Local Carer Engagement – Resourcing Best Practice
Coalition of Carers in Scotland, July 2014

Introduction

> *"At the heart of this concept is the view that providers and users should be consulted and empowered in the design and delivery of service. In particular there is a vision of empowered and active citizens working alongside paid public servants to create additionality which offers genuine opportunity for change[1]."*
>
> *(Christie Commission)*

As the Public Bodies (Joint Working) (Scotland) Act comes into force with a greater move to co-producing services with carers and service users, we need to establish whether appropriate structures and processes are in place to enable carers to participate effectively as equal partners in care.

The picture across Scotland is currently very mixed. In some areas resources have been invested to facilitate carer engagement, mainly through local carer organisations. Structures and lines of communications are already well established and carers are supported to have their views heard through a variety of methods, including representation through local carer-led organisations, involvement in locality planning, local carer engagement forums and through innovative methods such as social media networks. However, in other areas carer engagement is fragmented without dedicated staff support, appropriate structures are not in place and only a few isolated carers are involved in locality planning.

This paper looks at local arrangements in relation to carer engagement. It sets out current best practice and recommends what additional resources are required to ensure a level playing field across the country where carers are supported to meaningfully engage in the new integrated structures.

Recommendations

1. Funding is required to ensure each partnership area is able to support carer engagement in a systematic and meaningful way within the new integrated structures. Each local authority area requires a dedicated postholder to support this work. This should be hosted through a local carer organisation and should include:
    - Identifying, training and supporting carer representatives
    - Facilitating carer engagement events, such as consultation meetings or a carers forum

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[1] Commission on the Future Delivery of Public Services, 2011 (Christie Commission)

    - Hosting social media platforms to enable engagement with a wider community of carers.

2. A national post should also be resourced to help to support local activities. This should include:
    - Coordinating a national forum of carer representatives to facilitate shared learning, training on national policy developments and peer support
    - Promotion of best practice standards for carer engagement
    - Collation of issues from a local level to provide a national picture to inform ongoing policy development

3. Partnerships should be required to provide carer representatives with induction training and ongoing support as required. The annual report from partnerships should include information on carer engagement – such as the structures in place for carer engagement and the resources allocated to support this work

Background and Policy Context

Since 2002 carers have been recognised in legislation as 'key partners in providing care'[2]*. Caring Together*, The Carers Strategy for Scotland, further strengthened carer recognition in 2010 when carers were acknowledged for the first time as 'equal partners in care' . The term 'equal partners' was to recognise carers as providers of care with an equal status to other partners in the care-giving system in respect to their expertise and contribution as caregivers.

To address this, in 2011 NHS Boards were required to strengthen carer engagement through the inclusion of carer representatives on Community Health Partnership committees.[3] But this recognition has not always translated into meaningful engagement with carers and their inclusion on key strategic planning groups.

The Public Bodies (Joint Working) (Scotland) Act 2014 has the potential to further strengthen carer engagement through their participation in locality planning and membership of Joint Boards. The requirement for partnerships to consult and involve carers as key partners is set out in the Act and accompanying regulations which are currently being consulted on.

Best Practice Standards for Carers Engagement

In 2012, the Coalition of Carers in Scotland produced 'Equal and Expert' a set of three Best Practice Standards for Carer Engagement. These were jointly developed by carers and staff from local carer support organisations, local authorities and the NHS. The standards outline the structures and resources which need to be in place to ensure that carer engagement is

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[2] Community Care and Health (Scotland) Act
[3] Reference: CEL 6, 2011

meaningful, involves as wide a community of carers as possible and that carer representatives on strategic planning groups receive the support to influence and contribute to improved outcomes for carers.

The three Standards are:

Standard 1 – Carers engagement is fully resourced

As well as the reimbursement of expenses, such as travel and replacement care costs, resources are required for training, induction and ongoing support for carer representatives. In addition partnerships need to invest in local structures for carer engagement, such as carer forums and social media platforms.

