

More than equal

Valuing and supporting the expert
contribution of people with lived experience

April 2024



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Background

The Public Bodies (Joint Working) (Scotland) Act 2014¹ set out the requirement for Integration Authorities to include carer and lived experience representatives on their Integration Joint Boards (IJBs).



Since 2014, other legislative developments have extended the expectation of engagement with carers and people with lived experience within Health and Social Care (including, Carers (Scotland) Act 2016²; National Care Service (Scotland) Bill³). The Coalition of Carers in Scotland (COCIS) and the Health and Social Care Alliance Scotland (the ALLIANCE) provide support to networks of Carer and Lived Experience Representatives involved in IJBs across Scotland.

Since 2017, the Carer Collaborative, facilitated by COCIS, has produced Equal, Expert and Valued (EEV) reports⁴ which outline the experiences of Carer Rep involvement in IJBs and provide recommendations and examples of good practice. The ALLIANCE's IJB Lived Experience Representative Network has formed more recently, but Lived Experience Network Reps report similar experiences of involvement as those highlighted in the Equal, Expert and Valued reports.

¹ legislation.gov.uk/asp/2014/9/contents/enacted

² legislation.gov.uk/asp/2016/9/contents/enacted

³ parliament.scot/bills-and-laws/bills/national-care-service-scotland-bill

⁴ carersnet.org/carers-collaborative



Carer and Lived Experience Reps bring a wealth of knowledge, experience and expertise to the work of IJBs. However, experiences of involvement across Scotland are mixed and there are a number of key areas where the involvement of Reps falls short of best practice. This report draws on these experiences and starts with headline recommendations for improvement, under four thematic headings:

- 1. Strengthen recruitment and representation**
- 2. Build capacity**
- 3. Support equity of involvement**
- 4. Evaluate impact**

The subsequent pages give more detail on the key areas for development, actions which would support improvement, as well as links to resources that could help. The report concludes with brief good practice examples, final thoughts and thanks.

Note on language used in this report:

This report typically uses the word ‘Reps’ to refer to Carer and Lived Experience Representatives on IJBs (Lived Experience Reps are also sometimes known as Patient, Service User or Public Reps). Reps are usually unpaid carers (or former carers) or people who have experience of accessing health and social care services and support. It is noted that in some areas staff (e.g. from local carers centres; lived experience organisations; the local authority) fulfil the role. COCIS and the ALLIANCE are of the view that while this ensures carers and those with lived experience are represented to a degree, it is best practice to have unpaid carers and those with lived experience of services in the roles.

Recommendations

Recommendation	Areas for development and action
1. Strengthen recruitment and representation	<ul style="list-style-type: none"> • Proactive and inclusive recruitment to Carer and Lived Experience Rep positions to ensure representation and representativeness. • Ensure Reps have a clear and transparent role and remit. • Ensure robust succession planning and supportive induction processes are in place. • Involve Reps in key planning groups, particularly governance and decision-making structures.
2. Build capacity	<ul style="list-style-type: none"> • Support and resource structures for wider community involvement and ensure Carer / Lived Experience Reps have support to link with these structures. • Have a pool of carers/people with lived experience to populate strategic groups, share responsibility and enable peer support. • Provide training on the importance, value and benefits of involvement for IJB members and wider strategic partners. • Provide resources and training for Carer / Lived Experience Reps (and other IJB members) to support and enable them to undertake their role. • Ensure engagement and involvement of Carers and Lived Experience Reps in national policy discussions and structures.
3. Support equity of involvement	<ul style="list-style-type: none"> • Ensure Reps are treated as equal partners and have voting rights. • Ensure Reps are able to place items on the agenda and there is time for discussion. • Ensure meetings are accessible e.g. papers sent on time; addressing barriers, etc. • Ensure an expenses policy is in place and full remuneration of expenses, including replacement care. • Consider a form of payment for Reps on IJBs. • 'Carer / Lived Experience proof' policies and plans. • Ensure ongoing support to enable Reps to undertake their role.
4. Evaluate impact	<ul style="list-style-type: none"> • Evaluate the involvement of carers and people with lived experience. Publish findings in Annual Performance Reports to demonstrate progress and impact. • Monitor progress towards key national outcomes and indicators relating to carers and people with lived experience. • Report transparently on IJB/HSCP financial spend to support carers and people with lived experience. • Review processes and performance annually against these report recommendations.

Recommendation one:

Strengthen recruitment and representation

The context

IJBs appear to face challenges with the recruitment of IJB Carer and Lived Experience Reps.

