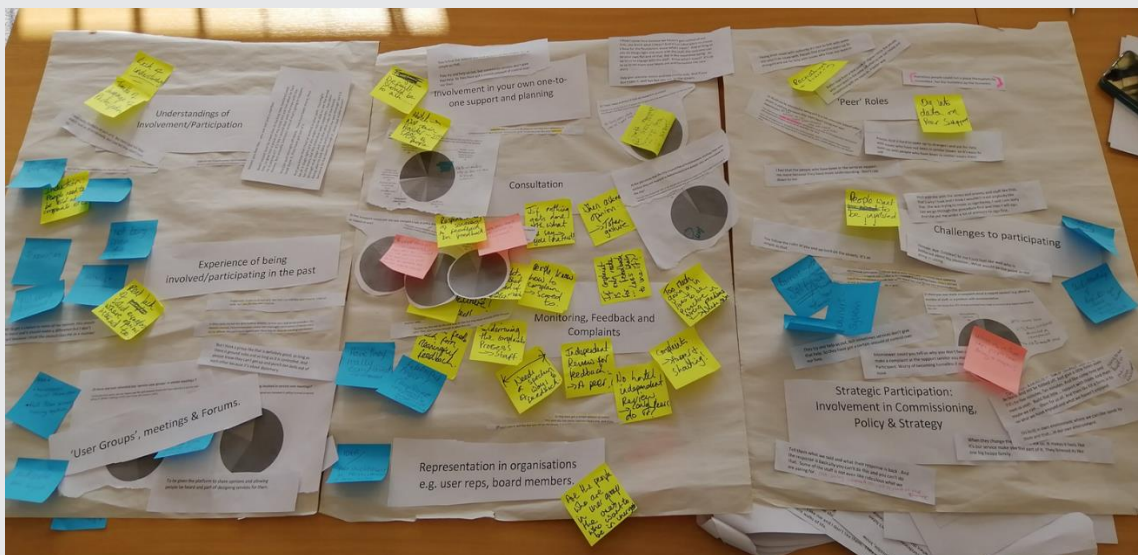


Newcastle Voices Peer Research Report June 2019



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Acknowledgements and Thanks

This research would not have been possible without participant's kindly taking time to speak to us and share their experiences, we would like to thank them for their insight.

Thank you to the Newcastle Homelessness Prevention Trailblazer Programme who funded this research and to Newcastle City Council for their support and collaboration with this project.

We would also like to thank and acknowledge the following organisations Newcastle City Council, Your Homes Newcastle, Crisis, Shelter, Changing Lives, Fulfilling Lives Newcastle and Gateshead, Home Group, Mental Health Concern, St Vincent Depaul, Depaul, praxis, West End Food Bank, The People's Kitchen and Tyne Housing Group for their insight and support. We would also like to thank volunteers from St Vincent De Paul for their assistance.

We are indebted to the members of the Steering Group for their guidance and support. Lastly, a very special thanks the peer researchers Danielle Gardner, Paul Adamson for their commitment, enthusiasm and passion throughout this project.

Introduction

This report sets out the findings of the peer research carried out as part of the Newcastle Voices project. The project was commissioned by Newcastle City Council and delivered by Groundswell to explore how people who are experiencing homelessness, or at risk of homelessness, can participate in the design, delivery and decision making in support services. This involved a mapping exercise to establish current involvement and participatory work within homelessness services and to identify existing good practice and a Peer-led research study with participants who are currently or at risk of being homeless. This research is the first stage of the Newcastle Voices project and serves as a starting point rather than a standalone project. The next phase of the project involves developing a toolkit for participation in Newcastle. This toolkit will include recommendations for this research from participants, the steering group and Groundswell and will also include guidance for how organisations and service can increase and improve participation.

Peer researchers supported by Groundswell played a central role in this project mainly in co-designing and delivering a questionnaire with people experiencing homelessness to find out how they would like to be involved in influencing decision making. The aims of the project were:

- To work with stakeholders across Newcastle to move service user representation towards meaningful participation across service design and delivery
- To improve understanding to inform Newcastle’s quarterly homelessness reviews
- To ensure that the views of people with experience of homelessness and the risk of homelessness participate in local decision making about these areas

This report concludes in our own suggestions and those made by research participants as to how support services and the City Council could offer opportunities for people who use services to participate in decision-making.

Groundswell’s history is founded on participation and was originally established in 1996 as part of a campaigning project within the National Homeless Alliance. Our aim then (and still is) to support people experiencing homelessness, so that they can be at the heart of creating and delivering solutions to homelessness. Today we continue to support participation of people experiencing homelessness through health advocacy and peer research. Groundswell has a long history and strong reputation for participatory processes is evidence in the expansion of their services nationally and winning the GSK Kings Impact Fund Award in 2016. Groundswell is therefore well placed to lead the Newcastle Voices Project.

What is participation?

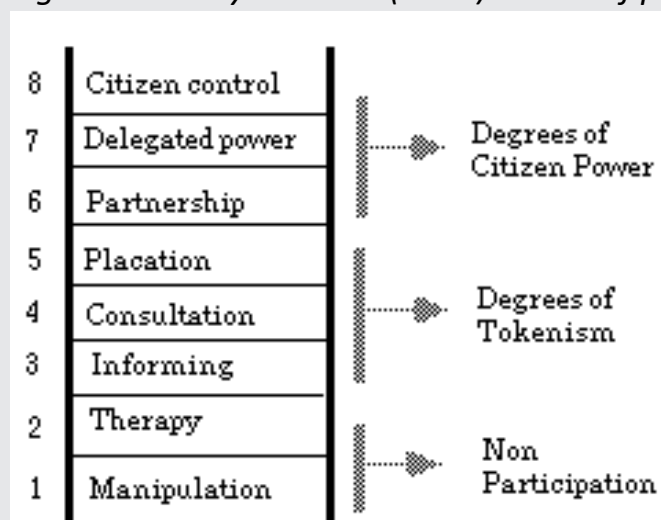
The concepts of participation, co-production, consultation and engagement are all connected. Participation is defined by Tikare and Youssef et al (2001:3)¹ as “the process through which stakeholders influence and share control over priority setting, policy-making, resource allocations and access to public goods

¹ Tikare S, Youssef, D, Donnelly-Roark, P, Shah, P. (2001). ‘Organising participatory processes in the PRSP’

and services”. Whereas, Bovaird (2007: 846)² argues that “the co-production approach assumes that service users and their communities can – and often should – be part of service planning and delivery”.

From exploring definitions of these concepts, it is apparent that the idea and practice of participation can be enacted in different ways and in varying contexts. Consequently, there are a variety of views on how participation is defined, who is included, what the expectations of it are and how it should be enacted. However, one common theme in all definitions is that participation always involves some form of decision-making, and that this is on a continuum. This idea of participation as a continuum and as a graduated and developing process was suggested by Arnstein (1969)³. As illustrated in the diagram below, Arnstein argues there are eight types of participation which begin from manipulation and end in citizen control. The ladder symbolises the fact that each step needs completed before the next can be achieved.

Figure 1: Sherry Arnstein (1969) ladder of participation



However, the ladder has been critiqued for being one dimensional, not considering different levels of participation and its suitability within a health and social care setting has been questioned. A practical example of a model

² Bovaird, T. (2007) Beyond Engagement and Participation: User and Community Coproduction of Public Services. *Public Administration Review*, 67:5, p. 846 – 860. Available open access at: <https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1540-6210.2007.00773.x>

³ Arnstein, S.R. 1969. “A Ladder of Citizen Participation,” *Journal of the American Planning Association*, vol.35, No. 4, July 1969, pp. 216-224.

developed is from National Service User Network (NSUN)⁴ – a network of people and groups living in England who have and do experience mental distress. NSUN developed an involvement and participation set of standards centred on ‘principles’, ‘purpose’, ‘presence’, ‘process’ and ‘impact’. The practical application of these models will be explored in more detail within the forthcoming toolkit.

As part of the Newcastle Voices project we felt it was important, and of course in the spirit of participation, to develop a working definition that works in the Newcastle context so that commissioners, service users and service providers are all on the same page.

