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# Public Involvement in Alcohol Research



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# Foreword



The importance of public involvement in health research is now very widely recognised. However, as a charity dedicated to funding research in alcohol we are aware of the gaps in our field. Alcohol research presents distinct challenges, and cuts across wide and varied sectors of society. Drink can affect people in an enormous range of ways, and research needs to be alive to this complexity.

For these reasons, we launched a project on public involvement in Autumn of 2016. Over the following year, through both group events and individual discussions, we spoke to many stakeholders from different backgrounds. Our annual conference, in April 2017, was a memorable celebration of the diversity of expertise in our field, and of the innovations already taking place in research design, development and communication.

This report represents our reflection on the conversations we have held over the year, and the excellent work being carried out by colleagues across the country. We are immensely grateful to everyone who joined that conversation, and who shared their knowledge and experience with us. I would also like to thank Dr Jo Cairns for her invaluable work in supporting this project and developing this report.

Public involvement is not simple, but creating stronger links between universities, services, volunteers, and individuals with lived experiences is essential if the work we fund is to continue to help improve lives. We hope this report provides useful insights and support for our colleagues working across the alcohol research field, and for anyone involved in developing research that addresses the challenges posed by alcohol. We look forward to working more closely with our own panel of experts by experience in future, and supporting more excellent, innovative and valuable research.

Dr James Nicholls  
Director of Research and Policy Development  
Alcohol Research UK



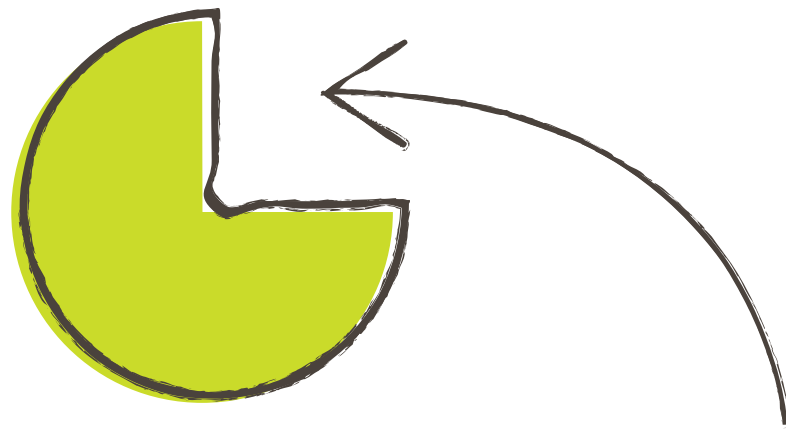
# Introduction

In late 2016, Alcohol Research UK initiated a programme of work exploring public involvement in alcohol research. Over the following months, we ran a series of national events with service providers, research leaders, funding bodies, academics, and experts by experience to discuss how those affected by alcohol harms could better be involved in research design, delivery and dissemination (see Appendix for details).

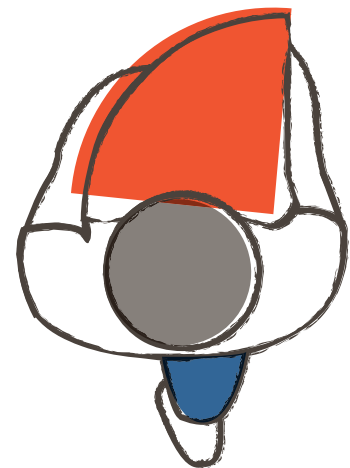
This report reflects those experiences. It sets out our views on the particular challenges presented by public involvement in alcohol research, as well as our goals in supporting better involvement in future.

Public involvement is now a key element of health research. It is supported by the National Institute for Health Research (NIHR) through its INVOLVE project, and a number of medical research charities have recently published reports promoting better public involvement in their fields<sup>1</sup>. Service user involvement (through, for instance, peer mentoring activities) is also increasingly central to the work of substance use services<sup>2</sup>. However, the specific aims and challenges of public involvement in alcohol research have not previously been set out<sup>3</sup>.

This report aims to meet that need. It is intended primarily for researchers working in this field; however, we hope it will also be useful for practitioners and services providers, especially in the discussion of how research involvement may aid recovery or improve services.



