

**EQUAL,
EXPERT**
and
VALUED

Enhancing Carer Representative involvement on
Integration Joint Boards





Thanks and acknowledgements

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Executive summary

Background

The Carers Collaborative is a project that seeks to

- Research the current landscape in relation to Carer Representation on Integration Joint Boards (IJBs)
- Develop and facilitate a forum for Carer Representatives on IJBs
- Make recommendations for future work in relation to ongoing support and training of Carer Representatives, and support for local Integration Authorities in relation our [Equal and Expert Best Practice Standards for Carer Engagement](#).

The Collaborative ran events and research activities between March and October 2016, involving 38 Carer Reps from 27 local authority areas, leading to this report.

AIM

The report offers positive and constructive insights in order to:

- Help improve carers' involvement in IJBs
- Help planning officers and commissioners to move from good intentions to better practice
- Start conversations and stimulate further progress by sharing good practice.

Equal and Expert?

In 2013 The Coalition of Carers developed 'Equal and Expert' 3 best practice standards for carer engagement. The standards were co-produced by carers and local carer support organisations, with support from the Scottish Government and the Scottish Health Council.

The report assesses evidence for the extent to which the three 'Equal and Expert' carer involvement standards have been met by IJBs to date:

STANDARD ONE:

Carer engagement is fully resourced

Practice varies. Carer Reps have found training and induction beneficial, particularly where it involves the full Board. Meeting papers are rarely sent in time to allow proper preparation. Where replacement care is provided for carers, it tends not to include time spent preparing for meetings.

STANDARD TWO:

Carers on strategic planning groups represent the views of local carers

This was the best evidenced of the three standards. Carer Reps have worked hard to be 'representative', but their visibility to other carers remains an issue. Some carers' centres support Carer Reps to represent local carer networks. Some areas struggle to engage carers, and most would like more carers in networks 'underneath' IJB board level. Where carers have been able to make contributions these appear to be valued (writing strategies, supporting consultations, improving governance, assisting inspections, contributing to commissioning etc.). It is important to note that strategic plans should reflect the issues which have been identified as priorities by Carers, not just carers' responses to consultation on pre-determined issues.



STANDARD THREE:

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

Carer Rep effectiveness appears to increase when they are included on Strategic Planning Groups, Carer Forums and IJB Agenda groups. Those with access to agenda-setting meetings report feeling more included and productive. There are some good examples of IJBs being trained in Carer Awareness (e.g. Dumfries and Galloway, North Ayrshire). However across Scotland Carer Reps' equality and expertise are still far from universally accepted.

Experience so far

Between May and October 2016 we analysed IJB Strategies and meeting minutes to determine how easily accessible information was and to identify any references to unpaid carers. 27 out of 30 Strategies include carer outcomes. 28 IJBs make their meeting minutes publicly available, and 26 publish meeting dates in advance. Between April and October 2016, 17 IJBs discussed carers or carer-specific issues.

Carers Collaborative meetings shared more detailed information on local practice. Although these focused on good practice examples, they highlighted some common gaps:

- Being listened to
- Agenda setting
- Consultation on plans
- Paperwork
- Power
- Process
- Voting
- Resourcing
- Engagement

The report gives more detail on these, and of good practice from around the country, leading to the recommendations listed below.



Recommendations to improve Carer Representation

The report shares five recommendations and 12 straightforward suggestions for improving carer involvement, all drawn from real life experience of what works for Carer Representatives across the country.

1. INCLUDE CARERS' REPRESENTATIVES IN DECISION MAKING

1.1 Find ways to involve carers in consultation and decision-making

It is important to recognise the demands on carers' time. Frequent or formal meetings can be a barrier to attracting or retaining carers. IJBs would benefit from sessions that enable carers to contribute more effectively, such as ideas exchanges. They should also consider ways to provide appropriate recognition and reward for Carer Reps.

1.2 Include Carer Reps in different groups

Ensure carers are represented on different groups within the wider structures of the Integration Authority, particularly groups that set agendas or agree decisions. Arrange collective voice meetings for service user reps, service provider reps, Carer Reps, and third sector reps – before agenda deadline dates. If you don't have one, establish a carers' advisory group.

2. INCREASE AWARENESS AND PROFILE

2.1 Raise profile of Carer Reps

Ensure that the Carer Rep's identity and role are clearly signposted on relevant websites, with contact details so other carers can get in touch. Give Reps an email address so they don't have to use their own. Business cards are a nice touch. Use locality groups to ensure carer issues are accessed and represented.

2.2 Raise IJB awareness of carers

Chairs, Chief Officers and other partnership staff can learn a lot about the impact of their decisions by attending carers' centres and meetings. Making Carers Awareness Training available for all IJB members has also been a popular and effective way to do this.

3. VALUE AND RESOURCE CARER REPRESENTATIVES

3.1 Value Carers Representatives and their contributions

Valuing Carer Reps can be as simple as inviting, minuting and acknowledging their contribution to meetings. The real test is then to listen, act and follow through.

