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Article

Enabling better carer involvement: A qualitative evaluation of the involvement service belonging to a carers organisation in the United Kingdom

Irtiza Qureshi[1,2,*], Yannis Pappas[3], Kerry Jones[1], Roma Mills[4], Tim Napper[4], Jitka Vseteckova[1]

[1] Faculty of Wellbeing, Education and Language Studies (WELS), The Open University, Milton Keynes MK7 6AA, United Kingdom
[2] Nottingham Centre for Public Health and Epidemiology, University of Nottingham, Nottingham NG7 2QL, United Kingdom
[3] Institute for Health Research, University of Bedfordshire, Luton LU1 3JU, United Kingdom
[4] Carers in Hertfordshire, Hertford SG14 1AX, United Kingdom
*** Corresponding author:** Irtiza Qureshi, irtiza.qureshi@nottingham.ac.uk

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Abstract: Background: Globally, unpaid carers face economic and societal pressures. Unpaid carers' support is valued at £132 billion a year in the United Kingdom (UK) alone. However, this care comes at a high cost for the carers themselves. Carers providing round the clock care are more than twice as likely to be in bad health than non-carers. These carers are therefore proportionately more likely to need statutory services such as health care provision. It is critical that carers are better supported to be involved in the shaping, delivery and evaluation of the services they receive. Unfortunately, qualitative evidence on how carer organisations can do this better is scarce. **Methods:** Working collaboratively with a community-based carers organization, we undertook a qualitative study. Purposive sampling was used to recruit 23 participants. Online, semi-structured, one-to-one interviews were conducted with carers, community organization staff and stakeholders to ascertain their experience and views on the involvement service. **Results:** Firstly, there are a range of benefits resulting from the involvement service. The carers see the service as an opportunity to connect with other carers and share their views and ideas. Secondly, staff and service providers also reported how involvement gave a platform for carers and was of value in helping them shape needs-led services. Thirdly, we found that barriers to good involvement include the lack of a clearly understood, shared definition of involvement as well as the lack of a diverse pool of carer representatives available for involvement activities. **Conclusion:** The findings from our study provide important insights into how carers, staff and service stakeholders view barriers and enablers to good involvement. The findings will be of interest to a range of community-based organizations interested in further involving members of their community in shaping the services they receive.

Keywords: carers; participatory research; community-based services; qualitative; evaluation; service user involvement

1. Introduction

1.1. The global context

Informal or unpaid carers play a vital role in meeting social care needs across the world. The care they provide has enormous value, both for the people they care for and for wider society. The overall number of carers in the world in difficult to gauge, however the International Alliance of Carer Organisations suggest there are around 63 million carers internationally (Embracing Carers, 2021). However, another study found that an estimated 43.5 million adults had provided unpaid care in the last 12 months in the United States alone (Hounsell et al., 2019). Not only is the number of carers contentious but so is the agreed definition of who/what a carer is (Molyneaux et al., 2011). However, for the purposes of this study we consider carers as those who, without pay, care for someone with a long-term illness, physical disability, or cognitive/mental condition. The conditions they care for can include cancer, Multiple Sclerosis, Parkinson's Disease, Dementia, Alzheimer's, Spinal cord injury, Muscular Dystrophy, other cognitive/mental condition or Congestive Heart Failure (Embracing Carers, 2021).

There are a number of specific issues that carers face including mental and psychological health issues, negative impacts and changing aspects for carers' social needs and social wellbeing, such as relationships and social networks, social isolation, social exclusion and social participation. Although different countries have implemented various carer focused policies to respond, the needs and pressures remain significant (Hill and Broady, 2019). Several international studies have investigated what carers want in terms of support. A Norwegian study found that carers particularly highlighted the need for involvement in services. They wanted to be involved as they reported feeling excluded, despite having useful resources, feeling powerless, and wanting cooperation with services (Weimand et al., 2011).

1.2. The United Kingdom context

There are an estimated over 8.8 million people carers in the United Kingdom (UK) (Carers UK, 2019). Over 1 million caring for more than one person, with 1.3 million carers providing over 50 hours of care per week. Unpaid/informal carers' support is valued at £132 billion a year (Carers in Hertfordshire, 2018). However, this comes at a high cost for the carers themselves. Carers provide round the clock care by providing practical help such as preparing meals, doing laundry or shopping; keeping an eye on the person they care for; keeping them company; taking the person they care for out; helping the person they care for with financial matters; helping the person they care for deal with care services; helping with aspects of personal care and providing physical help (Carers UK, 2019). The cumulative pressures of providing this kind of care means they are more than twice as likely to suffer from ill health than non-carers (Carers in Hertfordshire, 2018).

Carers are so vitally important to the UK's National Health Service (NHS), that it has been reported that the NHS would succumb to immense operational, budgetary, and social pressures if it were not for the carers and their efforts (Boughey and Mcsherry, 2016). The needs of these carers have been found to be largely in line with the global literature, including the importance of carers feeling they have a voice in their services (Boughey and Mcsherry, 2016; Public Health England, 2021). Furthermore, there has been specific research in the area of those experiencing poor mental health and those caring for them which also highlighted that existing studies which have explored how to facilitate carer involvement have mainly focused on clinician opinions and clinician led models of carer involvement and as a result there is a lack of patient and carer perspectives in the literature (Giacco et al., 2017).

Carers in Hertfordshire (CiH) is a countywide, community based, charity for unpaid carers in the UK. CiH has been established for over 25 years and provides various forms of support for carers (as well as recently bereaved carers). In Hertfordshire (UK county, population 1.1 million) CiH carried out a survey on the State of Caring in Hertfordshire (n = 1434 carers responded) (Carers in Hertfordshire, 2018). Only 11% of respondents stated that there was no impact on their wellbeing as a result of caring. The survey showed that unpaid carers felt stressed (74%), anxious (66%) and experienced insomnia (57%). Such consequences have increased since the previous survey in 2015 when the results showed 71%, 63% and 53% respectively. This indicates that carers in Hertfordshire (like those nationally) are at high risk of developing health issues, which may result in more care having to be provided by statutory services (funded by the government, set up by law and therefore increasing the burden on taxpayers). Furthermore, we know that there are long standing calls for carers to be better involved in the services the people they care for receive (Giacco et al., 2017). In this context it is imperative that carers are supported to have a voice and enabled to influence statutory service delivery (Boughey and Mcsherry, 2016).