Working with Peer Researchers we developed a working understanding of what the core elements of participation are (see below). This was used and updated through the course of designing and delivering the Peer Research project, informing research tools but also used as an anchor for discussions in every research meeting. The following diagram displays the core elements that Peer Researchers identified as being part of participation; these elements suggest that participant is a two-way process.

⁴ National Service User Network (NSUN) is a network of people and groups living in England who have and do experience mental distress and want to change things for the better. NSUN created a National Involvement Standards in mental health to improve involvement in the planning, delivery and evaluation of mental health services. The report can be viewed here:
<https://www.nsun.org.uk/Handlers/Download.ashx?IDMF=995617f8-1cd7-40af-8128-5eaaf2953b8e>

Figure 2: Core elements of participation as defined by Peer Researchers



Methodology

A steering group was established and attended by peer researchers, Newcastle City Council, representatives of local organisations. This group's aim was to:

“To ensure that the objectives of the Newcastle Voices Project are achieved by guiding and overseeing the implementation of the Project; sharing members knowledge, skills and experiences to inform the decisions made and actions taken to achieve the outcome of embedding the views of residents with experience of being at risk of homelessness, threatened with homelessness, or experiencing homelessness, in the review structures and decision making of the Local Authority” (Steering Group Terms of Reference).

Based on the research objectives, a mixed methodology that used quantitative, qualitative approaches as well as secondary data analysis. The methods adopted included focus groups, surveys and an online questionnaire for stakeholders. Using a mixed-methods approach allows for different types of information to be accessed giving a more comprehensive understanding of the topic being explored

Mapping of services questionnaire

Groundswell in consultation with the steering group designed an online questionnaire as a tool to be able to understand existing levels of participation across homelessness and housing services in Newcastle. The questionnaire was designed based on the National Survivor User Network 4Pi National Involvement Standards. The online questionnaire was sent out to service providers and commissioners across the city. The questionnaire had 12 completed responses from the City Council, Your Homes Newcastle, Crisis, Shelter, Changing Lives, Mental health Concern, Depaul and Tyne Housing Group. Each of these services completed one response apart from Your Homes Newcastle, Depaul and Changing Lives who responded twice.

Peer Research

The research employed a peer-led methodology with input throughout the design and delivery of the project from people with lived experience of homelessness. This also included all data collection which was centred on focus groups and one-to-one survey-based interviews.

Training & Preparation

Two volunteer Peer Researchers participated in the training and delivered the fieldwork. To support them to do this, we delivered a tailored training programme including confidentiality, consent and boundaries; the history of peer research; best practices in managing bias and pre-understanding and training on the employed research methods and techniques. During the training, researchers developed skills through practical and hands-on tasks and exercises where they tested and developed the tools while honing their own existing research skills. At the end of the second day of training Peer Researchers had developed a draft focus group topic guide and had refined consent forms and information sheets.

Focus Groups

The focus group guide was refined with the input of the steering group, and then was piloted in a Newcastle based homelessness service. The focus group topic guide was then updated based on learning from piloting which was used in further groups. In total seven qualitative focus groups were delivered in temporary accommodation, healthcare centre (Joseph Cowen House) and a day centre with a total of 38 participants. All focus groups were co-facilitated by an experienced Groundswell staff Peer Researcher and a volunteer Peer Researcher. All focus groups were audio recorded and professionally

What is Peer Research?

Peer research works with people from a community as co-researchers for the entirety of the research process from research design, data collection, data analysis and write up. This means, rather than simply being passive research subjects, peer researchers are actively engaged in research. The key advantage of taking this approach is that peer researchers can reduce problematic power relationships that can exist when interviewing people who are experiencing social exclusion, often resulting in richer data.

transcribed, then coded and using NVivo⁵. Informed consent was sought and received from all participants who took part.

One to one survey-based interviews.

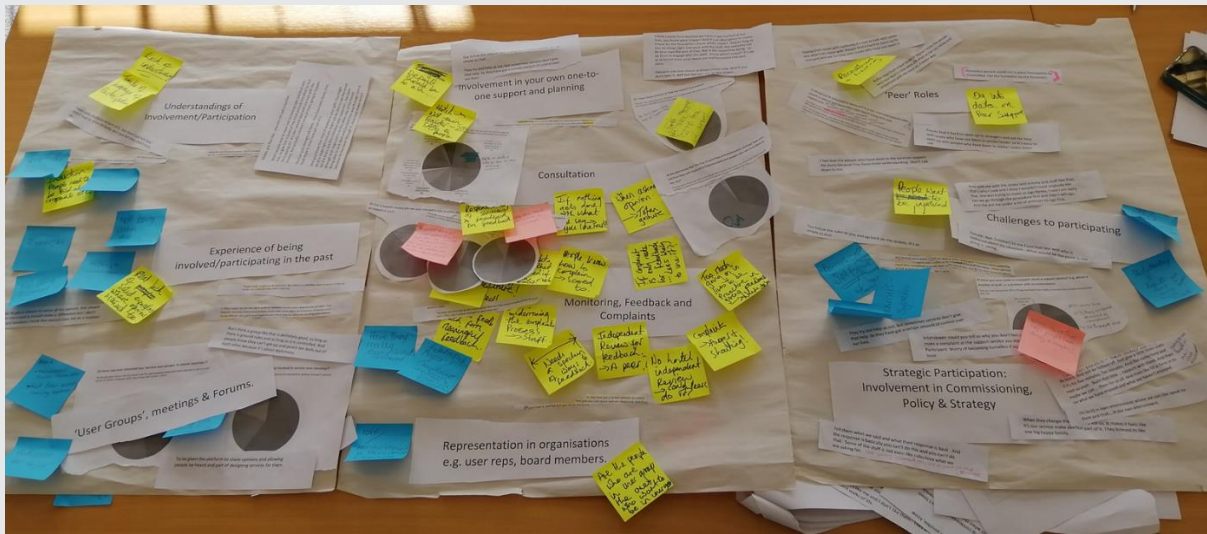
From the focus group topic guide a survey was developed by Groundswell staff. This was tested and refined by Peer Researchers before data collection. Surveys were quantitative based, but with qualitative follow-up questions to give more depth and insight around experiences on particular issues. The approach taken with the survey was to at first ask people about their own experience of participation in personal support, moving to experiences of services then to wider engagement with Newcastle City Council and other partner organisations. Therefore, through the course of the survey capturing experience and opinions at a broader levels. All data collection was completed on tablet computers with 60 delivered face-to-face a range of places including two day centres, a food bank and a training and education centre. A further ten survey-based interviews were conducted by telephone following referrals from Newcastle City Council, a housing association and a housing advice charity. Informed consent was sought and received from all participants who took part.

Analysis of data

To ensure the Peer Researchers were involved at all stages of the process, an analysis session was run in early April with Peer Researchers to feedback and steer the direction of further analysis. The workshop offered an opportunity for them to reflect, scrutinise and offer explanation around where different variables may have interrelated. The workshop was then used by Groundswell staff to conduct further analysis. The structure of this report, and how data has been presented, is based on the workshop.

⁵ NVivo is a qualitative data analysis computer software package produced by QSR International.

Figure 3: Peer research workshop analysis



Participant Profiles

Demographics of Participants

The participants in the Peer-Research phase of the project represented a broad range of backgrounds and demographic characteristics. The following is a breakdown of these characteristics – notably this is based on self-reported data.