3.2 Train and support Carer Representatives

Carer and User Representative training is essential to good involvement – and governance. Arrange regular training or development days for the whole IJB. Arrange inductions for new members, for example meetings with key officials. Supportive mentoring increases confidence.

3.3 Resource representation

Take steps to make sure Carer Representatives are not worse off as a result of contributing to the IJB's work. Provide travel costs and replacement care for the time they spend carrying out their IJB duties.

3.4 Ensure Carer Representatives have a clear remit

Agree clear roles for and with Carer Representatives. Make sure everyone knows what is expected of them.

4. SHARE PRACTICE AND LEARNING

4.1 Share practice between IJBs

Arrange exchanges with other IJBs to improve each other's practice. Support IJB Carer Reps to meet up to share ideas from different areas (it's where everything in this report came from!).

4.2 Improve communication

Ask what Carer Reps need. Make sure your agendas and minutes are publicly available. Carers can be fantastic conduits for 'bottom up' and 'top down' communication when supported by the right networks and structures.

5. MAKE MEETINGS BETTER

5.1 Create structures to allow agenda items to be raised

If you don't already, establish a pathway for agenda items to be raised. Set clear deadlines, establish an agenda setting meeting, committee or process. Join the dots between IJB and Strategic Planning Group meetings.

5.2 Make meetings, minutes and papers accessible

Produce minutes, agendas and meeting papers as promptly as possible. This lets representatives get feedback to and from their carer networks. It's especially helpful when officers identify issues affecting carers and seek advice before papers are tabled.



Introduction

This is the report of the work of the Carers Collaborative, a project that seeks to identify and improve the involvement of Carer Representatives on Integration Joint Boards (IJBs). The Collaborative ran events and research activities between March and October 2016, involving 38 Carer Reps from 27 local authority areas across the country (listed in Appendix 1):

- National meetings in May, August and October
- A scoping exercise assessing the Strategic Plans and Minutes from each IJB

This report aims to provide an honest and accurate picture of carer involvement in IJBs in 2016. It acknowledges that sometimes there is a gap between good intentions and good practice. But it offers positive and constructive insights in order to:

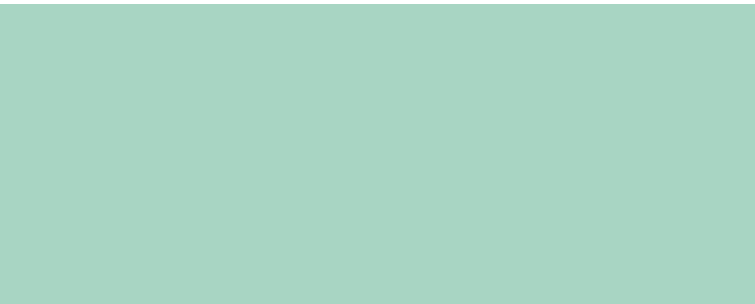
- Help to improve carers' involvement in IJBs
- Help planning officers and commissioners move from good intentions to better practice
- Open up conversations and stimulate further progress by sharing good practice.

The report begins with some background on carer involvement, then provides an overview of the extent to which 'Equal and Expert' engagement standards were evidenced by carers on IJBs. A section on the scoping exercise's results is followed by an overview of Carer Reps' actual experience to date. good practice is highlighted, before recommendations are made.

Note on language: The report typically uses the words 'Carer Reps' or 'representatives' to refer to Carer Representatives. These are usually unpaid carers (or former carers), but are sometimes staff from local carers centres.

Some IJBs now refer to 'stakeholder' representatives to describe carers, service users, people who represent voluntary organisations and the public. However, lived experience as carers is where many of the unique contributions – and challenges – of Carer Reps come from, so the report uses this term. This does not mean Carer Reps do not also have lived experience from other walks of life – quite the opposite:

'The Board didn't see our CVs and some assumed we had never worked or been involved in running anything before. A doctor sitting next to me asked, in a whispered aside, at our first formal meeting whether I knew anything about governance...I think they all know better NOW!' (Carer Rep – and company director)





Background

The Public Bodies (Joint Working) Scotland Act 2014 places a requirement on Integration Authorities to include a Carer Representative on their IJB. The Carers (Scotland) Act aims to build on this development, further extending carer engagement to other areas of health and social care planning not covered in the Public Bodies Act.

The implementation of these new duties in relation to carer engagement is at different stages throughout Scotland. The project began because of the need to achieve an accurate picture of developments across Scotland and because of the expressed desire of Carer Reps to meet and share experiences.

In 2013 the Coalition of Carers in Scotland developed '*Equal and Expert: 3 Best Practice Standards for Carer Engagement*'¹. While best practice is evident in some areas, the standards have not been consistently applied. The Carers Collaborative aimed to assess how the standards have been implemented across Scotland and identify where there needs to be further work at a local level to ensure carer engagement is meaningful and supported.

Defining the Role: Who are Carer Representatives and what do they do?