CiH offers various support to carers. This includes: information and care planning; training for capacity building; access to funding and services; as well as enabling carers' voice, co-production and participation in local services via its unique and well-established Involvement Service. Hertfordshire County Council and the Hertfordshire and West Essex Integrated Care Board fund CiH to provide the Involvement Service. This service supports family carers and caring friends to have a voice in the planning, commissioning and performance review of health and social care services for:

- Carers
- Children and Young People using Child and Adolescent Mental Health Services
- Adults with Mental Health issues
- Adults with Dementia
- Older Adults
- Adults with Learning Disabilities
- Adults with Physical Disability/Sensory Need
- Adults with Autistic Spectrum Conditions
- Adults who use Drug and/or Alcohol

The service aims to:

1) ensure all carers receive information, advice and support.
2) enable carers to participate in service planning and decision making.
3) be a platform for the voice of carers.

For a more detailed description of the overall CiH remit and structure please see Appendix A. The Involvement Service, with its inclusive and proactive approach, was set up in 2008 to support the delivery of CiH's stated aim to ensure that all carers in Hertfordshire can exercise a collective voice and can be involved in consultation and planning to ensure high quality support services for themselves and the people they care for. It provides unpaid carers with the information, skills and opportunities to enable them to share their views and experiences with commissioners and other stakeholders and, in consequence, to have a positive impact on service provision and development.

CiH were one of the first few carer services in the UK that developed an involvement structure which includes the potential for any carer to engage in involvement opportunities, as well as a 'network' of carers, bi-monthly meetings and named 'carer representative'. However, without evidence of where involvement has had a positive influence on service development and delivery, carers are often reluctant to give up their time to be involved in activities. Currently, the evidence obtained in relation to evaluation of the programme is anecdotal. CiH was keen to work with its carers in the community and commissioned The Open University (OU) & University of Bedfordshire (UoB) to understand more about the effectiveness of the involvement service.

1.3. Aim and objectives

It is in the above context that CiH & OU utilised a community-based participatory research approach with the overall aim to "To gather evidence for the continuous improvement of the Carers in Hertfordshire involvement services and support the organisation's agenda for commissioning, learning and participation".

The above aim was to be achieved through the following four objectives:

1) To map the existing service and communication practices.
2) To understand the factors that facilitate and hinder carers' involvement with the programme from the carers' perspective
3) To understand the factors that facilitate and hinder carers' involvement with the programme from the professionals' perspective.
4) To explore the experience and views of carers and professionals with regard to current vs ideal practice, if such distinction is found.

This manuscript presents the findings from the research carried out for the above aims and objectives.

2. Materials and methods

2.1. The research approach

A qualitative methodological approach was used, which is recognised as increasingly important in health services research, to build evidence in relation to the CiH involvement service. Conducting in-depth interviews with diverse samples is an established method for generating understanding of patients' and stakeholders' experiences and perspectives of health services (Ziebland and Hunt, 2014), within an interpretivist research paradigm. Our study utilised (online) semi-structured one-to-one interviews with carers, CiH staff and stakeholders to ascertain their experience and views on the CiH involvement service (Al Balushi, 2016). Professional stakeholders included service commissioners, service providers and community organisations. A total of 23 interviews were carried out consisting of 11 carers, seven CiH staff and five professional stakeholders (see **Figure 1**).

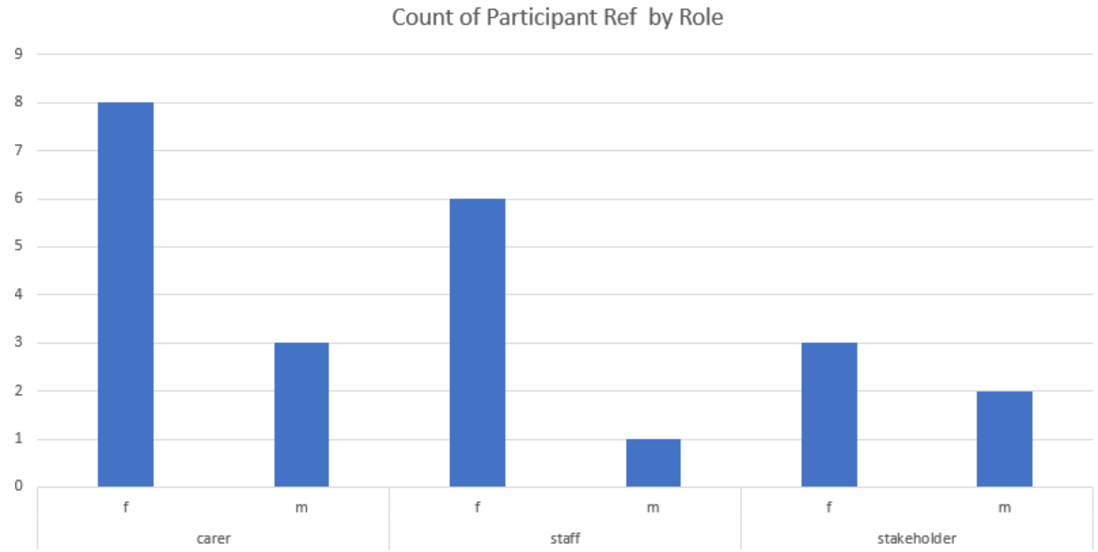

Figure 1. Sample details.

2.2. CiH and their critical role in the research

CiH were instrumental in developing the research approach. They had established a relationship with The Open University prior to the research being carried out and were critical in the recruitment of participants. They utilised existing governance infrastructure (such as consultation and involvement committees) to advertise and promote the research. Participants were able to volunteer, and some were approached. In conjunction with CiH, the researchers sent emails to invite carers, staff and stakeholders to take part in the research and clarified its aims, objectives and consent procedures via an attached information sheet.

Table 1 below shows how CiH were involved throughout the research process from recruitment to dissemination.

Table 1. Partner roles during research.

	Carer participants	**CiH Staff participants**	**Stakeholder Participants**
Recruitment	CiH	CiH	CiH
Consent	Research Team	Research Team	Research Team
Data Collection	Research Team	Research Team	Research Team
Data Analysis	Research Team and CIH	Research Team and CiH	Research Team and CiH
Dissemination of findings	Research Team and CiH	Research Team and CiH	Research Team and CiH

Please note: The Research Team consists of members of the University staff (IQ, KJ, YP and JV).

2.3. The sample

There were two groups of participants through the of use purposive sampling.

Group 1—Users of the services

This group consisted of carers (caring for family members including parents, children and partners) who were using the programme and services and carers who were involved in the programme.