At the time of writing (Apr 2024), this includes: Carer and Lived Experience Rep vacancies on up to seven IJBs; Rep roles are being undertaken by staff (on at least two IJBs); carers or people with lived experience being unable or unwilling to get involved due to the scope and scale of the role; lack of succession planning processes resulting in some Reps being in their roles for two or three terms (up to nine years); more needing to be done to ensure diversity of experience and representation from all sections of the community.

What needs to happen

Area for development	Actions to support improvement
Proactive and inclusive recruitment to Carer and Lived Experience Rep positions to ensure representation and representativeness.	<ul style="list-style-type: none">• Provide clear information on the role and the support which will be given to Reps to undertake the role.• Ensure unpaid carers / those with lived experience are appointed to Representative roles (rather than staff).• Ensure recruitment processes are inclusive and enable equity of access to apply for Representative roles.• Monitor representation (e.g. BAME; those with different support needs or caring roles; age groups) and proactively identify and take action to address gaps.
Ensure Reps have a clear and transparent role and remit.	<ul style="list-style-type: none">• Provide all Carer and Lived Experience Reps with a clear role description which outlines the scope and scale of the role; support, training and resources that will be provided; skills required.
Ensure robust succession planning and induction processes are in place.	<ul style="list-style-type: none">• Prioritise the development of succession planning and induction processes for Representative roles. This includes:<ul style="list-style-type: none">» Anticipatory planning in advance of their term ending» Exit interviews with outgoing Reps.» Handover period between new / existing Reps.» Provision of key information on the processes, functions, key personnel within IJBs scope/remit.» Introductory meetings with IJB members / key HSCP personnel (e.g. Chair/Finance Lead Officer).» Provision of named contact/s for on-going support/ information.» Developing a buddying and mentoring system to provide Reps with access to on-going support (either with other Reps or key HSCP personnel).

Area for development	Actions to support improvement
Involve Reps in key planning groups, particularly governance and decision-making structures.	<ul style="list-style-type: none"> • Ensure Reps have information about the IJBs wider planning and strategy groups and opportunities to be involved in these, particularly those related to governance and decision-making (e.g. budget setting; commissioning). • Provide support for Reps to be involved in wider planning groups to ensure carer / lived experience perspectives are considered in discussions and decisions.

Resources that can help:

The Carer Collaborative's **role description template**

carersnet.org/wp-content/uploads/2021/10/Carer-Rep-Role-Description.pdf

The ALLIANCE's **Engaging People with Lived Experience: best practice, challenges and opportunities** report.

alliance-scotland.org.uk/blog/news/new-report-engaging-people-with-lived-experience

Scottish Government's **Participation Framework**

gov.scot/publications/participation-framework

Recommendation two:

Build capacity

The context

IJBs need to develop a wider pool of carers and people with lived experience to ensure representation does not depend on a few people.

To ensure sustainable representation of the views of carers/people with lived experience it is vital that: Reps have opportunities and support to engage with wider involvement networks; IJBs support a wider pool of carers/people with lived experience to ensure Reps don't become overburdened with involvement in numerous IJB strategic groups.

Alongside this, capacity building training is key to ensure: Reps have the information and knowledge they need to undertake their role; IJB members and wider stakeholders have an understanding of the importance, value and benefits of involvement.

What needs to happen

Areas for development	Actions to support improvement
Support and resource structures for involvement and ensure Reps have support to link with these structures.	<ul style="list-style-type: none"> • Provide Reps with information and support to link with wider involvement structures* so they can fully represent carer / lived experience views. Be cognisant that Reps need time to engage with others (e.g. when issuing IJB papers). * Structures for involvement can include Carers Voice groups; voluntary sector orgs/networks that support people who access services; involvement teams within HSCP.
Have a pool of carers / people with lived experience to populate strategic groups, share responsibility and enable peer support.	<ul style="list-style-type: none"> • Provide support to a wider pool of carers / people with lived experience who can be involved in the range of IJB strategic groups to ensure sustainable representation including: <ul style="list-style-type: none"> » Sharing responsibility for different areas of strategic work so Reps don't become overburdened. » Offering opportunities for peer support to share experiences, knowledge and learning.
Provide training on the importance, value and benefits of involvement for IJB members and wider strategic partners.	<ul style="list-style-type: none"> • Provide regular training for all IJB members and wider strategic partners who support the work of the IJB to build: <ul style="list-style-type: none"> » A shared understanding of the importance and value of involvement. » An understanding of the range of expertise and experience Reps bring to the IJB. » A willingness to listen and desire to seek out the experiences of carers and people with lived experience. » An understanding of different approaches to involvement and barriers some may face. » Knowledge on safeguarding measures to ensure engagement is purposeful and people are able to contribute their lived experience in a safe and appropriate way

