PPIE and lived experience involvement in Scotland

Neurodisability/neurodiversity and criminal justice

Funded by Imagining Possible Futures, University of Chester

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Summary

This scoping exercise explored existing patient and public involvement and engagement (PPIE) and lived experience involvement at the intersection of neurodisability/neurodiversity and criminal justice in Scotland. It involved eight exploratory conversations with practitioners, academics and a university PPIE specialist. The exercise, however, does not provide an exhaustive account of activity across Scotland.

The conversations did not identify an established group focused on bringing people with lived experience into the process of shaping research at this intersection. They did, however, identify relevant lived experience involvement through the SOLD Network and the Lucy Faithfull Foundation's emerging group, alongside peer-led practice through Aid & Abet. These offer potential opportunities to build on existing lived experience involvement and leadership, learn from current practice and develop future research collaboration, including research on social care in prison and after release. All eight interviewees expressed interest in contributing to future work.

Interviewees highlighted the need for future involvement to reflect a range of social and cultural backgrounds, experiences of the justice system and geographical areas. Barriers to participation included practical costs, inaccessible information and meeting formats, stigma, lack of trust and limited organisational resources. Interviewees also emphasised that meaningful involvement requires contributors to have influence over decisions and their lived experience expertise to be recognised and put to use in shaping the work.

Interviewees identified limited training specifically supporting PPIE at this intersection of neurodisability/neurodiversity and criminal justice in Scotland. Wider provision included accredited peer research training and PPI training for researchers, offering potential connections for future training and capacity building.

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Purpose and approach

The main aim of the scoping exercise was to map existing PPIE and lived experience involvement at the intersection of neurodisability/neurodiversity and criminal justice in Scotland. The work was funded by the Imagining Possible Futures project at the University of Chester and supported by the Navigating Neurodisability through the Prison Gates project at the University of Sheffield.

The scoping exercise was guided by two key questions:

1. What PPIE groups already exist in Scotland that could contribute to neurodisability, neurodiversity and justice research?
2. What gaps exist in representation, geography, or expertise?

The exercise involved conversations with eight people: four third-sector practitioners working directly with people who are navigating, or have navigated, the criminal justice system; one practitioner working in violence prevention; one academic with expertise in criminology; one academic involved in developing accredited peer research training; and a PPIE specialist working in a Scottish university.

Conversations were semi-structured and exploratory, covering existing activity, gaps, barriers and opportunities for future collaboration. All conversations took place online. Recruitment initially involved targeted approaches, followed by snowball recruitment.

Contributors

The following people contributed to the scoping conversations. Two contributors are listed using the descriptions agreed during their conversations.

- **Lisa Mary Armstrong** - PhD Researcher, Scottish Centre for Crime and Justice Research, University of Glasgow.
- **Tony Bowman** - Policy and Development Worker, SOLD Network, ARC Scotland.
- **James Docherty** - Project Manager, Violence Reduction Unit.
- **Dr Lisa Garnham** - Lecturer in Social Work and Social Policy, University of Strathclyde; Course Lead, *From Experience to Evidence: Foundations in Peer Research*.
- **Kevin Neary** - Co-Founder and Mentor, Aid & Abet.
- **Mark Phillips** - Manager, Access to Industry.
- **Anonymous contributor** - University officer working in PPIE.
- **Anonymous contributor** - Representative of an organisation working in this area.

What is PPIE?

Patient and public involvement and engagement (PPIE) is an approach that brings people's knowledge and experiences into research. Involvement means people working alongside researchers and having a say in decisions throughout a project. Involvement can include identifying questions that matter to them, helping develop a funding application, joining an advisory group, reviewing research materials or deciding how findings should be shared.[1] The aim, therefore, is that people contribute their expertise to shape the research, rather than solely participating in more traditional ways such as being interviewed or completing a questionnaire. Alongside this, engagement creates opportunities for researchers and the public to share knowledge and discuss research, supporting public understanding and dialogue about its findings and implications.

Existing PPIE activity and relevant connections

As mentioned in the report summary, the conversations did not identify any established PPIE group dedicated to the intersection of neurodisability/neurodiversity and criminal justice in Scotland. They did, however, identify relevant lived experience involvement in policy and practice, alongside peer-led support. These forms of involvement offer potential connections for future work and are outlined below.

One interviewee had also consulted colleagues about PPIE activity at this intersection, but none was identified. They described examples of prison education and public engagement, including researchers sharing their work with people in prison. They did, however, distinguish these activities from involving people in shaping the research itself. This provided a wider basis for the finding, although the exercise remained limited to the conversations and networks consulted.

