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SUAB

at ManMet

**Involving People with Lived Experience in Research and Knowledge Exchange (PERKE)**

**A Working Strategy**

**Substance Use and Associated Behaviours (SUAB)**

**Research Group**

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# Introduction

This is a working strategy for involving people with lived experience (PWE) in research and knowledge exchange (RKE) conducted by members of the SUAB (Substance Use and Associated Behaviours) research centre.

Involving people with lived experience in teaching, learning and assessment is established practice for applied health and social care professions. However, people’s involvement in RKE has not kept pace. In recent years, PWE have increasingly been involved in research on a project by project basis with some funders, for example, National Institute for Health Research, providing small amounts of funding to facilitate people’s involvement in specific projects. Some academics have developed informal groups of people with experience on whom they can call for participation in various aspects of research bid development. We argue that these approaches are limited and fragmented in their approach and lack ongoing commitment at both institutional and research centre level to support and progress the contribution PWE can make at and beyond project level involvement.

This PERKE strategy seeks to address that gap. Its purpose is to ensure that the contribution of PWE is embedded and sustained in the ways we research and translate our research for policy, practice and the public. This is necessary, not only because funders require it, but because people with experience have a great deal to teach us and we have a great deal to learn from them. It is necessary because it will challenge us, including methodologically, to reflect on what is considered ‘gold standard’ approaches to RKE work and to ensure it is conducted in genuine partnership - moving away from top down or tokenistic involvement and processes.

This document is presented in three parts:

1. An overview of the proposed strategy with brief descriptions of how this will work in practice
2. A more detailed ‘unpacking’ of the approach with selected illustrations of the positive participation of PWE across the breadth of research and activity. This includes a rationale for the development, value and impact of the strategy.
3. An overview of suggested actions and associated investment to begin to implement the process.

# Part 1: An Overview of the PERKE Strategy

The PERKE strategy will explore, evidence and evolve the role of ‘lived experience’ in the work of the Substance Use and Associated Behaviours (SUAB) Research Centre. Its development is grounded in the long-term partnership between academic researchers and a community partner steeped in ‘real world’ experience and co-productive practice. Through our work to date, we have learnt much about the positive and challenging elements that contribute to the process. This strategy embeds this learning, providing a direction and progressive process for future work. It has actively involved people with experience[[1]](#footnote-1), academic researchers and others throughout its development. It aims to direct the SUAB research centre in working in partnership with people with lived experience as part of their research planning, execution and dissemination. The approach includes:

* **A set of five principles** evolved from the practice of the SUAB Research Centre and the experience of individuals from the lived experience community[[2]](#footnote-2) to date.
* **A** **process** to establish key participants, roles and outcomes across SUAB PERKE activity.

It is intended to speak to and serve a range of audiences, including the University (ManMet), its academic leaders in this area (the SUAB Research Centre), people with lived experience (involved in the strategy and those who may be in the future), research funders, practice providers and policy makers. This will bring value[[3]](#footnote-3):

* For ‘people with experience’ (PWE) - it will open up potential involvement, impact and influence, spelling out what this might ‘look like’, how it will be rewarded and supported and how they might shape this.
* For academic researchers – it will develop understanding, skill and practice adding value and impact to their work from design to dissemination.
* For the University – it will provide a potential model of excellence for research practice that becomes a vital component in securing ongoing research funding and provide a robust and accountable mechanism to justify the return on investment for all participants.

## The SUAB PERKE Principles

1. Seek to understand, recognise and reflect the diversity, richness and complexity of lived experience across all areas of our work.
2. Co-create innovative ways of seeking out and connecting with people with experience that build conditions for partnership and mutuality to grow.
3. Co-produce a system that demonstrates value, rewards their inputs as co-creators and the unique contribution to each stage in the research process.
4. Establish and invest in a strategy and resource that is fair and appropriate, aimed at building genuine and trusting relationships that seek to maximise the contribution made by PWE.
5. Build a system of accountability and independent challenge that captures, questions and communicates the impact and influence of our approach and contributes to our own and wider body of evidence.

### The SUAB PERKE Process

***Figure 1 – the PERKE Model***

# Part 2: Understanding the approach; how it might work and its potential value

This strategy will deliver an approach to involvement that will strengthen and add value to our RKE. It will deliver on ManMet’s RKE strategic goals (Manchester Metropolitan University, 2017) through adding quality to what we deliver, as well as improving relevance and delivering innovation, perhaps challenging the status quo. Further, it will also add impact to what we do and how we do it, through people’s access to wider networks and fora, and through regularly holding academics to account for the purpose and impact of any proposed RKE activity. In doing so, our research stands a better chance of reaching, and having impact upon, our communities and society. These aims are among the core principal features of ManMet’s RKE strategy.

