



An Inquiry into the Challenge of Care at Home Autumn 2018, Greater Manchester

“What would it take to help people to have a good life at home for as long as they choose?”



Acknowledgements

Thanks go to the members of the Challenge into Care at Home Inquiry, who placed their trust in the process and us as facilitators. This inspiring group of people came together week after week to share their opinions and experiences with each other and us in the hope that their efforts, openness and commitment might make a difference to those needing Care at Home services.

We wish to acknowledge funding and support from the Jam and Justice Action Research Collective, and thank our Reference Group and the numerous committed professionals who helped us shape this innovative project.

About the authors

The recommendations produced by the members of the Inquiry are reproduced in their own words. The remaining content was written by Jez Hall and Amanda Preece, with support from Jayne McFadyen and Katie Finney. No legal responsibility can be accepted for any loss or damage resultant from the contents of this document. It does not necessarily represent the view of Shared Future in relation to particular policy or projects.

About Shared Future

We are a community interest company primarily serving the North West of England, and with associates based across the UK. Our aim is to provide an excellent service that makes a difference to communities and individuals and works towards a fairer, more equal society.

Through our commitment to creating a fairer and more sustainable world, we decided to set up Shared Future in 2009. We've built a team of experienced consultants and practitioners with a diverse range of skills. We work together on worthwhile and stimulating projects that reflect our personal values.



www.sharedfuturecic.org.uk

December 2018



This work is licensed under a Creative Commons Attribution-NonCommercial-ShareAlike 4.0 International License.

Contents

Summary.....	4
Introduction.....	5
What we mean by an inverted Citizens’ Inquiry...6	
Unique features of this inquiry.....	6
Why in Greater Manchester?.....	6
What is Jam and Justice?.....	7
Why the focus on Care at Home?.....	7
The Project Delivery group.....	8
The Reference Group.....	8
Preparing for the Inquiry.....	9
Process.....	9
Recruitment.....	9
The Inquiry Sessions.....	11
Sharing experiences:	
Sessions one and two.....	11
Deliberation in action:	
Commentator sessions 3-5.....	13
What Participants learnt by taking part.....	15
Agreeing Recommendations:	
Sessions 5 and 6.....	16
Recommendations for Care at Home.....	18
What Happened Next.....	21
Appendix 1: Commentators’ Questions.....	23
Appendix 2: Launch Event Attendees.....	24
Appendix 3: Researching a new model for Professional-led Citizens’ Inquiries:.....	25



Summary

Between September and October 2018, thirteen participants, all working within or supporting Care at Home services, were invited to take part in sessions of intense deliberation to co-produce a set of recommendations that attempted to answer this question:

“What would it take to help people to have a good life at home for as long as they choose?”

In our highly participatory process members of the Inquiry shared their experiences, heard from expert commentators with lived experience of Care at Home services, and then produced a set of compelling recommendations; including reasons why they mattered or the benefits that would flow from adopting them within the delivery of Care at Home.

After the six Inquiry sessions, Shared Future hosted a launch event at the Manchester Mechanics Institute on 12th December 2018, at which the group’s recommendations were shared and discussed with invited local stakeholders. Members of the Inquiry, commissioners, care providers and stakeholders of all kinds took part.

This report summarises the process, lists the group’s recommendations, and describes what happened at the stakeholder event held in December 2018.

Twelve compelling recommendations for improving Care at Home appear on pages 18 to 20.

Introduction

The Care at Home Inquiry brought together a group of passionate and committed individuals to discuss the main things that affect people's health and wellbeing, and what can be done to improve their situation. Especially when:

- They are elderly
- They actively require care or medical support to enable them to continue to live at home.

It used the model of a Citizens' Inquiry, an example of a mini public, in which a diverse group of people are given the opportunity to share opinions and experiences with each other and to hear and question testimonies from others before producing a set of recommendations. This sort of inquiry process is sometimes known as a "Citizens' Jury".