Although IJBs are required to involve '*a person who the integration authority considers to be representative of*' carers², the purpose of doing so is not specified. The Carer Representative role is undefined. Some IJBs have created a role specification. Others give guidance or instruction as to what they feel the appropriate involvement from representative should be.

Sometimes Carer Reps have been instructed not to 'lobby' on behalf of carers. This highlights the tensions in raising issues on behalf of carers and being a member of a group looking at wider issues. The Act entitles IJBs to appoint (and remove) those people it considers appropriate. But to fulfil their role as 'representatives', Carer Reps would generally prefer to be appointed by carers, and to be given resources to engage with carers. (simple things like having an IJB email address, or displaying contact details on the IJB website help).

Clearly, work still needs to be done to clarify the role of Carer Representatives. If it is decided to continue the Carer Collaborative's work, facilitating clarity or agreement on this is likely to be a useful next step.

¹ <http://carersnet.org/wp-content/uploads/2021/10/Standards-for-Carer-Engagement.pdf>

² Public Bodies (Joint Working) Scotland Act 2014





Equal and Expert:

Overview of evidence

This section presents an overview of the 'Equal and Expert' Carer Engagement standards, and the extent to which they were evident in IJB practice from the Collaborative's work and research.

Key:

SEVERAL
GOOD
EXAMPLES
EXIST

SOME
EXAMPLES
EXIST, BUT
EXPERIENCE
IS MIXED

ISOLATED
OR LIMITED
EXAMPLES

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 address the needs and meets the aspirations of carers more fully.

Evidence of implementation Carers in representative roles will:

1. Receive training and a full induction.	Practice varies. Some Carer Reps have had thorough induction, others more ad hoc (e.g. support from officers), and others none.	SEVERAL GOOD EXAMPLES EXIST
2. Be supplied with the information they require timeously.	Meeting papers are rarely sent in time to allow proper preparation. Most are received less than a week in advance and often only one or two days before the meeting. Seven to ten days in advance was seen as a minimum.	ISOLATED OR LIMITED EXAMPLES
3. Be mentored.	Some CEOs and Chairs have proactively supported Carer Reps, albeit as informal 'mentors'. Some Carers Centres also do this.	SOME EXAMPLES EXIST, BUT EXPERIENCE IS MIXED
4. Be able to obtain the views of other carers via a strong network of carers.	Carer Reps have worked hard to be 'representative', linking into networks like carer forums, Carers Voice Groups and Carer Reference Groups, mainly facilitated by local Carers' Centres. Carer Rep visibility to other carers remains an issue.	SEVERAL GOOD EXAMPLES EXIST
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.	Some carers receive travel expenses and replacement care for time spent in meetings, but not for time spent preparing.	SOME EXAMPLES EXIST, BUT EXPERIENCE IS MIXED

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

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	Some carers' centres support Carer Rep networks, but not many have specific funding to undertake this work. Where they do it tends to be short term rather than core funding (e.g. Carer Information Strategy funds, the Change Fund).	
2. The number and carers involved in exchanging views through the network will grow.	Some areas struggle to engage carers, and most would like more carers in networks 'underneath' IJB board level.	
3. The diversity of carers involved in the network will be broad.	Membership of the national Carers Collaborative was relatively diverse, but carers would like more support to reach beyond 'the usual suspects'.	
4. There will be a continual emergence of new carers willing to undertake representative roles.	There appears to be no shortage of <i>willingness</i> , e.g. substitutes are often in place. Capacity is more of an issue and populating planning groups below IJB level with carer representatives is also a challenge.	
5. The information provided through and by the supported network will be of a high quality.	Where carers have been able to make contributions these appear to be valued. Examples include writing or approving strategies, supporting consultations, improving governance, assisting inspections, and contributing to commissioning.	

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

1. Carers will be placed on the right strategic planning groups including at the top level of governance structures.	Most IJBs now include Carer Reps. The importance of links between different groups has become evident. Carer Rep effectiveness appears to increase when they are included on Strategic Planning Groups, Carer Forums and IJB Agenda groups.	
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.	There are some good examples of training being delivered – and achieving outcomes (e.g. Dumfries and Galloway, North Ayrshire). However across Scotland Carer Reps’ equality and expertise are still far from universally accepted.	
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.	Meetings are reported by carers to be jargon-filled, with overly-full agendas and little opportunity for input. In some areas, carers have more influence outwith board meetings.	
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.	See above – papers are often last-minute. Examples like facilitated pre-meetings, or pre-meeting contact with Chairs, are the minority.	
5. The agenda will be jointly owned with all group members having the opportunity to place items on it or raise issues of concern.	Few areas have mechanisms that allow carers to contribute to, much less own, agendas. Reps with access to agenda-setting meetings report feeling more included and productive.	
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.	Some IJBs pay particular regard to carers in equality impact assessments (e.g. Aberdeenshire, North Ayrshire). Others ensure carers are consulted or get to sign-off policies (Edinburgh, Dumfries and Galloway).	
7. Through their network carers will be supplied with information about the opportunities for participation in strategic planning groups.	Carer Reps are very knowledgeable about the systems and structures in which their work takes place. Some areas support carer networks for this purpose.	
8. The outcomes of carer engagement will be evaluated.	No examples of this were evident in our scoping or events.	