This PERKE strategy is both proactive and responsive, supporting a dynamic and progressive approach. At its heart is genuine and true involvement of people with lived experience as co-creators throughout the whole research process. This aligns with current understanding of where expertise lies. It seeks to challenge current academic practice in order to improve its integration with real world ‘knowing’ and lead the way in research practice, its impact and influence.

To date, the involvement of PWE in SUAB research has been project focussed and, therefore, piecemeal. Some projects have involved PWE as peer researchers, others in a more voluntary capacity as contributors to SUAB events, and others that have been driven largely by our growing relationship with a community intermediary or partner. This approach remains tokenistic and fails to embed people from the wider community in our work, the research questions we ask and a range of research roles and tasks.

Our ambition is to develop and sustain a different model of involvement, where people with lived experience have a role in setting or leading the agenda as well as responding to, or participating in, ‘ours’. Even if this approach was not considered good research practice, it is a requirement of the majority of funders for our RKE activity that we involve people with experience from the outset, from the point of developing our research questions. We need a group of people who are working with us and ready to be involved at a moment’s notice to ensure we are able to meet funders’ criteria but to do so in a way that demonstrates we value them and their contribution in an ongoing and non-piecemeal way. One example of this is a successful research award from the National Institute for Health Research in 2019. What the five reviewers commented on as a particular strength of the bid were the combination of a) an experienced team and b) our involvement of a co-applicant who was a person with lived experience and a community intermediary. The ability for the latter to engage people in the community, many of who sit outside of services and are not ‘service users’, not only added value to our research proposal but also served to ensure the name of SUAB and ManMet were reaching people it would perhaps not normally reach. The intermediary received no payment for that work. That is not a sustainable, or value-driven, model.

## PERKE Principles in Action

The five principles are intended to help unpack the range of themes and activity needed to achieve the overall aim of the strategy. Although developed from a bottom up action learning approach, they also take national policy and guidance into account. *They will evolve as the Strategy evolves through use, challenge and constant testing in practice*. The brief examples below are a selection of activity that has been occurring informally (often done voluntarily and unfunded) that could be developed further.

### Principle 1 - Seek to understand, recognise and reflect the diversity, richness and complexity of ‘lived experience’ across all areas of our work

The lived experiences of people touched by substance use and associated behaviours are incredibly broad. This can include both the substance use type and the associated behaviours. Consequently ‘lived experiences’ should be looked at through a wide array of lenses, for example, social, political, economic, and so forth. As such, the strategy should seek to understand who people are, their situations and the implications on their lives. Through adopting this approach, people and their behaviours should not be stereotyped, nor should their circumstances. It will ensure relationships remain at the heart of the strategy, without assuming the nature and significance of these relationships.

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| **Example - End of Life Care and Substance Use Research Project (Galvani et al, 2018)**  A greater understanding of the breadth, context and range of lived experiences was  accessed through establishing a PWE Advisory Group for the above project. Rather than expect people to ‘sit round a table’ in a University building, our intermediary and lead researcher supported people to participate in their own environment or environments in which they felt comfortable. The PWE Advisory Group brought with them direct experience of living with end of life care and substance use needs as well as having wider connections with these issues. The advisory group highlighted that the research was taking an overly narrow focus in its sample recruitment and the early research findings. Ongoing discussions highlighted additional insights and suggestions around specific groups of people and circumstances who were currently overlooked in research. This included a more diverse landscape of where and how to find people. This formed a key element of the project reports and informed future learning.  <https://endoflifecaresubstanceuse.files.wordpress.com/2018/11/people-with-experience-summary-report.pdf> (Clayson, 2018) |

### Principle 2 - Co-create innovative ways of seeking out and connecting with people with experience that build conditions for partnership and mutuality to grow

Here we are seeking to develop a menu of ways of working that respond to where people are within their lived experience, including how people communicate and learn, the location of where this takes place and the vehicles to enable this to happen. This may include working through partners and ‘intermediaries’[[4]](#footnote-4) or building on established relationships that can facilitate the necessary processes. This is not about simply bringing together a committee or regular group of people with experience but more about developing approaches that are relevant to the research area at hand and the most appropriate people with experience who can be involved.

