

Collective Voice briefing: The barriers to, and facilitators of, voluntary sector drug and alcohol treatment and recovery services engagement with academic and clinical research projects.

Executive summary

In September 2023, Collective Voice and the Office for Life Sciences Addiction Mission convened representatives from voluntary sector drug and alcohol treatment and recovery organisations, for a roundtable discussion on the barriers to and facilitators of voluntary sector engagement with research bodies and projects.

Throughout the discussions, overarching challenges were highlighted which have contributed to limitations on voluntary sector organisations' ability to engage in clinical research projects. Some of these challenges relate to structural issues within the sector, such as limits on organisational capacity, the skills and expertise available within the voluntary sector workforce, or the nature of service commissioning and delivery.

Other issues such as regulatory constraints, constraints on providers' ability to engage with regulatory bodies, and burdensome processes to gain ethics approval or to complete necessary documentation were also highlighted.

Furthermore, there were a number of concerns raised around the nature of research proposed or undertaken. It was suggested that providers' relationship to their service users, and the type of research they would prioritise as being in their service users' best interests, might not always align with the priorities of researchers.

These challenges, along with measures suggested for overcoming them and some instances of good practice, are explored throughout this briefing before outlining the next steps that Collective Voice is taking to support the Addiction Mission to further engage with voluntary sector treatment and recovery providers in their work.



Background and context

It is vital that we generate strong evidence to inform interventions that will improve treatment and recovery services and support more people to make the changes they wish to see in their lives. Partnership working between those leading research and drug and alcohol services can ensure that services and their service users are able to feed into the development of research, so that research findings and innovations developed from them meet the needs of service users and can be effectively translated into practice.

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About Collective Voice

Collective Voice is the alliance of voluntary sector drug and alcohol treatment and recovery providers. We believe that anyone in England with a drug or alcohol problem should be able to access effective, evidence-based, and person-centred support. We know that treatment and wider support has a transformative power for people with drug or alcohol issues, their families, and communities.

The voluntary sector plays a key role in providing this support, comprising almost three quarters of the total treatment provider workforce¹. We were created through the collective leadership of treatment and recovery charities to ensure that the knowledge and expertise of this field can contribute to the development of policy and practice. Together, our sponsoring organisations² support over 200,000 people every year and are part of a wider ecosystem of charities across the country which include local, specialist and lived experience recovery organisations, working alongside statutory partners to support people with drug and alcohol issues.

About the Office for Life Sciences Addiction Mission

The Office for Life Sciences (OLS) is a joint unit between Department for Health and Social Care (DHSC) and Department for Science, Innovation and Technology (DSIT) that champions research, innovation, and the use of technology to transform health and care services and increase the UK's attractiveness as life sciences superpower.



The Government's 2021 Life Sciences Vision commits to a set of "Missions" to address some of the biggest healthcare problems of our generation by taking a Vaccines Taskforce style approach, fusing together the best of industry, academia, and the NHS to make rapid progress in these disease areas. The Addiction Mission was developed in response to Dame Carol Black's report and announced in the UK's 10-year Drugs Plan, From Harm to Hope.

The Addiction Mission is aiming to enhance the UK-wide research environment and incentivise the development and testing of innovative and effective new treatments, technologies, and approaches to support recovery, and reduce the harm and deaths these addictions can cause. £30.5m of Government funding has been committed to deliver this Mission

It aims to transform the UK's drug and alcohol addiction research ecosystem to:

- Grow the capacity and capability across the UK to deliver innovative research
- Better link researchers, treatment delivery partners, industry, and innovators.
- Accelerate the development, testing, and use of innovations targeting addiction.

In direct support of the Mission's goal of catalysing new innovations it has to date:

- Launched the £5 million [Reducing Drug Deaths Innovation Challenge](#) in partnership with the Scottish government to catalyse the development of innovations to improve detection of, response to, and intervention in potentially fatal drug overdoses, to prevent deaths.
- Launched the [£10 million Addiction Mission: Innovation for Treatment and Recovery i4i awards \(AMI\)](#), delivered with the National Institute for Health and Care Research, to support the creation of innovative medicines and technologies to help treat people with opioid or cocaine addictions and aid in their recovery.

Introduction

The roundtable brought together representatives from [Humankind](#), [Change Grow Live](#), [Changing Lives](#), [Kaleidoscope](#), [Phoenix Futures](#), [Project 6](#), [Turning Point](#), [Via](#), and [With You](#).

It was attended by these organisations' clinical directors, lead pharmacists, heads of innovation and development, and others, who shared their organisations' experiences of engaging with research activity.



This briefing summarises the discussions at the meeting, which focused on the challenges, barriers and enablers to voluntary drug and alcohol treatment and recovery providers engagement with research projects.

Experience, knowledge and expertise.

Organisations reported limited involvement with academic and clinical research projects, and most of the experience that does exist is consolidated within only a few providers. The research experience that was reported largely involved internal, service evaluation-type exercises, which would not meet the definitions of ‘research’ for which regulatory bodies require ethical review³. There were also examples of studies of a social scientific nature shared but much less engagement with clinical, pharmacological, and data-generating research.

