

May 2019



Equal, expert and valued Three years on

Enhancing carer representation on Integration Joint Boards

Third report from the Carer Collaborative of IJB Carer Representatives

Introduction and summary

The Carers Collaborative is a project that supports, evaluates and improves carer representation on Integration Joint Boards (IJBs).

This is the third annual report from the Collaborative.

Two high profile reviews of Health and Social Care Integration in 2018/19 (by Audit Scotland and by the Ministerial Strategic Group for Health and Community Care) made recommendations or proposals for improving involvement in integration.



This report focuses on carer involvement, reflecting on progress against report recommendations from 2017 and 2018. In summary:

- Recruiting and retaining new carers who are willing to undertake representative roles has become a challenge for IJBs.
- The template role description developed in 2018¹ can help. In some areas it has helped to inform not just carer but service-user involvement.
- Most IJBs continue to require Carer Reps to subsidise their public duties, with expenses not being provided and expenses policies not being in place.
- Involvement in agenda-setting has improved in some areas, but Carer Reps are still excluded in many others.

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¹ <http://carersnet.org/wp-content/uploads/2021/10/Carer-Rep-Role-Description.pdf>

The report then reviews evidence of effective involvement, using the 'Equal and Expert' best practice standards², and concludes with an updated set of straightforward recommendations, as shown below:

The Carers Collaborative recommendations:

Recommendation	Progress	Next steps – 2019+
1. Include Carers' Representatives in decision making	<p>Carers are better represented and consulted within IJB structures, with more opportunities to contribute to agendas.</p> <p>Recruitment and retention are a growing concern.</p>	<p>Continue to facilitate further carer involvement, particularly with SPGs and locality groups.</p> <p>Develop succession plans for Carer Rep roles. Build capacity across carer networks and develop systematic recruitment, induction and training processes.</p>
2. Increase awareness and profile of carers and Carer Reps	<p>The profile of Carer Reps has increased within IJBs and carer networks, resulting in greater access and improved links.</p>	<p>Provide Carer Reps with IJB email addresses and publicise these for easy contact.</p>
3. Value and resource Carer Representatives 3.1 Ensure Carer Representatives have a clear remit 3.2 Train and support Carer Representatives 3.3 Provide the expenses and resources necessary to perform the role	<p>Most IJBs still do not provide role descriptions, training or expenses for Carer Reps.</p>	<p>Use or adapt the Carer Collaborative role description to encourage mutual clarity on roles, remits and expectations.</p> <p>Develop and publish expenses policies that acknowledge and meet the costs of carer contributions to IJBs and other strategic groups. This should include travel, printing, preparation time (including consulting carers' networks), replacement care and loss of earnings.</p>
4. Make meetings better 4.1 Continue supporting Carer Reps to contribute to agendas 4.2 Continue to improve the accessibility of meetings, minutes and papers	<p>IJB meetings have become more accessible, with more opportunities for carers to contribute.</p> <p>Access to agenda-setting varies across the country and Carer Rep contributions to meetings tend not to be recorded.</p>	<p>Continue to issue papers sufficiently in advance to allow Carer Reps to read, consult and prepare.</p> <p>Provide more consistent access to agenda-setting, whether through SPGs, pre-IJB meetings or structured contact with Chairs and officials.</p> <p>Record Carer Rep contributions in meeting minutes.</p>

² <http://carersnet.org/wp-content/uploads/2021/10/Standards-for-Carer-Engagment.pdf>

Background

The Carers Collaborative

The Carers Collaborative is a project that supports, evaluates and improves carer representation on Integration Joint Boards (IJBs). The Collaborative has gathered evidence and facilitated events since March 2016, involving 51 Carer Reps from 29 authority areas. The first 'Equal, Expert and Valued' reports were published in 2017³ and 2018⁴. They identified good practice and set out recommendations to enhance carer involvement on IJBs. This update report is based on a further year's research, reviewing progress against these recommendations and revisiting evidence of effective involvement.

Aim

This third report is published one year into implementation of the Carers (Scotland) Act 2016 (and three years into the Public Bodies (Joint Working) (Scotland) Act 2014). It aims to:

- Build on the constructive insights and recommendations offered in our previous reports
- Provide ideas and signpost to resources for improving carers' involvement on IJBs
- Help Integration Authorities benchmark their practice
- Support continued practice improvement.

Methodology

The Carers Collaborative met four times between May 2018 and February 2019, providing a forum for Carer Representatives to provide mutual support, share their experiences as carer reps, develop best practice tools and scope current practice. In 2019, 19 Carer Representatives (and other IJB members) completed self-assessments against the '*Equal and Expert*' best practice standards, with a comprehensive scoping exercise also being conducted by an independent researcher. Consistent with previous years, the scoping exercise reviewed every Integration Authority's most recent strategic plan⁵, annual report, committee papers and minutes for references to carers, carer outcomes, carer involvement and the Carers Act. Achievement of National Health and Wellbeing Outcome Six⁶ was also assessed for each area via individual annual reports and the 2017/18 Health and Care Experience Survey⁷.