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| **Example - Novel Psychoactive Substances Conference - MMU - 2016**  Working through a community ‘intermediary’, a group of four people shared their real and raw experiences of NPS use as part of the SUAB Annual NPS Conference in 2016. This involved work to connect with the individuals (through informal networks, social media and peer contacts), building trust and ownership of the process and, most importantly, follow up and ongoing contact following the event. Digital recordings facilitated by the community partner enabled the voices and messages of the group to be captured and shared. Feedback from the conference suggested this was one of the most informative sessions with recordings being shared within services to support practice development.  Feedback from the people who took part identified many examples of how their participation had not only raised awareness of the issues but also stimulated others to come together to adopt a similar approach.  *‘In conversation: Novel Psychoactive Substances’ (1 of 6)* (Clayson et al 2016*)*  [https://youtu.be/KcT0a9J4MEk](https://youtu.be/KcT0a9J4MEk%20%20%20%20%20%20) |

### Principle 3 - Co-produce a system that demonstrates value, rewards their inputs as co-creators and the unique contribution to each stage in the research process

This principle includes setting the research agenda at the start of the process, actively contributing throughout the process, dissemination, and being equal participants in the process review and learning, that informs the process going forward. This can cover both the wider SUAB agenda and project specific initiatives. PWEs may also initiate the research rather than solely respond, having access to the central resources of ManMet where appropriate.[[5]](#footnote-5)

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| **Example - Relationships in Recovery: You / Me – An invitation to ‘See Differently’**  **(ESRC Festival of Social Science, 2019)**  The event was created by, and for, people who have experienced homelessness and substance use issues. The open and relaxed vibe of a community café created a welcoming backdrop to explore the nature and dynamics of ‘connection and relationship’. The café hosted artwork, music, films and recent research into end of life care. Over 50 people took part in a way that suited them best, using the trusted faces of people that they knew to explore and express issues important to them. Central to this was the visioning of more community-led research and influencing how and what is researched in the future. The design of the event reflected the evolving relationship between researchers from Manchester Metropolitan University, people with lived experience and community partner VoiceBox Inc. This included both financial support and commitment to follow up and integrate the outcomes of the day into ongoing SUAB research centre planning.  See Differently Trailer - <https://youtu.be/nB22ANunkHU>  Re-Search Poem - <https://youtu.be/d8J2051Hlck> |

### Principle 4 - Establish and invest in a strategy and resource that is fair and appropriate, aimed at building genuine and trusting relationships that seek to maximise the contribution made by PWE

Approaches to relationship building are likely to vary from person to person and context to context. This will reflect the needs of both the PWEs and the University. Creating and sustaining ongoing relationships may require investment in an intermediary’, or the cultivation of long-term relationships with individuals, organisations and communities. It should also recognise that there is likely to be a cost to exploring some of the issues that people will be exploring, e.g. emotional toll and the costs of providing the support required to respond to this.

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| **Example - Recovery Voice in Action** is a term developed by VoiceBox Inc to describe a broad range of community led social action and co-productive research activity across the recovery community across the Greater Manchester and Liverpool. The work is grounded in the long-term relationship between VoiceBox Inc (Amanda Clayson) and Manmet (Lucy Webb). This ongoing commitment to explore and evolve the role and relationship between PWE, the lived experience and academic research has led to an extensive portfolio of work. The impact and influence of this relationship is extensive, raising the profile of the university in its co-productive practice both locally, nationally and internationally. Examples include:   * Voices from the Brink (Conference Presentations, Peer Reviewed Publications) * Greater Manchester Recovery Federation Recovery Walk (2014) * Establishment International Co-Production Network * SUAB Conferences, seminars and research development activities * Alcohol Research UK Co-Production Workshops (lead presenters)   <https://youtu.be/-FGzDQn6rxs> |

### Principle 5 - Build a system of accountability and independent challenge that captures, questions, communicates the impact and influence of our approach, and contributes to our own, and wider, body of evidence

This is about adopting a critical culture and practice that is not self-referencing, yet supportive to all involved. Regular reviews of participation, keeping abreast of how other similar groups operate, staying alert to changing priorities. This will include reflecting on and recording the ways that PWEs add value from a range of perspectives such as sharing new ideas to focus research on, highlighting different people/groups to connect with, developing new methods, developing and refining analysis, ensuring a focus on real world application of findings, critical analysis of policies and practice, and being a loud voice for people who are often ignored.