Standard 2 – Carers on strategic planning groups represent the views of local carers

Carers are not a homogenous group. Carers fulfilling a representative role need to engage with a strong network of carers from different caring backgrounds. This network needs to be developed and sustained by a local carer organisation, properly resourced for this task. Without this, carers cannot speak with authority and may be viewed as an unrepresentative voice

Standard 3 – The involvement of carers on strategic planning groups is meaningful and effective

All those involved in the operation of strategic planning groups need to be ready to accept carers as equal and expert partners. This means having a commitment to listen and respond appropriately to the views of carers. This includes practical measures such ensuring meetings are accessible, allowing people to place items on the agenda, giving sufficient time for preparation, allowing time for discussion and evaluating the outcomes of carer involvement

These standards are already in evidence in part in many areas of Scotland. However, the resources directed towards carer engagement vary greatly and few areas have established best practice against all three standards.

The current landscape – Survey on Carer Engagement

To get a clearer picture of the structures and support already in place to facilitate carer engagement the Coalition of Carers in Scotland circulated a brief survey to its members. We received a response from 13 local authority areas and one national organisation. A full copy of the survey responses can be found at Appendix A

Resources currently directed to carer engagement

Ten of the respondents currently facilitate a carer forum or group which engages carers in local and national policy development. However, the resources they receive to undertake this work vary greatly.

Seven of the projects indicated that they received no funding or that they are forced to use core funding to undertake these activities. Those organisations receiving dedicated funding for these activities all received it through short-term Change Fund or CIS funding, with the exception of one project which received NHS funding (unspecified). Amounts varied from £5,000 to £38,600. In two cases funding was matched by the organisation (Stirling and Dundee). In one case the funding received was not exclusively for carer engagement activities, as the postholder also undertook other activities (Falkirk and Clackmannanshire)

Carer Representatives on Strategic Planning Groups.

We asked firstly if carers were involved in locality planning, for example through membership of their local Public Partnership Forum. 10 respondents answered yes to this question. 1 answered no, but stated that a staff member from the local carer centre attended rather than a carer (Falkirk and Clackmannanshire). One respondent answered No (Helensburgh and Lomond) and one respondent did not know.

Respondents were then asked if carers were members of the local CHP Board or Shadow Board for the new Joint Partnership Boards. Five respondents answered yes, six answered no and two did not know.

We gave people the opportunity to provide details. Responses were very mixed, some projects who were already well resourced indicated that things were working well, others identified various challenges, including the need to develop better structures for carer engagement, the need to involve all carers in planning and not just a select few, lack of certainty about how current structures will change following integration and finding the resources to take this work forward.

> *"Plenty of room for improvement here from statutory bodies but needs much more enforcement by SG around involvement and dedicated financial resource to carer centres to provide a platform, develop infrastructure, facilitate and co-ordinate involvement with statutory partners. There is also a need to ensure that this resource keeps abreast of legislative changes and provides this information to local carers to allow them to continue to be meaningfully and constructively involved in the planning and shaping of local services."*

> *"Carer representatives are on the local planning groups. But the whole thrust towards integration has meant that these groups are less involved in planning. We remain unclear how the new systems will involve carers and to date there is not much sign that this will be a strong focus on involving carers. The uncertainty over integration has meant that structures are unclear and it is hard to encourage carers to be involved as it feels like they may be wasting their time."*

How Carer Representatives Link with Local Carer Forums

A key standard for carer engagement is that carer representatives on strategic planning groups link with their local carer-led organisations, forums or groups so that they can maintain a representative voice and involve a wider community of carers in decision making. We asked respondents if this was happening in their area. Eight indicated that this was in place, three that it didn't happen and two did not know.

> *"Issues and areas for improvement are raised by carers at meetings four times a year and fed through advisory group to CHCP. Responses should then be fed back to carers."*

> *"This is heavily reliant on volunteers and volunteer support and at times can be more effective than others."*

What resources are needed to facilitate best practice in carer engagement

Finally, we asked respondents what they felt was needed in their area.

Almost all the respondents were in agreement that a dedicated resource was required, mostly in the form of a part time or full time worker with some additional development funding. Estimates on the amount of resource required ranged from £8,000 to £42,000, which may be a reflection of the resources organisations already have at their disposal.