A grayscale photograph of a desk setup. In the upper right, a calculator is visible with keys for 'CE/C', '0', '00', '1', '2', '3', '4', '5', '6', '7', '8', '9', and a decimal key. In the center, a clipboard holds a document with the title 'Summary Report' in a large, bold font. To the left of the clipboard, a pair of glasses is resting on the desk. In the top left corner, there are some small, light-colored flowers. The overall scene is softly lit and slightly out of focus.

Summary Report

Scoping summary

The aim of the scoping exercise was to develop a national picture of carer engagement within the integration of health and social care. It sought to identify:

- The extent of carer engagement in Integration Joint Boards across Scotland
- Examples of best practice in including carers in IJB plans, meetings and processes
- Challenges of engagement
- Recommendations for future work in relation to the ongoing support and training of Carer Representatives - and support for local Integration Authorities.

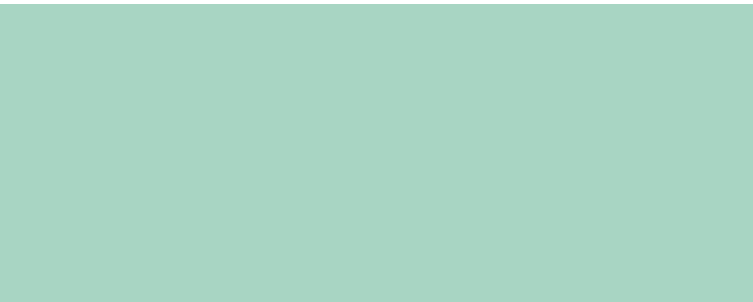
Methodology

The scoping exercise took place between May and October 2016, sourcing and analysing the three most recently available sets of minutes from each IJB or shadow board (pre April 2016). References to Carer Representatives' inputs were used as indicators of the nature and level of carer involvement in meetings (though this is a relatively crude measure, as carers commonly reported having more of a voice in other meetings and didn't necessarily expect these to be recorded in IJB minutes). Each area's Strategic Plan was also searched for references to unpaid carers. This was used as an indicator of the extent to which carers and carers' outcomes had been identified and prioritised.

The findings show that at October 2016, 30 Strategic Plans were publicly available, 27 of which included outcomes for carers. 26 areas had made their meeting dates available, and 28 had published their minutes. Carers were referenced in the minutes of 17 IJBs.

This information will provide a baseline for measuring future progress. Members of the Carers Collaborative also hope that more substantial indicators can be used to highlight greater involvement and progress, for example towards implementation of the Carers Act.

Strategic Plans Available	Carer Outcomes Included	Meeting Dates Available	Meeting Minutes Available	# IJBs Minuting References to Carers
30 plans	27 plans	26 areas	28 areas	17 IJBs. (Total number of mentions: 29)





- Somewhat Disagree
- Extremely Satisfied

2. To what extent do you agree with the following statement?

- Disagree Completely
- Strongly Disagree
- Somewhat Disagree
- Somewhat Agree
- Strongly Agree
- Agree Completely

The Carer Representatives' experience so far:

Overview

...working for T

BEING LISTENED TO

Probably the single biggest challenge to Carer Reps is to make themselves heard and understood. There are several aspects to this. Firstly, even carers with senior management or board experience describe IJB meetings as formal and sometimes intimidating. Secondly, it is not easy to contribute when agendas are full and meetings are fast. Thirdly, when they speak their contributions are not always recorded – a disempowering experience. Finally, IJB members don't necessarily agree on what is important. Many reps would like a greater focus on governance and strategy, to bring about the systemic transformations IJBs were designed to achieve. Operational matters dominate agendas (specifically, delayed discharge appears to recur) meaning nothing fundamentally changes for carers or the people they care for.

AGENDA SETTING

Some IJBs have pre-meetings. Issues relating to carers are often discussed at these meetings more than at the IJB. However these discussions and agreements involving carers are not reflected in IJB minutes. Where agenda setting committees are not available to carers, getting to know people on the Board has sometimes been a constructive way to participate and have influence. For example, by requesting a meeting with the Chief Officer, Partnership Manager or Chair, some carers have raised issues effectively. Carers in most areas felt they have good access to decision makers.

CONSULTATION ON PLANS

There has been good consultation in many areas in relation to the IJB Strategic Plan, where carers were able to feed their views in, for example via meetings and roadshows.

PAPERWORK

IJB members have a 'mountain of paperwork' to work through. Examples included having between 300-500 pages to read for each meeting. Often papers arrive with little time for representatives to digest them – typically a week or less, and in one case, at 5.30pm the day before a meeting. Carer Reps receiving papers more than a week in advance were the exception. This presents obvious challenges for people with caring commitments.

