



## **Best Practice Guidance – Lived Experience**

Best Practice Guidance/ Evidence

This is not exhaustive, but reviews some of the most relevant research and work in other organisations where lived experience is used. Much of the evidence is drawn from mental health projects where there has been a bigger drive to incorporate lived experience in developing services.

There is a substantial body of research around peer support and advocacy. However, there is much less around using lived experience to inform service and policy development.

Document / Paper name and authors	Key Points	Comments for relevance to Pathway EBE programme
<p>T. Basset, A Faulkner, J. Repper &amp; E. Stamou. 'Lived Experience Leading the Way: Mental Health peer support' – Together <a href="https://www.together-uk.org/wp-content/uploads/downloads/2011/11/li vedexpericereport.pdf">https://www.together-uk.org/wp-content/uploads/downloads/2011/11/li vedexpericereport.pdf</a></p>	<p>This focuses on peer support within mental health settings. It reviews types of peer support, financial costs, challenges of different types.</p> <p>Different types of peer support</p> <ol style="list-style-type: none"> <li>1. Informal/naturally occurring</li> <li>2. Formal – through employed/paid peers</li> <li>3. Through groups – peer led</li> <li>4. Through project initiatives</li> </ol> <p>There are 12 principles – including: mutuality, sharing with safety and trust, equity and empowerment, reduction of stigma, respect and inclusiveness. (most relevant to EbE work)</p> <p>Challenges – Maintaining independence and flexibility, being seen as credible, challenging existing culture, funding, the Welfare System, appropriate training for peers</p> <p>Employed peers – Issues around boundaries/disclosure, stress generated as a consequence of work, issues around responsibility/accountability/governance, support/supervision/training, need for clear roles</p>	<p>Although this focuses on mental health, some clear relevance to homelessness and inclusion health peer groups.</p> <p>If there is someone with lived experience employed as part of the team, clear support, boundaries and roles need to be in place to ensure the individual is supported.</p> <p>Pathway is not designed to be a peer support programme, it is about facilitating EbEs to use their experiences to influence health service development and policy for this group. However, peer support through informal support and group sessions, peer support is viewed by the EbE participants as important</p>
<p>S.L. Barker &amp; N. Maguire. 'Experts by Experience: Peer Support and its Use with the Homeless'</p> <p><a href="#">Community Ment Health J.</a> 2017; 53(5):</p>	<p>A review of 10 studies around Peer support in within homeless services (known as Intentional Peer Support – IPS). Only one study was thought to be of moderate/high quality. The others were low to moderate quality.</p> <p>General themes show that provided opportunities for social support, role</p>	<p>Peer support is not directly part of the EbE programme, but has emerged as a part of the programme through group sessions.</p> <p>This is particularly relevant during the lockdown</p>