Group 2—Those who are involved in the provision

This group included the following:

- CiH Staff members
- Commissioners—people who commissioned CiH to provide support to carers
- Stakeholders/partners—people who had a professional interest in carer involvement
- CiH Trustees

The table below provides sample details. The sample was drawn to capture a range of stakeholders' perspectives. Carers as well as strategic, policy and operational leads across local services were interviewed.

2.4. Data gathering

The one-to-one interviews were conducted online using semi structured topic guides (please see Appendixs B–D), one for each group of participants (carers, CiH staff and professional stakeholders). These interviews explore the participants' experiences and views on what hinders or facilitates carers' involvement in the service from the perspectives of carers, those who provide the service, and those who have a professional interest in the service. The topic guides were developed based on the main themes that emerged from a review of the literature in the area and the aim and objectives of the research. The topic guides were reviewed by officers at CiH including the Policy and Engagement Manager, Involvement and Development Worker and the Head of Finance and Business Support in order to ensure that the subject matter was relevant to the initial aim of the research and that the language used was accessible for all potential participants. Recommendations made by CiH were included in the final version of the topic guides (Jagosh et al., 2015). The semi-structured interviews were recorded via online virtual meeting software.

2.5. Data analysis

The interviews were professionally transcribed and the research team used a thematic analysis approach to analyze the data (Braun and Clarke, 2006). Although often utilized, we acknowledge that thematic analysis has sometimes been used in different ways over time, and that we must as researchers be consistent in our approach to be effective in conducting and reporting thematic analysis (Braun and Clarke, 2023). This approach enabled a thematic, organisation of narratives, which allowed the research team to compare and contrast responses to questions across carers, CiH staff and professional stakeholders. The number of interviews was sufficient to generate adequate thematic depth relating to the research objectives (Nelson, 2017).

Initial familiarization with the data took place through discussion with IQ, KJ, YP and JV. Coding was carried out by IQ, capturing interesting features of the data across the entire data set. Following this, themes were conceptualized capturing a deductive approach, informed by the topics within the semi structured topic guides, as Braun and Clarke describe, this is when a theme coheres around a shared topic and can be identified early on in the analytic process (Braun and Clarke, 2023). However, as they point out this approach alone risks producing relatively 'thin' or unidimensional analysis. Therefore, alongside this approach a more inductive approach to generating codes describing participants' experience and views was also incorporated as they emerged.

Themes and sub-themes were also discussed with CiH and redefined until a consensus was achieved. Therefore, generation of these involved a collaborative, organic, and iterative process of developing codes and themes (Braun and Clarke, 2021). The processes involved in identifying the final themes included sustained engagement with the data, and a reflexive interpretation and interrogation of underlying or latent meaning (Nind, 2011). This point was reached after the research team felt no new themes were present and there was agreement on the identified themes. This was an interpretative judgment based on the researchers' familiarity with the data; processes of active reflexivity; knowledge of the relevant literature which informed the initial topic guides; cross checking with researcher notes all contextualized within the wider purpose of the analysis. These various elements helped strengthen the rigor and trustworthiness of the data (Johnson et al., 2020).

Relevant reflexivity involved the researchers considering how our backgrounds and lived experiences may influence generation and interpretation of data and themes. The research team included people from different ethnic backgrounds (South Asian, White European and White British). The team was made up of both male and female trained qualitative researchers. Their academic and professional backgrounds included public health, health organization policy, delivering counselling and therapy, as well as significant academic experience in evaluating care services. Because of these backgrounds, the researchers felt they had relevant experience and insight to the issues being explored (which were ultimately set by CiH as the community organisation), however we were alert to the importance of challenging assumptions made based on our experiences and we sought to seek not only similarities, but also divergences in opinions and interpretation of data.

3. Results

The results section is set out under five overarching themes which emerged from the analysis. These themes were: Benefits of Involvement; Disadvantages of Involvement; Enablers for Implementation; Barriers to Implementation and Recommendations. Each of the overarching themes had relevant sub-themes as below.

3.1. Theme one: Benefits of involvement

This theme was present across participant groups. Carer involvement in planning and development of the services that the person they were caring for was receiving was seen as beneficial in general, however specific sub-themes emerged relating to how involvement provided specific benefits for carers as well as for the service providers.

3.1.1. Benefits of involvement for carers

Participants identified a range of benefits of involvement for carers including carers themselves seeing it as an opportunity to connect with other carers and share their views and ideas:

> *"And what I'm finding the most useful thing about getting involved and attending the meetings is actually getting ideas from other people that I hadn't thought about or just simply a different point of view.*" (P1, carer).
>
> *"It kind of helps you make sense of your own difficulties. So I personally find it*

> *very rewarding. For me as well actually believing that we can make changes is very empowering.”* (P5, carer).

Staff and service providers also reported how involvement gave a platform for carers:

> *“You want them to feel more confident and that they count, because they’re going to forums where they can be listened to, and carers often feel undervalued and ignored.”* (P12, staff).

3.1.2. Benefits of involvement for services

Professionals were clear on the benefits for service planning and delivery:

> *“Carers are there from the beginning helping design services and you get better, more efficient services that meet the needs of people. And they’re efficient because they’re meeting needs, they’re less wasteful, not doing things that aren’t wanted or cause problems.”* (P12, staff).

> *“A lot of these stakeholders maybe haven’t got the experience of what it’s actually like to use service or haven’t worked with people with the conditions. So it’s really important that they hear what it’s like for people, and for their families and carers, and make them understand what it’s actually like on the ground when you’re in receipt of the services or living with that illness.”* (P17, staff).

3.2. Theme two: Disadvantages of involvement

Although, involvement was seen as beneficial in general, some participants identified certain disadvantages to engaging in involvement, and specific sub-themes emerged relating to how involvement caused specific disadvantages for carers as well as for the service providers.

3.2.1. Disadvantages of involvement for carers

Participants were alert to the potential disadvantages, such as feeling let down, if involvement was not genuine in that feedback was not provided to carers and/or changes weren’t possible as a result.

> *“I suppose if carers are involved and they’re not seeing any change then that could make them feel cross and disappointed.”* (P12, staff).

> *“I think about the carer, whether it’s lip service, whether their involvement is tokenistic, so you’ve been involved but you’re not really involved in anything.”* (P22, stakeholder).

3.2.2. Disadvantages of involvement for services

Service providers as well as carers were keen to stress the problem of carers sometimes providing a very subjective, individual perspective to wider problems. This was not always seen as helpful:

> *“They (carers) get involved because they’re angry and they’ve seen something that’s wrong... and they’re really coming in because it’s about their own issue and then not having that breadth of vision about perhaps the whole group and therefore not very representative.”* (P12, staff).