Mini publics have been organised across the world on a variety of topics; some at a local or neighbourhood level, some at a regional level and on occasion at a national or on an international

scale. In 2017 Shared Future CIC wrote a literature review describing the key features of a Citizens' Inquiry, and this can be downloaded from our website: <https://sharedfuturecic.org.uk/literature-review-citizen-led-deliberation-processes/>

Deliberative processes such as Citizens' Inquiries have been praised for their ability to allow lay citizens to question the "expertise" of others, appreciate the knowledge and opinions of others and after intense deliberation to produce agreed conclusions which are for the public good.

This Inquiry was different to the standard model described above, and had two overarching aims.

- **To research whether a new model of an "inverted" Citizens' Inquiry was possible;**
- **To develop recommendations to improve Care at Home services to elderly people.**

Co-producing a new model of Care at Home.

Home care (also referred to as domiciliary care, social care, or in-home care) is supportive care provided in a person's home. It may be provided by healthcare professionals who provide medical treatment or by professional caregivers who provide assistance to ensure activities of daily living are met (such as washing, eating, etc.).

It may also be provided by friends, family or partners, or by organisations working outside formal social care structures. Part of the aim of this Citizens' Inquiry is to attempt to encourage a move from a largely medical model, which encourages services which respond to people's health and focuses on diagnosis and treatment, towards one which recognises the social and other determinants of health and wellbeing.

We favour this wider "social model" of care at home. This includes matters such as good housing; emotional well-being and supportive relationships; a sense of community; building self-respect; being heard and even, simply, having fun.

In order to achieve this wider model of "Living Well at Home", it is essential to enable citizens and stakeholders, such as social care providers and the NHS, to work closely together. To co-produce care at home. That requires they jointly examine the realities around care at home (such as what is working and what is not) and together chart a better course forward.

What we mean by an inverted Citizens' Inquiry:

The first difference from a standard Citizens' Inquiry was:

- **The participants were recruited as self declared "professionals".**

That is, in some capacity they were currently working within or had a professional interest in, the Care at Home sector. Therefore, they were not what can sometimes be termed 'lay' citizens.

Further, and again extending the model:

- **The commentators or witnesses were largely those with direct lived experience.**

That is, they had experience of care at home themselves, were a family member or friend helping to arrange care, or worked closely with receivers of care.

Why do I want to take part?

"Something needs to change now within social housing for the elderly for the better as it's getting increasingly worse. We need to end isolation." (Inquiry participant)

Unique features of this inquiry

These differences meant we had not one, but two outcomes in mind. Firstly to:

Research and innovate a different format for a Citizens' Inquiry.

One that was 'inverted', with professionals making up the primary participants, rather than lay citizens. However, like a standard Citizens' Inquiry we made



sure that they came from diverse backgrounds, bringing different skill sets, seniority and experience.

We wanted to test if this format, using a deeply deliberative process, could release fresh insights. By intentionally blurring the boundaries between professional roles and personal roles might we be able to release or at least enable a more emotional, holistic and empathetic response among professionals?

Secondly, we wanted to:

Produce robust and practical recommendations, which placed consideration of the 'individual' at the centre of the process and placed the 'system' second.

We wanted to influence how Care at Home services were conceived. We aimed to present those recommendations to other professionals, thereby influencing the unique situation brought about by devolution within Greater Manchester; combining, within one commissioning structure, both Health and Social Care budgets.

Why Greater Manchester?

The process of devolution in Greater Manchester presents the opportunity to re-design services to bring together the capacities of Local Authorities, the NHS and their partners within an integrated

commissioning framework. During the Inquiry, Shared Future engaged with the Greater Manchester Health and Social Care Partnership's "Living Well At Home" delivery group (formerly known as the 2020 delivery group), which was itself going through its own service re-design process.

What is Jam and Justice?

Jam and Justice aims to create a unique space for social innovation to co-produce, test and learn from new ways of governing cities. "Jam" is about trying to bring together different partners in the city to experiment and innovate to address shared problems. "Justice" is about re-connecting with those who have been disenfranchised and excluded from the search for solutions.