<p>598–612.</p> <p><a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5438434/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5438434/</a></p> <p>(accessed 26/08/20)</p>	<p>modeling and sharing experiences, which had some overall impact on homeless individual's recovery from drug/alcohol, social networks and quality of life.</p>	<p>months of COVID19 pandemic when the group were meeting on a virtual platform weekly.</p>
<p>Rittenbach, K., Horne, C.G., O’Riordan, T. <i>et al.</i> Engaging people with lived experience in the grant review process. <i>BMC Med Ethics</i> 20, 95 (2019).  <a href="https://doi.org/10.1186/s12910-019-0436-0">https://doi.org/10.1186/s12910-019-0436-0</a></p> <p><a href="https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-019-0436-0">https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-019-0436-0</a></p>	<p>There is recognised value in including the perspectives of people with lived experience of health conditions in health policy, health care, health research, and funding. However little evidence previously for including non-academic reviewers in the grant review process.</p> <p>A model of inclusion of people with lived experience into the grant review process was developed, allowing patient perspectives and experiences to be integrated throughout the process.</p> <p>The model has a three-stage review process for grant applications Stage 1: scientific review. Stage 2: Peer review. Stage 3: Steering committee review.</p> <p>Peer reviewers found it stressful at times and requested feedback on their reviews.</p>	<p>This shows the value of fully integrating lived experience into every aspect of healthcare. The Homeless EbE group are able to draw on their experiences of health conditions, health care usage and also their experiences of homelessness/exclusion.</p> <p>This model could be considered/adapted for papers submitted to the Inclusion Health conference.</p>
<p>C. Seymour. ‘Progress Through Partnership: Involvement of people with lived experience in Mental Health CCG Commissioning.’</p> <p>Rethink Mental Health:</p> <p><a href="https://www.rethink.org/media/2591/progress-through-partnership.pdf">https://www.rethink.org/media/2591/progress-through-partnership.pdf</a></p>	<p>Co-production (involvement of lived experience of mental health) is seen as the best way to develop effective service and empower those who use them.</p> <p>CCGs have been slow to take this up, despite being part of the 2016 Five Year Forward View for mental health review.</p> <p>Recommendations for CCGs:</p> <ol style="list-style-type: none"> <li>1) NHS England should demonstrate leadership through embedding co-production in national policy work</li> <li>2) NHS England should develop mechanisms to hold CCGs to account to ensure co-production is embedded in commissioning processes</li> <li>3) CCGs should use existing evidence for effective co-production models</li> </ol>	<p>Pathway’s model is very much about using co-production at the heart of the conference and encouraging homeless health practitioners, and mainstream health providers to consider the lived experience of homelessness service design, development and commissioning.</p>
<p>Live Experience in research – McPin -  <a href="https://mcpin.org/using-lived-experience-in-evaluating-mental-health-">https://mcpin.org/using-lived-experience-in-evaluating-mental-health-</a></p>	<p>‘The McPin Foundation exists to transform mental health research by putting the lived experience of people affected by mental health problems at the heart of research methods and the research agenda’</p>	<p>Pathway EbEs contribute to a variety of research projects through focus groups, conducting surveys, individual research interviews and some have been involved in conducting research.</p>

<p><a href="#">peer-support/</a>; <a href="https://mcpin.org/wp-content/uploads/McPin-Methods-Workshop-Slides.pdf">https://mcpin.org/wp-content/uploads/McPin-Methods-Workshop-Slides.pdf</a></p>	<p>This reports on the 'Side by Side' project which looks at co-production of research in mental health, with people with lived experiences involved and the benefits of this for both the individuals and the research itself. It recognises that there is a mutual benefit for both the peer researchers and others involved.</p>	
<p>Lived Experience Advisory Council. (2016). Nothing about us without us: Seven principles for leadership and inclusion of people with lived experience of homelessness. Toronto: The Homeless Hub Press. <a href="http://www.homelesshub.ca/NothingAboutUsWithoutUs">www.homelesshub.ca/NothingAboutUsWithoutUs</a></p>	<p>Seven Principles for including the lived experience voice in every aspect of work to end homelessness.</p> <ol style="list-style-type: none"> <li>1. Bring the perspective of our lived experience to the forefront</li> <li>2. Include people with lived experience at all levels of the organization</li> <li>3. Value our time and provide appropriate supports</li> <li>4. Challenge stigma, confront oppression and promote dignity</li> <li>5. Recognize our expertise and engage us in decision-making</li> <li>6. Work together towards our equitable representation</li> <li>7. Build authentic relationships between people with and without lived experience</li> </ol>	
<p>NSUN – 4Pi national involvement standards - <a href="https://www.nsun.org.uk/FAQs/4pi-national-involvement-standards">https://www.nsun.org.uk/FAQs/4pi-national-involvement-standards</a></p>	<p>4Pi is a simple framework on which to base standards for good practice, and to monitor and evaluate involvement. It should be considered at all level of service development, delivery and evaluation. The use of this framework should improve both mental health services and the wellbeing of those using them.</p> <p>The framework draws on the experience of many service users and carers who's shared their experiences in a variety of ways (both formally and informally)</p> <p>'Meaningful involvement means making a difference: it should improve services and improve the mental health, wellbeing and recovery of everyone experiencing mental distress. '</p> <p><b>4Pi standards are: Principles, Purpose, Presence, Process and Impact</b></p>	<p>The standards are useful when thinking about services for homeless people. Both within specialist homeless service and mainstream services where homeless or other excluded groups may attend.</p>



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