> *“Sometimes when people are passionate and they’ve had a negative experience, it can sometimes backfire, because if they actually harangue the services too much they’re going to not listen; whereas, it’s being able to do it in an*

> *appreciative way, in a constructive way."* (P5, carer).

3.3. Theme three: Enablers for implementation

A number of enablers were identified by participants which, in their view, helped good carer involvement. These enablers ranged in scope and impact. However, they could be categorized under the sub-themes of internal enablers (things that helped involvement from within CiH as an organization) and external enablers (things that helped involvement from within the wider commissioning and service provision landscape).

3.3.1. Internal enablers for implementation

There were some methods of communication, (such as the Carewaves newsletter and the website) which seemed universally appreciated by carers, in multiple media formats:

> *"I get a hard copy (Carewaves)... I'm not a convert to eBooks or e-anything like that, so I like to have the paper in my hands that I can turn the pages and read it and put it to one side and then pick it up again later."* (P2, carer).
>
> *"Carewaves comes as an email now. So I can look at that, yeah. And there's always quite nice information or stories from other carers in there, which is quite nice."* (P3, carer).
>
> *"Their website is really useful as well, it's really handy, I can just quickly click on and get an update of what's happening."* (P19, stakeholder).

The fact that CiH has such good relationships with both carers and service providers emerged as a clear finding within the research. This could also be seen as a potential enabler for good involvement:

> *"They built up into different areas and they collected lots of links. And I think (member of CiH staff) is really respected, has probably a unique ... knows those networks. (They are) really plugged into those networks."* (P12, staff).
>
> *"That's why they're a fantastic partner because I do think they work for co-production, to co-produce, to create all of these new streams of work with carers at the heart of it."* (P20, stakeholder).
>
> *"I link in with (CiH staff member X) regularly. If I contact (CiH staff member Y), you know, if she's not available we will be able to catch up for whatever reason it is. (CiH member of staff member Z) I work a lot with, with the Project Manager for the (service A), and she is, they're all very open and flexible."* (P19, stakeholder).

3.3.2. External enablers for implementation

A number of stakeholders reported how CiH was held in high regard, this could be seen as conducive to engaging agencies in the wider services landscape in involvement activities with carers:

> *"They are a fantastic organisation. A fantastic voluntary organization that we have here in Hertfordshire and they're the go to for carers, you know, for carer services, carer support."* (P20, stakeholder).
>
> *"I would just want to reiterate again how Carers in Herts and their input into the autism review was an absolutely critical part of its success."* (P23, stakeholder).

Participants across the sample group reported what they felt were good examples of involvement that they had been part of. These examples included the development of a dual diagnosis pathway for those with mental health needs and substance misuse needs as well as the development of a dementia strategy.

These examples of good involvement shared certain aspects which participants all commented on. One such aspect was involving carers throughout the processes of development and implementation of services:

> *"I would say how Carers in Herts work is from sort of the inception to conclusion. Carers are involved throughout. So from the very initial ideas, you know, we'll seek feedback on ideas. There'll be ideas from carers themselves and what they need, it's very carer-led, and that's what we'll take and create new services on behalf of that. And then we'll conclude and keep carers involved throughout so that it does actually meet their needs or is actually serving a purpose."* (P20, stakeholder).
>
> *"Oh yeah, we wrote a whole new protocol. We researched it really well. We researched it with the NICE guidelines, with the Department of Health guidelines, the Royal College of Psychiatrists guidelines, everything, and we all made our comments."* (P11, carer).
>
> *"We were supported from the initial idea, something needs to be done about service, through to actually being proactive and writing a research evidence report, through to presenting it, through to actually getting it onto the policy agenda, and then through to actually…. to seeing the change accepted."* (P5, carer).

3.4. Theme four: Barriers to implementation

Alongside enablers, participants also identified barriers which, in their view, hindered good carer involvement. These could also be categorized under internal and external as outlined below.

3.4.1. Internal barriers to implementation

There were reported barriers that related specifically to carers and their capacity to take part in involvement exercises:

> *"The only difficulty obviously with that is it's important to identify carers that are able to take the time from their caring role and to try and work around it to ensure that the meetings where possible will fit with the time perhaps that that carer might have available."* (P12, staff).
>
> *"There was a downside to it. It was an enormous amount of work, and the people who did it, the carers who did it were totally invested in it."* (P5, carer).
>
> *"Sometimes it does feel a little bit too much like work."* (P6, carer).

Some participants reported the perceived lack of diversity in carer representatives as a barrier for good involvement:

> *"I suppose some people would say that's the, you're just relying on a small group of people, pool of people and it's not diverse enough."* (P12, staff).
>
> *"Comments from the head of (x) services at the county council led me to believe that he thought that it was the usual suspects turning up."* (P14, staff).
>
> *"So the carers that I do see at boards, I've quite often seen them before in other settings. So I don't know how well we are doing at reaching out to a very broad*

> *base of carers in terms of carer involvement."* (P21, stakeholder).

3.4.2. External barriers to implementation

Some participants felt that they were not given the opportunity to genuinely contribute in meetings that were purportedly involvement opportunities. This reflected a reported 'tick box' approach to involvement on the part of some service providers:

> *"And I really felt that when I was in those meetings that these people were just here to give a good presentation and I would say that only one of them seemed to show that he really cared about what these carers were saying and ask questions; whereas others just did their presentation, they've done their bit in the meeting and now is the bit where the carers talk and we go oh yeah interesting, oh thank you very much for that*." (P1, carer).
>
> *"I don't feel that I have a productive role in terms of the local authority's co-production boards. I feel that that is actually a waste of my time, because I feel that they are just, it's lip service. There's still a lot of information items on those agendas that they don't bring something, that they should be bringing things to the co-production board and saying how they want our input. You know, we need to make some decisions in relation to this. But what they do they give us things for comment*." (P14, staff).

There were also more global barriers to implementation, such as a clear, shared definition of what involvement actually was or how to measure it:

> *"When you say involvement, I'm not sure whether you're specifically meaning."* (P1, carer).
>
> *"Yeah, I'm not entirely sure what the involvement is so, yeah, maybe I know it but I'm not aware of it. I don't know."* (P3, carer).
>
> *"For carers to have influence and a say in that as part of a generalised co-productive way of working, I think that's what carers involvement might be about. I hope I'm in the right sort of territory."* (P21, stakeholder).
>
> *"I guess it depends on what you mean by involved."* (P2, carer).
>
> *"I think it's very difficult to measure co-production."* (P14, staff).

