#### Co-planning

In co-planning, professionals and communities work together to agree on the problem to be solved, who to involve, which approaches to take, timeframes, funding and how initiatives might be managed.

#### Co-design

In co-design, professionals and communities work together to define the problem, develop ideas and test solutions. The ongoing delivery of the resulting solution might be done without their on-going involvement.

#### Co-delivery

In co-delivery, professionals and communities work together to agree how the initiative will be delivered, who should do what, where and how.

#### Co-evaluation

In co-evaluation, professionals and communities work together to agree what success looks like, what should be measured, whose opinion or view of the initiative should be sought or how data about the performance of the initiative will be secured.

The above diagram is taken from [‘Co-production putting principles into practice.’](#)

## Co-production in practice

Full co-production and service user involvement (SUI) can be a useful approach for some projects and streams of work. In this section, we provide an outline for how you can include SUI at the various stages of a project. For more information, please see the handbook on patient and public involvement created [by the NHS National Institute for Health Research.](#)

## 1. Identifying & prioritising

People using services and the public can:

- > Help inform priorities (e.g. through local user groups and organisations).
- > Be consulted about topics and priorities important to them.
- > Collaborate with staff to identify topics for projects and streams of work.
- > Identify topics for projects and streams of work themselves.

## 7. Monitoring and evaluation

People using services and the public can:

- > Have continued involvement with the project to maintain focus and address issues as they arise.
- > Collaborate with staff to evaluate the project process.
- > Reflect on their role and what they have learned.

## 6. Implementation

People using services and the public can:

- > Increase the likelihood that projects are implemented.
- > Develop information for new services/interventions within the community.

## 5. Sharing learning

People using services and the public can:

- > Advise on different avenues for sharing news about the project.
- > Jointly present updates alongside staff.
- > Write information for local patient groups/hospitals, etc.
- > Help distribute project updates within their informal networks.

## 2. Design

People using services and the public can:

- > Inform the design of the project or stream of work.
- > Clarify the reason it is happening and affirm its importance.
- > Ensure the methods selected are appropriate.
- > Assist in creating a strategy.
- > Review and comment on proposed methods.

## 3. Undertaking the project or stream of work

In setting up a steering group to manage or monitor the project or stream of work, people using services and the public can:

- > Steer the project throughout.
- > Help ensure the project or stream of work is ethical and acceptable to people impacted.
- > Aid in designing the detailed protocol.
- > Produce accessible and appropriate project updates.
- > Assist in conducting interviews and surveys.

## 4. Analysing and interpreting

People using services and the public can:

- > Assist the team in developing the project.
- > Be consulted to check whether they interpret the outcome and success in the same way as the staff team.



## Feedback loops

In order for SUI to work well, the resulting changes need to be seen and celebrated. SUI does not work as well when a person tells us something and they feel like their opinion disappears or that it is ignored. This can lead to distrust and a perception that SUI is tokenistic. It can also feed internalised stigma and can contribute to a person's low self-worth and the belief that their voice does not matter. Negative experiences around SUI also make it unlikely that the person will contribute again. Below is a diagram which shows how feedback loops are essential for ensuring views are shared and that there is an opportunity to act on what is being said.