Table 1: Table showing demographics, backgrounds and characteristics of research participants

Demographics, backgrounds and characteristics	Percentage
Gender	<ul style="list-style-type: none"> • 36.8% women (including trans women) • 63.2% men (including trans men)
Age	Age range 17 to 63 <ul style="list-style-type: none"> • Under 20 years – 5% • 20-29 years - 18% • 30-39 years – 32% • 40-49 years – 25% • over 50 years – 20%
Ethnicity	<ul style="list-style-type: none"> • 88% white British
Religion	<ul style="list-style-type: none"> • 42% Christian/Church of England • 41% atheist
Sexuality	<ul style="list-style-type: none"> • 83% heterosexual • 7% gay men • 7% bi-sexual • 3% prefer not to say
Pregnancy	<ul style="list-style-type: none"> • 11.4% of women
Registered with a GP	<ul style="list-style-type: none"> • 95%

The following table illustrates the current living situation of research participants:

Table 2: Table showing current living situation of research participants (%)

Current living situations	Percentage
Housing association/council properties	18%
Private rented accommodation	15%
Hostel	54%
Staying with friends	9%
Street homeless	3%

Of the research participants, 36% reported that their accommodation issue affects only themselves (i.e. there is not child or partner effected by their housing issue) where 31% have a child under 18 and 12.1% had a partner (including by marriage). The following table illustrates the length of time the

research participants who had an accommodation issue (92% of participants) had been experiencing their housing issue for.

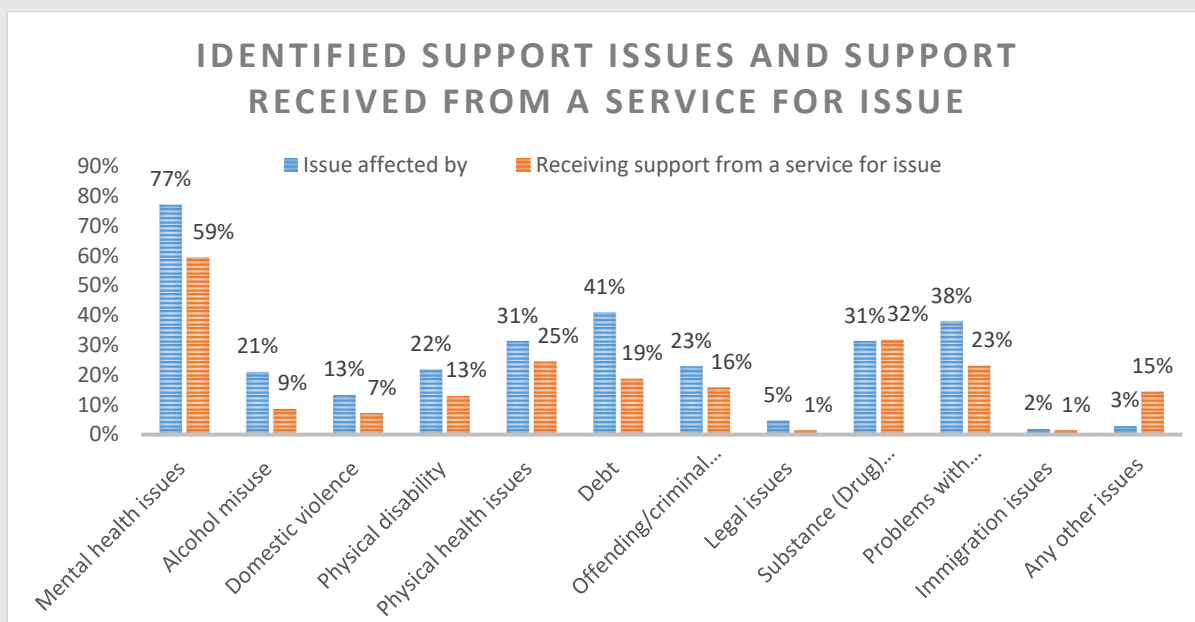
Table 3: Table showing how long research participants had experienced current housing issue (%)

Length of time experiencing housing issue	Percentage
Less than a month	11.5%
Over 1 month but less than 3 months	6.9%
Over 3 months but less than a year	25.3%
Over 1 year but less than 2 years	23%
Over 2 years but less than 5 years	18.4%
Over 5 years but less than 10 years	5.7%
10 years or more	9.2%

Support from services

While not the primary aim of the study, some insightful data was captured around participant’s self-reported needs and these are supported by services. For example, the questionnaire asked participants to report which type of service was their primary source of support and while over half of participants (54%) reported to live in hostels or other supported accommodation, only a quarter of these (27%) reported that their accommodation service was the main service that they use. The questionnaire also asked participants to identify issues they felt had an impact on their accommodation, and which they received support around. The following table demonstrates responses;

Figure 2: Graph showing identified support issues and support received from a service for issue



The chart reveals that for almost all identified areas of need that participants reported to be facing, a proportion were not receiving any support for that issue. However, it should be noted that participants may be receiving support for mental health issues but that does not necessarily mean they are receiving support from a specific mental health service.

However, this said, key areas of need that participants reported not to be receiving support for is debt where 41% reported to be affected by this, but only half of these were receiving any support. Support for alcohol misuse also revealed that less than half of the 21% who self-reported to be affected by this issue were receiving support. A lack of support for this may be due to the issue of obtaining support for people with dual diagnosis (mental health issue combined with addiction) and/or perhaps because people with substance misuse are reluctant to seek support.

Mapping of participation in Newcastle

The mapping exercise revealed that there were a range of existing participatory mechanisms and activities in services and commissioning bodies across Newcastle. Among those who responded to the survey (n=12), it was evident that levels of participation varied; at the very least it was included in all organisational agendas and between services there were varying levels of proactivity and resource backing participation. It is important to note that due to the small sample size substantial conclusions from this data cannot be made. Furthermore, while this survey was sent to various organisations the respondents were self-selecting. Notably, the responses in the following section are from organisational stakeholders who participated in the survey.

Organisational commitment to participation

The mapping questionnaire explored the level of commitment that different organisations or service providers made to participation. Overall, organisations participating felt that it was an important element of their work with all organisations rating their organisational commitment to involving people as between five and nine on a scale of 1-10. Half that completed the questionnaire rated their service as an eight or nine. All organisations indicated that their organisational values include elements of involvement, participation or related concepts. Participation or involvement was not always explicitly stated in the values of the organisation, and in some cases organisations highlighted concepts such as 'fairness', 'personalisation' or 'accountability' which are related, not but directly concerned with participation.

All but one organisation indicated that their organisation had a participation strategy. The most common elements of these strategies related to 'feedback' and involvement in care planning and support. Some strategies also highlight commitments to consult with service users through mechanisms like service user meetings. Some strategies explicitly set out roles for service users to engage in like involvement in recruitment of staff and peer support. All services and organisations with a participation strategy indicated that they had had a level of involvement from service users in the development of their approach to participation. This ranged from collecting 'informal feedback' through to strategies being developed through workshops and dedicated pieces of research. An example of developed mechanisms are highlighted in the response below:

“We hold monthly ‘have your say’ sessions through a member forum. Member can progress to be Member Ambassadors - representing [Organisation Name] and members both internally and externally. We also have member trainee progression coach roles - offering members of people with lived experience an 18 month traineeship. In Newcastle we also offer a member Christmas trainee role offer employment for 3 months. Around 24% of employees have lived experience. Our EBE[Expert by Experience] group help develop our participation strategy.” (Organisation Participating in survey)

Two organisations highlighted challenges with involving service users due to the short interactions they have with service users e.g. short term accommodation. Of the organisations that participated, ten indicated that their organisation had an assigned budget for service user participation and five specified the amount ranging from £500 - £18,000. Four organisations said they had a participation activity in the past that had ended. Key reasons given were difficulties with recruitment of service users, organisational restructuring, chaotic lives of service users and the model of participation not working effectively.

Where the organisation’s model of participation was reported to not work effectively this was either due to the size and geographic area of the organisation, issues with resourcing and maintaining relationships with people who had moved on from the service.

Participation in policy making and strategy development

Of the organisations participating in the survey, ten highlighted that they involved users in the development of their policy and strategy. Various mechanisms were described as to how this takes place including consultation meetings, conducting research and targeted feedback sessions on policies. Most referred to using mechanisms to feedback on policies and strategy as opposed to engaging people in the development process. Two organisations mentioned working with an external agency to provide consultation processes.

Organisations described a range of governance levels at which people who use their service are represented; most commonly this was at a service delivery and/or operational level. One organisation mentioned they had a service user

as a trustee, and two organisations mentioned service users ‘feed in’ at a board level. Often the described representation was project based and relating to consultation on specific streams of work.