**“Bringing together different types of expertise collectively producing knowledge greater than the sum of its parts.”<sup>4</sup>**



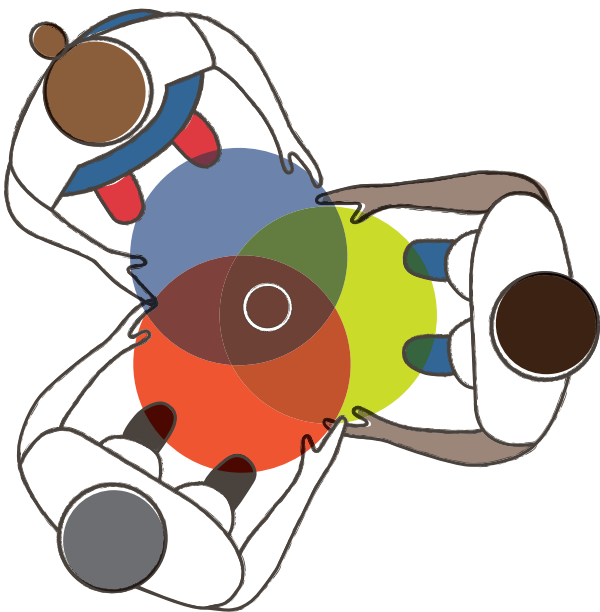
#### **Acknowledgements**

We would like to thank everyone who participated in our public involvement workshops, discussions, panel debates, symposia and conference. Your involvement ultimately shaped the reflections and guidance contained in this report.

# What is public involvement in alcohol research?

The term 'public involvement' in research covers a wide range of activities involving many potential partners. Broadly, it has been defined as research carried out *with* or *by* members of the public rather than *to*, *about* or *for* them<sup>5</sup>.

'The public' in this definition could be anyone with lived experience of a particular condition, patients (or potential patients), carers, people who use health and social care services, people who represent people who use services or are eligible to use services, practitioners, advocates, and the general public. Precise definitions will often depend on the research being conducted.



Public involvement can be applied to the research process at all stages. It can shape:

- Research strategy
- Funding allocation
- Development of research plans and proposals
- Carrying out primary research
- Data analysis and interpretation
- Peer review
- Communication and dissemination

The terminology around public involvement can be complex, and people may be anxious about what different terms mean. In medical research, for instance, 'public and patient involvement' is widely used to describe the involvement of patients, or those close to them, in the design, delivery and dissemination of research towards new treatments.

In substance use treatment, the views of service users are increasingly sought in the design of programmes – as well as in the delivery of interventions. In this context, the term 'service user involvement' is commonplace.

As is well known, however, not everyone affected by a particular condition or problem will access services. Furthermore, in the case of alcohol harms there may be a wide range of people – families and friends, for example – who are affected by someone's drinking. Therefore, the term 'experts by experience' is often used.<sup>6</sup> This can be broadly defined as people with direct or indirect experience of harmful alcohol use, harms to a family member or close friend, or experience as a service provider, practitioner or volunteer working with alcohol.

'Experts by experience' is broader than 'service user' or 'patient'. Experts by experience may have previously used services but are no longer doing so, or they may never have wanted to use services, even if they were eligible to do so. It could also be, particularly in the case of family members or carers, that there simply are no services available to them.

Finally, alcohol is a substance that is widely used across the population – and which can also affect people who don't drink. In this respect, very many of us are 'experts by experience': whether as social drinkers (potentially affected by population-level policy interventions), friends or family members of people experiencing alcohol harm, people who have directly experienced harm linked to alcohol, or people who struggle with their own drinking.

All the terms described above have legitimate uses in a range of contexts. Here, we use the term 'public involvement' because alcohol research can address issues and behaviours right across society – and, therefore, has a responsibility to consider the views and perceptions of the 'public' at large, as well as of specific groups. We also use the term 'experts by experience', especially when considering direct experience of harm. However, we recognise the limitations of terminology, and suggest that, in any given research context, terms should be agreed collaboratively to best reflect how partners define themselves.

There are many types of experience that may qualify someone as being an expert. This raises difficult questions for the concept of 'expertise'. We do not suggest that all forms of expertise are equal and interchangeable; rather, that good research requires a *triangulation* of expertise, and respect between different bodies of knowledge. This means a considered interlinking of knowledge, an acknowledgement that different partners have different skills and insights, and a careful attention to the roles that best maximise those strengths. It means asking:

- **WHY:** Why is public involvement appropriate for this specific project? What is its purpose?
- **HOW:** How will participants be involved?
- **WHAT:** What will they be doing throughout the course of the programme?