What we mean by 'Carer Representative'

The report typically uses the words 'Carer Reps' or 'representatives' to refer to Carer Representatives. These are usually unpaid carers (or former carers), but in some areas staff from local carers centres fulfil the role. The Carers Collaborative is of the view that while this ensures carers are represented, it is preferable to have unpaid carers in the role. Every effort should be made to recruit and, importantly, retain Carer Representatives on IJBs. As our 2018 report noted, and as we expand upon in this updated report, this is becoming harder as demands on the role grow and while many IJBs continue to fail to provide out of pocket expenses or IT support.

3 <http://carersnet.org/wp-content/uploads/2021/10/Equal-Expert-and-Valued-2017.pdf>

4 <http://carersnet.org/wp-content/uploads/2021/10/Equal-Expert-and-Valued-2018.pdf>

5 The collation of every plan and report on this site is particularly helpful for benchmarking: <https://ihub.scot/improvement-programmes/strategic-planning/integrated-joint-board-strategic-plans/>

6 'People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and well-being.' <https://www.gov.scot/publications/national-health-wellbeing-outcomes-framework/pages/5/>

7 <https://www.isdscotland.org/Products-and-Services/Consultancy/Surveys/Health-and-Care-Experience-2017-18/>

The Policy Context for carer involvement

The requirement for carer representation in planning and commissioning public services is set out by the Public Bodies (Joint Working) (Scotland) Act 2014, which requires Integration Authorities to include a Carer Representative on their IJB⁸. The Carers (Scotland) Act 2016⁹ extended the expectation of carer engagement to other areas of Health and Social Care. Furthermore, Scottish Government guidance on Health and Social Care commissioning states that services should be:

“Planned and led locally in a way which is engaged with the community (including those who look after service users and those who are involved in the provision of health and social care).”¹⁰

Since 2016, the Carers Collaborative have used the ‘Equal and Expert’ best practice standards¹¹ to assess the effectiveness of carer representation in health and social care integration. Our 2017 and 2018 reports have highlighted good practice from some areas of the country.

However, approaches to carer involvement remain inconsistent, in what the Scottish Government’s Health and Sport Committee described in 2017 as a ‘piecemeal’ approach.¹²

This report offers positive and practical insights to help improve standards and consistency. It begins with a reflection on the changing policy context for integration and involvement. A review of progress against previous years’ recommendations is then presented, before examining updated evidence for the three *Equal and Expert* standards:

- **STANDARD ONE:**
Carer engagement is fully resourced
- **STANDARD TWO:**
Carers on strategic planning groups represent the views of local carers
- **STANDARD THREE:**
The involvement of carers on strategic planning groups is meaningful and effective

The three Equal and Expert standards

- 1** Carer engagement is fully resourced
- 2** Carers on strategic planning groups represent the views of local carers
- 3** The involvement of carers on strategic planning groups is meaningful and effective



8 Public Bodies (Joint Working) Scotland Act 2014

9 <http://www.gov.scot/Topics/Health/Support-Social-Care/Unpaid-Carers/Implementation/Carers-scotland-act-2016>

10 Scottish Government (2015) Strategic Commissioning Plans Guidance

11 <https://carersnet.org/wp-content/uploads/2021/10/Standards-for-Carer-Engagement.pdf>

12 Are they involving us? Integration Authorities’ engagement with stakeholders Scottish Parliament Health and Sport Committee Published 12 September 2017 SP Paper 188

The changing context

During 2018/19, two reviews of Health and Social Integration took place, one carried out by Audit Scotland and one by the Ministerial Strategic Group for Health and Community Care. Both noted the importance of involvement and collaboration for effective health and social care integration and made recommendations or proposals for improvement.

Audit Scotland

Under the theme of ‘Meaningful and Sustained Engagement’, the Audit Scotland *Progress Report on Health and Social Care Integration*¹³ recommended that integration Authorities, councils and NHS boards should work together to:

‘Continue to improve the way that local communities are involved in planning and implementing any changes to how health and care services are accessed and delivered’.

The Ministerial Strategic Group for Health and Community Care

In its final report on Integration¹⁴, the Ministerial Strategic Group for Health and Community Care agreed with the Audit Scotland recommendations and proposed a number of steps for ‘meaningful and sustained engagement’ to be taken over the next 6-12 months (from February 2019):

‘6. (iii) We will support carers and representatives of people using services better to enable their full involvement in integration. Carers and representatives of people using health and social care services will be supported by partnerships to enable meaningful engagement with their constituencies. This will support their input to Integration Joint Boards, strategic planning groups and locality arrangements for integration. This would include, for example, receipt of IJB papers with enough time to engage other carers and people using services in responding to issues raised. It would also include paying reasonable expenses for attending meetings.’