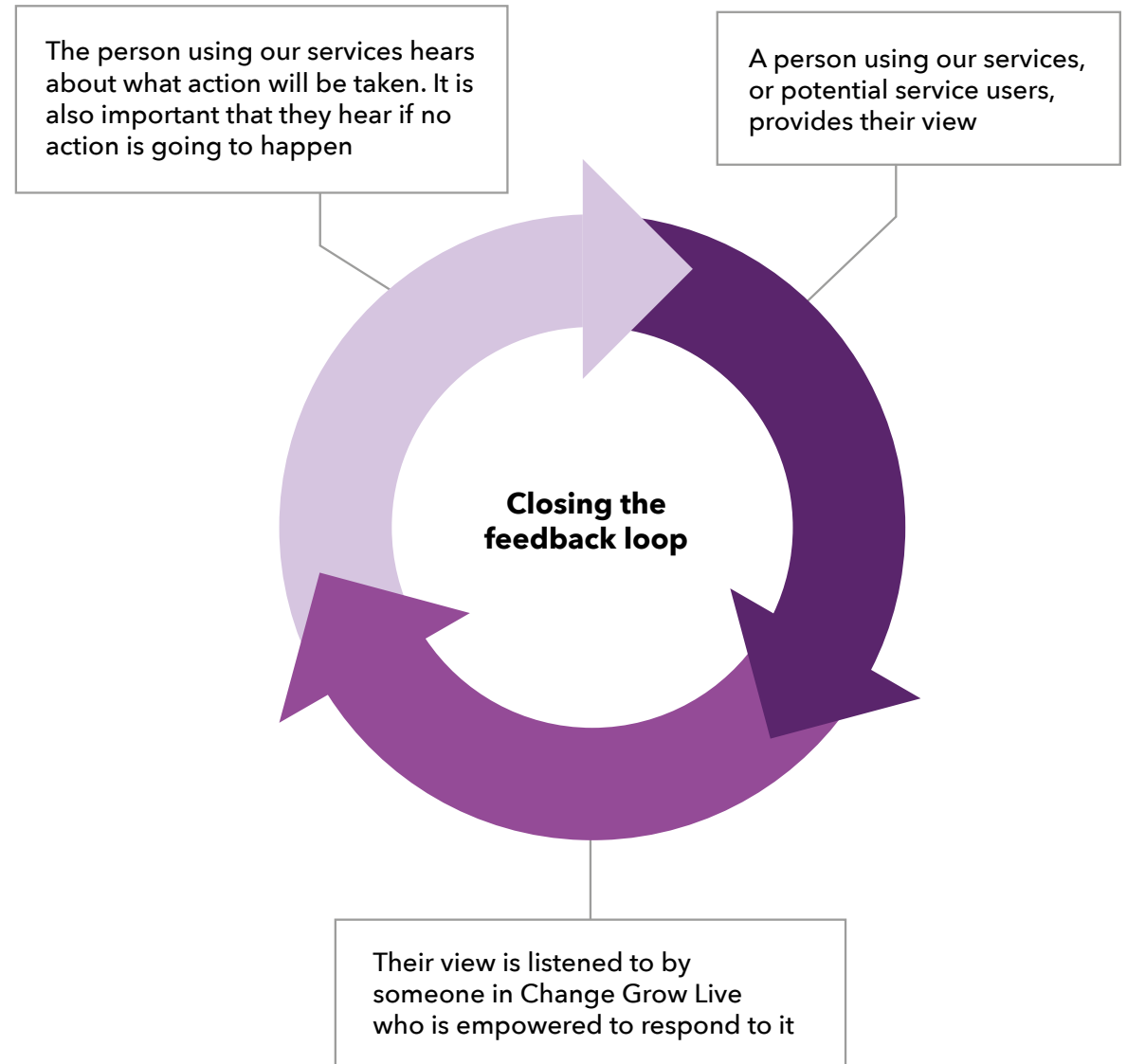


Diagram 2: Feedback loops

## Escalation and closing feedback loops

It is important that we acknowledge when feedback has been given and that the person who gave it gets regular updates about what is happening with it.

If we have the ability to respond to a service user's opinion in the moment it is given, we should. This could be online, in a forum, a meeting or any other time, space or place where we listen. It is important to ask the person how they would like to be responded to. If you can, offer a response in person or over the phone rather than only putting it in an email or a letter.

We recognise that sometimes there will be barriers or challenges to closing feedback loops. The diagram below illustrates how people working and volunteering within Change Grow Live can escalate when feedback cannot be responded to locally.

At Change Grow Live, we recognise that feedback loops work in both directions with platforms like Care Opinion helping connect central services to feedback given about local services.