## Knowledge and power

The emergence of public involvement not only reflects an increased awareness of the need to understand the perspectives of research subjects and beneficiaries; it also reflects challenges to conventional power structures in health research.<sup>7</sup>



There are many ways to consider the varying degrees of public involvement and the relationships of power they reflect. A recent adaptation of Arnstein's 'ladder of participation' describes it as follows:<sup>8</sup>

- **Educating** (the unidirectional flow of information to service users)
- **Informing** (explaining the reasons for decisions)
- **Consultation** (establishing surveys or meetings to gather service user views)
- **Engagement** (ensuring limited input into actual decision-making)
- **Co-design** (user involvement in the design of services)
- **Co-production** ('an equal relationship between people who use services and the people responsible for services')

INVOLVE set out three different types of activities:<sup>9</sup>

- **Participation** – where people take part in a research study
- **Engagement** – where information and knowledge about research is provided and disseminated
- **Involvement** – where members of the public are actively involved in research projects and research organisations

Co-production is a more radical extension of public involvement, with some practitioners arguing that it demands a wholesale 'change in the power dynamics between researchers, professionals and the public'.<sup>10</sup>

The relationship between power and knowledge is complicated – as is defining what we mean by 'the public'. Public involvement does not always imply full co-production, nor is it about simply doing away with structure, leadership or role allocations. Rather, it is about carefully considering how power is dispersed in a given research programme, who benefits from the outcomes (and in what ways), and how different bodies of knowledge are effectively harnessed to a common goal.

### Public involvement and research design

Public involvement can inform any type of research irrespective of the methodological approach.

Understandably, it may be felt that public involvement sits more easily with qualitative research, especially compared to technically complex projects involving, for instance, advanced statistical analysis. This is not necessarily the case: while lay participants may lack technical expertise in quantitative methods, they can still provide critical input in areas such as scoping, validity and communication of findings. Furthermore, it is critical to remember that qualitative field research is not, simply by definition, more co-productive than other methodologies: *conducting research on, or about, members of the public is not the same thing as public involvement.*

Genuine public involvement means engaging members of the public, or particular experts by experience, in research from design through to dissemination. It also means paying attention to power, and accepting that there will be a shift of power away from researchers as part of the process.

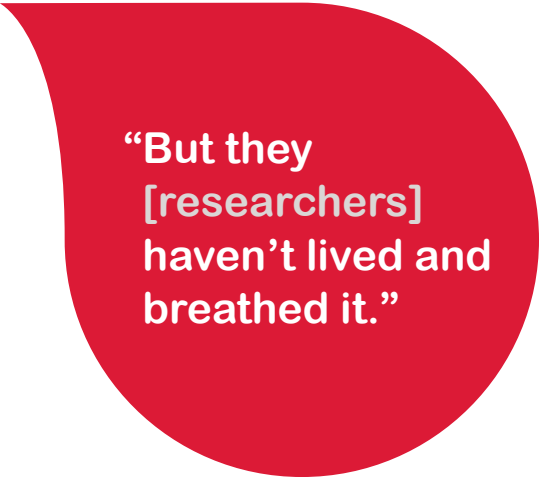
In alcohol research, models of involvement are liable to differ depending on the nature of a project. Work on treatment practices, for instance, may require close working between researchers, service users and treatment professionals. Work on broader public health interventions, by contrast, may require careful consideration as to how the perspectives of 'everyday' drinkers can be meaningfully incorporated into research design and delivery.



# Why involve the public?

**There are both ethical and practical arguments for public involvement in research: both that 'people should not be excluded from research that describes and affects their lives' and that 'knowledge constructed without the active participation of practitioners can only be partial knowledge'.<sup>11</sup>**

For many researchers, public involvement is important largely because it is increasingly a requirement of funding organisations. However, to be carried out effectively it needs to be inherently valued for its ability to enhance research.



**“But they  
[researchers]  
haven’t lived and  
breathed it.”**

In our engagement with both researchers and experts by experience, a number of key themes emerged that pointed to the value of these approaches.

## The values of involvement

### Voices

Public involvement requires us to ask who speaks to, for and through our research? How do we listen better to one another? How do we ensure all voices are heard?