The proposal closely reflects ‘Equal, Expert and Valued’ standards and recommendations, so it is pleasing that one IJB that we are aware of has already set up a working group to explore its implementation.

Locality arrangements for integration

As noted in our 2018 report, the locus of IJB decision-making has begun to widen out from central board meetings, towards Strategic Planning Groups (SPGs) and, increasingly, locality planning groups. As anticipated, this presents opportunities for effective carer representation, but also risks.

In some areas, locality meetings are only open to Health and Social Care Partnership (HSCP) staff, or they involve service providers but have no service user or carer representation. In two examples shared with the Collaborative, locality managers and infrastructure are in place, but no meetings are held, removing any opportunity for involvement. Practices like this go against the letter and spirit of health and social care integration.

In contrast, areas like Fife and Angus have invited carer (and service-user) representatives to form part of ‘core groups’ for locality planning and improvement. This has provided more opportunities to contribute to agenda-setting and decision-making than might be available through IJB board meetings or SPGs. Public representatives and other stakeholders have been provided with the information and/or training they need to perform their roles effectively. This helps to attract and retain representatives, building capacity within local communities and reducing the risk of ‘burn out’ among IJB Carer Reps.

¹³ <http://www.audit-scotland.gov.uk/report/health-and-social-care-integration-update-on-progress>

¹⁴ <https://www.gov.scot/publications/ministerial-strategic-group-health-community-care-review-progress-integration-health-social-care-final-report/>

Progress with previous *Equal, Expert and Valued* themes

Carer Collaborative meetings begin by sharing good practice from around the country, so new examples, innovations and improvements are always emerging. In 2018/19 these have included:

- Some IJB meetings being filmed and broadcast (e.g. via YouTube), providing a fuller record of meetings (and carer contributions) than minutes allow.
- More pre-agenda meetings taking place, allowing Carer Reps (and others) to raise questions and propose agenda items.
- The allocation of NHS or Council email accounts to Carer Reps, improving security of sensitive documents and making Reps more accessible to their constituents.
- IJBs allocating monies to carers centres to pay expenses, arrange replacement care and support succession planning, recruitment and induction training.

In the sections that follow, we review progress against core themes and recommendations from the 2017 and 2018 *Equal, Expert and Valued* reports in more depth. A new theme is also introduced, that of ensuring Carer Rep contributions to IJBs are appropriately minuted:

- Role descriptions
- Carer Representative recruitment and retention
- Expenses policies
- Agenda setting
- Minuting Carer Representative contributions.



Role descriptions

The 2018 report presented a template role description setting out the purpose, role, expectations and requirements for Carer Representatives. Four IJBs are known to have used the role description, including two (Dundee and Edinburgh) which have adapted it for use when appointing other public representatives (i.e. service user reps). One IJB has found the *Equal and Expert* standards so useful that it is considering using them to evaluate its approach to the involvement of all members, not just Carer Reps.

Carer Rep recruitment and retention

Recruiting and retaining new carers who are willing to undertake representative roles has become a challenge for IJBs. Many Carer Reps are coming, or have come, to the end of their tenures in 2018/19. Typically appointed for two to three-year terms, several Carer Reps have now stepped down and replacements have not been easy to find. At the time of writing we have identified nine new Carer Reps who have come into post in the last year; two IJBs have vacant Carer Reps posts; and two more have Reps whose tenure is ending. Several members of the Collaborative were originally due to step down in 2018, but have been asked by their IJB to extend their tenure in the absence of replacements being found, as illustrated by this example:

'I officially stepped down from my role as IJB carer rep in 2018. However, the carers centre have been unable to identify anyone who is willing and able to take on the role. I have temporarily taken on the role again until they find a replacement.'

The topic of succession planning was the focus of a Carer Collaborative meeting in 2018, exploring how IJBs can go about identifying, preparing and recruiting new Carer Reps, resulting in the following recommendations:

15 <http://carersnet.org/wp-content/uploads/2021/10/Carer-Rep-Role-Description.pdf>



Identifying potential Carer Reps

Carers Centres and established carer involvement groups are likely to be the most productive source of potential applicants. IJBs might encourage members of existing fora to become IJB Carer Reps by promoting the importance of the role, giving clear information about mutual expectations and commitments, and providing expenses and resources necessary for carrying out the role.



Preparing Carer Reps

Carer Reps bring significant personal and professional experience, but IJBs can help new or prospective Reps by providing structured induction and ongoing training. Newly appointed Reps report benefitting from shadowing and handover with existing Carer Reps and from having facilitated introductions to their fellow board members.