POWER

There is a perception that decisions are often made at Strategic Planning Groups, rather than at the IJB. Some issues are debated and agreed at sub-groups or other planning groups and issues are not discussed at the IJB. Several Carer Reps were on both IJBs and Strategic Planning Groups, which helps them stay informed and sometimes gives them more influence.

PROCESS

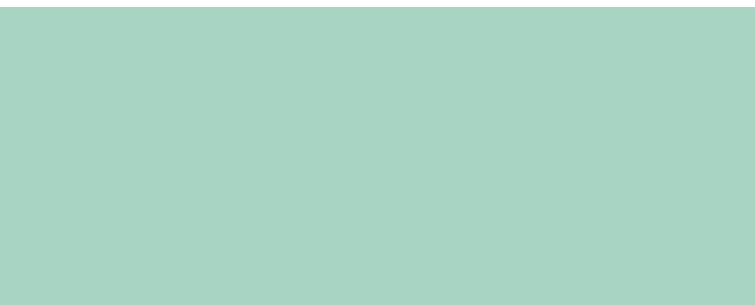
The Carer Rep experience is that IJBs are 'consumed by' process and operational concerns. Integration Schemes were one example, where each IJB had invested significant time and resources in development, despite the end-products being very similar to each other.

VOTING

There was a view that IJBs rarely use formal voting mechanisms, though examples do exist. Carer Representatives felt that they cannot be equal members of IJBs – or contribute appropriate governance oversight - without being voting members. Voting members (representatives of statutory bodies) have the real power. However there was an interesting minority view that being non-voting members enables Carer Reps to speak more freely and to influence decisions.

RESOURCING

To fulfil their IJB commitments, some carers are using their SDS budgets or respite/replacement care entitlements, meaning they lose out on breaks from caring that they might otherwise have had. Carers should not be worse off by contributing to IJBs.



ENGAGEMENT

Ultimately the quality of carer contributions – and how they are valued – is what matters. But the number of carers and how they are selected remains an issue. Not all IJBs have two carers on board, though it is considered to be good practice as it allows carers to support one another. This is important because one representative reported feeling isolated and unsupported, and two others reported that colleagues had had to give up their IJB roles due to work commitments.

Another reason for having two representatives is to reduce the stress that comes from knowing that there is nobody to represent carers if an individual can't make a meeting. Some areas have a process which allows for a substitute Carer Rep to attend, allowing carers to share the load. However other areas only allow substitutes to sit in the public gallery, not to contribute, which limits the benefit that those IJBs get from carer involvement.

There was general agreement that a 'network' of carer involvement underneath the IJB level (e.g. at each appropriate level within the Integration Authority's structures) is required. Carers are also represented at locality level in many areas.

'It's hard to say what gives a carer credibility – it requires Chairs to be interested in carers and localities, and see the need for other Carer Reps underneath that, networks of support and involvement at all levels in councils and NHS.' (Carer Representative)

In some areas it has been agreed to have staff as Carer Representatives, due to difficulties recruiting or retaining carers to take on the role. In others, it has been agreed that the Carer Rep had to be an unpaid carer, rather than a staff representative from a carer support organisation.

'Work in Progress'

It became evident during both the scoping activity and the group events that progress was being made. During early scoping (May-June) for example, only 17 IJBs had published meeting minutes, and carers had been mentioned just four times in these. However by October, 28 had minutes available and carers had been mentioned 29 times. The tone of conversation had also changed. For example at the first Collaborative meeting in May, there was some frustration about lack of training, level of involvement, quality of governance etc. But by October, positive improvements were being reported. For example, some Carer Reps had been able to ensure that the Carers Act appeared on the agenda.

VALUED AND RECOGNISED INTERESTING, CHALLENGING, RESPONSIBLE NON-INCLUSIVE **CHALLENGING, TIME CONSUMING, VALUABLE**
THERAPEUTIC COMPLEX, CHALLENGING, INTRIGUING **INCLUSIVE, EMPOWERING, CHALLENGING** FRUSTRATING MONEY, POWER – FOLLOW!
FRUSTRATING, INFORMATIVE, ALMOST **NOT ENOUGH TIME!** SIDELINED, PERSISTENT, HOPEFUL **SOCIAL CARE...COSTS!** EXCLUDED
WELL-OILED MACHINE POTENTIAL AWAITING RESULTS **GRADUALLY LESS PATRONISED** FORCED-MARRIAGE, FORMAL, FINDING ITS WAY
GETTING THERE SLOWLY CHALLENGING, FRUSTRATING, POSITIVE JARGONISTIC WORK IN PROGRESS **VALUED, RESPECT, LISTENED**
LEARNING-CURVE, FRUSTRATING, EYE-OPENER FRUSTRATING, INTERESTING, INFORMATIVE **LEARNING** CHALLENGING, FRUSTRATING, HOPEFUL

Carers Reps use three words to describe their IJB experience.



Sharing experience:

Good practice notes from around the country

This section of the report is based on mapping and scoping activities carried out during the three Carer Collaborative meetings. It aims to put a spotlight on good practice and to draw attention to practice that can be improved.