Public involvement can also help develop our ability to listen. Research is about discovery, and this requires openness to new ideas and challenging perspectives. By opening up to voices beyond the academic 'comfort zone', researchers can both widen their horizons and, hopefully, discover new truths.

### Connections

Public involvement is about understanding and developing connections. These can take many different forms: collaborations, partnerships, personal relationships or wider channels of communication.

By seeking better connections, research can achieve wider goals. By triangulating expertise, it can develop powerful ways of solving some of our society's most deeply entrenched problems.

### Journeys

Many of those participating in this project described research in terms of journeys, whether of discovery, empowerment or recovery. By engaging with one another in new ways, both academic researchers and experts by experience described an experience in which knowledge was achieved *through* research not just extracted *from* research.



### Insight

Our participants often spoke about the new insights they gained from engaging with new forms of experience. They described how public involvement opened them up to new complexities in lived experience, shifted their perspectives, and allowed them to look at research problems in a new light.

Alcohol research has a long history of breaking new ground in terms of understanding complex human behaviour. Public involvement presents new ways of achieving this.

### Change

Participants gave numerous examples of how public involvement led to change – both personal and professional. For those who found research involvement aided recovery, it contributed to change of profound importance. Projects of this kind also produced change in how research was carried out, and the kinds of knowledge it sought. Finally, at its best, this approach to research helps promote effective changes in policy and practice by more explicitly speaking for, and to, the people whose lives it is designed to improve.

### Empowerment

Throughout all our events, participants described research involvement as deeply empowering. For many, it played a role in their own journey of recovery: helping them reflect on their own experiences while engaging in activities that were both meaningful and valuable. It allowed people who were often marginalised to find a voice, to move beyond feelings of shame or guilt, and speak on equal terms with researchers, practitioners and funders. It opened avenues and possibilities that helped change perspectives and build confidence.

**“Research has traditionally benefitted the researcher; the individual in terms of their career and the institution in terms of its prestige and its profile.”**

Research involvement also helped improve the work of alcohol services. Not only did involvement provide individuals with empowering ways to express, and explore, their own experiences, it also led to tangible changes in practice. This is likely to become increasingly relevant as peer mentors play a more central role in service provision.

# Benefits of involvement

In addition to the broad value of public involvement in the research process, our participants noted a number of specific benefits.

## Relevance

Not all alcohol research has direct beneficiaries. However, where it does then early involvement of those potential beneficiaries – ideally at the stage at which research questions are decided – will help ensure outputs are relevant and meaningful. Academic researchers are undoubtedly experts at identifying gaps in the published evidence base; however, they may not fully grasp the nature of unmet needs among service users or practitioners without engaging them in early phases of research development.

## Recruitment and responses

A review of patient involvement in mental health research has shown that there is a positive association between patient involvement and successful recruitment.<sup>12</sup>

Experts by experience are increasingly employed to conduct research among people with similar experiences (often referred to as 'peer researchers'). Involving peers in research as interviewers, for instance, may help elicit more honest and reliable accounts as well as helping to build a rapport. It can also create a sense of shared ownership of the research.

## Impact

Public involvement in research can help increase impact. Involving potential beneficiaries in research development, delivery and dissemination means that not only is research more likely to address their needs, it is also more likely to be communicated in ways that positively impact on practice.

Publication in high quality, peer reviewed journals remains a guarantor of research quality. Conventional metrics, such as citations and impact factors, reflect the extent to which findings influence the wider research community. However, social impact also requires a focus on bringing research outputs to a range of audiences, through a range of media and engagement activities. Public involvement can be at the heart of this: moving from 'dissemination' of research outputs to a more dynamic promotion of social outcomes requires co-working and co-development between researchers and the wider public.

INVOLVE's recent review of published literature on the impact of public involvement highlights improved impact in relation to research agendas, research design and delivery, research ethics, research participants and the wider community.<sup>13</sup>

None of this is to say that there is a one-size-fits-all approach to public involvement in research. There are many forms of public involvement, and the degree to which it shapes research will depend on the context and questions being addressed. However, where used well it can – as many of our participants attest – be transformative.