A range of ways that service users had led to organisational systems change including making changes or developing service delivery (like changing opening hours), involvement in the commissioning process and design and delivery of staff training. Two services detailed that a charter or agreement was produced with service users which was then used as a framework for future decisions. As one participant from a stakeholder organisation explains;

“[Our] Client manifesto which was created at the annual conference has been used with board meetings and policies and key changes such as recruitment of education workers/ review of ICT systems in each service/ staff training program has been developed with the feedback in mind / recruited mental health specialists in each region”

Participation in decision making

Ten participating organisations said they involved service users in decision-making and the remaining two were unsure. Various methods were used to involve service users in decision making, for example service user groups, consultations and collecting face-to-face feedback. An organisation gave examples of the format of this;

“Menu of Engagement which allows residents to participate as individuals, collectives and, where appropriate, an overall customer group”

Organisations gave a range of ways that service user voice had created change in their services, predominantly relating to changes in service delivery. One highlights how they involved service users in developing their service;

“When our service first began in 2017 our Ops guide stipulated to not meet people in any accommodation project they may live in but to only meet them in the community. We had feedback from several people that they would prefer to meet within a project, at least to begin with. As a result we changed our way of working to incorporate this.”

Decisions made by the organisation were communicated to service users using a variety of systems predominantly web/social media, notice boards and newsletters. Half of the organisations participating mentioned that decisions are communicated face-to-face through group meetings or in support work.

Monitoring, Evaluation and Performance Management

Performance management was an area where few services/organisations have a level of service user participation. In some cases service user groups or other feedback mechanisms were used to actively include service users. Three participants highlighted that their organisation had trialled, or were about to trial, scrutiny processes and one participant mentions that their organisation had a 'Peer assessor' role; *"We use peer assessors to monitor the delivery of services and they award a gold, silver or bronze rating."*

Participants highlighted a wide range of ways in which they involved service users in monitoring and evaluation these included:

- Involving service users in the development of outcome, output or impact indicators (6/12 participants)
- Inviting service users to share their own views about their services (10/12 participants)
- Conducting exit interviews with service users (7/12 participants)

Related to monitoring and evaluation is feedback procedures. The type of compliments that the service received from service users tended to be about staff who had provided good quality support. Often complaints related to changes or disruption in a service, difficulty accessing a service or the quality of/access to facilities. As this example illustrates;

"We have had no formal complaints. Common suggestions are around whether their Asset Coach can attend certain meetings in order to support them, this is more an issue of clarification than suggestion. People have also asked whether they can meet their Coach more frequently. We have received a multitude of compliments which we compile alongside any photos we take of people with their Asset Coach. People really like the way we work, treating people as individuals and not being authoritative."

Service user groups, meetings and forums

Nine organisations participating highlighted that their organisation had a user group or forum. The purpose of these meetings was described by participants most commonly as being for feedback or for monitoring and service or policy development. Some described the function as a way to communicate with service users. A representative explains;

“To highlight any concerns from the residents. To get resident's ideas on activities. To inform service users of opportunities and the direction of the hostel”

Among those who reported to have a forum of some kind, five highlighted that their meeting/forum was chaired by a member of staff. Most said the agenda was set in collaboration with staff and service users and all were minuted. Participation in groups tended to be on a voluntary/open basis. One group had a democratic process where participation was based on nomination from peers. Meetings of groups varied in regularity; every quarter (3/9), every month (4/9) every week or two weeks (2/9) and five participants had evaluated their forum/user group.

Involvement in personal support

Commonly organisations participating described their support as being collaborative with the service user/customer in delivery and five of twelve described their support as personalised and/or person centred. It was commonly described that collaboratively planning and agreeing targets were part of the support work role. One response included an excerpt from their Service User engagement strategy to answer this question:

“All practitioner staff are expected to co-design support packages with service users, wherever possible and capacity allows. Where the service user does not have capacity, for example in dementia services, the practitioner must make all reasonable efforts to include family carers and life history information to inform support package design.”

Roles for service users

The most common roles that were on offer to service users were as volunteers delivering various areas of service delivery or on specific projects like furniture restoration. Three organisations mentioned their service had employed people

with experience of the issue they support people (e.g. homelessness or mental ill health) and three stated they have apprenticeships/traineeships that are targeted at service users.

Challenges to participation for service providers

Organisational participants highlighted a range of challenges that they faced in terms of engaging service users in truly meaningful participation. These included (in order of prevalence):

- Chaotic lifestyles/high support needs preventing meaningful engagement or willingness to engage
- Engagement with all/range of people who use services (not just the same people)
- Service users having mistrust/feeling they do not have a voice/aren't listened to/lack of confidence/lack enthusiasm
- Short interactions with the individuals they support
- Feedback/continuing engagement from former service users
- Size/geography/range of services that organisation offers
- GDPR

Peer Research Findings & Exploration

Understandings and experience of Participation

The study explored how the concept of 'participation' was understood among participants, further exploring related concepts of power, control and being 'listened to'. The peer-researchers found that the concept of participation was far easier for participants to understand when it was discussed in relation to practical examples. Therefore, participant's understandings were often led by personal experience.

[The meaning of participation for participants](#)

For many of those who were participants in this study, the concept of participation and understanding of the various pillars of how it may be enacted in support services could be a difficult concept to grasp. While enthusiasm for aspects of participation like being listened to or being in control of your own support was common, often speaking about what this meant was challenging. Similarly, the language that service providers use to describe their services, terms like *coproduction* or *personalisation*, were often met with misunderstanding, to an even larger extent than among service providers

themselves. A key challenge that the research team faced in delivering this project was in using a language around participation that can be commonly understood, which was particularly evident in qualitative elements of the research. Instead participants were much more comfortable speaking about the tangible ways they had engaged with rather than broader concepts of participation. This highlights the need for the council and organisations concerned with participation to develop accessible language relating to participation. This will be considered in the development in the subsequent stages of this project and in the development of the toolkit.

Experience of participating in the past

Understandably, those that had experience of user-participation activities were more likely to have an understanding of what participation can look like in practice, but also meaning that those who haven't engaged in this way may find it harder to conceptualise it. Furthermore, of those who have had less than positive experiences in the past may also have a tainted opinion or view and may be less willing to engage in participation activities. This participant describes how they felt let disappointed about a lack of trust after their volunteered to participate;

“I was really chuffed to be part of it. But then I just felt they didn't trust us. It hurt us really, but I just felt they didn't trust us”.

Offering chances for participation and doing it badly in some cases meant that participants reported seeing activities as token gestures which could lead to disempowerment and a lack of trust in services. There were some clear cases where when an opportunity to input or share opinions had been given, it had been done badly and there was a real lack of solid examples where opinions have been listened to. For example, participant spoke about how a service had a mechanism where feedback and complaints could be written on anonymous pieces of paper but that they were never read or nothing was ever done about them. Another participants describes how they regularly participate in meetings but nothing happens with their input;

“We have a meeting every Tuesday. We have our say in the meeting, so what we would like to happen in the service and stuff like that. So

[name] over there like he will go and email the managers and everything to say this is what has been said in the meetings, this is what they would like to happen. But then nothing actually does happen."

Power, control and rights

Within the research, participants had differing opinions of the extent to which they felt had power and control in their lives. When asked if they felt they had control in their lives, 32% either disagreed or strongly disagreed, 44% strongly agreed or agreed and 24% neither agreed nor disagreed. Therefore, it is clear that most participants felt in control of their lives. For example, one participant illustrates this by saying they are fully responsible for their life and it was their own fault they were homeless. However, others spoke of how because they were homeless this indicated that they did not have control over their lives; *"not when you are homeless no (you don't have control). I don't think. In my opinion"*.

The extent to which participants had control over their lives influenced whether or not they felt involved in the services that they use and in local Government and council strategy on how services are commissioned, designed and run. Largely, the more control people felt they had the more influence they felt they had on services.