The Coalition's experience suggests that to meaningfully involve carers in such meetings would require reliable support (and training) and an infrastructure to enable them to gather the views of other carers and disseminate information back to them from the meetings.

> *"Dedicated financial resource specifically for Development Officers/Managers to focus on the specific role and remit of the job."*

> *"Someone given the dedicated lead and appropriately resourced."*

> *"Continued dedicated resource to allow us to further develop carer engagement."*

> *"The same level of resource we are currently receiving, £38k, would allow us to employ a dedicated worker to promote, recruit, train and support carer engagement."*

> *"Full implementation of the Carer Engagement Standards. NLCT has used these effectively in consultations, however, it would make big difference to sustainability of volunteers if these could be adopted with statutory partners."*

> *"Definitely, funds would be used to employ a dedicated Carers Engagement Officer to facilitate a carers' forum to work in tandem with our Carers Training Coordinator. These are two separate areas of work which require to be fully resourced! We would certainly welcome opportunities to take forward this area of work."*

Views of Local Carer Representatives

We asked two carers about their experience as representatives on strategic planning groups. One is on the Board of their local CHP. The other has recently joined the Shadow Integration Board. A more detailed report is included as Appendix B

In terms of training and support provided. One carer had been on a residential training for carer representatives provided by COCIS, but had not received any induction or support locally before joining the CHP Board. The other carer had not received any formal induction, but had met with some of the key staff members in advance of the first meeting. It was felt that support and good links with local carer networks were an essential mechanism for support, although these were not always available.

> *"No formal training as such ... just accumulated experience, being nosey, liking to know how things are done and problem solving how to make them better."*

> *"I received training through COCIS on being a carers' representative on a CHP. I have received ongoing support both from COCIS and peer support from fellow delegates. At the time there was no Carers' Centre in Shetland and the repeated message that I got from fellow delegates was that they went to their carers' centre when they needed help/advice/support."*

Both carers gave a mixed response when asked if they had been treated as an equal partner. The carer on the CHP said that had been her experience to date but that with new integrated structures emerging she did not have confidence that her role would continue to be recognised. The other carer on the shadow board said she had experienced differing attitudes

> *"Anyone in the real world knows a level playing field is impossible. There are different attitudes around different tables to "citizen reps". The whole gamut from friendly and interested to " what would they know, we are the professionals"."*

> *"On the Community Health Partnership I am the Carers' Representative and, on the whole, I have been treated as having an equal voice, although I am not an equal partner in that I have no voting rights. At the very least I am able to remind those present at meetings that supporting carers is very good value for money; much cheaper than providing the care that they themselves have provided."*

Both carers identified the need for training and support for themselves They also mentioned the need for training for staff members to ensure they recognise the role of carers as equal partners

Current Challenges

Resources: As our survey shows there is a great deal of variation in the way carer engagement is resourced across Scotland. Only a few projects receive funding to enable them to employ dedicated staff to facilitate this work. Many projects receive small grants or use core funding to facilitate some carer engagement work, but almost all are struggling with capacity issues and feel they could be doing more. Of those projects who are fully funded, they have expressed concerns that funding is short term and may soon come to an end.

> *"My main concern right now is that the funding for this post is due to end in March 2015. There is a real danger that all of the good work developed to involve carers using Change Funding will be lost."*

Having the Structures in Place for Carer Engagement: This was also a recurring theme. While structures were well developed in some areas, with carer representatives and carer forums connecting to locality planning groups, in others structures had not yet got off the ground or carer forums were established but were not well connected to locality planning. In order for carer engagement to be effective and meaningful these lines of communication require dedicated resources.

Treating Carers as Equal Partners: Embracing the concept of carers as equal partners will require partnerships to establish a new culture with a more open way of conducting meetings, sharing information and enabling others to contribute to decision making. The current experience of carer representatives is mixed. Overall, the view seems to be that progress has been made, but improvements are still required. Carers will need to have a strong voice, be well informed and have the ability to challenge if they feel they are being side-lined. As well as focussing on preparing and training the workforce for change, partnerships must also ensure carer representatives are similarly prepared for the role they will play in the future.