RECRUITMENT, INDUCTION AND ROLES	
Examples of good practice	Examples of practice to be improved
Several Carer Reps were appointed after an application process and interview. In one example this was carried out by the Carers' Centre, meaning this was a more open process and the representative role of the Carer Rep was clearly established from the outset. Unsuccessful applicants now form a consultation group, which means their expertise and willingness to engage has not been lost.	Some areas do not yet have a Carer Representative, or have appointed on an interim basis. This risks losing continuity of 'the carer's voice'.
Many IJBs allow for two Carer Representatives. This helps to share the workload and the pressures. If the Carer Rep can't make a meeting, a substitute can be agreed with the IJB Chair.	Some IJBs only allow for one Carer Representative. Others do not allow deutes to take part in meetings, only observe them, sometime without access to all the papers.
A few areas have provided Carer Reps with a role description. A small number of IJB Chairs have given helpful guidance on the Carer Rep's role. For example, about their right to comment on, or challenge, issues that are raised at meetings.	Most IJBs appear not to have identified a description of the Carer Rep's role or purpose.

SUPPORT AND RESOURCES	
Examples of good practice	Examples of practice to be improved
In some areas, carers are provided with travel expenses for attending meetings. In others, replacement care is provided for time spent in meetings.	Some areas do not provide travel expenses or replacement care. Where replacement care is provided, this does not cover time spent reading papers and preparing for meetings.
Some IJBs identify a Carers' Champion or lead officer who can work directly with Carer Reps and Carer Centres.	It is not always know who the local Carer Lead is, or what their role is.
Carer Reps find IJB development sessions beneficial – some IJBs schedule these every other month, between formal Board meetings.	Some Carer Reps have received no induction or training.

STRUCTURES FOR INCLUSION AND REPRESENTATION

Examples of good practice	Examples of practice to be improved
Several Integration Authorities have run 'carer aware' training for members of IJBs and other key partners	In some areas carer reps report a lack of understanding of the contribution of unpaid carers and the value carer reps bring to IJBs through their lived experience.
Some areas have good support structures to encourage different levels of involvement and coordination of carers' views. Carers Reference Groups and Carers Voice Networks have been particularly helpful, as have pre-Board meetings with other public representatives.	These are often facilitated by Carer Centres or Third Sector Interfaces, but not always resourced by Integration Authorities.
'Carer forums' can help ensure Carer Reps hear and represent the wider views of carers. Some IJBs raise Carer Representatives' profiles by including their photos, biographies and an IJB email address on their websites.	Some areas do not have good carer networks to connect carers at different levels.
Some areas are further ahead in ensuring carers are represented at Strategic Planning Groups 'underneath' the IJB and at a locality level and that there are good lines of communication between the different planning structures and the IJB	This work is still developing in some areas and carers are not fully involved at a strategic planning level and locality level

MEETINGS AND PAPERS

Examples of good practice	Examples of practice to be improved
Meetings are made accessible to Carer Reps. For example, one rural area rotates its meetings around the region. Video links can help, but need careful planning and facilitation.	Barriers to involvement include long or unfocused meetings; jargon; meetings being conducted at high speed; and an emphasis on process.
Papers are made accessible by being provided in time to let carer prepare, in electronic and paper versions. In one area papers can be collected from a local access point. One IJB provides Carer Reps with I-pads. In some areas, Carer Reps receive confidential 'green papers' including financial information, which helps them fulfil their governance role.	Papers are frequently lengthy and sent too late to allow Carer Reps to prepare. Several Carer Reps are not included in 'green paper' circulation.
Carer Representatives are able to request agenda items and submit papers via Agenda Committees, SPG Chairs, IJB Committee Services, pre-Board meetings or under 'Any Other Business'.	Several Carer Reps have no way to influence or contribute to agendas.

STRATEGY

Examples of good practice	Examples of practice to be improved
Some IJBs are actively preparing for the Carers Act, for example discussing it at Board level; reviewing their Strategic Plans in readiness; scheduling development days on the Act; and asking Carer Reps to prepare Board papers or presentations on the Act.	Several IJBs have not discussed or begun preparing for the Carers Act.
A small number of Strategic Plans use several indicators for National Health and Wellbeing Outcome 6, giving a rounded measure of carer outcomes. Some IJBs have worked with Carer Reps and carer centres to develop appropriate indicators.	Most areas use just the one indicator (“I feel supported to continue caring”).

Spotlight: AYRSHIRE AND ARRAN

provide travel expenses
and replacement care

The following pages contain short case studies highlighting how some of these elements work in practice.

Spotlight: FIFE

Carer Rep was appointed through interview by the Carers' Centre. Others applicants now form a consultation group.

Spotlight: MORAY

issues papers 7-10 days ahead of meetings, giving carers time to prepare.

Spotlight: SHETLAND

A Carers Forum facilitated by a carers support worker gives carers the opportunity to voice individual concerns

CARER VOICE COORDINATOR

The role of Carer Voice Coordinator in Highland was created as a self-employed consultant role to be carried out by a carer. The ethos behind the role being self-employed was to allow the carer to have complete flexibility to fit the requirements of the role around their caring responsibilities. The funding has come through NHS Highland from the Integrated Care Fund.