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| **Example - SUAB Launch Conference 2016 -** [**https://youtu.be/m85oyHUGggA**](https://youtu.be/m85oyHUGggA)  Establishing and evolving the involvement, impact and influence of PWE has been firmly on the table from the inception of the research centre with significant investment from PWE to challenge and change. Designing and facilitating PWE led activity is of significant importance. Challenging the more traditional conference approach led to an innovative and involving multimedia ‘installation’ that extended the reach, participation, impact and influence of the event. The approach not only send out a positive message around the work of the SUAB research centre but shaped how subsequent activity could (and should) be developed. |

## PERKE Process in Action



The aim of the SUAB PERKE model is designed to reflect and inform the diverse make-up of people touched by the actual and potential work of the SUAB research centre. Whilst the initial implementation is likely to involve a core membership to drive early implementation, the longer-term goal is to develop a more dynamic and fluid process that can extend the reach and impact of the PERKE process. Learning from our work to date has provided much positive value through the participant stakeholders described here.

The strategy also aligns closely with good practice as outlined in national guidance on the effective use of “community intermediaries” *‘Knowledge That Matters: Realising the Potential of Co-Production’* (N8 Research Partnership ESRC, 2016). They will offer a bridge for academic researchers to a wider substance use community. They will be drawn upon to inform engagement strategies and specific approaches within such strategies. This will, in part, be based on their own lived experience and importantly, their personally developed tacit knowledge and expertise

The membership of the PERKE group, their roles and activities will be developed as part of the implementation of this strategy. Some examples of the activities that the PERKE membership group and community intermediary could include are to:

Develop and sustain links with PWEs through informal networks, particularly people not usually engaged or participating in research

Strengthen relationships and support PWEs to participate where necessary

Shape the research agenda and contribute to research bid development

Be involved in the design and delivery of dissemination activities and approaches, particularly those outside the traditional academic approaches

Participate through traditional approaches, such as conference presentations, publications and so forth

Operate as a resource to provide advice, guidance and learning for academic researchers and student researchers

# Part 3 - Next steps

The flow chart below (Figure 2) provides a dynamic and adjustable model to do begin to implement the PERKE strategy. Each stage in developing the strategy will require discussion, debate, collaboration and creative ways of engaging people. Some stages will require further planning, for example, recruitment of the PWE group and can draw on previous experience of recruitment of PWE to participation groups and processes[[6]](#footnote-6) (see Clayson, 2018).

**Figure 2 – Flowchart illustrating early implementation process for PERKE strategy**

### Resource required

The costs for beginning this strategic work would include:

* Payment for an intermediary to support and develop recruitment to the group - networking, communication and support time
* Payment for PWE participants’ time and travel
* Refreshments for meetings

Academics’ time has not been costed in and additional funds for specific research tasks have not been included. Clearly as the process emerges, we would seek to evaluate it and its impact on our RKE activity from a jointly established set of criteria and this will require some resource.

### Breakdown of costs

* Intermediary Costs – Daily Rate (£500)

1. Networking, communication and support time – 4 days - £2000.00
2. Ongoing liaison and support to facilitate ongoing wider participation - £1000.00 (this would be reviewed dependent on the level of activity required)

* Initial PERKE meeting

1. Lunch for 12 people - £120.00
2. Travel - 12 x £10 max local travel - £120.00

* PERKE ongoing meetings

1. Refreshment costs - £500 (for year 1 meetings)
2. Payment for group attendance/training sessions - £1500.00 (4 x 2hr meetings of 10 people max @ £12.50/hr plus 4 half days for intermediary at £250/half day plus travel

**Initial funding sought - £5240.00**

1. ‘People with experience’ are people who have personally experienced the impact of substance use and associated behaviours in their lives. [↑](#footnote-ref-1)
2. The use of the term community does not imply any cohesive relationship or exhaustive ‘reach’ [↑](#footnote-ref-2)
3. Further detail is provided in Part Two of this document. It will also be captured and communicated as part of the strategy itself. [↑](#footnote-ref-3)
4. “Intermediaries are individuals who can translate and negotiate between academic, organisational and community practices and priorities… . Intermediaries have the skills and mind-set needed for effective partnership building. …A critical part of the intermediary role is being able to provide clarity over expectations, including the sensitive task of indicating what is not possible or appropriate.” (Campbell, Vanderhoven et al. 2016) [↑](#footnote-ref-4)
5. Open and shared decision making is a key ambition for the strategy and not solely determined by the University. [↑](#footnote-ref-5)
6. This may include a wide range of activity such as advisory groups, peer researchers or community disseminators. [↑](#footnote-ref-6)