Voluntary sector drug and alcohol treatment and recovery services do not have significant numbers of staff within their workforce with knowledge, expertise, and experience of academic and clinical research. This can limit their ability to engage with research bodies and take on partnership roles within research projects.

All organisations expressed an interest in greater involvement in research, provided it was aligned with their organisational ethos and capacities and if certain infrastructure and support mechanisms were put in place.

Capacity and funding

Voluntary sector service providers reported being largely unable to commit the resource that would be necessary to initiate, process, or develop upon research requests, nor to undertake research work itself. It was noted that engaging with research can take significant resource and there is not ‘protected time’ for research work, and limited infrastructure and support.

To improve their ability to process and respond to research requests, one organisation reported having ‘streamlined’ its internal governance structures, which has enabled them to better deal with the volume of requests received, while another organisation has created a cross-departmental innovation and research unit. It was noted however that this is not as feasible for smaller organisations.

Furthermore, participants highlighted that commissioners often do not place a high value on research, meaning that resource is not allocated to it. The impacts of this lack of dedicated resource are compounded by a lack of general resource, particularly in the context of inflationary pressures on contracts which have not received uplifts. As a result, core services remain the priority and engaging with research is challenging.

Engagement with commissioners to highlight the benefits brought to services and service users by engaging with research was suggested.

Engagement with research infrastructure, regulatory frameworks, and support.

The infrastructure, guidance, and support for research in healthcare does not recognise and acknowledge the voluntary sector's role in the provision of drug and alcohol treatment and support. For instance, the UK Policy Framework for Health and Social Care Research¹ doesn't specifically acknowledge the role of the voluntary sector in delivering drug and alcohol treatment and recovery services alongside the NHS.

Ethical approval for research is challenging to navigate in this landscape. NHS ethics guidance and approval guidelines do not currently appear to extend to voluntary sector organisations providing drug and alcohol services. In addition, as highlighted above the sector does not necessarily have knowledge and skills in this area to understand when and what ethical approval is required. This leaves organisations less able to confidently engage with research and to the perception of the sector as less suitable as a research site.

Where organisations have had engagement with health research infrastructure bodies these were based around individual contacts which were often lost when individuals moved roles, rather than being structurally and systematically embedded in the work of these bodies.

Recognition, by these regulatory frameworks and bodies, of the role of the voluntary sector in the provision of drug and alcohol treatment and recovery services, similar to the recognition of the sectors role in social care is needed. Terminology on a range of documents often only refers to NHS and social

¹ <https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/>

care and not voluntary sector who deliver publicly funded healthcare or support to people who want to change the way use drugs and alcohol.

A review of the guidance to ensure it is appropriate and suitable for voluntary sector drug and alcohol treatment and recovery settings is also needed. One participant at the roundtable shared that they have found the ‘Brunswick Templates’ helpful in navigating the necessary documentation for research projects and similar support aimed specifically at voluntary sector organisations could be helpful.

It was also suggested that the skills and capacity of the sector could be enhanced through mentoring or coaching relationships between academic researchers and providers. Given that smaller organisations within the voluntary sector are likely to be disproportionately affected by the limited experience and knowledge described above there might also be scope for large organisations with more experience of research to support smaller ones through similar coaching and mentoring relationships.

Partnership arrangements and relationships

The voluntary sector is not always treated as an equal partner in research partnerships. Experience was shared that pharmaceutical companies can overlook the voluntary sector, particularly for research involving randomised controlled trials. This was linked to the lack of clarity within research frameworks and regulations about the position of voluntary sector settings as research sites. Another provider raised their experience of being treated as a ‘loophole’ by researchers wishing to circumvent the NHS ethics approval processes.

Organisations reported requests for research involvement that appeared ‘extractive,’ where providers were treated merely as an access route for service users with researchers having reportedly often adopted a ‘take it or leave it’ approach, unaccommodating of providers’ terms and requirements for research to be conducted. The importance of a trauma-informed approach to research was noted. Some providers also said they felt that terminologies of academic research may tend towards ‘stigmatising’ language which they would not approve of. Multiple participants reflected their views that they would not engage with research if they felt there were questions about its benefit to service users.

Negotiating, and re-negotiating, the terms of contracts proves burdensome and demotivating. It was shared that research bodies may be unwilling to accommodate providers’ terms for partnerships,



meaning that multiple rounds of negotiation take place with costly legal fees being required for each round.

This can involve navigating complex contractual agreements within an unfamiliar legal territory for voluntary sector providers. There were multiple instances shared in which organisations' ability to engage in research was curtailed by the use of complex and unfamiliar contractual documentation, including one instance of a research body insisting on the signing of foreign legal documents and non-disclosure agreements.

For smaller organisations, these issues are even more disproportionately burdensome, as they are far less likely to have legal professionals in-house and unlikely to have resource to hire external lawyers.