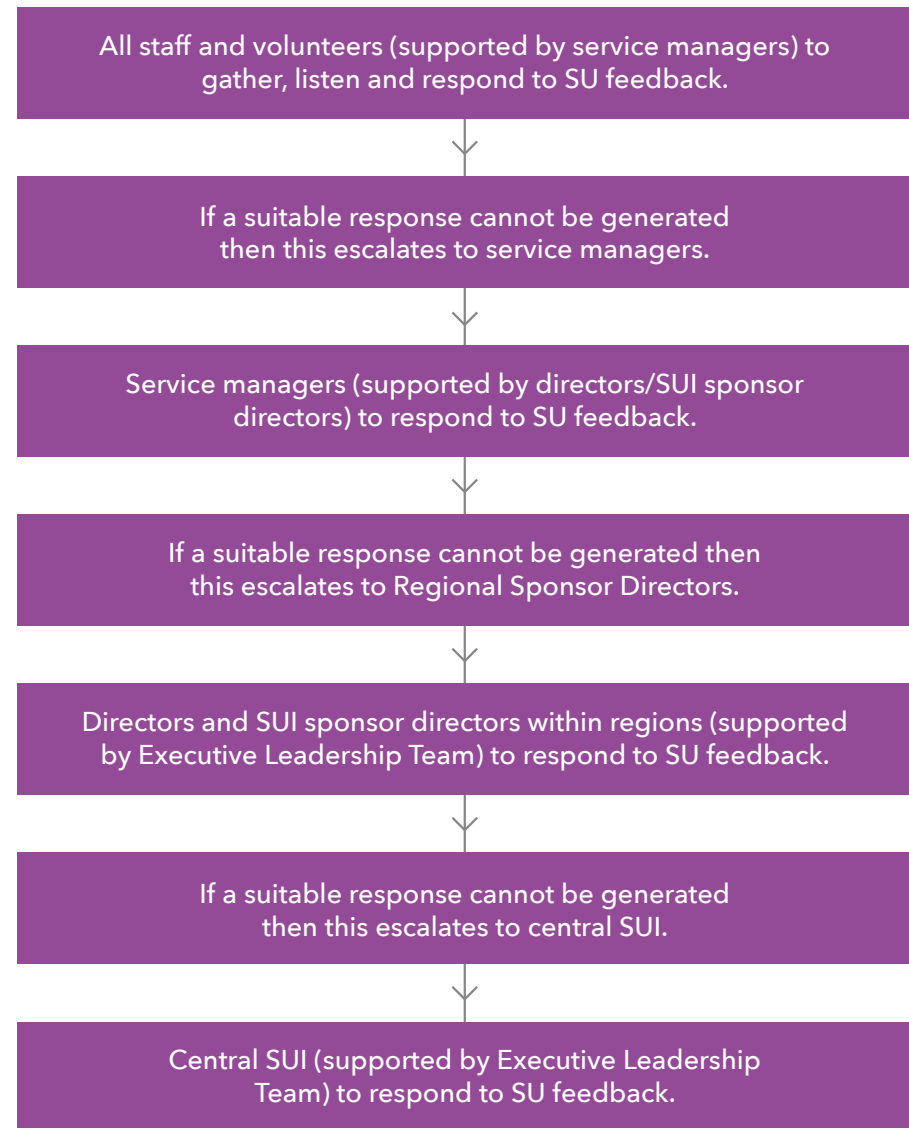


Diagram 3: Responding to Feedback

## Key principles and ethical considerations

There are, of course, ethical considerations to Service User Involvement. We have developed the following principles to guide people when carrying out SUI:

- > Be committed to creating an environment that respects and values diversity, with a positive and supportive culture where everyone feels welcome, empowered, and represented
- > Be considerate of involving people from a wide range of cultures, communities, circumstances, backgrounds, and ages. Make sure that information about being involved is easy to find and understandable
- > Be clear with people about the purpose of their involvement and how their contributions will be used
- > Recognise the skills and experience of everyone involved. Work in a way that is open, flexible, and accessible. Offer a range of ways to be involved and ensure people are comfortable with how they are involved
- > Recognise people's commitment and contribution and ensure that feedback is provided so everyone feels valued and respected
- > Make sure that involvement opportunities make a real contribution
- > Measure, review, and report on the outcomes of involvement activities
- > Work with other relevant organisations and agencies to develop and share good involvement practices

## Do I need to get formal consent?

One of the most commonly asked questions regarding ethics and SUI is whether you need to obtain formal consent for a project as part of the service user involvement plans. While you do not need to obtain formal consent to involve people in your projects, the National Research Ethics Service (NRES) and INVOLVE provide the following advice:

*'The active involvement of patients or members of the public does not generally raise any ethical concerns for the people who are actively involved, even when those people are recruited for this role via the NHS. This is because they are not acting in the same way as research participants. They are acting as specialist advisors, providing valuable knowledge and expertise based on their experience of a health condition or public health concern. Therefore, ethical approval is not needed for the active involvement element of the research (even when people are recruited via the NHS) where people are involved in planning or advising on research e.g. helping to develop a protocol, questionnaire or information sheet, member of advisory group, or co-applicant.'*

While no formal consent is required for SUI, it is generally recommended to draw up terms of reference for service users involved in research or co-production. This ensures that both parties are fully aware of the level of involvement and the associated expectations towards each party.

You can find the full NRES INVOLVE Statement [here](#).

If you work at Change Grow Live and would like to undertake research, then you must contact our central research and innovation team who will be able to guide and advise around ethical clearance for studies.

# Service User Involvement (SUI) at Change Grow Live

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Change Grow Live is the largest third sector drug and alcohol treatment provider in the United Kingdom. We have over 100 services across the country, organised into three regions (the North, the South, and the Midlands). This means we impact on the lives of hundreds of thousands of service users and their families. Service user involvement means that we hear their voices and respond to what they are saying.

There are at least 82,665 people using our services currently. Imagine the power of those voices if we all work together to listen, share, and respond to what people using our services are telling us.

## Levels to participation at Change Grow Live

Service user involvement (SUI) is an ongoing journey, and we will always be in a position where we want to do more of it. The model below highlights ways to think about different levels of participation. Ultimately, it is the responsibility of people working within the project to create conditions best suited for meaningful SUI and appropriate participation.

*'I hope I can become more actively involved again and become a volunteer' - Change Grow Live service user, 2022*