3.5. Theme five: Recommendations

When exploring potential ways of working for the future, participants suggested a number of recommendations. This presented itself as the fifth and final theme, which in turn presented the sub-themes of internal recommendations (things which could help involvement from within CiH as an organisation) and external recommendations (things which could help involvement from within the wider commissioning and service provision landscape).

3.5.1. Internal recommendations

There were a number of participant recommendations for possible ways of working. Each of these recommendations is related to a perceived problem. **Table 2** below demonstrates some of these problems and solutions, relevant to internal workings of CiH:

Table 2. Recommendations relevant to internal organization at CiH.

Perceived Problem	**Proposed Solution**	**Participant Reference**
Lack of capacity/communications across teams/organisation in CiH	*So the (carer) passport really is an information gain ... So that allows the other teams to access that information.*	P13, staff
	CSAs needed a bit more training about what involvement actually means and it might be perhaps for some of them to have some sort of short script to follow	P18, staff
	There's one communications and marketing officer.... but I suspect in order to really achieve we've all got to get better at it across the board so that we know what to ask for. Even if it's other specific officers doing the work, we need to have a much better picture of how to do it and how to use social media	P14, staff
	But it would be nice to have a base, a few bases in the county where we could come together.	P14, staff
	Carers in Hertfordshire has (could have) an events team that organizes the general events. You know, whatever is happening so then the involvement team can focus on the actual detail of what the meeting's about so that they can organize the carers' responses and listen to them more fully in that way	P15, staff
Lack of diversity in carer representation	*I mean on the ethnic minority diversity side ... I think that it might be good to do some targeted events*	P14, staff
	You've got to find a way of bringing people in. I wonder whether having single issues is easier.	P12, staff
	So it starts from these hub meetings that some people need to be accountable for picking up specific ideas and asking people if actually they would be interested in finding out more about	P1, carer
	You might say OK this quarter we're going to concentrate on this issue. And you go out to local BAME groups and say would you like to join in this discussion? That might be a way to do it and sort of build up to a focal point like…	P12, staff
	In Hertfordshire ... we lack diverse integration. And Hertfordshire's a little bit diverse you know. And they're the individuals that we need to access through our support. And so that could be a focus of Carers in Hertfordshire too, which they're working on.	P20, stakeholder
	So I've always moved me, before COVID, obviously, moved my meetings around the county. I've always travelled. Every year the meetings have been in different places throughout the county.	P17, staff

3.5.2. External recommendations

Similarly, **Table 3** below demonstrates some of these problems and solutions, relevant to policy and practice external to CiH as an organisation but relevant to the wider service landscape:

Table 3. Recommendations relevant to policy and practice external to CiH.

Perceived Problem	**Proposed Solution**	**Participant Reference**
Lack of shared definition of involvement	*People's understanding of co-production, what co-production is and what it isn't can be a barrier. And then again people's understanding of involvement, what it is and what it isn't, when you should and when you shouldn't be involving people is another issue as well.*	P22, stakeholder
Carer capacity to take part in involvement exercises	*I suppose maybe if money was no object, give people paid leave to go to relevant meetings like that that might get more people.*	P2, carer
	I'd like to alleviate some of their caring roles, so maybe be able to pay for care so some of them could come and actually work with us,	P14, staff
	So task and finish groups that they've got a particular interest in, or have a group of carers that might attend the board and then whoever happens to be free they can attend rather than it be a big commitment on these carers	P17, staff

4. Discussion

Our research adds to the qualitative evidence base which can help improve service improvement and delivery of caring (Ziebland and Hunt, 2014). We know that caring responsibilities can have a detrimental impact on the health outcomes for carers and this needs to be countered strategically by the services they use (Public Health England, 2021).

Our findings align with the existing literature including the added pressures that carers face including, negative impacts and changing aspects for carers' social needs and social wellbeing. Utilizing an involvement service can help carers feel more connected to others in similar circumstances, therefore helping to counter a sense of social isolation. Helping to develop policy and practice gave a sense of empowerment and satisfaction for some participants, engaging with local services counters the known social exclusion noted in the evidence base. This engagement with services and co-production of services can be seen as an enabling of social participation, which is mentioned in the literature as often missing for carers (Hill and Broady, 2019).

Furthermore, although some participants felt that their contributions in service development were 'tick box' exercises our findings provide some positive reports of other participants feeling valued and making a difference when being involved in service planning and development. This is significant as previous studies have noted the negative impact of carers not being able to be involved, "*They (carers), find it crucial to be involved when health professionals are shaping and processing the care for their next of kin, but their struggle to achieve involvement may end up in their feeling powerlessness*" (Weimand et al., 2011). This feeling of powerlessness is a considerable negative outcome alongside feeling excluded and wanting cooperation with services. Having an effective involvement service for carers is an important strategy in guarding against these previously mentioned negative outcomes for carers.

Our findings can help inform those services for the benefit of carers. Critically, our findings have emerged from a co-designed and co-produced piece of research which placed the community-based carers organisation as equal partners in the whole research process. The methods utilized in this research were specifically adopted as they aligned with the project outcomes as envisaged by the community-based organisation. Therefore, our research provides novel carer and stakeholder views on a range of benefits of involvement for carers. Benefits included carers seeing involvement as an opportunity to connect with other carers and share their views and ideas. Staff and service providers also reported how involvement gave a platform for carers and was of value in helping them shape needs-led services.

There are some internal and external barriers to good involvement that have been identified, including the lack of a clearly understood shared definition of involvement as well as the lack of a diverse pool of carer representatives available for involvement activities. This lack of diversity needs to addressed to develop cultural competence in public services, including mental health and social care provision (Bhui et al., 2007; Gilligan and Akhtar, 2006). The results of our research are being drafted into a report for CiH and an easy read version of that document will be available for all carers involved with the service. The next steps section suggests some ways in which similar organisations may wish to build on the identified enablers and counter some of the barriers to good carer involvement. The recommendations within the section can be built upon, amended, or adopted for future clinical practice, health education, public health policy and related research.