Select positive experiences were shared where providers have been treated as equal partners within research. This included providers being involved from the earliest stage possible, including research design and grant applications, which has brought additional benefits in terms of generating greater buy in from both staff and service users for the project. The preference was also expressed for involvement in devising research outcomes and outputs, which allows organisations to better determine the benefits which will hopefully arise for those whom they support.

Furthermore, one representative raised their organisation's positive experiences of working relationships with a university, with whom they host student placements and undertake joint funding applications. In this relationship the provider is treated as a collaborative partner, rather than as a research participant or a way to access subjects.

The competitive commissioning processes through which service delivery is procured were also said to have had a potential limiting effect on collaboration in research between voluntary sector organisations. Voluntary sector organisations must compete for contracts which can create a degree of mistrust between providers and mean organisations are less willing to share information. It was suggested that having research questions and processes jointly agreed, at the initial stages, between researchers and the different collaborators (providers) may encourage a greater degree of collaboration.

Research agendas and priorities.

From a service provider perspective, the ‘clinical’ aspect of a treatment programme represents only one part of an individual’s recovery. Psychosocial interventions, or interventions which address housing, welfare, or other material issues may be as important as, or in some cases more important than, clinical interventions, and so strengthening research on these areas should also be considered by the Mission and wider medical academic establishment. Closer working relationships with research bodies would be welcomed but there was a view that this should be within a balanced approach to research that recognises the value of both clinical and psychosocial interventions and thus both clinical and social scientific inquiry.

It was pointed out that research agendas are often set by research bodies, and it is much harder for voluntary sector organisations to take ideas to researchers or work to jointly identify priorities. A platform to facilitate ideas, researchers, methods, and research sites to be ‘matched’ or connected with each other and allow those working within services to develop and find researchers interested in specific research questions could support improved partnership relationships.

Regulatory issues***Risk***

Service providers’ capacity to take on risk can also act as a barrier to research involvement. Organisations existing insurance policies, while sufficient for service delivery, may not adequately cover them for research activities. Unlike NHS bodies who are automatically indemnified against any risks associated with research that has NHS ethics approval.

Data

Organisations shared frustrations with the limitations of the National Drug Treatment Monitoring System (NDTMS). It was noted that NDTMS does not publicise all the data that is collected, particularly on key issues such as polydrug mortality.

In addition, what is collected at a national level is only a ‘fragment’ or the data providers hold. However, the sector can be viewed as ‘data poor,’ despite voluntary organisations having a great deal of valuable data, because of a lack of infrastructure to share and deploy this effectively. This is compounded by the



interoperability of providers' data, along with challenges relating to data sharing and General Data Protection Regulation (GDPR).

Conclusion and next steps

The barriers to voluntary sector drug and alcohol treatment and recovery services engagement with academic and clinical research projects are not insignificant. However, there are examples of good practice and the desire and opportunities to overcome these barriers. We have highlighted areas for improvement in this briefing that would enable a future in which voluntary sector drug and alcohol treatment and recovery providers can play an important role as an equal partner within the UK drug and alcohol dependency research ecosystem.

Collective Voice is supporting a number of immediate next steps to support the Addiction Mission to address these barriers including:

1. Participating in the Addiction Mission's work with the James Lind Alliance to complete a Priority Setting Partnership (PSP). This PSP is bringing together clinicians, patients, and carers to identify and prioritise the Top 10 evidence gaps or unanswered questions in addiction treatment and recovery that could be answered by research. This PSP was launched in March 2024. Collective Voice are represented on the PSP steering group and will ensure wide input is invited from voluntary sector services into the process.
2. Collective Voice will also be supporting the Addiction Mission's work with the Health Research Authority (HRA) to explore how to provide clearer guidance and support to voluntary sector drug and alcohol services when designing and implementing research studies in these settings.

Collective Voice will continue to work with the OLS Addiction Mission to explore further policy approaches to address the barriers identified within this briefing, and to support the Mission to deliver its ambition of creating a pioneering, UK-wide capability, within both voluntary sector and NHS treatment providers, to test and trial all types of addiction treatments and technologies ultimately creating new innovations to improve the lives of those with drug or alcohol addiction.



Thank you to all who attended the roundtable discussion including:

- **Jess Mullen** (Meeting Chair), Chief Executive Officer, Collective Voice
- **Prof Anne Lingford-Hughes**, Chair, Addiction Mission
- **Dr Tom Dalliston**, Senior Policy Advisor, Office for Life Sciences
- **Devon DeSilva**, Innovation and Research Unit Manager, Via
- **Emma Griss**, Lead Pharmacist, With You
- **Faye Sunter**, Recovery & Wellbeing Lead, Changing Lives
- **Gabriel Shaya**, Research Group Chair, Turning Point
- **James Armstrong**, Director of Marketing and Innovation, Phoenix Futures
- **Liam Doherty**, Policy & Engagement Officer, Collective Voice
- **Lisa Kieh**, Clinical Governance and Services Director, Kaleidoscope
- **Mark Crowe**, Research and Development Co Ordinator, Humankind
- **Milena Marinkovic**, Researcher, Humankind
- **Vicki Beere**, Chief Executive, Project 6
- **Zoë Welch**, Head of Research, CGL