Readiness of partnerships: Concerns were expressed that the current changes in relation to Integration are creating further uncertainty and in some areas are seen as a step backward. In terms of current priorities partnerships are seen to be focussing on organisational structures and workforce issues. They have not yet begun to prioritise preparing for the new role carers and service users will play in the new integrated partnerships

> *"Everyone on planning and commissioning groups need to be empowered to take decisions. It is not just carers who currently lack decision-making authority. Often the real decision makers sit behind the scenes where the real decisions are taken."*
> *(Carer response to consultation on proposals for Integration, September 2012*)

In summary it appears that the current landscape is not yet conducive to carers being able to meaningfully participate in the new integrated structures

Recommendations

4. Funding is required to ensure each partnership area is able to support carer engagement in a systematic and meaningful way within the new integrated structures. Each local authority area requires a dedicated postholder to support this work. This should be hosted through a local carer organisation and should include:
    - Identifying, training and supporting carer representatives
    - Facilitating carer engagement events, such as consultation meetings or a carers forum
    - Hosting social media platforms to enable engagement with a wider community of carers.

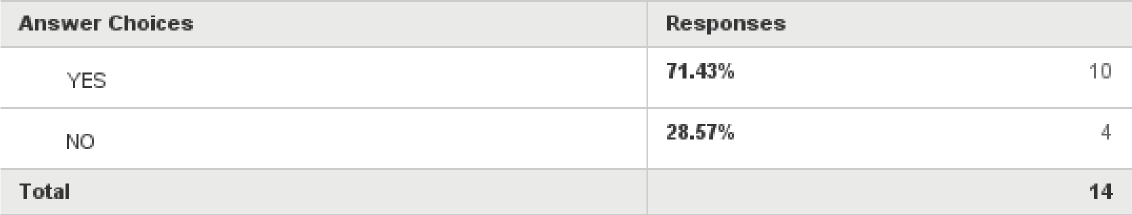
5. A national post should also be resourced to help to support local activities. This should include:
    - Coordinating a national forum of carer representatives to facilitate shared learning, training on national policy developments and peer support
    - Promotion of best practice standards for carer engagement
    - Collation of issues from a local level to provide a national picture to inform ongoing policy development

6. Partnerships should be required to provide carer representatives with induction training and ongoing support as required. The annual report from partnerships should include information on carer engagement – such as the structures in place for carer engagement and the resources allocated to support this work

Appendix One

Responses to Survey on Carer Engagement

1. Does your organisation facilitate a local carer forum or group which involves carers in local decision making

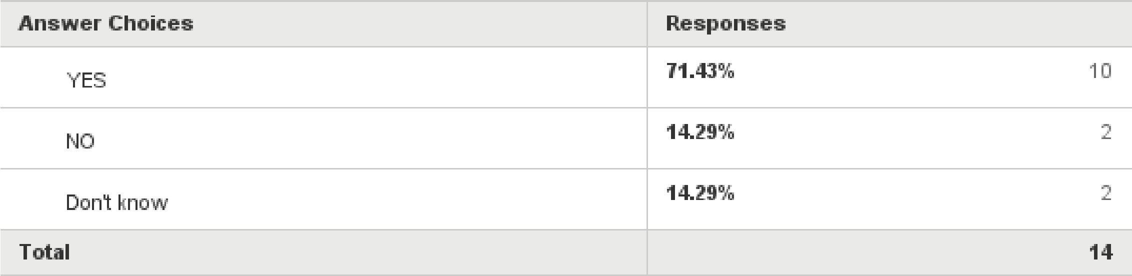


Answer Choices	Responses	
YES	71.43%	10
NO	28.57%	4
Total		**14**

2. How is this funded? And how much funding do you receive?

- Not currently funded - we have had to incorporate this into our core work
- NHS Funding. Funding for a full time Involvement and Support Manager and Administrator, covering Tayside.
- This is on an informal basis, not funded, but facilitated through existing staff in response to consultation exercises, new legislation etc. as appropriate.
- We try to facilitate this using our core funding grant from the local authority to support carers
- As part of core funding from North Lanarkshire Council
- Carer Information Strategy £5000
- Reshaping Care for Older People - this remit is included in funding for a development post for which we receive approx. £38600 p.a. for 29 months. However, this has been a challenging post as it also includes a number of other onerous tasks.
- We sort of do this. We did have one off funding (£5,000) last year but there is a need to continue this work.
- CIS funding: £23,914 in 2013-14. This amount is match funded by the organisation.
- We did but had to stop after staff support was withdrawn from council and other agencies.
- Change Fund - £32K - top up with private funding to cover costs of hiring venues, teas/coffees/carer cover/support costs/admin etc. etc. - total costs around £42K