The remit is to increase the engagement and involvement of carers in the planning and delivery of services that affect their lives and the lives of the people they care for. In this vision, any organisation or group which has contact with unpaid carers will have a carer involved in planning and decision making of the service provision.

The Carer Voice Coordinator takes up opportunities for involvement wherever they can, then looks at how the relevant organisation operates with a view to identifying a carer that could replace them. They also facilitate a carer reference group for the Highland Carer Improvement Group. Improvement groups are in place in NHS Highland to inform and commission services for adults, with each group having members from many sectors working under the umbrella of improving the experience of Adult Health and Social Care for different groups in the community.

‘The vision for Highland to have carers involved in the planning and delivery of all services that affect their lives is a work in progress, however with the creation of this role, we now have someone who has that ambition at the core of their role and is dedicated to making the vision a reality.’

Karen Anderson, Highland Carer Voice Co-ordinator

Spotlight:

on best practice:

HIGHLAND

STARTING OFF

In North Ayrshire, carers were on the shadow board and helped to establish how the IJB structures and meetings would operate. All board members received the same training, which reinforced the feeling of equality among partners. Councillors also received carer awareness training.

STRATEGY

The IJB Strategy has an accessible summary, and includes a section on carers, which was approved by carers before going to print. The Carers Strategy sits underneath this, written with carers.

STRUCTURE

To provide a link between communities and the IJB, a Carers Advisory Group brings carers together from different localities and carer groups. It is chaired by a 'Carer Champion', a councillor with a remit for social work. Carers from the Carers Advisory Group populate other strategic planning groups, which helps provide a network of support underneath the IJB Board. In these and other ways, community members can raise issues and get items on the agenda.

SPEAKING

At a practical level, even the decision about where to hold meetings was consulted on. Members chose the council chambers to give appropriate gravitas to meetings. This might sound formal, but it helps involvement: anyone can speak by pressing a button when they have something to say. In other areas, Carer Reps miss out if they feel like they are 'interrupting'.

SUCCESS FACTORS

Marie McWaters, a Carers Rep, puts these successes down to the positivity of councillors and council leaders towards involving carers. Other carers could see the benefits that involvement was having, so more signed up.

'Once you make the pathway it's easy – you just keep using the same path.'

Spotlight:

on best practice:

NORTH AYRSHIRE

In Perth and Kinross, Carer Reps have the support of a community engagement officer based at Perth and Kinross Voluntary Association Services (PKVAS).

Before this, and without support, the Carer Reps felt they had less of an impact. A thorough induction was the first step, with three induction meetings.

The engagement officer facilitates meetings with other IJB stakeholder reps (e.g. public and third sector representatives). These pre-IJB meetings ensure that representatives have the necessary papers, anticipate discussions and identify any issues they want to raise.

'The Engagement Officer's support is invaluable to us for our input.'

Maureen Summer and Bernie Campbell, IJB Carer Reps



Spotlight:

on best practice:

PERTH



Recommendations to improve
Carer Representation

1. INCLUDE CARERS' REPRESENTATIVES IN DECISION MAKING

1.1 Find ways to involve carers in consultation and decision-making

It is important to recognise the demands on carers' time. Frequent or formal meetings can be a barrier to attracting or retaining carers. IJBs would benefit from sessions that enable carers to contribute more effectively, such as ideas exchanges. They should also consider ways to provide appropriate recognition and reward for Carer Reps.

1.2 Include Carer Reps in different groups

Ensure carers are represented on different groups within the wider structures of the Integration Authority, particularly groups that set agendas or agree decisions. Arrange collective voice meetings for service user reps, service provider reps, Carer Reps, and third sector reps – before agenda deadline dates. If you don't have one, establish a carers' advisory group.

2. INCREASE AWARENESS AND PROFILE

2.1 Raise profile of Carer Reps

Ensure that the Carer Rep's identity and role are clearly signposted on relevant websites, with contact details so other carers can get in touch. Give Reps an email address so they don't have to use their own. Business cards are a nice touch. Use locality groups to ensure carer issues are accessed and represented.

2.2 Raise IJB awareness of carers

Chairs, Chief Officers and other partnership staff can learn a lot about the impact of their decisions by attending carers' centres and meetings. Making Carers Awareness Training available for all IJB members has also been a popular and effective way to do this.

3. VALUE AND RESOURCE CARER REPRESENTATIVES

3.1 Value Carer Representatives and their contributions

Valuing Carer Reps can be as simple as inviting, minuting and acknowledging their contribution to meetings. The real test is then to listen, act and follow through.

3.2 Train and support Carer Representatives

Carer and User Representative training is essential to good involvement – and governance. Arrange regular training or development days for the whole IJB. Arrange inductions for new members, for example meetings with key officials. Supportive mentoring increases confidence.