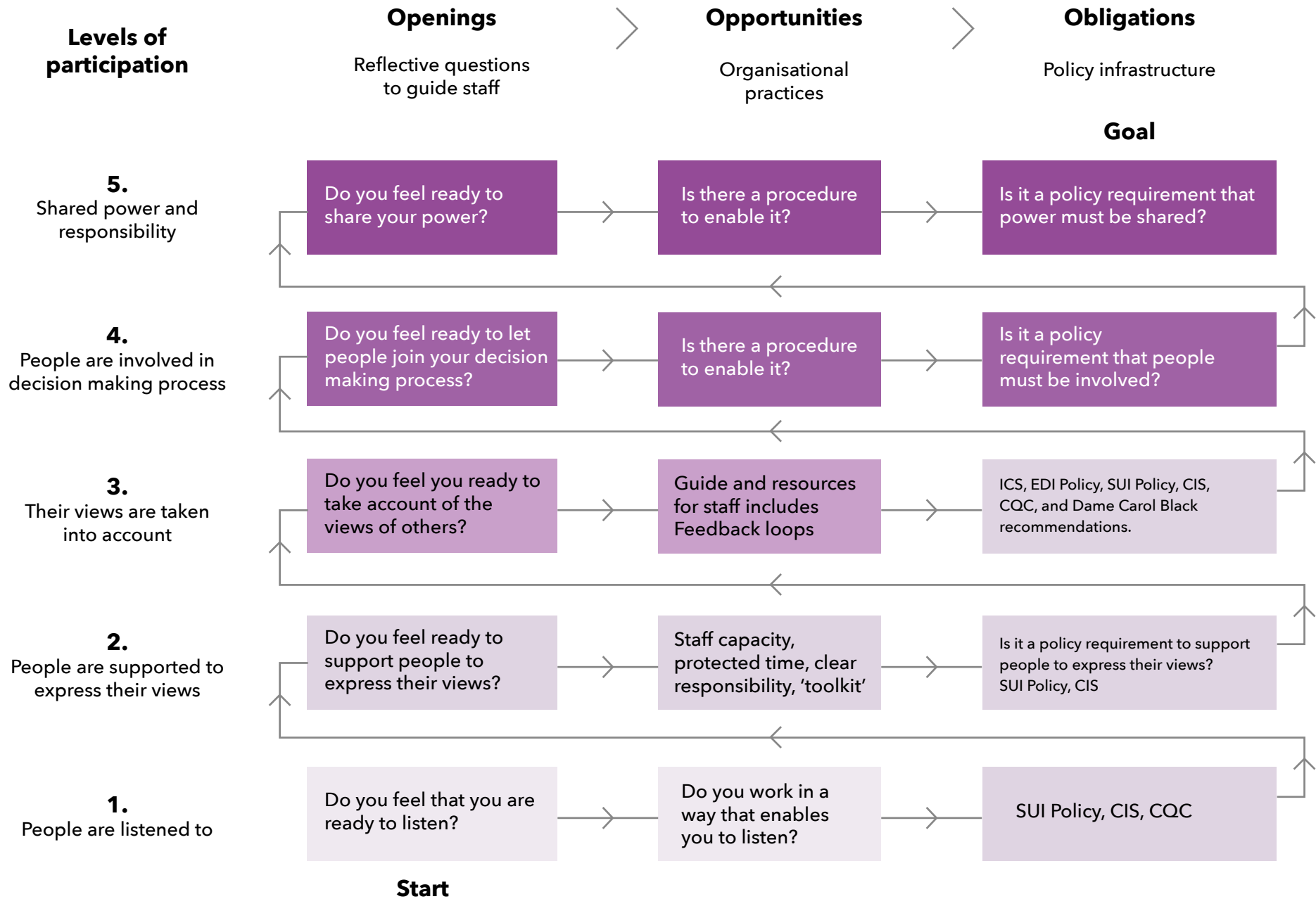


Diagram 4: Pathways to Participation at Change Grow Live

## Central Service User Involvement Team

Change Grow Change Grow Live's Central Service User Involvement team is responsible for providing support to our teams across the country, helping to release this potential.

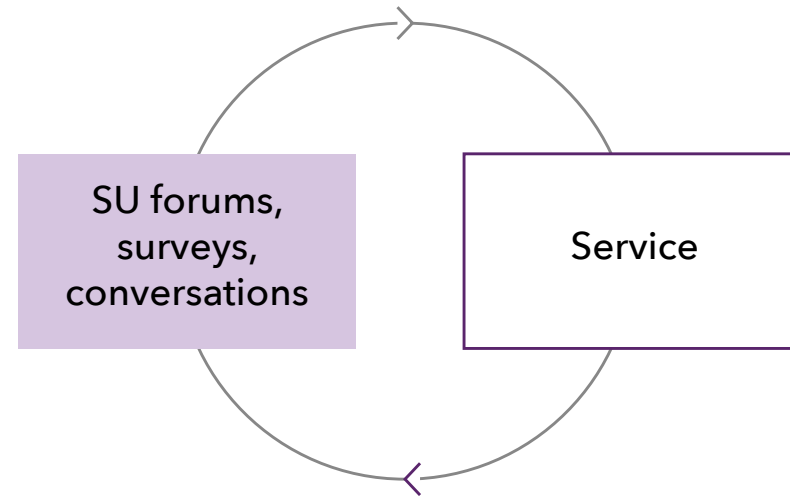
The table below shows how the Change Grow Live SUI Team collaborates with other central services and how feedback directs change. This way of working means that we can all help to break down barriers so that feedback can get back to those making decisions and responses can be implemented quickly.

Central Team	Collaboration opportunity
Human resources and volunteering	Inform decision making around recruitment and retention of staff/volunteers
Learning and Development team	Provide and create training/resources to benefit the people we serve
Change team	Provide assurance and ensure the SU voice influences current & future organisational change.
Business development	Shape what new services offer, share organisational developments with others such as (commissioners and local government).
Research and innovations team	Undertaken research to understand experiences, evaluate current/new ways of working. Create new knowledge.
Marketing and communications	Share what we hear and do with others throughout the country.
Digital and IT	Update, change and create effective digital options which meet the needs of people accessing services.
Volunteering	The national volunteer management team is responsible for supporting services with volunteers and peer mentors, helping them recruit and manage volunteer opportunities.

None of the above would be possible without feedback from services and our teams across the country.

## Local Feedback

Local feedback refers to the collection of feedback in a local area/service. It is often used to inform local decision making but can also be shared to influence service delivery elsewhere in the organisation.