The idea of 'knowing your rights' was felt to be an important concept among participants. Reflecting this, 68% of people agree they have rights in services but only 46% of people said they know what their rights and rules were. Examples discussed were around evictions from accommodation where often participants felt they did not know what their rights were and that power and control firmly was with support staff. One participant describes;

"You follow the rules or you end up back on the streets. It's as simple as that. They try and help us out, but sometimes services don't give that help. So they have got a certain amount of control over our lives". – Focus Group Participant

Often participants discussed how by warrant of their homeless situation, control in their lives had been removed from them. The power-imbalance was clearly highlighted by many and a feeling of disempowerment was common.

“I think we come here because we haven’t got control of our lives, you know what I mean? And it’s an ideal place to create a base for the foundation, know what I mean. And as long as you do things right and work with the staff, the outcome can be your own flat and all that. Know what I mean? It’s up to us to tell them what your needs are and formulate the care plans.” – Focus Group Participant

Informing people who use services of what they are entitled to, what the rules are and ensuring they are understood can be challenging, but it is key to people feeling in control of their situation. Informing people on the initial contact with a service can mean that people are not in a position to comprehend and fully take in this information. It also represents a time when there is a strong power imbalance where the service provider can act as a gatekeeper to a service (particularly when people are moving into accommodation), and people wishing to access the service do not feel comfortable questioning the information delivered. This demonstrates the need for this information to be revisited regularly during their interaction with the service so that people can fully understand what they are entitled to and what the process of support is. Furthermore, one way of addressing power dynamics, especially at the early stages of support, is that existing service users could take the role of welcoming clients and informing them of the rules and mutual expectations.

Control in personal support

Participants in surveys and focus groups were asked about the level of control and input they have in their own personal support; 49% of people feel they have a choice in how their own support is provided and 38% don’t. This is an interesting finding and quite a high proportion given that so many services promote themselves as 'person centred' and guided by client choice. One participant describes; *“they [staff] give you one choice and one choice only. And if you don’t take it, well bye bye you are on the streets.”*

Participants were asked to the detail the extent to which they agreed with the statement, *‘my support worker often explains my options to me’*; over half of participants (53%) feel that their support workers explained their options and

26% didn't. Of those didn't feel their options were explained there was a feeling that staff have feel they know what is best for the person.

In terms of choice of services, 56% feel they have a choice about which services to use and 32% feel they don't. One participant spoke of how they felt they could choose whatever service was best for their mental health; *"I go to which one is best for my condition. I have got PTSD or whatever it is. So I go to the ones that's the best."*

Related to this, participants were asked which services they 'mainly used' (i.e. the support service they perceived to be their primarily source of support) and there is indication that people may have chosen to find support away from their immediate surroundings. For example 54% of participants were currently residing in hostels, yet only 25% of respondents named a hostel or accommodation service as their main support service. Of those participants, many were seeking support from mental health services and services that support with offending/criminal justice issues and substance abuse services.

Monitoring, Feedback and Complaints

*"In order to assess the impact of involvement, service users and carers should be involved throughout the monitoring and evaluation process"*⁶

Having the opportunity to share opinions about a support service on an ongoing basis is key to ensuring that a service is meeting, and continues to meet, the needs of those that use it. It also is a significant step towards letting service users know that their voice matters. Opportunities for feedback (both positive and negative) on an on-going basis is necessary as if complaints are the only mechanism for feedback services often do not find out about issues until they become significant.

Giving Feedback

We asked survey participants if they were given the opportunity to feedback about the services they used. Our survey shows that 57% had experienced being asked for feedback about the main service they used, but 37% told us they had never been asked. It was felt by many participants that it was

⁶ Involvement for Influence: 4PNI National Involvement Standards
<https://www.nsun.org.uk/Handlers/Download.ashx?IDMF=995617f8-1cd7-40af-8128-5eaf2953b8e> (page 32)

important to be asked their opinions, but having a follow-up and seeing change was key. If nothing gets done with feedback then it can damage trust. One participant explained what happened when they offered feedback:

“[We] tell them what we [...want] And the response is basically you can’t do this and you can’t do that. Some of the stuff is not even like ridiculous what we are asking for.” – Focus Group Participant

Support services have a responsibility to gather the feedback of those who use services and offer a spectrum of ways to feedback in a way that is accessible and that allows for people to be able to positively feedback in a way that is meaningful. Survey participants were asked how feedback is gathered in the services they use, most commonly through feedback forms (57%), surveys (22%), in group meetings (19%) or on a one to one basis (22%). With the most common way that participants are asked to feedback is through feedback forms, a question could be asked about whether this represents a meaningful and accessible medium, particularly with the high proportion of people who may have learning or literacy difficulties. It also represents a one-way direction of feedback with limited opportunity for those receiving the feedback to check that the message is understood.

Making a complaint

Complaints were a topic that created a strong reaction from participants, and often triggered a heated debate in focus groups. We asked participants about their experience of making complaints and the responses they received. Among survey participants, 37% had experience of making a complaint at the service they use and 59% have never made a complaint. The research found that 59% reported that they knew how to make a complaint about the service they use. It is evident from participant responses around experiences of complaining, that the route often taken did not often follow formal complaints procedures. For example, some questionnaire participants explained their experience of complaining which was often delivered verbally:

“Made a complaint straight to staff member verbally and didn't feel listened to felt like they were calling me a liar.”

“[I complained] verbally. Went okay. Made them listen. I come across aggressively but I’m not.”

“I got angry and told them to their face. They talk us around. Go away. Come back later. Work things out myself.”

By the time people feel they need to make a complaint it can be that people have become angry about the issue which can mean that the information is delivered in a way that may not be seen by the recipient of a complaint as constructive. What is a legitimate concern can be seen by staff as ‘challenging behaviour’. The result may be that the issue stemming the complaint is not addressed, trust is damaged and in some cases the individual making the complaint is penalised.

“The problem is I lose my temper when I don’t feel listened to or don’t understand what they say. Sometimes can’t find the words or fill in forms.” – Questionnaire Participant

When a complaint is made informally it is also more likely that it will not be recorded, actioned or any elements of follow-up enacted. Whether complaints are made either formally or informally and the individual does not receive a response it can lead to a further level of mistrust. As one questionnaire participant explains:

“Nothing ever gets done so I feel like there is no point in complaining. I have no respect at all for [Service Name]- they tried to move me out of this area. I was threatened by a man on the phone and he said he would report me if I didn’t apologise to him. I got investigated for 18 months. I tried to complain about him but nothing got done.”

While 71% of participants felt confident to make a complaint, almost a third of participants reported that they did not feel confident to make a complaint about a service they use. The most common reasons given were they felt that ‘if I made a complaint staff would hold it against me’ or they were ‘too scared to ask or cause trouble’. One participant even explains they “worry of becoming homeless if reporting an issue”. These examples display a clear feeling among participants that there is an imbalance of power, where even if there is a legitimate issue they are fearful of attempting to address it.

Participation in Decision making

User participation is not only about setting up structures and systems for consulting with people although that is part of it, it is about giving up some or all of the power to make decisions. While not all decisions related to homelessness service provision can be made collaboratively, sharing some

power and allowing decision making to be made in a collaborative way is a further step towards meaningful participation.

Who makes the decisions?

Participants in focus groups and questionnaires reported that they very rarely had an opportunity to make decisions that had impact beyond their personal situation. In many cases participants found it difficult to find an example of where they had been asked to input on any decisions. It was acknowledged by some that the decisions that they had input into tended to have limited consequence. As one survey participant explains; *“just small day to day issues like cleaning tasks but not with bigger decisions”*.

For those who had been asked to input they could feel that it was a tokenistic gesture, lacked meaning or their suggestions were ignored. In the few cases that participants gave where they had been asked for their input the experience of just being asked could be positive in itself. One participant describes how being involved in making decisions makes them feel;

“When they change the rules they ask us. It makes it feels like it's our service make you feel part of it. They listened it's like one big happy family.” – Focus Group Participant

Decision making in services

Within support services, particularly in residential settings, people will have regular contact often on a daily basis offering the best opportunity for people to regularly participate in decision making. The study explored how participants had been involved in the past with making decisions with 64% of participants reporting they had not been consulted or been involved in decision making when changes were made to a support service that they utilized. This is disempowering for service users and doesn't capture any information useful for that particular service. Participants commonly gave examples where rules or policies had been changed within a service and they felt they had no input.