Areas for development	Actions to support improvement
Provide resources and training for Reps (and other IJB members) to support and enable them to undertake their role.	<ul style="list-style-type: none"> • Provide 'baseline' training on the topics / key areas of focus that are discussed within the IJB remit (e.g. policy landscape). • Regularly discuss other training and support needs with Reps – these will differ for each person. • Have a dedicated training budget to provide on-going capacity building support for Reps.
Ensure engagement and involvement of Reps in national policy discussions and structures.	<ul style="list-style-type: none"> • Provide information for Reps about national involvement networks (e.g. COCIS' Carers Collaborative; the ALLIANCE's IJB Lived Experience Representative Network). • Provide information on key areas of national policy development (e.g. National Care Service) and other national structures that Reps could link with (e.g. COSLA board).

Resources that can help:

COCIS' Carer Collaborative

carersnet.org/carers-collaborative

The ALLIANCE's **IJB Lived Experience Representative Network**

alliance-scotland.org.uk/lived-experience/networks/ijb-lived-experience-representative-network/

Mind's **Influence and Participation Toolkit**

mind.org.uk/workplace/influence-and-participation-toolkit

Recommendation three:

Support equity of involvement

The context

Across Scotland Reps report mixed experiences of being involved as equal partners on IJBs.

It should be noted that within this recommendation there was a divergence of views about Reps having voting rights (as recommended in the Independent Review of Adult Social Care⁵). Whilst both Carer and Lived Experience Reps were keen for equity in the form of voting rights, some Lived Experience Reps noted that they would only be comfortable having voting rights if they were able to effectively engage with others with lived experience.

Alongside this, there was a divergence of views around establishing a form of payment for Reps. Payment can be a complex issue and should be fully assessed to mitigate any adverse implications (e.g. tax, benefits, employment law).

What needs to happen

Areas for development	Actions to support improvement
Ensure Reps are treated as equal partners and have voting rights.	<ul style="list-style-type: none">• Ensure Reps are able to effectively and regularly engage with other carers / people with lived experience to ensure their views are represented and considered in decision-making. This includes ensuring there is time to consult and engage with others on decisions.
Ensure Reps are able to place items on the agenda and there is time for discussion.	<ul style="list-style-type: none">• Ensure there is a clear and accessible process for Reps to submit items for the IJB (and strategic groups) agendas.• Allow time in meetings for discussions and questions.
Ensure meetings are accessible e.g. papers sent on time; addressing barriers to involvement.	<ul style="list-style-type: none">• Ensure meeting papers are issued sufficiently in advance, to allow Reps to read, consult with wider carer / lived experience networks and prepare for meetings.• Discuss any barriers to involvement (including format of IJB papers; participation support needs; meeting timings e.g. for carers/people with lived experience who work) and take action to address these.
Ensure an expenses policy is in place and full remuneration of expenses, including replacement care.	<ul style="list-style-type: none">• Provide Reps with the IJB expenses policy at induction (or during their tenure if already in post).• Publish expenses policy on the IJB/HSCP website.• Provide expenses forms and a clear, straightforward claim process.• Ensure replacement care expenses are available to Reps who need these (without requiring them to use their own network of support or existing care packages).

⁵ gov.scot/publications/independent-review-adult-social-care-scotland

Areas for development	Actions to support improvement
Consider a form of payment for Reps on IJBs.	<ul style="list-style-type: none"> Consider a range of options for payment (e.g. financial recompense; vouchers), take legal/financial advice (e.g. tax/benefits/employment law) and discuss with Reps to ensure payments would not have adverse implications.
'Carer / Lived Experience proof' plans and policies.	<ul style="list-style-type: none"> Ensure plans and policies produced by the IJB (and its strategic groups) are impact assessed for carers / people with lived experience and that their needs and aspirations are considered. For example, the needs of carers / people with lived experience being included in Equality Impact Assessments/Statements.
Ensure ongoing support to enable Reps to undertake their role.	<ul style="list-style-type: none"> Examples of on-going support which Reps report can help include: <ul style="list-style-type: none"> » Pre-meetings with support staff / other IJB members to discuss papers and ask questions. » Support with admin e.g. IJB papers; claiming expenses. » Key contact person for IJB-related business and processes who acts as a 'go to' for any questions. » Links with organisations that support people with lived experience and carers (e.g. Carers Centres; lived experience orgs/networks).