# Expert by experience involvement in alcohol research: two perspectives



*I have worked on many projects since joining The Sheffield Addiction Recovery Research Panel (ShARRP) panel in Sheffield. There are three that were most fulfilling and where I also felt that I contributed greatly.*

*Firstly, working alongside the university students, giving them some insight to the very nature of addiction was an advantage to them and their project. I received positive feedback from them, in regard to how powerful addiction can be, the consequences of addiction, and the massive impact that it has on family, friends and work colleagues.*

*Secondly, I thought that the project "Faith support groups" was something that I could truly contribute to. As a leader in a local church, I facilitate a Twelve Step group for Christians. I have knowledge that there is an enormous need for support to Christians. I also work with a Polish church, and part of their culture is drinking. After giving suggestions to this field and the project, we thought that this was a bigger issue than first thought. It was suggested that we look at this project and welcome others around the same issues. I personally enjoyed working on this project.*

*Working with the ShARRP, has given growth in my own recovery and continues to support others too. Working with a diverse group on the panel, brings a freshness to the team. I have been asked to represent the ShARRP on two occasions, in Birmingham and also in London. I feel that we, the ShARRP in Sheffield, will continue to be challenged and make a difference to recovery within the city and nationally as we move forward.*

**Steven Collier-Ellen**





*In my experience, people affected by alcohol are mostly regarded with pity, judgement or severe condemnation in our society. As such, I believe that despite the best of intentions, service user involvement in research in the alcohol field, is all too frequently still met with suspicion and/or tokenism by academics.*

*Since I accessed detox and treatment almost ten years ago, I have been involved in research as a participant, consultant, co-applicant for funding, and increasingly as a researcher myself. These experiences have been facilitated by several different universities, local authorities and research institutes. Overall, it has been a positive and rewarding journey which has empowered me and enriched my knowledge and experience of the field.*

*However, having sat on both sides of the fence, I am still all too often frustrated by academics underestimating the significance of directly consulting with people who have lived experience of the phenomenon under investigation. I've heard eminent academics joke that they don't need to consult service users because they "like a beer or two" themselves or that they understand detox as they quit smoking cigarettes in their teens.*

*Whilst I firmly believe that addiction is a spectrum and there is value in trying to identify with others I think there remains a cultural resistance to the "hassle" of consulting service users particularly in quantitative circles.*

*I would strongly challenge this, as in my experience the benefits of service user involvement are significant and vastly under-utilised. I have seen recruitment targets met with unprecedented ease and findings disseminated in much more creative and interesting ways when service users are directly consulted. Moreover, if you believe in the social value of research my experience tells me that service user involvement can be incredibly empowering. Personally, it gave me the courage to apply for a Master's scholarship and subsequently doctoral funding.*

*This is in no way to suggest that service users have the monopoly on insights into alcoholism or problem drinking, but rather a shout out to readers to say... as an ex-service user involved in research and as a budding academic my experience shows me that when it is done properly, service user involvement in research produces better research*

**Anonymous**



# Practicalities and principles



Public involvement requires investment in time and training, and our workshop participants identified a range of practical and ethical issues that need to be considered.

## Capacity building

Public involvement is new and unfamiliar to many researchers. It may be perceived as a threat to established ways of working or as an exciting, but daunting, opportunity. Participants in our workshops said many of their colleagues were 'enthusiastic but nervous'. Avoiding both anxiety and tokenism means recognising what those concerns are and helping to address them. This requires support, guidance, training and reassurance that a degree of trial and error is accepted.

## Language and terminology

Language can be a source of concern and, sometimes, conflict. 'The public' is often far too broad, 'service users' may be too narrow, 'experts by experience' may raise difficult questions about the nature of expertise. Agreeing on terminology is often a constructive part of the co-production process – and it is important that people recognise no-one has the perfect solution to this problem.

## Recruitment

The greatest challenge in recruiting people into research projects is avoiding tokenism. Research teams need to think carefully about what experience is needed, what communities need to be engaged, and where best to find representatives. Local service user forums can be a powerful resource in some respects, though they will not reach people who are not in touch with services. The people we want to engage are often the hardest to reach.

At the other end of the scale sits the difficult question of how broader public health research engages those it seeks to affect. While there is no simple solution to this problem, the random (or convenient) selection of individuals for limited consultation is unlikely to achieve representativeness.


To address this, researchers need to allow sufficient time to support involvement: to build it into planning from the start. They need to seek to enable the widest range of views, while accepting that all involvement is partial and imperfect. There is no ideal model, so there needs to be room to innovate.