Recruiting

Equal and Expert and our *template role description*¹⁶ can help. IJBs should carry out succession planning, identifying when tenures end and allowing time to recruit and train replacements. Of course, existing Carer Reps are likely to be able to assist these processes. Some IJBs work with or delegate their local carers centres to carry out recruitment and selection, a process which many existing Carer Reps found helpful.

Good practice spotlight:

Capacity building and recruitment in Falkirk

In Falkirk, the role of Carer Rep is advertised through the Carers' Centre at the appropriate time and carers are encouraged to put themselves forward. Over time, members of the Carers' Forum have also been encouraged to take up roles on different committees that feed into the IJB. This creates capacity with individual carers and the wider network, equipping them to take on new responsibilities.

Prior to recruitment, an initial interview takes place with the Carer Engagement worker at the Carers' Centre. This is followed by an interview with an IJB member where details of the duties and expectations of the role are provided. Following this, regular IJB development sessions take place throughout the year in which the carer representative participates.

Good practice spotlight:

Succession planning in Dumfries and Galloway

Before the Carer Rep, Jim McColm, steps down from his role, the IJB has issued a press release to celebrate his work and attract new applicants. This is an excerpt:

'A man who has served as a Carer for the past 54 years is to step down from a key role on the Board responsible for the region's health and social care. Jim McColm is now encouraging someone else to now step forward and serve on the Integration Joint Board (IJB).

Speaking about his role, Jim said: "I've gained an awful lot from being a member of the IJB over the past three years. It's been a fantastic honour to represent the 14,955 unpaid Carers we have living in the region, and I've gained a lot of confidence speaking up and out on their behalf. It's incredibly important that Carers are represented on a Board which directs the vast majority of health and social care work in Dumfries and Galloway, and so I'm really keen that someone passionate and outspoken can fill this post."

¹⁶ <http://carersnet.org/wp-content/uploads/2021/10/Carer-Rep-Role-Description.pdf>

Expenses policies

The 2018 *Equal, Expert and Valued* report highlighted that most Carer Reps were required to subsidise the public duties they carry out on behalf of Integration Authorities because out-of-pocket expenses and replacement care were not being provided. Since then, HSCP Chief Officers have ‘undertaken to consider’ Carer Representative expenses collectively and as individual IJBs. Some IJBs are reportedly of the view that expenses should come from Carer Act Implementation monies, despite Carer Reps fulfilling statutory IJB duties under the Public Bodies Act. Wherever expenses are provided from, it is a basic point of principle and good practice that people should not be financially worse off for undertaking voluntary public duties, affirmed by the Cabinet Secretary for Health and Sport in 2017:

‘We expect the integration authorities to ensure that those who participate in the process can do so without detriment.’¹⁷

Written expenses policies are essential for processes to work effectively, as these carers’ experience shows:

‘I have had travel expenses reimbursed, but my last claim took 12 months to process. There were no clear systems in place to process it which is what caused the delay.’

‘The problem is that people do not like to ask for such things. If there were schemes, arrangements or forms in place that were routinely made available, so that people do not feel that they are asking for something that they are not entitled to, then this would help.’

The table below shows that there has been little or no improvement in IJB practice over the last 12 months. From 20 self-assessment returns received, only six IJBs have a visible expenses policy; 14 out of 19 Carer Reps have never received a copy. It is possible that the number of IJBs paying expenses for all IJB-related meetings has declined.

	2018/19 (20 Carer Rep/IJB returns)	2017/18 (17 Carer Rep/IJB returns)
Does your IJB have a written expenses policy?	Yes: 6	Yes: 5
	No: 5	No: 9
	I’m not aware of it: 7	I’m not aware of it: 3
Have you been given a copy?	Yes: 5	Yes: 4
	No: 14	No: 13
Is replacement care included?	Yes: 5	Yes: 5
	No: 3	No: 3
	Don’t know: 2	Don’t know: 5
	Not applicable to me: 3	Not applicable to me: 1
Are expenses only for IJB meetings, or for other meetings and preparation?	All meetings: 7 / Only IJB: 3	All: 12
	None: 2	None: 3
	None: 3	None: 2

¹⁷ Are they involving us? Integration Authorities’ engagement with stakeholders Scottish Parliament Health and Sport Committee Published 12 September 2017 SP Paper 188



Agenda setting

The ability of Carer Representatives to contribute agenda items still varies greatly depending on local area. In some IJBs, only voting members may attend pre-IJB meetings, with no opportunity for non-voting members to influence or inform agendas. Others, like East Ayrshire, Midlothian and Perth & Kinross IJBs, hold briefing meetings for non-voting members a few days before IJB meetings. Similarly, Edinburgh IJB has introduced time for informal discussion for all members prior to IJB Meetings, which can make discussions more inclusive. In a small number of IJBs, papers are annotated to highlight their relevance to carers, something Dundee is considering developing further with a 'Carers Impact Statement' for every item on the agenda. Similarly, in Clackmannanshire and Stirling, the impact on carers is included in policy impact assessments.