Resources that can help:

The Carer Collaborative's **expenses policy template**

carersnet.org/wp-content/uploads/2021/10/Carer-Expenses-Policy.pdf

The Carer Collaborative's **briefing paper on Carers and Equality Impact Assessments**

carersnet.org/wp-content/uploads/2021/10/Carers-and-EQIA.pdf

The ALLIANCE's **Engagement Insights Report**

alliance-scotland.org.uk/wp-content/uploads/2021/05/Engagement-Insights-Report.pdf

Scottish Human Rights Commission's **Paying People with Lived Experience for their Participation: a review of legislation, literature and practice research** report

scottishhumanrights.com/media/2251/paid-participation-report-ufinal.pdf

Scottish Government's Guidance: **Paying participant expenses and compensating for time**

gov.scot/publications/guidance-paying-participant-expenses-compensating-time/pages/1/

Recommendation four:

Evaluate impact

The context

The development and implementation of robust, co-designed evaluation processes is essential to understand the impact of involvement.

Alongside this, it is important to provide consistent and transparent feedback on progress made, what improvements are needed, and links to wider outcomes frameworks. Clear information about financial spend against support for carers and people with lived experience should also be provided to ensure transparency and enable Reps to fully undertake their roles.

What needs to happen

Areas for development	Actions to support improvement
Evaluate the involvement of carers and people with lived experience. Publish findings in Annual Performance Reports to demonstrate progress and impact.	<ul style="list-style-type: none">• Have regular and robust evaluation processes that enable the impact of Reps' involvement to be assessed.• Involve Reps in the design of evaluation processes and identification of the outcomes which are important to assess.• Share evaluation feedback with Reps and identify any changes needed to improve involvement processes.• Share details of involvement processes (e.g. how Reps are involved in IJB) and plans for improvements within IJB/HSCP Strategic Plans. Provide details of progress towards actions for improvement and the impact of involvement within HSCP Annual Performance Reports.
Monitor progress towards key national outcomes and indicators relating to carers and people with lived experience.	<ul style="list-style-type: none">• Identify key national outcomes and indicators relating to people with lived experience and carers (e.g. National Health & Wellbeing Outcome 6; National Performance Framework, National Outcomes relating to Human Rights and Health).• Ask for Reps' views on the key national indicators which would be important to monitor locally.• Report on progress in HSCP Annual Performance Reports.
Report transparently on IJB/HSCP financial spend to support carers and people with lived experience.	<ul style="list-style-type: none">• Provide details of funding awarded and financial spend that is related to supporting people with lived experience and carers (e.g. Carers Act funding) in IJB Annual Accounts and HSCP Annual Performance Reports.
Review processes and performance annually against these report recommendations.	<ul style="list-style-type: none">• Use these recommendations, areas for development and action to develop a framework to monitor progress of involvement locally, and to compare nationally.

Resources that can help:

Scottish Government's **National Performance Framework**
nationalperformance.gov.scot

Scottish Government's **National Health and Wellbeing Outcomes Framework**
gov.scot/publications/national-health-wellbeing-outcomes-framework

Evaluation Support Scotland's **range of resources and tools to support impact measurement**
evaluationsupportscotland.org.uk

Sharing good practice

To support progress towards the recommendations made in this report, a small selection of good practice examples from across Scotland are provided below.

As noted at the beginning of this report, the Carer Collaborative has been operating for a number of years and the IJB Lived Experience Network has formed more recently, therefore most of these examples are more focused on Carer Rep feedback on involvement practices in their local area. However, as can be seen below, many of the improvements mentioned can equally apply to involvement of Lived Experience Reps.

COCIS and the ALLIANCE believe that increased national opportunities for IJB members/key HSCP personnel to come together with Reps from the Carers Collaborative and the IJB Lived Experience Representative Network, would support the sharing of good practice and the development of more consistent, high-quality involvement in IJBs across Scotland.



In **East Dunbartonshire** members of the Public Service User and Carers (PSUC) group receive a full induction to prepare them for their role. An induction meeting takes place with the HSCP Development Officer and a Service User/Carer Rep who gives them a service user/carer's viewpoint of the role. A full description of the role and remit is given as well as an induction pack with all the paperwork needed for the role including induction policy; full expenses policy and claim forms; terms of reference; mentoring policy; communications strategy; confidentiality agreement; aide memoire and glossary of terms; code of conduct; training record; meeting preparation and notes forms. Reps also have regular awareness sessions and can request specific topics when they feel they need more information to help them contribute to meeting discussions.