3. Are there carer representatives on your local strategic planning groups? For example your local Public Partnership Forum

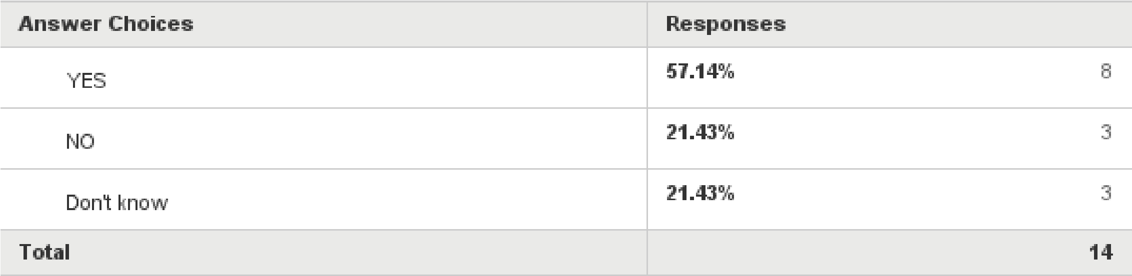


Answer Choices	Responses	
YES	71.43%	10
NO	14.29%	2
Don't know	14.29%	2
Total		**14**

4. Please provide details

- Plenty of room for improvement here from statutory bodies but needs much more enforcement by SG around involvement and dedicated financial resource to carer centres to provide a platform, develop infrastructure, facilitate and co-ordinate involvement with statutory partners. There is also a need to ensure that this resource keeps abreast of legislative changes and provides this information to local carers to allow them to continue to be meaningfully and constructively involved in the planning and shaping of local services.
- Local forums are very important, it gives carers who have something they want to say a voice but means they do not have to commit to attending formal meetings or to be representing all carers and take on the full responsibility of that.
- There needs to be true representation of carers across the board. Quite often it is carers who are involved with larger carers organisations who are invited along to strategic planning groups etc. There needs to be the opportunity for smaller localised engagement so that carers can truly have their voices heard
- On the whole we have positive commitment from the NHS and local authority. The young carers side of things could be improved
- Carer representatives are on the local planning groups. But the whole thrust towards integration has meant that these groups are less involved in planning. We remain unclear how the new systems will involve carers and to date there is not much sign that this will be a strong focus on involving carers. The uncertainty over intergtration has meant that structures are unclear and it is hard to encourage carers to be involved as it feels like they may be wasting their time.
- North Lanarkshire Carers Together exists to give carers a voice in the planning of services at a strategic level including the North Lanarkshire Carer Strategy Implementation Group the NHS CIS Group and the Health & Care Partnership and associated partnership board. There will also be carer representation on the new Integration Board. NLCT is key in representing carer developments within the RCOP programme.
- We are actively seeking volunteers to become more involved in locality planning, whilst many carers are happy to volunteer services within the office and as part of carer events there is a lack of interest in carers wishing to become more involved in co-production and strategic representation. Support to embed carer engagement standards has been highlighted as a priority and our organisation is currently looking at threading this into a revised job description.