Through the development of an Action Research Collective (ARC) in Greater Manchester, Jam and Justice brings together academics, practitioners, citizens and political leaders to exchange knowledge and develop creative responses to emerging urban governance challenges.



The ARC co-initiated a series of action research projects to test and learn from different approaches to citizen engagement. Our Inquiry is one of those projects.

Alongside offering essential funding to enable the Inquiry, it brought in an experienced researcher, Susanne Martikke, who works for the Greater Manchester Centre for Voluntary Organisation. Susanne attended many of the design and delivery sessions, documenting our process in detail.

Jam and Justice also promotes networking, debates and learning within the UK and internationally. This

is to enable critical reflection on how to organise knowledge better, to make positive urban transformations happen, in ways that are inclusive and equitable.

The Jam and Justice project is funded by a grant from the UK Economic and Social Research Council. More information on the work of Jam and Justice is available at: <https://jamandjustice-ric.org/>

Why focus on Care at Home?

Across the UK people are living longer but potentially spending more years in ill-health; although death rates have declined, the overall health burden is increasing. By 2039, the number of people in Greater Manchester aged 65+ is expected to increase by over 50%, compared to an increase of only 5% in the number of people of working age.

Sickness and chronic disability are causing a much greater proportion of the burden of disease as people are living longer with several illnesses. By 2035, 30% of those aged 65+ in Greater Manchester will have a limiting long-term illness that limits their day-to-day activities, higher than the national average of 25% (Thorley, 2018b).

Not supporting older people adequately in their own home for as long as possible can result in unplanned hospital admissions. Research by organisations such as Age UK has found that an increasing number of older people are being admitted to hospital for conditions which could have been dealt with at home. However, due to failures in the care for people in the community these services are not available.

The estimates show that older people have seen the largest increases in hospital admission rates with percentage changes of over 100% for each of the different age brackets aged 65 and older in the 14 years since records started.

Age UK, says a "revolution" is needed in social care to support the ageing population in their own homes (*Manchester Weekly News*, 11 Oct 2018).

The Project Delivery group

Action Research members within Jam and Justice are also closely connected to initiatives in Greater Manchester connected to Health and Social Care transformation and wanted to explore a research project that focused on co-production.

In addition, our external social care stakeholders had stated that they would be interested in a radically different way of exploring change. These discussions identified a need for providing an opportunity for deliberation around the care provided for elderly people, particularly for the most vulnerable.

Therefore a small delivery group was pulled together, led by Shared Future CIC, and supported by members of the Action Research Collective (ARC).

Once the focus on Care at Home had been decided, and the model to be used agreed we moved onto the development of the key question for deliberation by the Inquiry. This was the task of our project reference group.

Why do I want to take part?

“I would like to be involved for two reasons; one is the service I work for have a remit to work with people aged 50 and over and we have service users planning their later life care, worrying about money and what options they have, including wanting to utilise the asset of their own home and having an excellent standard of care with continuity. The second reason is; I was a personal assistant for a person who managed their personal budget and used this to employ a team to provide 24 hour support, giving a consistency and continuity of staff.

I think this is something that could be replicated and would like to contribute these experiences to this group.”
(Inquiry participant)

Why do I want to take part?

“Although our work is usually centre based, I have become very involved in the home and care lives of several of our more isolated service users who cannot rely on family or friends for support in transitioning from good to poor to bad health and the associated changes to home and lifestyle that this necessitates.

I am interested in the small practical tasks that appear to fall between commissioned services, e.g. who cleans the cat tray out, who orders a new bed, and how to maintain a healthy diet when your carer has a limited time slot for visiting (which means inevitably microwave meals).” (Inquiry participant)

The Reference Group

In order to develop the focus of the deliberations and overall objectives of the project further a reference group was formed. The group was made up of public and voluntary social care professionals with an interest in improving Care at Home services for the elderly.

At the initial reference group meeting, the members set the question, agreed on the location of the Inquiry, made suggestions as to the make-up of its members and the recruitment methods to use, as well as providing ideas for commentators. They also started to make suggestions as to how the recommendations could be shared and actioned.