3.3 Resource representation

Take steps to make sure Carer Representatives are not worse off as a result of contributing to the IJB's work. Provide travel costs and replacement care for the time they spend carrying out their IJB duties.

3.4 Ensure Carer Representatives have a clear remit

Agree clear roles for and with Carer Representatives. Make sure everyone knows what is expected of them.

4. SHARE PRACTICE AND LEARNING

4.1 Share practice between IJBs

Arrange exchanges with other IJBs to improve each other's practice. Support IJB Carer Reps to meet up to share ideas from different areas (it's where everything in this report came from!).

4.2 Improve communication

Ask what Carer Reps need. Make sure your agendas and minutes are publicly available. Carers can be fantastic conduits for 'bottom up' and 'top down' communication when supported by the right networks and structures.

5. MAKE MEETINGS BETTER

5.1 Create structures to allow agenda items to be raised

If you don't already, establish a pathway for agenda items to be raised. Set clear deadlines, establish an agenda setting meeting, committee or process. Join the dots between IJB and SPG meetings.

5.2 Make meetings, minutes and papers accessible

Produce minutes, agendas and meeting papers as promptly as possible. This lets representatives get feedback to and from their carer networks. It's especially helpful when officers identify issues affecting carers and seek advice before papers are tabled.

This section gives **five recommendations** and **12 simple suggestions** for implementing them, all drawn from the real life experience of what works for Carer Representatives across the country.





Next steps

‘Very productive meeting today. Interesting to see what’s happening all over Scotland and where we find it, sharing good practice and not so good shall we say!’ (Feedback at Carer Collaborative meeting)

DISSEMINATE THE REPORT AND EXPLORE WAYS TO ADDRESS THE RECOMMENDATIONS

To some extent this report has a ready audience, with Carers Representatives, IJBs and Scottish Government all keen to learn from its findings. Carer Reps certainly see the report as the start of something, not the conclusion: the report can be used to facilitate conversations. For example, Carer Reps may take an individual lead on introducing and sharing the report locally, or they may work collectively to make presentations through national structures like the IJB Chief Officers’ network.

How ever it is disseminated, we hope the report equips IJBs to build on existing good practice towards better and more effective carer involvement. In 2017 the Collaborative will develop an action plan to help implement the recommendations above.

CONTINUE THE COLLABORATIVE, BUT INCLUDE REGIONAL EVENTS

During conversation in the final session, the general feeling was that there should be an end point to the Carers Collaborative’s work, but that point had not yet been reached. All 14 of the Carer Reps who took part in an end of programme poll indicated that the Carer Collaborative should continue, and continue to be facilitated by the Coalition of Carers. Seven felt it should carry on using its national format, two said it should be regional, and five saw the need for both.

Should the meetings be held:	
Nationally	7
Regionally	2
Both	5

‘I do think it would be useful to meet with IJB reps in the same health board area.’

‘(There should be) Improved access (video conferencing) for carers who cannot travel to the central belt because of their caring commitments would be good. Apart from that it appears to be working well.’

‘Have the national meetings held in places other than Edinburgh or Glasgow.’

RETAIN THE PRACTICE SHARING FORMAT

The format, based on sharing practice, has been effective for building Carer Reps confidence, and their ability to understand their own IJB’s practice in the context of developments elsewhere.

‘I think we are doing reasonably well which gives one more confidence to keep being persistent - in a helpful and positive way of course!’

‘Done an excellent job so far and we mostly know each other and are happy to share information. Great summaries/reminders/notes of meetings, comfortable relationship with SG policy teams, and what we have is a sort of baseline for what happens in the first “real” 3 years of IJBs.’

‘I now feel that I can approach the Chair of the IJB on the issue of User and Carer Reps being allowed to have pre-board meetings.’

‘It has been beneficial to hear what is working well and not so well, which increases my confidence to approach the IJB I attend to raise issues and or to encourage carer involvement within the IJB process.’

CLARIFY THE ROLE OF CARER REPS

As noted above, the role of Carer Reps could be clarified, and members of the Carer Collaborative might want to explore whether a common or agreed standard would be useful.

‘Briefings are useful - maybe something about the role of the carers Rep at IJB meetings’

Appendix 1: Areas represented at Carer Collaborative meetings

- | | | | | | | |
|--------------------|---------------------|-----------------------|----------------|-----------------------|----------------------|-------------------------|
| 1. Aberdeen | 5. Clackmannanshire | 9. East Lothian | 13. Fife | 17. Moray | 21. Renfrewshire | 25. West Dunbartonshire |
| 2. Aberdeenshire | 6. Dumfries | 10. East Renfrewshire | 14. Glasgow | 18. North Ayrshire | 22. Scottish Borders | 26. West Lothian |
| 3. Angus | 7. Dundee | 11. Edinburgh | 13. Highlands | 19. North Lanarkshire | 23. Shetland | 27. Western Isles |
| 4. Argyll and Bute | 8. East Ayrshire | 12. Falkirk | 16. Inverclyde | 20. Perth | 24. Stirling | |



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