5. Do they currently link with your local carer forum / groups?



Answer Choices	Responses	
YES	57.14%	8
NO	21.43%	3
Don't know	21.43%	3
Total		**14**

6. How do they do this?

- The Carer Rep on the Shadow Board is a member of our Board of Directors
- They attend local carer voice meetings
- Issues and areas for improvement are raised by carers at meetings four times a year and fed through advisory group to CHCP. Responses should then be fed back to carers
- This is heavily reliant on volunteers and volunteer support and at times can be more effective than others
- The individual in mind is conscious of the need to represent carers as opposed to individual carers and is therefore one of the main supporters of the carers forum and gets involved in planning and consultation. We promote the carers forum and pass on issues and questions for him to raise. However the individual is also very able and does not require support to understand or prepare for meetings. Neither do they ask for support with anything to do with their caring role
- Through the local Carer Involvement Groups
- Via the local groups, which meet on a quarterly basis
- There are 3 sector based forums, which elect reps on to the Carers Reference group, which in turn elects reps for the carers planning and implementation group (strategic group)

7. Are there any carers represented on your local Community Health Partnership Board / or the Shadow Integrated Partnership Board

Answer Choices	Responses	
YES	35.71%	5
NO	42.86%	6
Don't know	21.43%	3
Total		**14**

8. In order to improve carer engagement in your area – what is needed?

- From my experience to meaningfully involve carers in such meetings would require considerable support (and training) and an infrastructure to enable them to gather the views of other carers and disseminate information back to them from the meetings.
- Dedicated financial resource specifically for Development Officers/Managers to focus on the specific role and remit of the job.
- Part time worker and running costs
- A clear lead officer with responsibility for carers issues. Clear structures for involving carers (and others) with a clear role. Once we have these, I will feel a lot better about encouraging carers to be involved. We then need to support them in this role.
- Someone given the dedicated lead and appropriately resourced
- This is currently working well and we have lots of idea's moving forward. The Involvement and Support Manager is one year into a three year SLA with NHS Tayside.
- £42,000
- £10,000 for part time post plus expenses for carers
- Continued dedicated resource to allow us to further develop carer engagement
- The same level of resource we are currently receiving, £38k, would allow us to employ a dedicated worker to promote, recruit, train and support carer engagement
- £8,000 with total flexibility on budget would allow us dedicate staff to ensuring carers are widely engaged and supported
- Full implementation of the Carer Engagement Standards. NLCT has used these effectively in consultations however, it would make big difference to sustainability of volunteers if these could be adopted with statutory partners.
- The Forum and Carers' Strategy Group is still tokenistic and the CHCP do not really engage so a commitment would be helpful. The CHCP committee is still a very top down agenda body and the ppf cannot table items so there is a lack of bottom up information. I do feel strongly that a dedicated resource is required. Carers' Centres are busier than ever and the skills a worker requires to do community engagement/capacity building are different from those of information and advice workers. Additional resource is also required as from our experience locally, we require more than one forum, the needs of parent carers are different from a carr of someone with dementia, who is in turn different from a carer of an adult caring for another adult, who in turn is different from a young carer. Yes there are common issues but we find separate forums are more rewarding with delegates from smaller forums coming together to talk on behalf of the

wider group. Very resource intensive and still made no mention of transport, admin, venue hire, providing alternative care arrangements etc I also feel strongly that CHCP's should not be able to lead on this, and to properly ensure carers views are truly represented, carers themselves with support from carers' centres and/or other support organisations should lead on this with commitment to attend and engage coming from local authority and health board departments

- Support to facilitate a forum which represents other carers groups, parents, adults etc To my mind this is at least a part time (half week) post. Practical costs, publicity, training, venue hire, transport, alternative care arrangements, admin, printing the numerous papers they would be expected to read etc
- More meaningful involvement at a local and strategic level. A dedicated staff member to facilitate this area of work. Also at Community Planning Partnership level. I have been trying to make inroads in this area and have a meeting with the newly appointed CPP Manager later this week.
- Definitely, funds would be used to employ a dedicated Carers Engagement Officer to facilitate a carers forum who would work in tandem with our Carers Training Coordinator. These are two separate areas of work which require to be fully resourced! We would certainly welcome opportunities to take forward this area of work.
- A dedicated carers BME support worker is required to focus on this area of work
- Funding for the cost of running the forums and the staff time to help prepare carers to take part effectively and confidently in forums. funding for replacement care and transport to enable carers to take part.