“Changed visitors rule in service so I couldn't have my family around. Just told and no say in what happens. Never ring back or resolve.” – Questionnaire Participant

In a number of cases the policy change had made the service more difficult to access for the individual.

“Food bank changed rule meaning I have to go somewhere else first to get a good voucher, this will cost bus fare I can't afford” – Questionnaire Participant

Just under one third (30%) of respondents agreed (24%) or strongly agreed (6%) that they are asked their opinions when changes are made to support services they use. Related to this, 36% feel their views are valued when something is going to change, with 34% of participants reporting that they feel their views aren't valued, the remainder were unsure. The following quote is representative of many of the qualitative responses:

“Tell them what we said and what their response [...] is basically you can't do this and you can't do that. Some of the stuff is not even like ridiculous what we are asking for. Not being listened too [Needs] to be part of the change.” – Focus Group Participant

Overwhelmingly, participants in this study want to be consulted around decisions, if not be involved in decision making itself; notably 91% of participants reported that they want to be asked for their views before a change to a service they use. Only a tiny minority of participants (3%) disagreed when asked if they want their opinions to be taken into account when changes are made to services they use and 6% preferred not to say. Reflecting this, 82% of participants would be interested in being involved in decision making about services. One participant explains his views on this:

“Be heard, and not be fobbed off. Just give a little listen even if it's for 5 minutes, ten minutes. And like come here and meet us yeah. Build that little rapport. And then maybe we can...[...] tell them what we enjoyed and what we haven't enjoyed.” – Focus Group Participant

“[We need] To be given the platform to share opinions and allow people be heard and part of designing services for them.” – Questionnaire Participant

Participants also acknowledged that there was a need for services to be proactive in engaging their clients, making opportunities to input accessible. It

was felt that there was a need for decision makers to visit services where there is a captive audience and not ask decision makers to come to them.

“It’s best in our own environment where we can speak to them and that...in our own environment”. – Questionnaire Participant

Involvement in Newcastle City Council Commissioning, Policy & Strategy

A large proportion of participants had had no experience of engaging with the City Council. 81% of participants had no experience of being involved in decision making at a strategic level, and 75% feel they are not asked their opinion when the council make decisions about the services they use. Although 14% of participants told us they had been involved in decision making and 11% felt they were asked their opinion, there were limited actual examples within qualitative responses of when this had happened. Overall, responses indicated some lack of trust of the City Council participation processes. The following responses from focus groups and questionnaires illustrate this;

“Interviewer: What would it take for you to get involved? To sit on a committee?”

Participant 1: What would it take? For them to offer.

Participant 2: To be wanted.

Participant 1: Aye.

Interviewer: And did you feel like there is a lack of people coming forward and asking you to be involved in the services that you are involved in?”

Participant 2: Maybe its people don’t know that you want to be involved.” – focus group participants

“It’s nice to get a chance to voice of my opinion, this should happen more and it should make a difference but I don't think I will because I think the council class me as a number” – Questionnaire participant

There were also discussions around how welcome participants felt within council meetings, events and offices:

“Interviewer: Have you been to any council meetings or anything like that?”

Participant: “No never. People – the likes of us will never get invited in the council...”

Despite this, the majority of participants (95%) wanted to be involved when the council makes decisions about services. There was a strong feeling that the council did not place homelessness and related issues high up enough on their agenda, but given the opportunity they would very much like to be involved.

“I want people to listen, stand up for us especially councillors because I feel things could be different with more support.” – Focus Group Participant

It was felt that more engagement would rectify this issue. Participants had many suggestions for achieving this including councillors and council staff visiting services, doing more research and consultation, and meeting in groups and in one-to-one settings to hear people’s opinions. One participant suggests;

“To get homeless all in a group with Newcastle city council in a massive group to let them see us and feel us and for them to see how emotional it is also how nice and caring people we are as not to be all judged and discriminated” – Questionnaire Participant

Through this research it became evident from stakeholders that staff do visit services regularly, this is perhaps not communicated well to service users.

Related to this, a topic that was discussed in interviews and focus groups was around the City Council’s Homelessness strategy. Questionnaire participants were asked if they were aware that the City Council has a homelessness strategy that sets out how they will respond to homelessness and people who are homeless in the city. Notably over half of participants (59%) were not aware and 38% of participants were aware. Of the research participants 69% would like to be involved in helping to shape this strategy in the future. Evidently it is the case that participants may not be aware of the commitments the council is making in this area, for example that homelessness is a key priority and that funds for this have been protected given with significant cuts to the council’s funding⁷.

⁷ https://www.newcastle.gov.uk/sites/default/files/active_inclusion_newcastle_-_briefing_note_2018-19_1.pdf

‘Service-user Groups’, Meetings & Forums

Holding specific service-user groups and other spaces for discussion and feedback among people who use services is a key participative mechanism. Many participants spoke of how they have weekly meetings in their accommodation and make suggestions to what services or support they would like. For some, this was an opportunity to be listened to and make changes. As one participant describes; *“We have house meetings on a Wednesday. And they come up and we will get all of them sitting [around] and they talk about what we want. Is everything alright? Do you need anything? They are helpful”*.

Another participant describes a committee that meets and how service users make decisions;

“They have actually got...something like a client’s committee. Where there is about three or four people that go into the meetings that the staff organise to discuss whether they are going to organise a trip or there is going to be a film on or whatever. There is four or five people on the committee.” – Focus Group Participant

Over half of participants (54%) reported to have attended a service-user group or similar meeting. Feedback on these meetings was varied with some reporting disappointment with what they found when attending. One participant describes their experience:

“So they say they will do this and they do that but they never actually follow through what they...don’t follow through to what they say.” – Focus Group Participant

Another adds;

“I feel it is not worthwhile things I say are not acted on not put forward nothing changes so I feel they are a waste of time.” – Questionnaire Participant

The above quotes demonstrate the importance of the groups having follow-up on the points discussed to avoid them being seen as tokenistic gestures. Across all participants, over half (58%) reported they were interested in getting involved in service user meetings, while 23% said they are not and 19% were not sure. However, among participants who had been to service user group or

meeting in the past, a fifth (20%) reported that they would not be interested in getting involved again. Of participants who would be interested in getting involved, 38% reported that they had not attended this sort of group in the past.

Some participants shared the importance of boundaries and a clear role for the group as key to it being successful. The following participant explains the importance of ground rules:

“But I think a group like that is definitely good, as long as there is ground rules and as long as it’s controlled. And people know they can’t get up and punch ten bells out of each other because it’s about diplomacy.” – Focus Group Participant

Some participants also shared how being part of groups, whether user groups or Peer support groups can have benefits in terms of mutual support and overcoming isolation. One questionnaire participant explains:

“The first group I went to was carer and user forum. [It’s] More formal if no shared experience [and] you have to comply. It’s about power. Shared experience supports each other. Feel like a team.” – Questionnaire Participant

Participants also shared examples of where they had built up confidence from attending such meetings. When asked whether attending a service user meeting had been worthwhile the following participant responded in this way:

“At first no because I could not express my opinions and getting upset, as time went on I seen the benefit of meetings, helped to improve my confidence, self-esteem” – Questionnaire Participant

The data demonstrated that where groups are facilitated well with follow-up, boundaries and with a clear remit the sense that they are a worthwhile experience is greater, and people are more likely to attend and engage.

Roles for people with lived experience

The findings of this study highlight the willingness and enthusiasm from participants to be able to fulfil roles in the services that they use. This was in

regard to using lived experience to support others in explicitly ‘Peer’ Roles⁸, but went far beyond this to fulfilling other functions within organisations. The mechanisms of an organisation or a service can provide exactly the structure and opportunity for people to move themselves out of homelessness.