## Integrity

If public involvement forms part of a research project, it needs to be integral. This means supporting involvement from design through to dissemination, not least because prior research suggests there is a relationship between the extent of service users' involvement in research and its capacity to serve an empowering function<sup>14</sup>.

There is a need to avoid the 'black hole of public involvement', in which people are consulted but the research continues unchanged. Similarly, researchers need to consider the longer-term role of people who become involved in projects: involvement can be a powerful experience, but a disheartening one if the research team moves on once an engagement phase is complete.





**“Service users need to be involved from the beginning to sustain and empower them as well.”**

Building public involvement into research also has implications for funders. We need to incorporate expertise by experience into our work, from identifying priorities to considering grant applications. This is not a process of replacing one body of expertise with another, or suggesting that all knowledge is interchangeable. Rather, it is about identifying how different expertise can be applied to various elements of the research process such that it achieves the best possible outcomes.

### **Communication**

Managing public involvement means managing relationships, and ensuring that voices are heard in meaningful ways. People invited to contribute to research should feel that they are able to speak, and that their ideas will be taken seriously.

Members of the public may often also find academic jargon alienating. This is not to say that precise, technical language should be avoided: it is essential in the right context. However, a commitment to public involvement also means a commitment to communicating complex ideas in ways that can be understood by the wider public.

### **Support**

Participants also need to be supported throughout the project in which they are involved. Context and preparation are critical: being a lone expert by experience in a meeting of established research professionals may be intimidating, even counter-productive. The structures of engagement, and support to maximise its impact, need careful consideration.

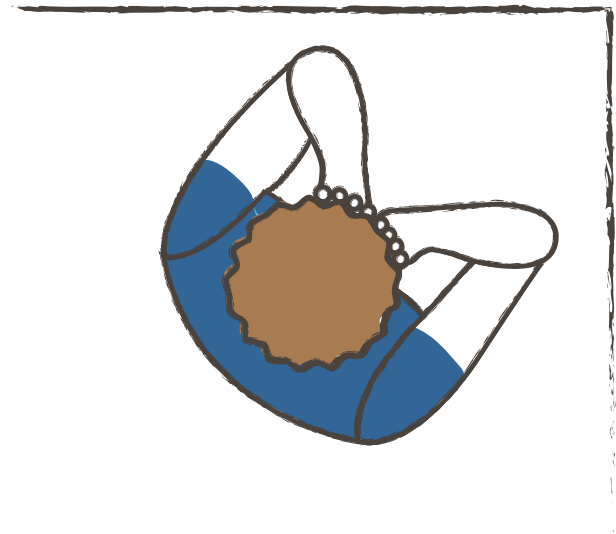
There are also important budgetary implications, especially when working with people directly affected by alcohol harms. Often participants will be on low incomes, so systems need to be established to support travel to meetings as well as consideration of payment for the time involved.

Remuneration may take the form of cash payment or voucher. There are mixed views on this but it has recently been argued that cash demonstrates greater trust in those involved.<sup>15</sup> Cash payments are likely to have tax or benefit implications, however, which need to be made clear.

# Challenges of involvement

Although there are many benefits, researchers need to be realistic about the challenges posed by public involvement. As discussed previously, non-tokenistic public involvement can require considerable time commitment, as well as engaging researchers in unfamiliar methods and potentially complex relationships. In the case of alcohol dependency, these issues can be acute: while many of our participants reported that research involvement was an aid to recovery, other participants warned that engaging in intensive – and potentially stressful – work around alcohol could create triggers and cues that might risk relapse.

Depending on the nature of the proposed involvement, research teams may want to consider specialist training in safeguarding to mitigate the risk of unintended harms to participants or researchers.



**“Stigma is a barrier to absolutely everything when it comes to alcohol research problems.”**

Stigmatisation is a particular issue in alcohol research, especially if working with people drinking at harmful levels. On the one hand, involvement may help to overcome stigma by helping participants feel valued and respected, giving them the opportunity to express themselves, and developing new skills and networks. However, the public disclosure of having experience of alcohol harm – especially in unfamiliar environments – may increase anxiety around stigma. Research teams need to consider this and have mechanisms in place to mitigate the risk.