Existing lived experience involvement and peer-led practice

1. The SOLD Network

The SOLD (Supporting Offenders with Learning Disabilities) Network is a national network that aims to improve access to justice for people with communication support needs, including people with learning disabilities and autistic people. It convenes a monthly user group of people with lived experience of the criminal justice system, whose contributions inform the network's work to influence policy and practice.[2]

SOLD is hosted by ARC Scotland (Achieving Real Change for a more inclusive Scotland), which runs the user group in partnership with People First (Scotland). ARC Scotland works with people with learning disabilities, autistic people and others with additional support needs. It provides training, consultancy and networks that connect people with lived experience with those who plan and deliver services.[3] People First (Scotland) is a disabled people's organisation controlled by its members, all of whom have a learning disability. Members decide its priorities and activities, meet in local groups to discuss issues important to them, offer each

[1] https://www.lboro.ac.uk/internal/research-ethics-integrity/research-ethics/guidance-investigators/ppie/
[2] https://arcscotland.org.uk/networks/sold/
[3] https://arcscotland.org.uk/

other advice and support, and campaign to improve the lives of people with learning disabilities.[4]

Members of the SOLD user group have written Easy Read guides explaining justice processes, including what constitutes a crime, arrest, and people's rights at a police station.[5] The police-station rights guide was produced by People First (Scotland) on behalf of the SOLD Network and published by the Scottish Government.[6] The SOLD Network and its members also contributed to an Easy Read guide published by the Scottish Sentencing Council, explaining how courts determine sentences, the sentencing options available, and what happens at sentencing hearings.[7]

The SOLD (Supporting Offenders with Learning Disabilities) Network represented the clearest established example identified through this exercise of a lived experience group at the intersection of neurodisability/neurodiversity and criminal justice informing justice policy and practice, and its experience offers a relevant connection for future PPIE activity in Scotland.

2. Aid & Abet

Another potential collaborative organisation identified through scoping discussions is Aid & Abet, a peer-led organisation offering support to people when they are released from prison.[8] Aid & Abet's approach draws on mentors' own lived experience of the criminal justice system and understanding of the barriers faced in prison and when returning to the community. Its focus is on recovery and preventing a return to prison, and supporting people to engage with housing, financial, health, and addiction support services. The scoping conversation also highlighted how mentors accompany people to access services upon release, rather than primarily signposting. Whilst Aid & Abet is not specifically a neurodisability/neurodiversity or PPIE-focused organisation, its experience of peer-led practice, building trust and supporting transitions suggests it could be a key collaborator for future work in this area.

3. Lucy Faithfull Foundation

A further emerging lived experience structure identified during the scoping exercise was in the work of the Lucy Faithfull Foundation, an organisation that aims to prevent child sexual abuse by working with people at risk of causing harm, and supporting others to help keep children safe.[9] The Foundation's Autism Project focuses on early intervention, reducing risk and preventing harmful sexual behaviour and child sexual abuse among autistic adults. It explicitly recognises that autism does not cause child sexual abuse, and that autistic people are in fact far more likely to be survivors of abuse.

To support this work, the organisation is establishing a lived experience group, inviting people interested in supporting the work, but with a specific reference to autistic people who have experience of the criminal justice system.[10] Proposed contributions include reviewing progress and providing feedback on the project, advising on developing and sharing learning, informing the design of resources, workshops and training materials, identifying priorities for prevention,

[4] https://peoplefirstscotland.org/people-first-scotland/about-us/

[5] https://arcscotland.org.uk/resource/sold-easy-read-guides/

[6] https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2023/04/rights-police-station-easy-read-version/documents/rights-police-station-easy-read-version/rights-police-station-easy-read-version/govscot%3Adocument/rights-police-station-easy-read-version.pdf

[7] https://www.scottishsentencingcouncil.org.uk/media/pnahpnrc/sentencing-in-scotland-easy-read-guide.pdf

[8] https://www.aidnabet.org/

[9] https://www.lucyfaithfull.org.uk/#about

[10] https://www.lucyfaithfull.org.uk/scotland-newsletter/

and helping to shape future areas of work and project development. The group is currently expected to meet every two to three months until March 2028.

The group represents a potential connection for future PPIE at the intersection of neurodisability/neurodiversity and criminal justice in Scotland, with opportunities to explore collaboration and learn from its developing approach to lived experience involvement.

Further organisations offering relevant experience in peer-led support and creative participation are included in the directory of organisations at the end of the report.

4. Scottish Violence Reduction Unit

The Scottish Violence Reduction Unit takes a public health approach to preventing violence, working with partners, organisations and communities across Scotland. Its work includes prevention with children and young people, supporting people affected by violence, and working with people to move away from violence. Its experience of partnership working, peer mentoring and lived experience involvement offers relevant expertise and connections for developing future PPIE work at this intersection.[11]

5. Access to Industry

Access to Industry supports people facing barriers to employment, including people with experience of prison and community sentences, to access learning, training and work.[12] It provides support before and after release. Its relationships across prison and community settings offer a potential connection for future PPIE, particularly in reaching people with different experiences of the justice system.