Lived experience as an asset in support roles

Working with someone who has shared experience was widely seen to be an asset in support, allowing a deeper understanding of the challenges that people face, informing empathy and breaking down a potential lack of trust. 61% of participants had received support from someone who had a shared experience with them and across the board feedback on the quality of that support was very positive. 72% of participants agreed that it is helpful to get support from someone with a shared experience. In focus groups and questionnaires, participants commonly responded using terms like ‘better understanding’ and ‘more trust’ in relation to working with someone who has shared experience.

“Having trust issues with authority it’s nice to talk with someone who I can relate with. People find it hard to open up to strangers and to ask for help with issues who have not been in similar issues so it’s easy to open up with people who have been in similar issues themselves”. – Questionnaire Participant

A number of participants discussed how having staff with shared experience not only created trust in the individuals, but also meant that organisations providing support may be seen in a better light. One participant explains:

“[It’s] easier to connect with it [Service] which has had a positive impact on the service I’m receiving” – Questionnaire Participant

‘Peer’ Roles

Data from surveys and focus groups suggests that only a few participants had given or received support from someone in a ‘Peer role’. However, many felt that this sort of support would be highly beneficial; 66% of participants would be willing to take part in peer support. Participants spoke of how peer support would be good for providing role models, obtaining quality advice from people

⁸ When we refer to Peer Roles we mean roles that are explicitly designed to make use of lived experience to maximise the success of the role. However, lived experience can be an asset across many different roles which was a clear finding of this research.

who are ‘experts’, breaking down barriers and building trusting relationships with people who may have a better understanding of people’s needs. A participant describes the difference between being support by someone with lived experience and someone who does not; *“rather than from a text book or degree I think the people who have been in the same situation as me can relate and empathized with me more in a better way”*. One participant describes the importance of peer support and how it can help to guide people;

“And you know that they’ve walked in your path. You might be at a stage right and you might not be able to see the wood for the trees, but this individual peer supporter... has been through that stage and is on the other side of the forest. Being able to look back and [see] the way through isn’t it, because he has been through it.” – Focus Group Participant

Another adds how peer support would help to give them strength; *“you can pull strength off them. They have been there, they have done it, they have got out of it”*.

While participants valued the opportunity to receive support from a Peer, there was also a strong desire from participants to be able to deliver these roles. 66% of participants were interested in taking part in a role that would involve them utilising their own experiences to support others. Only 15% of participants said no when asked if they would be interested in using their own experience in a support role for others. The desire to help others or ‘give back’ was a strong motivator for fulfilling these roles and would indicate that creating more of these roles in Newcastle would be popular.

Training and recruitment

Some participants also gave examples of how they felt they could be involved in supporting recruitment and training of staff. A number of participants discussed how they had been on panels to recruit staff and that they felt this had meant that people who were recruited were more likely to be suited to the role. One survey participant explained:

“[You] Get people who have the right qualities and life experiences for the job. Some people in services don't care and it can have a massive impact on their lives.”

Other participants explained how they had been involved in the training of staff and that this had been a powerful tool for informing staff of the realities of homelessness. One participant with lived experience of homelessness describes their experience of training staff; *“I gave a talk to all of the managers. I had the whole room in tears actually.”*

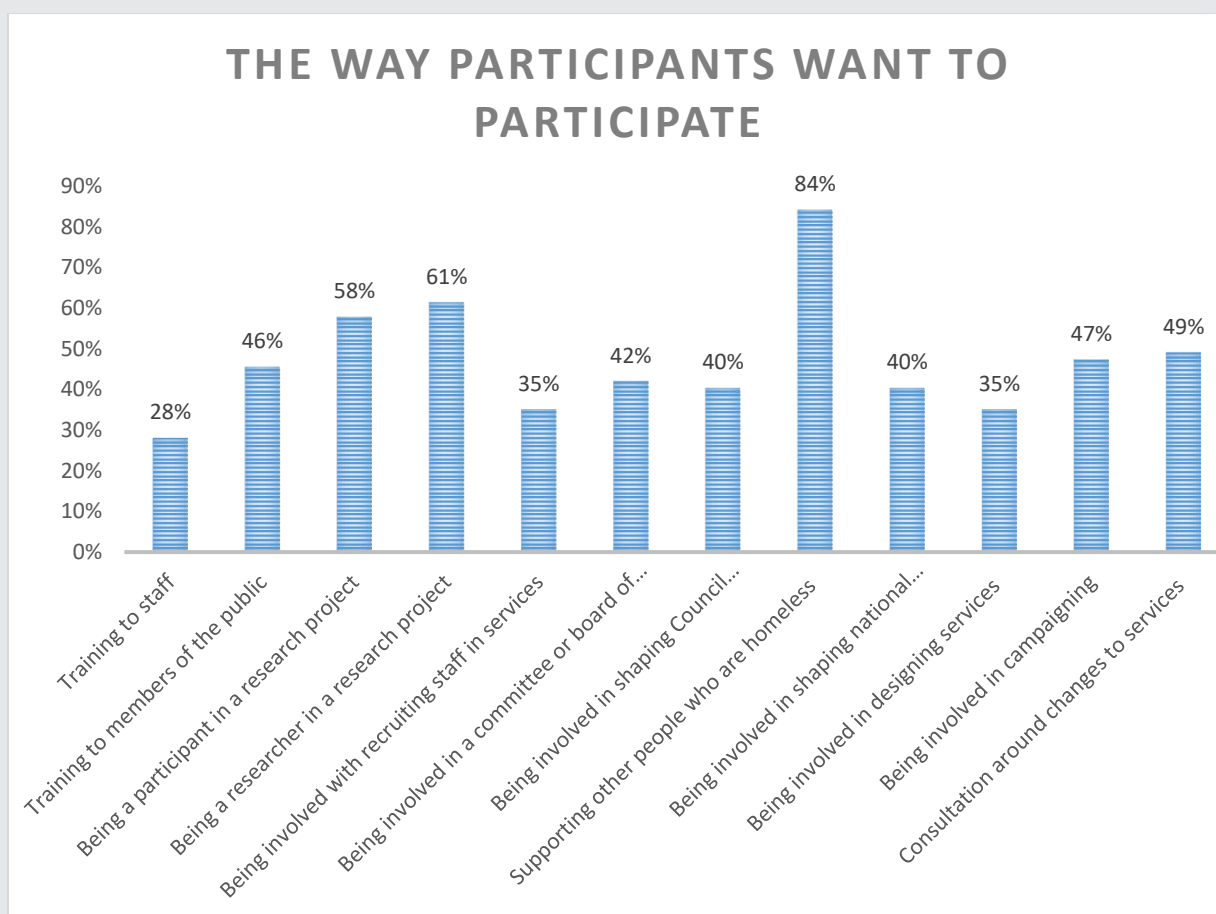
What could participation look like?

Effective user participation is inclusive and anti-discriminatory. Support and access should be provided to enable people to be engaged to the extent and at the level with which they feel comfortable.

The ways that people want to participate

Throughout the delivery of the fieldwork, researchers were met with enthusiasm from participants to have the opportunity to actively participate in the services they use. Questionnaire participants were asked about the type of activities they would like to engage in. The activity that most participants (84%) wanted to engage in was supporting other people who were homeless, this correlates with the high numbers of participant who wanted to engage in Peer Support as discussed earlier in the report. The second most popular was engaging in research projects, either as a researcher (61%) or as a participant (58%). There was also enthusiasm to engage in consultation around changes to services (49%) and campaigning for the rights of homeless people (47%). ‘Other’ suggestions included; a desire to be involved in supporting people who have been domestically abused, being employed in services but getting support with it.