The Inquiry answered the following question:

What would it take to help people to have a good life at home for as long as they choose?

Preparing for the Inquiry

Process

The Inquiry took place on six Thursdays from September to October 2018. Each of the sessions lasted some two and a half hours.

During these informal and relaxed sessions, a diverse group of participants were encouraged to think and talk about well-being and health services for the elderly in their own home.

A number of experts (called “commentators”) were invited to come and speak at some of the sessions to add knowledge of their lived experience and to help the participants explore how things could be changed.

Recruitment

Central to a Citizens’ Inquiry process is the recruitment of participants. A large amount of effort was put into making sure that a diverse group were able to take part.



What you need to know

- Participants in the inquiry will not be paid, except for meeting essential expenses.
- You will have to commit to meeting over six evenings, each meeting lasting around 2.5 hours, in central Manchester. Food and refreshments will be provided.
- You will be working as a team from all levels of the NHS and its partners. Different skills, but everyone equal. No voice will hold more sway than another.
- It will be a unique opportunity to learn about and influence how Care at Home is delivered in Greater Manchester.
- Your recommendations will be shared widely, and presented directly to lead commissioners, politicians, care deliverers and those responsible for NHS and social care services.
- Recommendations will be sent to the GM H&SCP Living Well at Home delivery team.
- While it will consider adult social care the focus will be on older people's 'Care at Home' services.

When is it going to happen?

We are recruiting participants now. By responding to our simple sign up form we will put your name in the hat. Because we are seeking a balanced and diverse group of participants we can't guarantee you a place now. It will take place over 6 weeks in September and October starting on 20th September 2018.

Who is supporting the Inquiry?

Primarily the participants, who will make it work. They will be central to the whole process. They will be supported by:

Witnesses – who we are calling ‘commentators’ will be invited to some sessions to bring in their lived experience and offer different perspectives. These will be front line volunteers, carers and people receiving ‘care at home’

Expert facilitation led by Shared Future CIC will help participants explore the boundaries between your ‘personal’ and ‘professional’ roles. Guiding the participants towards making innovative and deliverable recommendations for change.

An oversight group with a range of expertise to help the facilitation team design and deliver the inquiry. Key commissioners and public engagement experts see the ‘Inquiry Question’: A compelling ‘call to attention’ that we will use to frame your conversations.

Collaborating Out Loud will help amplify the influence of the Inquiry, help recruit participants and share the learning. Find out more about them at <http://collaboratingoutloud.org/>

Everyone involved will have personal experiences of the care at home system, and we know NHS staff and social care teams are doing what they can, and have stories related to themselves or family members. The inquiry seeks to build on that passion, professionalism and empathy.

Take part or to find out more

Our team is led by Jez Hall, Amanda Preece and Katie Finney, and includes Andrew Burridge of NWADASS, Claire Haigh of Collaborating Out Loud, Liz Richardson, of Manchester University, and Susanne Martikie, researcher from Greater Manchester Centre for Voluntary Organisation.

More information at: <https://sharedfuturecic.org.uk/inquiry-into-challenge-care-home/>

The aim was to recruit people who are usually excluded from the detailed discussions behind commissioning or service processes.

The project delivery and reference groups met on a number of occasions to identify a strategy for reaching people in the target categories.

Deviating from the practice used in our previous Inquiries, no recruitment letters were sent out. We concentrated on a web and social-media based recruitment campaign.

A flyer, as shown in the pictures on this page, was produced outlining the aims of the Inquiry, explaining the time commitment required, and noting that no payment would be made for participation, though limited expenses were available if required.



Join the Inquiry into the Challenge of Care at Home

The Care at Home Inquiry

Keeping safe, happy and well in their home is one of the biggest challenges faced by individuals, their families, the NHS and local authorities.

Too many vulnerable, and mostly elderly citizens enter expensive hospital services for preventable reasons, and then become stuck inside the medical system. Unable to go home, into supported care-homes or leave hospital. The problem is getting worse, not better.