**Benefits and challenges of public involvement**

**For Researchers**

BENEFITS	CHALLENGES
Widens horizons	Time commitments
Improved research relevance	Unfamiliarity with methods, language and approaches
New connections in the wider community	Lack of training in safeguarding or relationship management
Impact in policy and practice	Avoiding tokenism in recruitment
Accessible and innovative research outputs	Loss of control over research activities
Applicants address funding requirements	Demonstrating impact in context of conventional academic publication metrics
Increased credibility among stakeholders	Difficulty applying for grants where methods are unconventional
Development of new research methods	Budgeting for external costs

**For Experts by Experience**

BENEFITS	CHALLENGES
Widens horizons	Time commitments
Influence on academic practice and priorities	Unfamiliarity with methods, language and approaches
New working relationships with researchers	Risks to wellbeing if experience is stressful or creates triggers
Impact in policy and practice	Lack of meaningful involvement or perception of tokenism
Opportunity to have voice heard	Lack of sustained involvement, especially at the end of research phase
Participants feel valued and respected	Stigma due to disclosure
Increased confidence and skills	Intimidating or unfamiliar environments
Improved experience in research	Financial implications if costs not covered

# Recommendations

**1**

## **MAKE IT FIT**

The level and nature of public involvement in a given research project should be appropriate to the research subject. There is no one-size-fits-all approach: the goal should be the best possible triangulation of expertise and experience to address the problem under consideration.

**2**

## **INVEST TIME IN BUILDING RELATIONSHIPS**

Public involvement is about developing relationships. Taking time to make sure people know, and feel comfortable with each other, builds trust and helps ensure involvement is meaningful for all parties. Try to involve people as early as possible in research, ideally while research questions are being formulated.

**3**

## **MIND YOUR LANGUAGE**

Technical language can be a barrier to involvement as it can be alienating for those who do not come from an academic background. Similarly, people may come at projects with different terminology for 'service users', 'experts by experience' and so forth. Try to find common language that everyone is comfortable with and use it throughout the project. Remember that outputs should also be accessible.

**4**

## **MANAGE EXPECTATIONS**

It is important to manage expectations, including your own. Public involvement does not guarantee the success of a research project, and outputs may not always have the desired impact. It helps to remember that every experience on projects of this kind is valuable.

**5**

## **PROVIDE REMUNERATION AND REIMBURSE EXPENSES**

Public involvement requires time investment for both the researcher and those involved. While the researcher's time may already be paid for either by the institution or the grant, those involved are not always factored into the costs despite dedicating their time. It is, therefore, appropriate to factor such time into grant applications (and that funders view this as a legitimate cost). No one should be out of pocket as a result of their involvement.

6

### **PROVIDE TRAINING AND SUPPORT**

Training and support are essential for those coming into research for the first time. INVOLVE provides a helpful guide on this.<sup>17</sup> If there are no in-house training resources there may be external training opportunities. Researchers may well also need training in key areas such as safeguarding.

7

### **BE IMAGINATIVE AND MAKE IT FUN**

Public involvement in research should be an enjoyable and meaningful experience for all parties involved. Take the opportunity to push boundaries and explore new ways of learning.

8

### **THINK ABOUT POWER**

Public involvement in research means sharing power. Without a meaningful distribution of power, the relationship can become unbalanced: the researcher drawing from lived experience, but imposing their frame of reference, and their interpretation and values, onto that experience. Also remember that meetings can be intimidating and language can be alienating. Unequal power relationships can create barriers to involvement, even where this is not a conscious intention.<sup>18</sup>

9

### **AVOID TOKENISM**

No public involvement group will be perfectly representative; however, anyone developing public involvement has a responsibility to plan carefully to avoid tokenism. This means striving for diversity in order to obtain a rich mixture of perspectives and experiences.

10

### **AIM FOR SUSTAINABILITY**

Research projects will have a finite lifespan. However, it is important to think about the sustainability of public involvement and what happens to relationships after a project comes to an end.

## APPENDIX

# Public involvement in alcohol research – projects and networks

**This report builds on the exchanges and input from a series of workshops and discussions with researchers, funders, services users, service providers and people directly affected by alcohol harms.**

### Research roundtable

In October 2016, we convened a national roundtable involving academics, funders and service providers, to scope out the particular challenges around the development of public involvement in alcohol research.