Figure 3: Graph illustrating the different ways participants would like to participate

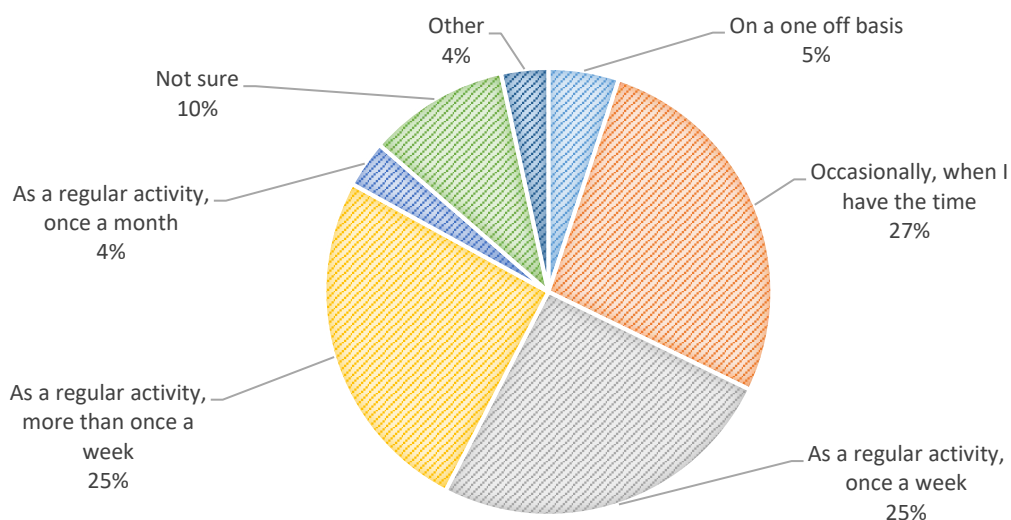


The study also explored the basis on which participants wanted to engage in these activities. Any participants who indicated whether they would like to engage in the above activities with 75% responding they would do it on a voluntary basis, 61% for a voucher or another incentive and 56% would like to do one of the above activities as a paid worker.

Participants were also asked how regularly they wished to engage with activities. Half (50%) of participants indicated that they would like to engage once a week or more in these types of activities with the remainder highlighting they would like to engage either every month or when they have time.

Figure 4: Graph illustrating how often participants would like to participate

HOW OFTEN PARTICIPANTS WOULD LIKE TO PARTICIPATE IN ACTIVITIES



While there was enthusiasm for engaging in activities, it is important to remember that not all participants, and indeed people who use support services want to engage in this way. Some participants have too much going on in their lives or want to leave the homelessness sector behind them. One focus group participant tells; *“I am too much involved with my outside stuff to participate in anything.”* Another adds, *“I want to be as far away from this world as possible, know what I mean?”*

Challenges to Participating

The study explored what participants felt were the challenges to participating and how they could be overcome. In many cases the challenges that participants identified related to support needs and are likely to have been a cause and/or a consequence of participant’s experiences of homelessness. For example, a large number of participants in the questionnaire responded that their biggest challenge was around their need to focus on their own recovery:

“First challenge is to get myself sorted - to deal with my mental health issues”

“Getting to my appointments due to my epilepsy my mental health and confidence”

“In order to keep myself safe and clean I have to distance myself from the homeless drug people”

There were also challenges felt around understanding how to participate, what people’s rights were and having the correct language to being able to engage meaningfully. Participants highlighted a risk around miscommunication and misunderstanding of definitions. The following participant, who is a native English speaker, explains that they faced challenges communicating with staff:

“I think that sometime we don't have the tools to speak such as a translator. It's difficult to get involved we don't have the knowledge to ask sometimes there is a little bit of like we are in this situation and we need them and depend on them [Staff] if we were better prepared we would do better. We should get more involve we are just following.” – Questionnaire Participant

Participants also identified challenges around staff culture and power dynamics within services that could make it hard to meaningfully participate. In some cases participants explained that they were worries about speaking up as they felt they did not want to be seen as confrontational or even that they risked losing accommodation. This was often routed in misunderstanding and mistrust between service users and service providers and the council. The following quotes are illustrative of this mistrust:

“Drug addiction. No one listens to a drug addict!” – Questionnaire participant

“Being homeless not having a permanent address, don't feel I would be wanted there.” – Questionnaire participant

However, many participants also felt that with the right support they could meaningfully participate. For example, offering training and ongoing support was seen to be the way to overcome these issues. The following quotes are illustrative of this:

“[I need] Mental health and confidence training about what we are aiming to do.” – Questionnaire Participant

“Need support to keep focused and with boundaries with other people. Communication help to understand about what being asked. Confidence. Trust.” – Questionnaire Participant

Conclusion

This report started by exploring how organisations support people experiencing homelessness in Newcastle to participate in the design, delivery and decision making of services in the city. The research showed that most organisations did have a strategy for participation and a budget to support this. In most cases, respondents reported that service users were involved in this strategy. Furthermore, the data suggests that, to varying degrees, organisations value and have a commitment to participation.

However, we found that few service users were involved at board or trustee levels. Furthermore, where input was sought this was mostly as feedback about a service rather than feeding into the development of it. In addition to this, challenges to participation as told by organisations included; chaotic lives and support needs of service users; feelings of mistrust between users and staff; reliance on the same service users to participate; short interactions inhibiting meaningful participation and challenges related to size, geography and the range of services that organisations offer.

Through peer-led research with people who were experiencing, or at risk of, homelessness we found that participation in the design, delivery and decision making of services was mostly positive. For example, 57% had experienced being asked for feedback about the main service they used and 68% of people agree they have rights in services. One participant spoke positively about his experience of delivering training to other service users on behalf of a rehab. There was some evidence to suggest that input from service users was valued and listened to.

However, there were barriers to participation for service users and these included; negative past experiences of participation, inaccessible language, feeling they won't be listened to or taken seriously, conflict with services and chaotic lives meaning they have more pressing concerns. Furthermore, participants spoke of incidences where they were not involved or their involvement was not followed through well. For example, 37% told us they had never been asked to give feedback on the primary service they use and a third of participants did not feel confident to make a complaint.

This study, therefore, suggests that although many services are supporting the participation of service users in design, delivery and decision making, there is

still a gap between the ethos and values of organisations focus on participative principles and the participation of service users in practice. This quote about service user meetings exemplifies this;

Question: “Do you feel that it was a worthwhile experience?”

Survey participant: “Yes to a degree. It was a good platform but it was tokenistic and people were uncomfortable expressing views”

This illustrates that in some cases the opportunity to meaningfully engage is being missed and is seen as tokenistic. As mentioned in the introduction, true participation is not a separate activity, but an approach to working with people that is integral to the culture and ethos of the service and the working practices of all staff. While many organisations highlight the commitment and opportunities for participation, it is evident from this research that these are not always available to, or at the very least effectively communicated. Some of these structures may be in place, but it would appear that a universal culture is not.

There was evidence in the study that participants feel that professionals asking their opinions is a tokenistic gesture. However, the vast majority of participants also highlighted the value they placed in having the platform to share opinions and be part of decision making and designing services.

We recognise that not everyone who uses a support service has the capacity or even the desire to participate, and there may be other things that people wish to address first, focusing on themselves rather than broader decision making. For this reason, the starting point for any participation is working in a collaborative way with a support worker to gain trust and to support the service user to resolve any outstanding personal issues. Support should be provided to enable people to be engaged to the extent and at the level with which they feel comfortable.

Adopting a truly participative approach at all levels of service delivery can offer a transformative approach to the way services are run and the impact they have on individuals. We recognise the challenges that services and commissioners face in terms of resources and in some cases legislative frameworks. The learning from this study would indicate that ‘doing participation’ badly can do more harm than not doing it at all. It’s better to offer opportunities within available resources and to do it well. Otherwise, the

risk is that service users and staff become disillusioned with the process which may affect their willingness to participate in the future.

In the next phase of the project, we will develop a *Toolkit* for participation in Newcastle. This toolkit will include recommendations for this research from research participants, the steering group and Groundswell. This will encompass the key lessons learned from the Newcastle Voices Peer Research which will be taken forward in the next steps of the project. It will also include guidance on a set of activities that service providers and commissioners can action. In most cases, service users want to participate and recognise the value of participating in a meaningful way. This includes participating in the way services are designed, delivered and commissioned. We hope to take this learning to the next level and to create a range of ways that people can meaningfully participate in Newcastle.