We want people who deliver ‘Care at Home’ services to take on this challenge by joining the ‘Care at Home Inquiry’. Too often the service provided is reduced to performing tasks in the shortest possible time. Help us find ways to care that work on an emotional, person centred and practical level.

Seeking caring professionals

In this unique ‘challenge’ we want to recruit ‘citizens already working within health and social care’. Drawn from across a range of specialisms and professional grades. Such as GPs, nurses, GPs, social workers, and frontline care providers. We aim to recruit as diverse a group as possible, who will meet as equals during six evening inquiry sessions.

Producing recommendations that will make a real difference to the lives of vulnerable older people, their families and to the work of public bodies.

Get involved in the Challenge

Everyone has personal experiences of the ‘care at home’ system, and has stories related to themselves, their work or family members. Our expert facilitators from Shared Future will help participants explore the soft boundaries between your ‘personal’ and ‘professional’ roles.

What would it take to help people to have a good life at home for as long as they choose?

We want our inquiry members to be inspired by that kind of real and ‘lived experience’; of themselves, and of the commentators we will bring to the inquiry; and then use that energy towards making their own and collective recommendations for changing how Care at Home services operate. Keeping people out of hospital wherever possible, fulfilled, happy and safe, living well in their own home and within a supportive community.

For more information, visit the Shared Future Care at Home Inquiry webpage: <https://sharedfuturecic.org.uk/inquiry-into-challenge-care-home/>

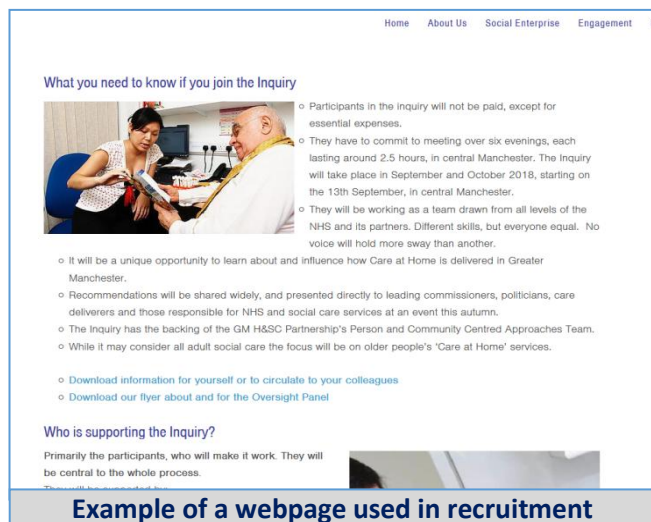
A Citizen Jury Case Study: Wirral Alcohol Inquiry

Commissioned by Wirral Borough Council and led by Shared Future, local residents considered “What can we all do to make it easier for people to have a healthier relationship with alcohol?” Over nine sessions, they were encouraged to think and talk about the impact of alcohol in their community. Experts informed their thinking, but couldn’t offer solutions. The group included people with direct experience of alcohol harm and those with none. During the last two sessions the group produced a set of 21 prioritised recommendations, which they then presented to politicians, health service managers and other key stakeholders with the aim of changing how local policies and services were implemented. Like: “Limit the number of licensed premises. Educate the public they can have a say on local licensing.” But there were many more recommendations produced, covering a huge range of topics.

Our Inquiry into Care at Home is different. Inquiry members will be professionals, and the experts will come from the general public, from voluntary organisations and from academics studying Care at Home.

We used networks within our existing contacts to circulate information.

Recruitment was supported by a page on the Shared Future website, and an online sign-up form. Social media and professional networks were used to spread the word.



Participation was voluntary and unpaid.

To incentivise consistent attendance within a Citizen's Inquiry, participants would normally receive rewards or vouchers equivalent to around £20 per session, given out part-way through or at the end of the Inquiry sessions. There would also be a budget for participants' support costs (such as child care). This level of resource was unavailable within this pilot project, though travel expenses were available upon request.