Minuting Carer Representative Contributions

In 2018/19 a new theme emerged, that Carer Representatives' contributions to IJB meetings, and the decisions that arise, are often not minuted. We understand that individual contributions tend not to be minuted, but we believe minuting Carer Rep (and other public representatives') contributions and the resulting decisions helps to improve involvement because:

- It provides a historical record of discussions for the Representative, their constituents and their substitute¹⁸ or successor. (It is interesting to note that Edinburgh and Perth & Kinross IJBs now broadcast their meetings to provide a public record, with the latter also being made available on YouTube).
- It prevents issues and commitments being lost or forgotten.
- It encourages more engagement in future, showing that voices are heard.
- It increases Carer Representatives' visibility, making them more accessible and credible to their constituents.

We therefore suggest that any contributions made by Carer Representatives, and the responses or decisions that they generate, should be minuted appropriately.

¹⁸ Some IJBs have two full Carer Representatives, some have one active Representative but permit another to act as a shadow or substitute. But some substitutes do not receive papers and are excluded from the public gallery for some discussions.

Equal and Expert: Overview of evidence

This section presents an overview of the *'Equal and Expert'* carer engagement standards and shows the extent to which they were evident in self-assessments received from 20 Carer Representatives or their IJB colleagues. Seven indicators show improvements since 2018, with none worsening.



Key:

Several good examples – overall, practice is good

Some good examples exist, but experience is mixed

Limited examples – some local good practice may exist but overall practice is poor

Standard One: Carer engagement is fully resourced

Outcomes:

1. Carer Representatives will feel confident in undertaking the responsibilities of their role and be able to express clearly and fully the views of other carers.
2. The strategic groups will benefit from the views of carers being regularly and directly represented and will produce work which addresses the needs and meets the aspirations of carers more fully.

Evidence of implementation Carers in representative roles will:

<p>1. Receive training and a full induction</p>	<p>Self-assessments show structured induction to board roles and operations was provided by 8 out of 20 areas. Ongoing training commonly takes the form of development sessions before or between board meetings. In some areas, induction consists of short introductions to senior HSCP staff. 6 out of 20 Carer Reps report receiving no induction.</p>	<p>Met: 8 Partially met: 4 Not met: 6</p>
<p>2. Be supplied with the information they require timeously</p>	<p>Electronic mailings and posting papers online have helped achieve improvements in this indicator. 12 out of 20 self-assessments reporting receiving papers at least a week before meetings, though hard copies generally follow later and lengthy papers remain commonplace.</p>	<p>Met: 12 Partially met: 3 Not met: 4 Improvement on 2018</p>
<p>3. Be mentored</p>	<p>Most IJBs do not offer structured mentoring. Where it exists, it tends to take the form of peer support (e.g. between new and retiring Carer Reps, or between newly appointed IJB members) or officers being available to provide information or answer questions.</p>	<p>Met: 3 Partially met: 3 Not met: 10</p>
<p>4. Be able to obtain the views of other carers via a strong network of carers</p>	<p>Most Carer Reps have good access to carer networks, forums and reference groups. However, 1 in 6 of the population is thought to be a carer, so resources and creativity are needed to overcome constraints arising from geography, resource and time. Equally, BME and some condition-specific carer groups are felt to be under-represented in traditional forums. Some Carer Reps have suggested classing carers as a 'hard to reach' group within local strategies to further support their inclusion.</p>	<p>Met: 13 Partially met: 5 Not met: 1</p>
<p>5. Have the full costs of their work in and for the strategic groups met – this includes the costs of any substitutionary care that is required</p>	<p>Only 6 of the IJBs in our research have a written expenses policy, and less than half (9 out of 20) of Carer Reps report having expenses paid. Where policies exist, they tend to include replacement care, though 'informal arrangements' are just as common.</p>	<p>Met: 9 Partially met: 5 Not met: 3</p>

Standard Two: Carers on strategic planning groups represent the views of local carers

Outcomes:

1. Carers on strategic groups will be:
 - (a) representative of the various communities of carers
 - (b) able to express in informed ways the views of a range of carers
2. The other partners on the strategic groups will know with confidence that they are learning of the views of a range of carers.
3. The work produced by the strategic groups will fully take into account the views of carers.