Possible gaps or missing perspectives in representation

The conversations identified perspectives that may be overlooked in PPIE and lived experience involvement in research, policy and practice at the intersection of neurodisability/neurodiversity and criminal justice. These reflect interviewees' accounts rather than a comprehensive assessment of representation across Scotland.

Social and cultural representation

The conversations highlighted a risk that PPIE favours people who have higher levels of formal education, are confident in expressing their views and have the time and resources to participate regularly. Interviewees also discussed how stigma associated with disability and justice involvement can be experienced differently according to people's social and cultural background, emphasising the need for recruitment to allow sufficient time for outreach and relationship building through trusted community organisations.

Including different justice experiences

Interviewees highlighted the importance of including people from a range of criminal justice settings - those currently in prison, those who have left prison, and those serving community sentences - in future PPIE and lived experience involvement at the intersection of

[11] https://www.svru.co.uk/what-we-do/
[12] https://accesstoindustry.co.uk/

neurodisability/neurodiversity and criminal justice. The conversations emphasised that a focus on prisons could overlook the perspectives of people serving community sentences, and thus a significant proportion of people navigating the criminal justice system. Restrictions on people currently in prison joining an existing lived experience group were also identified. Family, friend and carer perspectives were also raised as relevant to future involvement.

Geographical reach

Geographical representation was raised in the conversations, with areas including Fife and the Borders suggested as requiring greater attention in future PPIE and lived experience involvement. Interviewees also described difficulties maintaining involvement for people living further from meeting venues, highlighting the need to consider how future PPIE activity could reach people across Scotland.

Training

University of Strathclyde: From Experience to Evidence

The University of Strathclyde's *From Experience to Evidence: Foundations in Peer Research* course provides a relevant example of capacity building for lived experience involvement.[13] The course prepares people to undertake research as peer researchers, rather than specifically preparing them for PPIE roles. The ten-week, face-to-face module offers 20 credits at SCQF Level 7, equivalent to a first-year undergraduate level course, and requires no previous formal qualifications or university study.

The conversations highlighted a rationale for accredited provision: people contributing as peer researchers may receive project-specific training without formal recognition of the skills developed. The course was therefore designed to provide a broader grounding in research, and to provide academic recognition of that learning.

The course covers the development of research questions, surveys, interviews and focus groups, creative methods, and the sharing of findings. Learners develop a community-based research proposal, submitted in writing or through a recorded or live presentation. Teaching combines short presentations, practical activities, peer discussion, and tutor support. Published fees range from £450 to £1,800, depending on the sponsoring organisation. The conversations also highlighted the use of accessible terminology, including "numbers-based" and "words-based" data, and the integration of ethics throughout teaching, including emotional wellbeing, boundaries, and responsibilities towards others.

Although not specific to neurodisability/neurodiversity or criminal justice, the course offers a potential training connection for future peer research in this area. The conversations identified scope to adapt delivery, practical activities and content to the intended research roles and the learning and accessibility requirements of those taking part. Any adapted provision would require further discussion.

Wider PPI training

The University of Edinburgh's Clinical Research Facility also provides PPI (Patient and Public Involvement) training for researchers. The training focuses on public involvement rather than

[13] https://www.strath.ac.uk/humanities/cpdandmicrocredentials/fromexperiencetoevidencefoundationsinpeerresearch/

the wider scope of PPIE. Its published provision includes a free, self-directed introduction to PPI, alongside courses on incorporating PPI into funding applications, creating and sustaining involvement groups, and working with under-served communities. The latter includes identifying barriers to involvement and building trusting relationships with contributors.[14] There is also scope to discuss bespoke training with the team.

Although this provision is not specific to neurodisability/neurodiversity or criminal justice, it offers a further potential training connection for researchers working in this area.

Developing training and support for PPIE contributors

The scoping exercise identified limited formal training specifically preparing lived experience contributors for PPIE roles at this intersection. This suggests a potential area for development, with contributors involved in deciding what preparation and ongoing support would be useful. Such provision could help people understand their roles and influence within research, alongside ensuring that researchers and organisations are prepared to support meaningful involvement.

Barriers to involvement and ways to support meaningful participation

Practical access

The conversations identified practical considerations for supporting participation in future Scotland-based PPIE activity. Interviewees highlighted travel costs, travelling distances, and family responsibilities as potential barriers to participation. Having to cover travel costs upfront while awaiting reimbursement was also raised, alongside the difficulties of travelling or leaving home. Interviewees discussed difficulties with banking access and described alternatives to bank transfers, including cash reimbursement for travel and vouchers. Payment was considered an important recognition of people's contributions, although concerns were raised about its administration and potential implications for social security payments.