5. Conclusions and recommendations

Our research approach demonstrates genuine co-design and co-production with the community-based organisation, The attached Community Policy Brief sets out the detail and adds to the value of this project for the community stakeholders. This is at the heart of our approach and suggested next steps. Therefore, we suggest community-based carer services and researchers should consider:

- Commissioning research on the individual barriers and enablers for good involvement in their particular service.
- Carrying out a specific communications exercise with carers, staff and stakeholders on producing and utilizing a shared definition of involvement.
- Investigating their evidence base and if appropriate identifying strategies for addressing lack of diversity in carer representation.
- Researching the wider financial implications of their organisation’s involvement work – to demonstrate value for money for service commissioners.
- Disseminating the various benefits of involvement activities as identified in this research to carers, stakeholders and commissioners.
- Using relevant research for developing a tool for evaluating individual pieces of involvement work.
- Producing good practice guidelines based on case studies of good involvement work as identified in this research.

Author contributions: Conceptualization, JV and RM; methodology, IQ, JV and YP; validation, YP and KJ; formal analysis, IQ; investigation, IQ; data curation IQ; writing—original draft preparation, IQ; writing—review and editing, IQ, JV, YP, RM, TN and KJ; funding acquisition, JV. All authors have read and agreed to the published version of the manuscript.

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Availability of data and materials: The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Limitations: We faced specific challenges during the course of conducting this study. These included being unable to access all of the participants that showed initial interest in the research. Carers, by nature of the role, often have multiple responsibilities and busy schedules. Managing to arrange times for interviews and then participants being available on the scheduled dates was a challenge. We acknowledge that the research aim and objectives were driven by CiH as the community organisation and as such there may have been limited researcher reflexivity in considering devising study aim and objectives and consequent data analysis. Alongside this, the bespoke arrangements put in place for this research in collaboration with the community organisation may make it challenging for other organisations to completely replicate the study.

Conflict of interest: The authors declare no conflict of interest.

Abbreviations

UK	United Kingdom
CIH	Carers in Hertfordshire
OU	Open University
UOB	University of Bedfordshire

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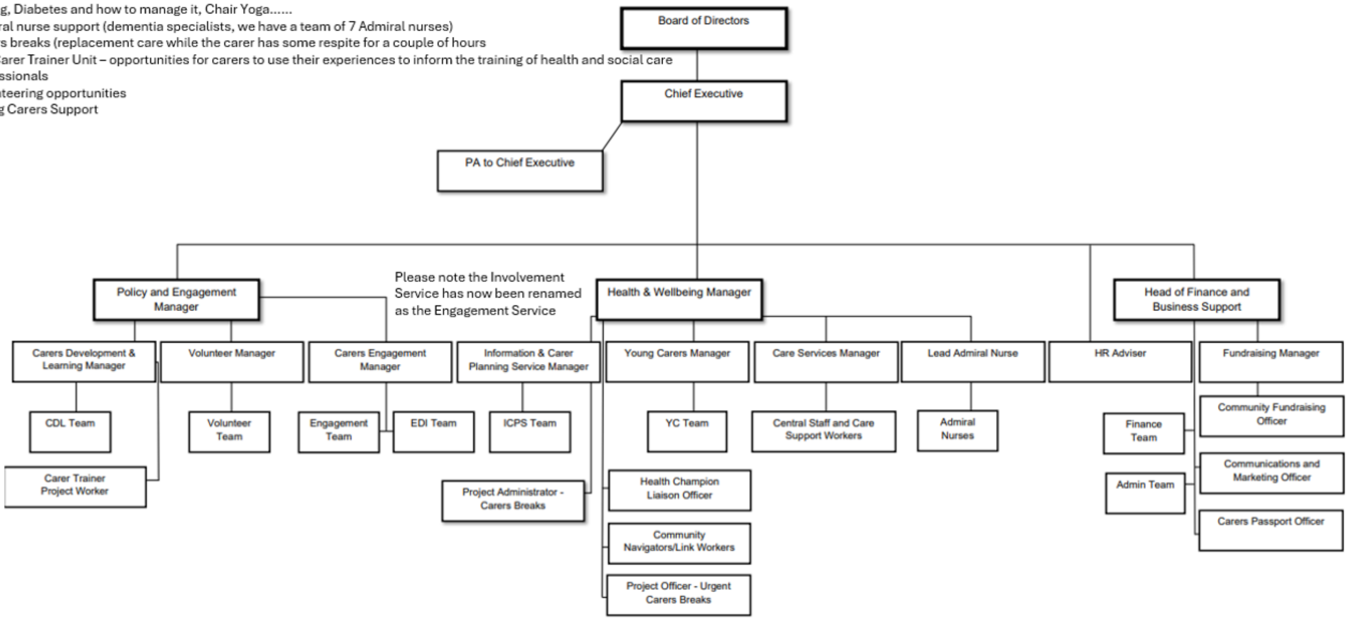
Appendix A

CiH Organizational Chart

CiH offers:
A Carers Passport or Discount card
1:1 Information, Advice and Support
16 face-to-face Carer Support groups; 3 online groups (Evening, Morning and Men's Group)
Peer Mentoring
Making a Difference grants (small grants related to addressing/improving health issues)
GP Liaison work
Workshops and courses (online and face to face) ranging from: Introduction to Mindfulness, Resilience building, creative writing, Diabetes and how to manage it, Chair Yoga……
Admiral nurse support (dementia specialists, we have a team of 7 Admiral nurses)
Carers breaks (replacement care while the carer has some respite for a couple of hours
The Carer Trainer Unit – opportunities for carers to use their experiences to inform the training of health and social care professionals
Volunteering opportunities
Young Carers Support



Please note the Involvement Service has now been renamed as the Engagement Service

Appendix B

Topic guide for CiH staff

Carers in Hertfordshire—Involvement Services Evaluation

Topic Guide (For staff)

HREC/4081/Vseteckova

Research Aim:

To gather evidence for the continuous improvement of the Carers in Hertfordshire involvement services and support the organization's agenda for commissioning, learning and participation.

Research Objectives:

1) To map the existing service and communication practices
2) To understand the factors that facilitate and hinder carers' involvement with the programme from the carers' perspective
3) To understand the factors that facilitate and hinder carers' involvement with the programme from the professionals' perspective
4) To explore the experience and views of carers and professionals with regard to current vs ideal practice, if such distinction is found.