Evidence of implementation Carers in representative roles will:

<p>1. Carer organisations will be properly resourced to establish and support a strong carer network, which offers a variety of ways for carers to get involved</p>	<p>There is good evidence of consistent practice around the country, with IJBs providing resource for carer networks, e.g. via carers centres and carer advisory groups. In some areas, concerns continue about tendering exercises, increasing workload and reduced funding. As with 1.4 above, extra efforts are needed to reach the diversity of carers and ensure equality of involvement.</p>	<p>Met: 14 Partially met: 4 Not met: 0</p>
<p>2. The number and carers involved in exchanging views through the network will grow</p>	<p>Numbers have continued to increase through initiatives like training programmes to prepare carers for Locality Planning Group involvement (Fife, North Lanarkshire) and Carers' Advisory Groups being set up to inform IJB meetings (North Ayrshire, Scottish Borders). It is important for the sustainability of strategic and board-level involvement that these initiatives continue to increase capacity and confidence throughout carer networks.</p>	<p>Met: 12 Partially met: 3 Not met: 3 Improvement on 2018</p>
<p>3. The diversity of carers involved in the network will be broad</p>	<p>Most carer networks are reported to have diversity in the range of caring situations and conditions that are represented. However, Carer Reps in some areas identify the need to do more to increase demographic diversity, particularly age, ethnicity and professional background.</p>	<p>Met: 9 Partially met: 3 Not met: 4</p>
<p>4. There will be a continual emergence of new carers willing to undertake representative roles</p>	<p>Only three areas report that this is being achieved. In most other areas, ongoing work is needed to support and encourage representatives from other forums (e.g. Carers' Advisory Groups) to step into IJB roles.</p>	<p>Met: 3 Partially met: 9 Not met: 6</p>
<p>5. The information provided through and by the supported network will be of a high quality</p>	<p>In their self-assessments, Carer Reps shared examples of being provided with good information. Several also reported being able to provide evidence and information from carers (or carers centres) to HSCP officers and IJB processes.</p>	<p>Met: 13 Partially met: 1 Not met: 0</p>

Standard Three: The involvement of carers on strategic planning groups is meaningful and effective

Outcomes:

1. Carers will be treated as equal and expert partners in strategic groups.
2. The views of Carer Representatives will be evident in the strategic decisions taken and the plans that are developed.
3. Carers will be treated as equal and expert partners in the provision of care.

Evidence of implementation Carers in representative roles will:

<p>1. Carers will be placed on the right strategic planning groups including at the top level of governance structures</p>	<p>Carer Rep involvement in appropriate strategic planning groups has increased over the last two years. This has required them to give more of their time but has generally enabled more effective contributions to IJB, due to the more detailed planning and discussion that takes place in these groups. However, in some areas, locality meetings are only open to Health and Social Care Partnership (HSCP) staff, removing opportunities for effective involvement. This is against the spirit, of the Public Bodies (Joint Working) (Scotland) Act.</p>	<p>Met: 13 Partially met: 3 Not met: 2</p>
<p>2. Other partners in strategic groups will have had Carer Awareness training so that the perspectives brought by carers are understood and accepted as the statements of people who are “equal and expert” partners</p>	<p>Carer Awareness training has been planned in many areas but was only evident in six self-assessments. In some areas, the sustained presence of Carer Reps on the IJB has raised awareness of – and respect for – carers’ experience and views. Ongoing training is nevertheless important for keeping abreast of developments, for instance Falkirk held IJB development sessions on the Carers’ Act, Eligibility Criteria and the Carer Assessment process.</p>	<p>Met: 6 Partially met: 4 Not met: 3</p>
<p>3. Meetings will be open and inclusive, allowing time for discussion and contributions from all members of the group. Language will be accessible and jargon will be avoided</p>	<p>Meetings are generally reported to be becoming more inclusive, though pre-IJB planning meetings and Strategic Planning Groups tend to give more opportunities for discussion than IJB board meetings. Carer Reps accept the inevitability of jargon but note that IJBs are making efforts to minimise it.</p>	<p>Met: 12 Partially met: 2 Not met: 5</p>
<p>4. Sufficient time will be given for preparation. Papers will be sent out in advance in a timely fashion and Carer Representatives will have the opportunity to clarify any information in advance</p>	<p>Electronic publication and circulation have made a difference to the timely receipt of papers, though experience around the country is still mixed. The volume of papers continues to present a challenge for preparation, particularly for Carer Representatives who need time to be properly consultative and representative.</p>	<p>Met: 13 Partially met: 2 Not met: 3 Improvement on 2018</p>

Standard Three (continued)