Participants included representatives from:

- Addaction
- Aquarius
- Changes UK
- Drink and Drugs News
- INVOLVE
- Manchester Metropolitan University
- Plymouth City Council
- Public Health England
- Scottish Health Action on Alcohol Problems
- Sheffield Addiction Research Recovery Panel (University of Sheffield)
- Teesside University
- The Addictions Service User Research Group (King's College London)
- The Association of Medical Research Charities
- The Edinburgh Photovoice Project (Edinburgh University and Serenity Café)

### Research co-production workshop

In January 2017, a research co-production workshop was held at Changes UK, Birmingham. This event captured the perspectives of experts by experience (service user representative, research panel members and a peer researcher who all have either direct or indirect experience of drinking at harmful levels).

Presentations and performances were given by experts by experience from:

- Changes UK
- Public and Expert by Experience Research Programme (Bedfordshire University)
- Sheffield Addiction Research Recovery Panel
- Voicebox Inc (Manchester Metropolitan University)

A short commentary was produced following this event in further explored discussions which was published in INVOLVE's summer newsletter.<sup>19</sup>

## National conference, early career symposium and panel debate

In April 2017 we held our annual conference in London, entitled Working Together: People, Practice and Policy in Alcohol Research. This event, including an Early Career Symposium and evening panel debate, took place over two days and included contributions from:

- Bereaved Through Alcohol and Drugs (BEAD) project (Adfam and CRUSE)
- Glyndwr University
- INVOLVE
- Manchester Metropolitan University
- The Addictions Service User Research Group (King's College London)
- The Communities Together Project (Alcohol Concern Cymru)
- The Edinburgh Photovoice Project (Edinburgh University and the Serenity Cafe, Edinburgh)
- The Family Life in Recovery Project (Sheffield Hallam University)
- The Public and Expert by Experience Researchers (PEERS) project (University of Bedfordshire)
- The Service User Research Enterprise (King's College London)
- The Sheffield Addiction Recovery Research Panel (University of Sheffield)
- UKCTAS Alcohol Discussion Group (Stirling University)
- Voicebox Inc.

As part of the conference, we commissioned Voicebox Inc – a community interest group that promotes coproduction in substance use research and practice – to provide an installation and capture insights on delegate's views about public involvement at our annual conference. In total, 74 of the 120 conference delegates participated in the Voicebox, natter bar and/or roving microphone throughout the course of the day.



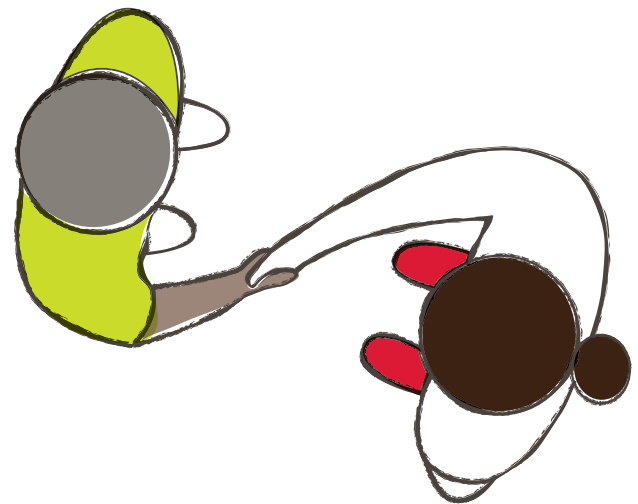
A video capturing this input was produced by Voicebox Inc. and is available here: <https://www.youtube.com/watch?v=qmgWEhHPyzi>

**“I learnt about the use of panels and engaging differently with people at different stages of research and how that can have a positive outcome both in terms of people being involved in research but also for researchers.”**

## Research workshop

In June 2017, a research workshop was held in collaboration with FUSE the Centre for Translational Research in Public Health. This brought together researchers and practitioners working to reduce alcohol-related harm. Participants included:

- ADFAM
- Blenheim CDP
- Club Soda
- Drinkaware
- FUSE (Durham University)
- Hope UK
- London South Bank University
- Scottish Health Action on Alcohol Problems
- University College London
- University of Liverpool
- University of Surrey



The workshop considered the history of and context for public involvement and reflected on what 'knowledge' is in the public involvement process.





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<sup>3</sup> For a discussion of public involvement in substance use research see Neale, J. Bouteloup, A., Getty, M., Hogan, C., Lennon, M., McCusker, M., Strang, J. (2017) Why we should conduct research in collaboration with people who use alcohol and other drugs. *Addiction* doi: 10.1111/add.14015

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