Why do I want to take part?

"I feel being part of this process will be invaluable. I will be able to utilise my skills and experience working with patients in the community and in their own homes and build upon my current skills through being involved with this project." (Inquiry participant)

Comments in orange boxes in this report use information gathered within responses to our online expression of interest form.

Why do I want to take part?

"I have been a Community Occupational Therapist in Manchester for about 10 years. I am interested in how best we can support older people to remain in their own homes. I am particularly interested in patient pathways within the NHS and reducing duplication and assessment."
(Inquiry participant)

In the Flyer, potential participants were asked to visit our webpage, where there was a link to express interest in taking part, either in the Inquiry, or as a member of the reference group.

They were invited to complete our very simple one-page online form to register their interest, describe their role and work background, provide a personal statement of why they were interested in taking part, and some basic demographic information, such as age, gender, ethnic background, location, etc.

We received 25 applications to join the Inquiry, from a wide range of health professionals including commissioning officers, directors of care services, occupational therapists, care service trainers, district nurses and a community mental health social worker. All applicants were contacted with the confirmed dates and times of the Inquiry and were invited to join the first session on 20th September. Out of the 25 initial applicants, 11 people attended at least 3 of the sessions.

Work commitments were the primary reason for non-attendance, a challenge which was considered during the planning stages of the Inquiry. However, it was recognised that any set day and time would be difficult for Health Professionals to maintain regular attendance when working shifts.

All applicants were kept up-to-date with the process of the Inquiry by email to ensure they remained 'in the loop' and encouraged to attend whenever they were able.

The Inquiry Sessions

Sharing experiences: Sessions 1 and 2

The first two sessions were designed to create a relaxed and informal atmosphere and enable people to connect and feel comfortable participating. Detailed explanation of the project, the delivery team in the room and the process, as well as clarity of the aims and objectives, established an intention and expectation of openness and transparency.

Establishing a relaxed, open and informal approach supported participants to share both their professional and personal experiences throughout the process.

Having taken time to learn more about each other's lives and motivations, participants divided into two smaller groups to capture their thoughts about the experience of an older person living at home with some degree of support need.

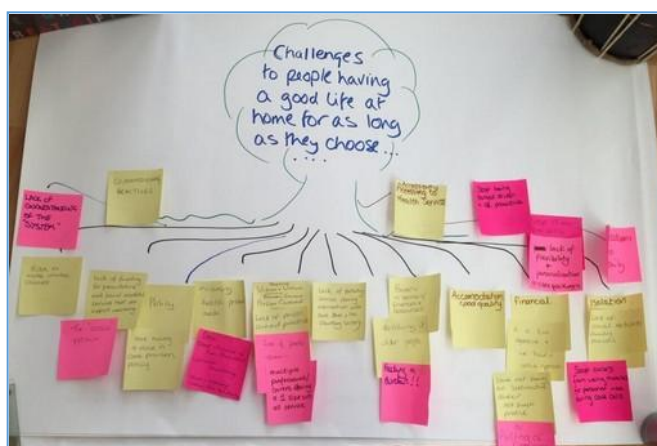
Challenges that exist to people having a good life at home for as long as they choose

As a way to start the process of thinking about the challenges of the Inquiry Question each group suggested what needs to stop, start, or continue in order for older people to have a good life at home for as long as they choose.

These discussions and notes identified a number of the challenges that exist to people having a good life at home for as long as they choose. Each group captured their thoughts on a picture of a house with an older person at the centre of it.

Secondly, we asked the group to develop a “challenge tree” formed partly from earlier discussions. Both activities stimulated a great deal of conversation, with people sharing their opinions and personal experiences.

The “challenge tree” involved drawing a large tree on a flipchart on each table. On the trunk of the tree was written the problem under consideration.



Challenges to people having a good life at home for as long as they choose

The group was encouraged to share what they felt were root causes of the problem. These were then written on post-its as the roots of the problem tree. The facilitator repeatedly asked the question “why is that?” to help participants identify the root causes of each problem.