Evidence of implementation Carers in representative roles will:		
<p>5. The agenda will be jointly owned with all group members having the opportunity to place items on it or raise issues of concern</p>	<p>More IJBs now have mechanisms in place to allow Carer Reps to place items onto agendas or raise concerns. These include: draft agendas being for comment (Dumfries and Galloway); participation in agenda-setting meetings; and invitations to contact Chairs or other members outwith meetings.</p>	<p>Met: 8 Partially met: 4 Not met: 4 Improvement on 2018</p>
<p>6. All plans and policies produced by strategic groups will be 'carer proofed' so that the impact on carers is explicitly stated to ensure that carers' needs and aspirations have been fully considered</p>	<p>In most areas this is now a 'work in progress', with examples including: public engagement and consultation on plans that affect carers; Carer Reps being asked to check draft documents prior to publication; and the impact on carers being included in impact assessments of policies and plans. In practice, a combination of approaches will ensure that 'carer proofing' is more than a tick box exercise.</p>	<p>Met: 7 Partially met: 7 Not met: 3 Improvement on 2018</p>
<p>7. Through their network carers will be supplied with information about the opportunities for participation in strategic planning groups</p>	<p>Carer Reps around the country have made efforts to encourage and facilitate involvement opportunities for other carers, conscious of the need for capacity building and succession planning. While IJB Carers Reps have a responsibility to supply information to their networks, they cannot set up and lead such participation opportunities alone. In most areas, they are supported to do this by carer services and networks. For example, Perth and Kinross IJB Carer Reps have been provided with an email address and telephone number to encourage direct carer contact.</p>	<p>Met: 12 Partially met: 4 Not met: 0</p>
<p>8. The outcomes of carer engagement will be evaluated</p>	<p>Where the outcomes of carer engagement are evaluated, it tends to relate to the impact of carer involvement in policy development and consultation, rather than IJB board membership. In one interesting example, North Lanarkshire conducted a review of engagement in Health and Social Care structures, referencing the three Equal and Expert standards.</p> <p>The outcomes of carer engagement in the Carer Collaborative are shared in a separate section below.</p>	<p>Met: 7 Partially met: 4 Not met: 4 Improvement on 2018</p>

Summary of scoping results and good practice spotlights

Alongside the Carer Rep/IJB self-assessment each year, the Carers Collaborative undertakes desk-based research to assess the visibility of carers in IJBs plans and processes.

References to carers (and Carer Representatives) in Strategic Plans and meeting minutes are used as simple indicators of the extent to which carers and carers' outcomes are identified and prioritised by Integration Authorities. This year, the scoping exercise also included Annual Reports.

All Integration Authorities continue to publish their Strategic Plans and Annual Reports (though four of them were only obtainable through the Healthcare Improvement Scotland's information hub rather than the IJB or HSCP's own sites). Fewer IJB meeting dates were available in advance than in previous years, possibly

because the scoping activity took place in January 2019 when some meeting schedules may not yet have been set for the year. The easy accessibility of these documents continues to be important for carer involvement, making it easy for carers to find the information they need, including the impact of local carer representation on the IJB.

All annual reports measure progress towards National Health and Wellbeing Outcome Six.¹⁹ Most compare local achievement against the Scottish average of 37% carer satisfaction.²⁰ Many also report performance against their 2015/16 results, though several chose not to. Achievement of Outcome Six increased in seven local authority areas.

Year	Strategic Plans available	Annual Reports (AR) available	AR references to carers	IJB meeting dates available	Meeting minutes available	IJB minutes referencing carers
2016/17	30	n/a	n/a	26	28	17 IJBs 29 total references to carers
2017/18	31	31	n/a	31	31	30 IJBs 89 total references to carers
2018/19	31	31	1648*	21	29	20 IJBs 79 total references to carers

* average of 53 per area

¹⁹ 'People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and well-being'. www.gov.scot/Topics/Health/Policy/Health-Social-Care-Integration/National-Health-WellbeingOutcomes

²⁰ Health and care experience survey 2017 to 2018: national results <https://www2.gov.scot/Topics/Health/Policy/Health-Social-Care-Integration/National-Health-WellbeingOutcomes>

Five of these were previously performing below the national average so the baseline for improvement was relatively low. 22 areas performed worse in 2017/18, reflecting a fall in the national average from 40% to 37%. Two areas' score stayed the same. We continue to believe that comparison with a low national benchmark is not a useful measure of success.



Good practice spotlights:

As with previous years, we seek and share examples to encourage good practice

In **Dumfries and Galloway**, the Carer Representative provides an update from their participation in the Carer Collaborative as a standing item on every IJB board meeting. Meetings continue to take place around the region for ease of access.

Edinburgh IJB has introduced several positive approaches that support carer involvement. It has adapted the template role description developed by the Carer Collaborative for use when appointing carer and service user representatives. Board meetings begin with 30 minutes information discussion, helping relationships to be developed away from the more formal conducting of board business. Board meetings are also recorded and broadcast, providing a record of discussions and Carer Reps' input to them. It should be noted that each of these measures can improve participation generally, not just for Carer Reps.