Local feedback can be used for assurance purposes, for example in inspections by regulators or contract reviews. It can also be used to develop, innovate, and improve what is already being offered by a service.

A service may not also be able to respond to the feedback they receive. For example, a decision maker may not be available, or available funding may prevent a specific response. Sharing the reason why a change cannot happen is important as people need to know that their feedback was considered.

If services are experiencing barriers to responding, it is important to share these with regional and central teams who may be able to make changes and reduce barriers to responding.

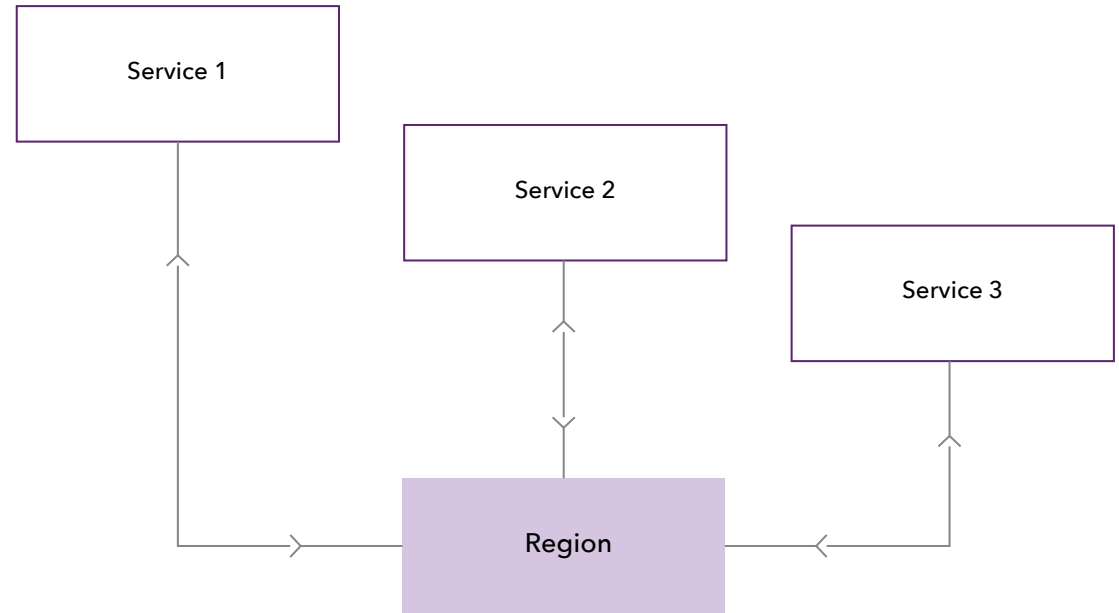


## Regional feedback

### Sharing challenges and responses across services within a region

Regional feedback happens when multiple services within a region share their feedback with each other. Regional service user forums/ cluster meetings occur throughout the year in different areas and provide a way for services to share ideas, challenges, feedback and learning in relation to listening, and responding to feedback. For example, where one service does not have the room to accommodate a support group, another service may have already responded to this barrier by finding a suitable venue within the community to host the group.

At Change Grow Live, services come under one of three regions - the North, the South and the Midlands. Within each region there is a dedicated 'Service User Involvement Sponsor Director' who supports service user involvement. The Service User Involvement Sponsor Director is responsible for supporting and championing SUI within their prospective regions. They achieve this by organising regional service user forums and meetings, service user events and supporting individuals' services around challenges for service users.