Three HSCPs, **Falkirk, North Ayrshire** and **South Ayrshire**, publish their expenses policy on their websites (Falkirk HSCP also publish their claim form).

In **Fife** Carer Support Workers (funded by the HSCP) were appointed by the local Carers Centre in early 2020 to engage directly with carers in each of the localities and gather their views and experiences. Carers Strategy funding has also been used to create a new team within the HSCP dedicated to supporting the involvement, participation and engagement of unpaid carers. The Carer Rep noted that the engagement conversations so far have been exceptionally good, with a range of different views and experiences being shared, and excellent collation, analysis and reporting after the meetings. The Carer Rep is now keen to see more carers involved in these engagement meetings, and that the evidence gathered through these engagement activities is listened to more widely and influences policy development and decision-making.



In **Perth & Kinross** representation of carers' (and lived experience) views has greatly improved since publication of the first COCIS Equal, Expert and Valued report in 2017. The IJB Carer Rep noted that when they started their role seven years ago, they were the only representative member on the IJB which felt very difficult and isolating. The key things which have been improved and made a difference are: there are now four Representatives on the IJB (two carer and two lived experience); there is an established Carers Voice Group which Carer Reps can link with to obtain views; the IJB understands that Carer (and lived experience) Reps have a representative role which is based on the views of a network of carers / people with lived experience. These positive changes mean the role feels less tokenistic and more representative of the wide range of views.

In **South Lanarkshire**, the IJB Lived Experience Rep is also the Chair of the South Lanarkshire Health and Social Care Forum. The Forum has four localities who deal with local issues and feed into the Forum, and, through the Chair, to the IJB. The Forum has 65 members, 15 of whom represent local organisations, thus covering almost 100,000 people in the community. The Forum also has a training and mentoring programme for members to ensure they understand their roles and responsibilities. Members also have representation on a variety of IJB and other subgroups and regularly receive presentations from the Chief Officer and Head of Commissioning and Performance enabling members to actively influence health and social care services. The IJB Lived Experience Rep is also Chair of an Independent Advisor Panel with membership from the Forum, third sector organisations, Chair of the Adult Protection Committee and a senior Union Representative, to ensure any service changes have appropriate consultation.

Final thoughts...

Whilst there has been undoubtable and welcome progress in the involvement of carers and people with lived experience on IJBs, this report has highlighted areas where focused attention and action are still needed.

Carer and Lived Experience Reps bring huge value to IJBs, sharing their experiences, expertise and knowledge willingly and generously. This requires a significant investment of Reps' time, which they balance with their other life commitments and responsibilities.

The benefits of Carer and Lived Experience Rep involvement in IJBs is significant, supporting the voices and perspectives of carers and those with lived experience to be central to local policy and service development. But as this report highlights, there remain key areas for improvement and development to ensure Reps are seen as equal partners on IJBs with valuable expertise and perspectives to share. The proposed plans, within the National Care Service (Scotland) Bill, to reform and enhance IJBs gives opportunities to formalise the role of Reps and achieve more consistency in relation to support across Scotland.

And thanks...

This report ends with a huge thanks to all Carer and Lived Experience Reps, who have given, and continue to give, their time, experience and expertise so generously to IJBs to improve health and social care policy, services and support in local areas.

A further thanks goes to the Reps who are part of the Carer Collaborative and the IJB Lived Experience Representative Network, whose experience, knowledge and expertise contributes to key national health and social care policy developments, and to the recommendations in this report.



The ALLIANCE is the national third sector intermediary for health and social care, bringing together a diverse range of people and organisations who share our vision. We work with our members and partners to ensure lived experience and third sector expertise is listened to and acted upon by informing national policy and campaigns, and putting people at the centre of designing support and services.

Since our formation in 2006, the ALLIANCE has built a strong and diverse membership of over 3,600 organisations and individuals. Our vision is a Scotland where everyone has a strong voice and enjoys their right to live well with dignity and respect. Our broad range of programmes and activities deliver support, research and policy development, digital innovation and knowledge sharing. We manage funding and spotlight innovative projects working directly with people, using their experience to find ways to improve wellbeing and support rights-based self-management approaches.

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The Coalition of Carers exists to advance the voice of carers by facilitating carer engagement and bringing carers and local carer organisations together with decision makers at a national and local level. It is our vision that carers in Scotland will achieve full recognition as equal partners in care. Carers will have the right to quality services and access to personalised support at every stage in their caring role to ensure they enjoy good health and a life outside of caring.

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