During the second session, the group talked in depth with each other to ensure the challenges identified in session one were correct and consider whether they wanted new challenges to be added.



Each person was then given seven anonymous votes to identify which issues they felt were the most important. The results helped decide which topics needed to be explored in greater depth over the next four sessions.

The table below shows the views of the participants on the biggest challenges to people having a good life at home for as long as they choose.



[Brackets are the facilitators clarifications.]

<i>Rank</i>	<i>Challenges to people having a good life at home for as long as they choose</i>	<i>Explanations/clarifications (in the participants' words)</i>
1st =	Lack of person-centred practices	Loss of people's stories.
	Poor Commissioning practices	Multiple professionals/carers offering one size fits all approaches
2nd =	Policy	Not having a voice in care provision policy
	Isolation	Lack of social networks
3rd =	Increasing health problems [and] needs	[Poor] Pain management. [Lack of] Holistic pain management Overuse of pain medication
	Good quality accommodation	[Lack of]
	Lack of flexibility and personalisation in care packages	Stop 15-minute visits
	Workforce	[Lack of] Development and career pathways
4th =	Statutory services not sharing information with others	Including with the voluntary sector
	Power in terms of finances and resources	Feeling a burden Devaluing older people
	Financial constraints	Pulling of resources [Care at Home] not high profile
	Transport	[Lack of means not] Enabling access to social and medical needs
5th =	Lack of funding for preventative and social orientated services that also support wellbeing	Crisis approach
	Accessibility to health services	[Lack of] e.g. GPs
	End of Life Care	[Lack of] Respecting wishes
	Expectations on family	[Lack of Support]
6th =	Understanding of the system	[Lack of Understanding of complexity]
	Support to make informed choices	[Lack of]
	Stop being target driven and be proactive	[Lack of a preventative approach]

Deliberation in action: Commentator sessions 3 to 5

The Inquiry now moved into the Commentator phase: Commentators are an essential part of the Inquiry process and were invited to speak on the issues that the participants prioritised in week two, in order to further their understanding.

Commentators offer new perspectives to participants to inform the development of their recommendations.



Unlike other Inquiries, our commentators were predominantly recipients of care or people whose family members were receiving care or in need of care at home. The Inquiry therefore presented commentators with a rare opportunity to engage directly and share their experiences with care professionals.

The commentators were, in effect, our “expert witnesses”, called to give their testimony: the participants could decide what to accept and what to investigate further or challenge.

Each commentator was identified based on the issues prioritised by the participants. The commentators were briefed in advance to guide their contributions. All commentators were invited to talk for 10 minutes. In their presentations they were encouraged to include:

- Details of who they are (and the organisation they are linked to where appropriate);
- An explanation of what they feel the problem or issues are;
- An explanation of what they feel are some of the solutions.

Essential to the success of the process is the use of clear, simple, easy-to-understand language.

A red card system was used where participants were encouraged to show the red card if they needed clarification on what was being said.

After each presentation, commentators were asked to leave the room to allow participants the space to talk with each other about their learning and to write any questions they may have. These questions were then shared with the facilitator. Finally without a commentator being present, participants

Commentators to the Inquiry were:

Mark Fitton: Director of Operations Adult Social Care, Stockport MBC, and member of the Greater Manchester Health and Social Care Living Well at Home Delivery group

Bob Jones: Volunteer and trustee at Crossroads Together & carer for elderly parent who still lives in their own home

Muriel Powell: Retired coordinator for a volunteer-led good neighbours project and member of an older people’s advocacy and empowerment project

Joanne Wilcock: Recipient of Care at Home services and member of an older people’s advocacy and empowerment project

David Sutcliffe: Retired voluntary sector communications manager, and coordinating care for a parent living at home in a location remote to himself

were asked to reflect and deliberate with each other on their learning. This helped to ensure that the conclusions reached are their own and that they felt ownership over the eventual recommendations.