Summary of Survey Reponses

Local Authority Area	**Organisation facilitates a local carer forum for carer engagement**	**Funding Source and amount**	**Carers on local planning groups**	**Carer Reps link to local carer forum**	**Carers on local Board (CHP or Shadow Board)**
Stirling	Y	Change Fund £32,000 Matched £10,000	Y	Y	N
Dundee	Y	CIS £23,914 plus matched £23,914	Y	Y	N
East Lothian	Y	£5,000 last year – none this year	Y	Don’t Know	Y
Falkirk and Clackmannanshire	Y	Change Fund £38, 600 (funding not exclusively for carer	N (carer support workers)	Y	N

		engagement)			
Inverclyde	Y	CIS £5,000	Y	Y	Y
North Lanarkshire	Y	Core funding	Y	Y	Y
East Ren	Y	Core funding	Y	Y	Y
Edinburgh	N	Unfunded – previously funded	Y	N	N
Dumfries and Galloway	N	Unfunded Does not facilitate carer forum	Y	N	N
Helensburgh and Lomond	Y	No specific funding	N	N	N
Perth, BME Project	N	Did not answer	Don't Know	Don't Know	Don't Know
Tayside	Y	NHS Funding	Y	Y	Y
Not Specified	Y	Not funded	Y	Y	Don't Know

Appendix Two

Experience of Carer Representatives

Carer Representative on Shadow Integration Board

On Training and Induction

I have been recently appointed to the Integration Board but its very early days. Induction has been largely meeting with key individuals. We went into our first Board with a short briefing with the Communications Manager. It has been generally agreed by the four "citizen reps" as we like to think of ourselves this would all have been impossible without our respective considerable backgrounds in such things. So no formal training as such...just accumulated experience, being nosey, liking to know how things are done and problem solving how to make them better

On Being an Equal Partner

Us newbies feel on the "Integration" we are in a pretty good place to engage with all sorts of carer issues and feedback from and to our respective "constituencies"...we shall see

I think I can influence things by a) speaking up, it seems to surprise "professionals" we can think and speak!, and b) respectfully challenging common professional assumptions

Anyone in the real world knows a level playing field is impossible. There are different attitudes around different tables to "citizen reps". The whole gamut from friendly and interested to " what would they know, we are the professionals". Citizen reps have no voting entitlement on Integration Boards, but their view is that if things have to go to a vote then integration isn't working, again we shall see

Carer Representative on Community Health Partnership

On Training and Induction

I received training through COCIS on being a carers' representative on a CHP. I have received ongoing support both from COCIS and peer support from fellow delegates

At the time there was no Carers' centre in Shetland and the repeated message that I got from fellow delegates was that they went to their carers' centre when they needed help/advice/support. I was able to take this message back to the meetings/consultations that I attended subsequently and speak of the direct experience of other people. This was perhaps the most useful thing that I took back

On Being an Equal Partner

On the Community Health Partnership I am the Carers' Representative and, on the whole, I have been treated as having an equal voice, although I am not an equal partner in that I have no voting rights. At the very least I am able to remind those present at meetings that supporting carers is very good value for money; much cheaper than providing the care that they themselves have provided.

However, at the first joint meeting of the Social Work Committee and the Community Health Partnership, in the Health and Social Care Options Appraisal it was stated quite clearly that this integration will not include carers (nor the third sector, nor service users); although we will have the right to be in attendance. On pushing the point, and insisting that the guidance from government is that all should have a place at the table, all be it a non-voting place, and that surely a carers' representative should have a higher standing than, say, others in attendance, like the press, I don't feel I was given the reassurance I sought. The Health and Social Care Options Appraisal document states:

The Council and the Health Board would each delegate functions and resources to the Joint Board of the Body Corporate. The Joint Board would have equal membership of elected members of the Council and non-executive members of the Health Board. Representatives of third sector partners, carers and service users would be in attendance.

I feel that this is symptomatic of the value placed on us by some of those in authority within the statutory bodies; a minor inconvenience which is permitted to attend rather than having an equal place at the table.

Training also needs to be delivered to those with whom we are 'equal partners', to ensure that this equality is recognised! What is needed is formal, mandatory training at a strategic level to those in the public sector on their duties to support carers in general, and carer participation in particular