Introduction

- Thanks.
- Introduce self, explain role as researcher/Carers in Hertfordshire (CiH) staff
- Give background to the study: Explain that this study has been funded by the CiH and The Open University (working with the University of Bedfordshire in order to help evaluate the involvement aspect of carers in CiH.
- Explain I would like to understand your experiences and views on:
  - ➢ existing service and communication practices
  - ➢ factors that facilitate and hinder carers' involvement with the programme
  - ➢ current vs ideal practice
- Explain that the research team will also be talking to carers and CiH staff
- Brief outline of the interview: It is structured so that I will ask you about a number of issues including:
  - ➢ Your role in relation to CiH and its involvement service
  - ➢ Your understanding of how CiH ensures carers' involvement
  - ➢ What you think CiH (and/or the wider system does that enables better carers' involvement)
  - ➢ What you think CiH (and/or the wider system does that prevents better carers' involvement)
  - ➢ What practices/processes/structures you think could be put into place to better help carers' involvement going forward.
- Explain about the consent procedure, emphasise confidentiality, and tape recording the discussion, length of discussion (approx 45 minutes).
- The information from the research study will be written up as part of a report and subsequent academic/policy publications and findings will inform recommendations.

- Ask if they would like you to come back and tell them about what the research found.
- Any questions about the research study or the interview before we start?

Note: This discussion needs to relate to objectives 1, 3 and 4 of the research. As such the questions are colour coded respectively; red, yellow and green.

START QUESTIONS

1. Your role in relation to CiH and its involvement service

I would like to start our discussion by asking about your role

- Please state your official capacity in relation to CiH?
  - ➢ explore what role they hold, job title, level of seniority, where they fit into the organizational structure
  - ➢ get them to explain about their overall role (function/purpose/remit/scope)
- Please explain how you contribute to carers' involvement with CiH?
  - ➢ explore how they support carers' involvement with CiH or more globally

2. Your understanding of how CiH ensures carers' involvement

- What is your understanding of how CiH ensures carers' involvement in services?
  - ➢ explore what they know about CiH carers' involvement (practice, processes, policies, governance infrastructure etc)
- What informs your opinion about how CiH ensures carers' involvement?
  - ➢ explore who tells them about the involvement of carers in service planning, implementation and review
  - ➢ explore what methods/media/forums are used to inform them of this information (to what extent are online methods used? How comfortable are they with these?)

3. What works? What you think CiH (and/or the wider system does that enables better carers' involvement)

I would now like to continue our discussion by asking about your views on what works currently

- In your view what are the key things that are currently in place that help carers' involvement
  - ➢ explore key practices, processes, policies, governance infrastructures, people that help better carers' involvement
  - ➢ explore these within CiH
  - ➢ explore these in relation to their role
  - ➢ explore these in relation to the wider commissioning/planning/service delivery landscape
  - ➢ explore reasoning why they suggest what they do

4. What doesn't work? What you think CiH (and/or the wider system does that prevents better carers' involvement)

I would now like to continue our discussion by asking about your views on what doesn't work currently

- In your view what are the key things that are currently in place that prevent carers' involvement
  - ➢ explore key practices, processes, policies, governance infrastructures, people that act as barriers to better carers' involvement
  - ➢ explore these within CiH
  - ➢ explore these in relation to their role
  - ➢ explore these in the wider commissioning/planning/service delivery landscape
  - ➢ explore reasoning why they suggest what they do

5. How should we proceed? What practices/processes/structures you think could be put into place to better help carers' involvement going forward.

I would now like us what you think could/should be done to improve the current situation

- What would you suggest as recommendations for the future?
  - ➢ explore for how their suggestions relate to current practice, policy, processes, governance infrastructures, etc
- Who should be responsible for these changes?

  - explore for who is best positioned to implement their suggested changes (CiH staff, trustees, commissioners, others?)
- Are there any other factors not already mentioned?
  - explore ideas that do not relate to the status quo
  - encourage innovative thinking (if money was no object? if we could wave a magic wand? what does ideal look like for them in their role? Etc)

6. Closing

I would like to bring the discussion to an end now by summarizing your recommendations and giving you an opportunity for any final comments

- Summary of suggestions/recommendations.

***Thank participant for their contribution, stress confidentiality.**

Appendix C

Topic guide for stakeholders

Carers in Hertfordshire—Involvement Services Evaluation

Topic Guide (For stakeholders including trustees and commissioners)

HREC/4081/Vseteckova

Research Aim:

To gather evidence for the continuous improvement of the Carers in Hertfordshire involvement services and support the organization's agenda for commissioning, learning and participation

Research Objectives:

1) To map the existing service and communication practices
2) To understand the factors that facilitate and hinder carers' involvement with the programme from the carers' perspective
3) To understand the factors that facilitate and hinder carers' involvement with the programme from the professionals' perspective
4) To explore the experience and views of carers and professionals with regard to current vs ideal practice, if such distinction is found.

Introduction

- Thanks.
- Introduce self, explain role as researcher/Carers in Hertfordshire (CiH) staff
- Give background to the study: Explain that this study has been funded by the CiH and The Open University (working with the University of Bedfordshire in order to help evaluate the involvement aspect of carers in CiH.
- Explain I would like to understand your experiences and views on:
    - existing service and communication practices
    - factors that facilitate and hinder carers' involvement with the programme
    - current vs ideal practice
- Explain that the research team will also be talking to carers and CiH staff
- Brief outline of the interview: It is structured so that I will ask you about a number of issues including:
    - Your role in relation to CiH and its involvement service
    - Your understanding of how CiH ensures carers' involvement
    - What you think CiH (and/or the wider system does that enables better carers' involvement)
    - What you think CiH (and/or the wider system does that prevents better carers' involvement)
    - What practices/processes/structures you think could be put into place to better help carers' involvement going forward.
- Explain about the consent procedure, emphasize confidentiality, and tape recording the discussion, length of discussion (approx 45 minutes).
- The information from the research study will be written up as part of a report and subsequent academic/policy publications and findings will inform recommendations.
- Ask if they would like you to come back and tell them about what the research found.

- Any questions about the research study or the interview before we start?

Note: This discussion needs to relate to objectives 1, 3 and 4 of the research. As such the questions are colour coded respectively; red, yellow and green.

START QUESTIONS

1. Your role in relation to CiH and its involvement service

I would like to start our discussion by asking about your role

- Please state your official capacity in relation to CiH?
    - ➢ explore whether trustee, commissioner, other role
    - ➢ get them to explain about their overall role (function/purpose/remit/scope)
- Please explain how you contribute to carers' involvement with CiH?
    - ➢ explore how they support carers' involvement with CiH or more globally

2. Your understanding of how CiH ensures carers' involvement

- What is your understanding of how CiH ensures carers' involvement in services?
    - ➢ explore what they know about CiH carers' involvement (practice, processes, policies, governance infrastructure etc)
- What informs your opinion about how CiH ensures carers' involvement?
    - ➢ explore who tells them about the involvement of carers in service planning, implementation and review
    - ➢ explore what methods/media are used to inform them of this information (to what extent are online methods used? How comfortable are they with these?)