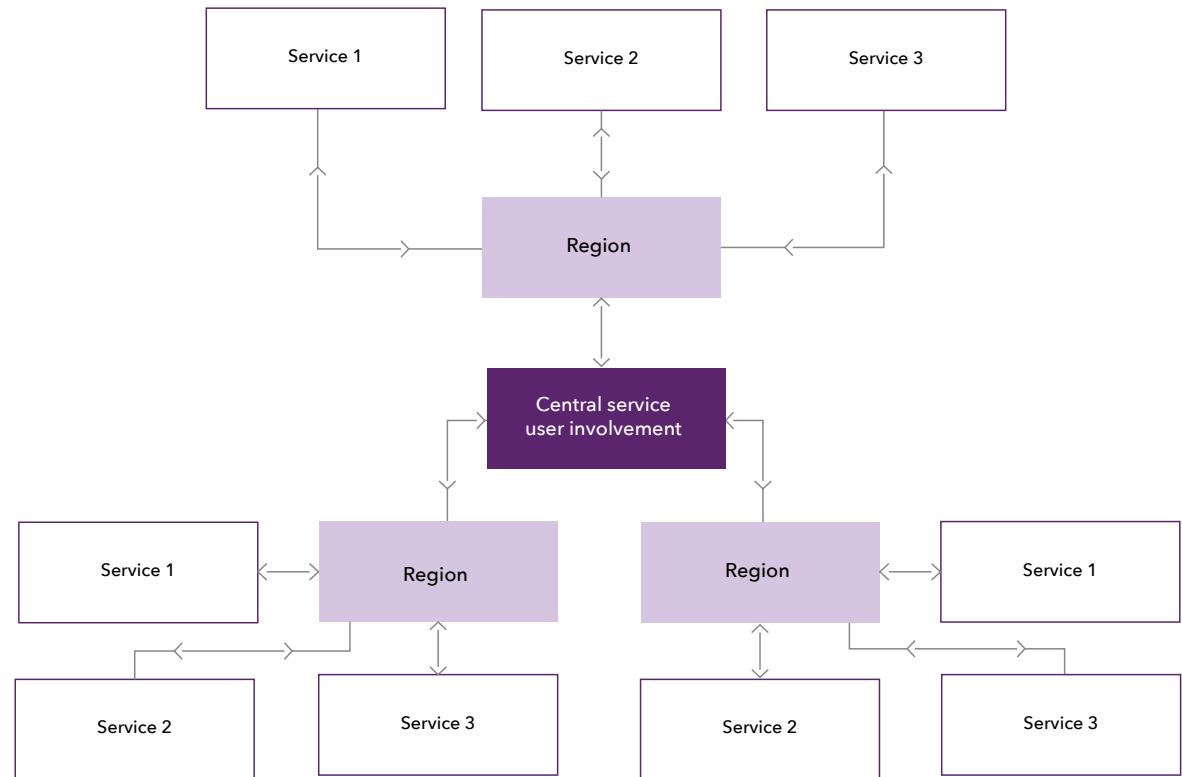
Sharing and discussing feedback at a regional level promotes innovation across different services and helps services work together to devise new responses. For example, regional feedback can be shared with local health watch boards to highlight the needs of people using services and potentially secure additional funding for specific areas.

## National feedback

At Change Grow Live, the Central Service User Involvement (SUI) Team and National Lived Experience Group (NLEG) work to develop and support SUI nationally. Gathering and responding to national feedback often requires more time than with local and regional feedback. This is because national feedback:

- > Involves listening to more people
- > Involves more planning and coordination
- > May be impacted by wider factors such as the law, regulators, and guidance from the Office of Health Improvement and Disparities
- > Can require additional work such as undertaking additional consultations or research

The benefit of national feedback is that it has the potential to have impact across the sector. National feedback can help us to have a bigger impact for example influencing and changing things such as policy.



## Case studies

The following stories and case studies are drawn from across the UK to provide examples of where Change Grow Live is successfully embedding SUI and where it is leading to positive change.

### **Identifying hidden trends using web chat:**

Change Grow Live's Central SUI team found that analysing web chat messages from our website highlighted trends ahead of traditional data sources and provided a unique real-time insight into drug use in communities around the UK.

For example, in response to increasing conversations happening around cocaine and illicitly used prescription medications during COVID lockdown, Change Grow Live developed harm reduction guides which were hosted on the website. Making this information more readily available meant a better experience for people using our services and reduced pressure on the team responding to the webchat conversations.

**Identifying specific groups' needs via feedback:** In 2019, Change Grow Live used feedback from veterans to deliver veteran specific support services and develop a strategy to raise veterans' awareness of this support.

Change Grow Live has since signed the [Armed Forces Covenant](#) and given teams, where there are a high number of veterans using our services, specialist training and literature. These materials were co-produced with veterans.