Interviewees also highlighted the importance of digital access, identifying limited access to devices, unreliable internet connections and unfamiliarity with online platforms as potential barriers to participation. Interviewees described the value of offering different ways to take part, including in person and online, rather than relying on digital participation. The conversations included an example of how losing access to hybrid meeting facilities had put continued involvement at risk for members living further away. Interviewees further emphasised the importance of flexibility and attention to individual circumstances when considering how people could take part.

Accessible participation

Interviewees highlighted the importance of using plain language in PPIE discussions and related materials, sharing information in advance, and allowing time for people to process it and respond. The conversations drew attention to dyslexia and how its effects on understanding and communication can be underestimated, alongside the need to recognise that people may be uncomfortable with reading and writing, or may prefer other ways to contribute. Visual activities, creative methods and discussion were therefore suggested as ways to make participation more accessible and engaging.

[14]https://clinical-research-facility.ed.ac.uk/patient-and-public-involvement/ppi-training

Interviewees recommended breaks and shorter sessions, with contributors involved in determining the format of the meeting. Interpreter provision, where required, was also identified as a further means to address any potential language barriers to participation.

Relationship building

Interviewees recommended allowing time to build relationships before involvement begins, including spending time in communities and working with organisations that already have established relationships with potential contributors. Face-to-face contact was seen as particularly valuable in building those relationships and trust.

Within groups, interviewees highlighted the importance of agreeing expectations with contributors, maintaining transparency and accountability, and ensuring that discussions are not dominated by the most confident members.

Organisational conditions and meaningful participation

The conversations highlighted the organisational time and resources required to build trust and sustain community relationships, with implications for the planning and costing of future PPIE activity. For involvement within prisons, interviewees identified restrictions on regular access and communication with people in custody as challenges that require advance planning with prison partners. The preparation of researchers and other staff was also highlighted, particularly their ability to communicate accessibly and work effectively in prison and community settings.

Interviewees emphasised the importance of establishing clear roles, expectations and boundaries from the outset, including explicit agreement about the ownership of outputs and who would benefit from them. Meaningful participation was discussed in terms of recognising lived experience as expertise and enabling contributors to influence the work, including through greater control over its direction. Explaining how contributions had informed decisions was also identified as important to recognising contributors as respected partners, and demonstrating that their expertise was being fully utilised in shaping the work.

The scoping conversations identified the UK Standards for Public Involvement as a framework used to guide practice while adapting approaches to individual projects.[15] The standards cover inclusive opportunities, working together, support and learning, governance, communications and impact, and support reflection and improvement across different approaches to public involvement in research. An Easy Read version is also available.

Building on existing networks

The conversations highlighted the risk of overconsultation and suggested working through existing networks where possible, rather than creating additional structures. This aligns with the commissioning brief's emphasis on avoiding duplication and protecting community ownership, and suggests that future PPIE development should first explore opportunities to collaborate with existing groups.

An offer to circulate information about future work through an emerging Scottish network of PPI professionals was also made during the conversations, providing a potential route to further expertise and connections.

[15] https://sites.google.com/nihr.ac.uk/pi-standards/home

Conclusion

The conversations did not identify an established PPIE group specifically focused on shaping research at the intersection of neurodisability/neurodiversity and criminal justice in Scotland. They did, however, identify relevant groups and organisations that could contribute to future research. These include the SOLD Network's established user group, the Lucy Faithfull Foundation's emerging lived experience group, and Aid & Abet's experience of peer-led support. Their different roles offer opportunities to build on existing relationships, knowledge, and lived experience involvement in keeping with the brief's emphasis on avoiding duplication and protecting community ownership.

In relation to gaps, interviewees highlighted the need to include people with different justice experiences, particularly those serving community sentences and people currently in prison, alongside family, friend and carer perspectives. They also raised questions about social and cultural representation and geographical reach, including access for people living further from meeting venues.

The exercise identified no formal training specifically preparing lived experience contributors for PPIE roles at this intersection, suggesting an opportunity to develop provision with contributors around their needs. Relevant expertise was identified across the contributors and organisations consulted, although the exercise did not establish a comprehensive picture of gaps in expertise across Scotland.

Future PPIE development should therefore explore collaboration with these existing groups while considering whose perspectives may be missing and what support would enable their participation. Interviewees emphasised trust, accessible ways of working, adequate resources, and meaningful influence over decisions. All eight interviewees expressed interest in contributing to future work, providing a basis for taking these connections forward.