3. What works? What you think CiH (and/or the wider system does that enables better carers' involvement)

I would now like to continue our discussion by asking about your views on what works currently

- In your view what are the key things that are currently in place that help carers' involvement
    - ➢ explore key practices, processes, policies, governance infrastructures, people that help better carers' involvement
    - ➢ explore these within CiH
    - ➢ explore these in the wider commissioning/planning/service delivery landscape
    - ➢ explore reasoning why they suggest what they do

4. What doesn't work? What you think CiH (and/or the wider system does that prevents better carers' involvement)

I would now like to continue our discussion by asking about your views on what doesn't work currently

- In your view what are the key things that are currently in place that prevent carers' involvement
    - ➢ explore key practices, processes, policies, governance infrastructures, people that act as barriers to better carers' involvement
    - ➢ explore these within CiH
    - ➢ explore these in the wider commissioning/planning/service delivery landscape
    - ➢ explore reasoning why they suggest what they do

5. How should we proceed? What practices/processes/structures you think could be put into place to better help carers' involvement going forward.

I would now like us what you think could/should be done to improve the current situation

- What would you suggest as recommendations for the future ?
    - ➢ explore for how their suggestions relate to current practice, policy, processes, governance infrastructures, etc
- Who should be responsible for these changes?
    - ➢ explore for who is best positioned to implement their suggested changes (CiH staff, trustees, commissioners, others?)
- Are there any other factors not already mentioned?

- explore ideas that do not relate to the status quo
- encourage innovative thinking (if money was no object? if we could wave a magic wand? what does ideal look like? etc)

6. Closing

I would like to bring the discussion to an end now by summarizing your recommendations and giving you an opportunity for any final comments

- Summary of suggestions/recommendations.

***Thank participant for their contribution, stress confidentiality.**

Appendix D

Topic guide for carers

Carers in Hertfordshire—Involvement Services Evaluation

Topic Guide (For carers)

HREC/4081/Vseteckova

Research Aim:

To gather evidence for the continuous improvement of the Carers in Hertfordshire involvement services and support the organization's agenda for commissioning, learning and participation.

Research Objectives:

1) To map the existing service and communication practices
2) To understand the factors that facilitate and hinder carers' involvement with the programmer from the carers' perspective
3) To understand the factors that facilitate and hinder carers' involvement with the programmer from the professionals' perspective
4) To explore the experience and views of carers and professionals with regard to current vs ideal practice, if such distinction is found.

Introduction

- Thanks.
- Introduce self, explain role as researcher/Carers in Hertfordshire (CiH) staff
- Give background to the study: Explain that this study has been funded by the CiH and The Open University (working with the University of Bedfordshire in order to help evaluate the involvement aspect of carers in CiH.
- Explain I would like to understand your experiences and views on:
    - ➢ existing service and communication practices
    - ➢ factors that facilitate and hinder carers' involvement with the programme
    - ➢ current vs ideal practice
- Explain that the research team will also be talking to carers and CiH staff
- Brief outline of the interview: It is structured so that I will ask you about a number of issues including:
    - ➢ Your role in relation to CiH and its involvement service
    - ➢ Your understanding of how CiH ensures carers' involvement
    - ➢ What you think CiH (and/or the wider system does that enables better carers' involvement)
    - ➢ What you think CiH (and/or the wider system does that prevents better carers' involvement)
    - ➢ What practices/processes/structures you think could be put into place to better help carers' involvement going forward.
- Explain about the consent procedure, emphasise confidentiality, and tape recording the discussion, length of discussion (approx 45 minutes).
- The information from the research study will be written up as part of a report and subsequent academic/policy publications and findings will inform recommendations.

- Ask if they would like you to come back and tell them about what the research found.
- Any questions about the research study or the interview before we start?

Note: This discussion needs to relate to objectives 1, 2 and 4 of the research. As such the questions are color coded respectively; red, yellow and green.

START QUESTIONS

1. Your role in relation to CiH and its involvement service

I would like to start our discussion by asking about your role as a carer

- Please explain how and why you came into contact with CiH?
  - ➢ explore who they care for and how
  - ➢ explore whether they reached out to CiH or the other way round, how was first contact made?
- Please explain how you contribute to carers' involvement with CiH?
  - ➢ explore how they support carers' involvement with CiH or more globally

2. Your understanding of how CiH ensures carers' involvement

- What is your understanding of how CiH ensures carers' involvement in services?
  - ➢ explore what they know about CiH carers' involvement (practice, processes, policies, governance infrastructure etc)
- What informs your opinion about how CiH ensures carers' involvement?
  - ➢ explore who tells them about the involvement of carers in service planning, implementation and review
  - ➢ explore what methods/media are used to inform them of this information (to what extent are online methods used? Are they comfortable using these?)

3. What works? What you think CiH (and/or the wider system does that enables better carers' involvement)

I would now like to continue our discussion by asking about your views on what works currently

- In your view what are the key things that are currently in place that help carers' involvement
  - ➢ explore key practices, processes, policies, governance infrastructures, people that help better carers' involvement
  - ➢ explore these within CiH
  - ➢ explore these in the wider set of services the carer uses
  - ➢ explore reasoning why they suggest what they do

4. What doesn't work? What you think CiH (and/or the wider system does that prevents better carers' involvement)

I would now like to continue our discussion by asking about your views on what doesn't work currently

- In your view what are the key things that are currently in place that prevent carers' involvement
  - ➢ explore key practices, processes, policies, governance infrastructures, people that act as barriers to better carers' involvement
  - ➢ explore these within CiH
  - ➢ explore these in the wider set of services the carer uses
  - ➢ explore reasoning why they suggest what they do

5. How should we proceed? What practices/processes/structures you think could be put into place to better help carers' involvement going forward.

I would now like us what you think could/should be done to improve the current situation

- What would you suggest as recommendations for the future?
  - ➢ explore for how their suggestions relate to current practice, policy, processes, governance infrastructures, etc
- Who should be responsible for these changes?
  - ➢ explore for who is best positioned to implement their suggested changes (CiH staff, trustees, commissioners, others?)

- Are there any other factors not already mentioned?
    - explore ideas that do not relate to the status quo
    - encourage innovative thinking (if money was no object? if we could wave a magic wand? what does ideal look like for them? Etc)

6. Closing

I would like to bring the discussion to an end now by summarizing your recommendations and giving you an opportunity for any final comments

- Summary of suggestions/recommendations.

***Thank participant for their contribution, stress confidentiality.**