### **Survey responses and changes to Medication Assisted Treatment (MAT):**

Change Grow Live's 'Service User Pulse Survey' was launched in June 2020. It has since received over 6000 responses which have informed decision making as well as [published research](#). The survey is currently the largest qualitative survey undertaken to explore the experiences of people using drug and alcohol service in the UK and can be accessed [here](#).

For example, the pulse survey showed how many people benefited from changes to prescribing during the pandemic. The feedback revealed how less restrictive prescribing regimes empowered people to take ownership of their medication and make positive changes to their lives as a result.

One person using our services commented that: 'Collecting medication fortnightly means I can do overtime at work.' Another person spoke about how it meant they had 'no temptation to use' as they were 'not bumping into people daily.' This kind of feedback was influential to the organisation adopting one weekly pick up instead of daily supervised consumption where appropriate.

# Co-creating what works at Change Grow Live: What happens next?

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We will roll this guide out nationally as a SUI Resource. It will be piloted and tested with a number of selected services to develop further. Once we have a fully developed SUI resource, accompanied with additional support for its implementation, we want to share it with other organisations to inspire further development in our sector.

Our full guide will:

- > Support organisational decision making
- > Provide assurances and develop what we do as an organisation
- > Provide us with the evidence base to influence national conversations

By refreshing and energising our approach to SUI, we are giving ourselves a tool to be able to understand the experiences of the diverse populations we serve and make evidence-based decisions at local, regional and national levels.

By working together, we have the potential to amplify the unheard voices of marginalised people and make sure that they are heard by people who have the power to make change happen.

## Help us to improve this guide

Please tell us what you think about this guide by using [this online form](#). Your feedback will help us make future developments to this guide.

## Additional resources and further reading

Bieler, M., Maas, P., Fischer, L., & Rietmann, N. (2022). [Enabling Cocreation With Transformative Interventions: An Interdisciplinary Conceptualization of Consumer Boosting.](#) *Journal of Service Research*, 25(1), 29-47.

Boyle, D. & Harris, M. (2009). [The Challenge of Co-Production: How equal partnerships between professionals and the public are crucial to improving public services](#) (). NESTA, New Economics Foundation, The Lab.

Cahn, E. 'No More Throwaway People: The Co-production Imperative.' Washington DC: Essential Books.

Hugh McLaughlin, [What's in a Name: 'Client', 'Patient', 'Customer', 'Consumer', 'Expert by Experience', 'Service User' –What's Next?](#), *The British Journal of Social Work*, Volume 39, Issue 6, September 2009, Pages 1101-1117.

Karen P. Hayhurst, Zoe Welch, Chris Barnes, Mark Pryke & Tim Millar (2022) The shift from face-to-face to remote care during the COVID-19 pandemic: a qualitative survey analysis of users of UK drug and alcohol services, *Drugs: Education, Prevention and Policy*.

Ostrom E. Crossing the great divide: co-production, synergy, and development. *World Dev.* 1996;24(6):1073-87.

Masterson D, Areskoug Josefsson K, Robert G, Nylander E, Kjellström S. (2022) Mapping definitions of co-production and co-design in health and social care: A systematic scoping review providing lessons for the future. *Health Expect*, 25(3). 902-913.

Michie, S., van Stralen, M.M. & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Sci* 6, 42.

Roper, Grey and Cadogan, (2018). From Co-production Putting principles into practice in mental health contexts. *International Journal of Mental Health Nursing*, 27(4), 1201-1203.

Stephens, L., Ryan-Collins, J. and Boyle, D. (2008) 'Co-production: A Manifesto for Growing the Core Economy.' London: new economics foundation.

Turk E, Durrance-Bagale A, Han E, Bell S, Rajan S, Lota M M M et al. International experiences with co-production and people centredness offer lessons for covid-19 responses *BMJ* 2021; 372:m4752.

## Useful websites

[Care Inspectorate Improvement Strategy](#)

[Care Quality Commission Strategy](#)

[Nesta](#) design, test, and scale new solution to society's biggest problems. They offer a variety of services including, data analytics and experimentation techniques.

[Nonformality](#) has a library of information on the origins of different models and theories of participation.