In **Fife**, the Carer Rep was invited to join one of three Clinical and Care Governance Committees which provide reports to the IJB. The Rep contributes a carers' report, which is then included in full in the papers for the meeting. They are also on the Mental Health Dementia Strategy Group, where any contributions

made are minuted. A new development is that there is now a whole section on carers on the Health and Social Care Partnership's website, giving multiple links to information and resources and raising the visibility of carers in Fife.

Midlothian advertise representative positions, including role descriptions. For those interested in finding out more, arrangements are first made to meet over coffee for informal discussions about the role and remit before an application is made. Interviews then explore the applicant's interests and further information is offered about the demands of the position. Once appointed, the new representative meets the Carer Planning Officer or Public Engagement Coordinator before their first meeting (or meetings) and members of the IJB are also introduced.

East Lothian and **Aberdeen** both provided exit interviews for departing Carer Representatives whose tenures ended. This allows appreciation to be shown and learning to be shared. As noted elsewhere in this report, planning for succession, recruitment and handover while the representative is still in post are also important.

Making a difference

The Carer Collaborative follows the Equal and Expert standards in its own work.

During 2018/19, Carer Reps reviewed the collective contribution our work had made and the individual impact of their involvement in local IJBs. The standout theme is that Carer Reps are now more involved in IJBs, with better representation in strategic planning groups. They have more opportunity to influence agendas. They have also influenced decisions, for instance regarding local funding, service design and commissioning (and decommissioning), and, particularly in 2018, Carers Act implementation.

Overall, Carer Reps feel their voices are more listened to and better respected than they were when the Collaborative began in 2016. In turn, more carers are aware of changes in policy and practice and that,

through the Carer Reps, they have a voice and their issues are understood. Indeed, there are also signs that IJB awareness of carers has increased, for example with Carer Reps organising Carer Awareness Training, policies being carer-proofed, or simply through IJB members working together over time.

There is still more to be done. Carer Reps' views are taken into account, but this doesn't always lead to action or impact. 'Consultations' still sometimes take place after decisions are made and some IJBs' agendas and Strategic Planning Groups remain closed to Carer Rep input. We therefore conclude this report by revisiting our recommendations for continuing improvements in Carer Representation.



Recommendations to improve Carer Representation

This section updates the recommendations from our initial report (2017) and identifies next steps for improving carer representation.

Recommendation	Progress	Next steps – 2019+
1. Include Carers’ Representatives in decision making	<p>Carers are generally better represented and consulted within IJB structures, with more opportunities to contribute to agendas.</p> <p>Recruitment and retention are a growing concern.</p>	<p>Continue to facilitate further carer involvement, particularly with SPGs and locality groups.</p> <p>Develop succession plans for Carer Rep roles. Build capacity across carer networks and develop systematic recruitment, induction and training processes.</p> <p>Provide Carer Awareness Training for IJB members.</p>
2. Increase awareness and profile of carers and Carer Reps	<p>The profile of Carer Reps has increased within IJBs and carer networks, resulting in greater access and improved links.</p>	<p>Provide Carer Reps with IJB email addresses for increased security of sensitive information and publicise these for easy contact.</p>
3. Value and resource Carer Representatives 3.1 Ensure Carer Representatives have a clear remit 3.2 Train and support Carer Representatives 3.3 Provide the expenses and resources necessary to perform the role	<p>Most IJBs still do not provide role descriptions, training or expenses for Carer Reps.</p>	<p>Use or adapt the Carer Collaborative role description²¹ to encourage mutual clarity on roles, remits and expectations.</p> <p>Develop and publish expenses policies that acknowledge and meet the costs of carer contributions to IJBs and other strategic groups including travel, printing (or IT equipment), preparation time (including consulting carers’ networks), replacement care and loss of earnings.</p>
4. Make meetings better 4.1 Continue supporting Carer Reps to contribute to agendas 4.2 Continue to improve the accessibility of meetings, minutes and papers	<p>IJB meetings have become more accessible, with more opportunities for carers to contribute.</p> <p>Access to agenda-setting varies across the country and Carer Rep contributions to meetings tend not to be recorded.</p>	<p>Continue to issue papers sufficiently in advance to allow Carer Reps to read, consult and prepare. If using electronic circulation, provide appropriate IT resources (e.g. laptop, tablet) to enable their use.</p> <p>Provide more consistent access to agenda-setting, whether through SPGs, pre-IJB meetings or structured contact with Chairs and officials.</p> <p>Record Carer Rep contributions in meeting minutes as appropriate.</p>

21 <http://carersnet.org/wp-content/uploads/2021/10/Carer-Rep-Role-Description.pdf>

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The logo features a stylized green handprint with fingers spread, positioned to the left of the word 'Coalition'.
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