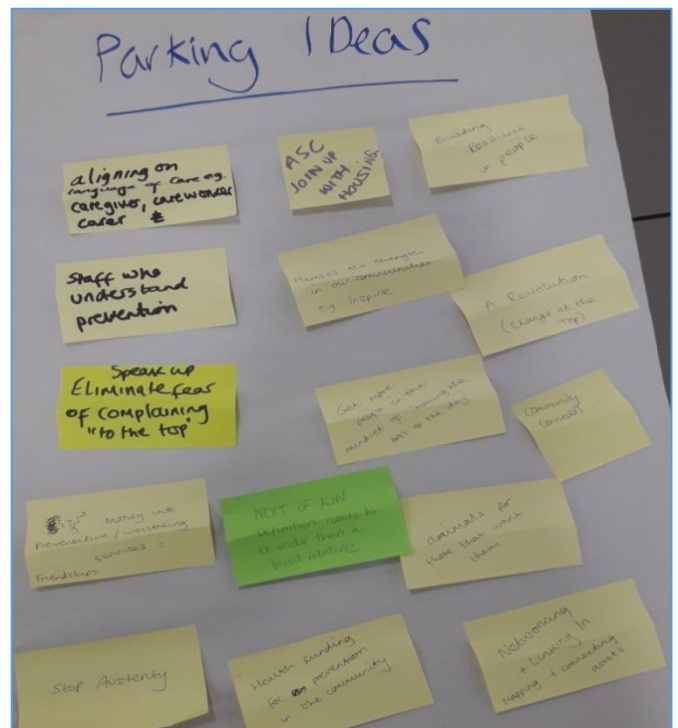
Questions written by participants for the commentators are listed in Appendix 1.



The facilitators gave attention to the group dynamic and participant interaction throughout the Inquiry process. Opportunities for participants to hear from each other, as well as commentators, were designed into the process. Participants shared stories of their personal experiences of Care At Home and their feelings about the challenges their recommendations would seek to address.

This was achieved through creating lots of small group spaces for people to talk in, as well as paired and whole group discussions. Sometimes the participants chose which groups they would join.

On other occasions they were allocated to groups to ensure that everybody spent time with each other.



On one occasion a “speed-dating activity” was used to get participants talking to each other about what had interested them so far in the discussions and to give them an opportunity to share with others anything they felt had not been talked about yet but felt was of great importance. This also brought out their own personal stories and emotional responses to this challenging topic.



What did Participants learn by taking part?

Leading up to and including the week 6 session, Inquiry members also considered what they had learnt during the Inquiry. A summary of their thoughts is recorded within the box on this page.



What did we learn about Care at Home?

Participants were asked to express what they had learnt, what they were inspired or challenged by, or what they were left feeling, as a result of the Inquiry into Care at Home.

We added to the learning board throughout the sessions. In no particular order, they said:

- The care sector is broken
- Frustrated by gloss— politicians [need to] answer
- Positivity 😊 get the message out that there are people to help.
- People just need to recognise that someone needs help then help make [it better]
- The importance of valuing the person— of getting to know what is important to that person —and then a “can do” attitude to make it happen
- Too health focused = dominance of the NHS
- Very powerful hearing Muriel’s and Joanne’s stories and wondering what happens next! People are amazing! And Pets!
- Personal stories matter
- Speed is essential to keep costs to the public purse low— change our political mantra.
- Going around in circles
- We need to invest in services to strengthen communities
- Disappointed with the number of people’s poor experiences of care, hoped there would be some good examples
- Let’s not reinvent the wheel. Let’s listen to people, find what’s out there and connect people to each other—and let people have cats 😊
- Sharing personal experiences and learning some of the group’s common points
- I felt surprised that so many of the group shared the same concerns and thoughts
- Building strength in communities—building relationships important— people and communities better connected.
- Repeating the same things— not feeling hopeful
- We are a bit too service led
- When addressing the question ‘help people have a good life at home’ need to focus also on the life of the unpaid carer
- The privatisation of the care sector has not led to a wholesale improvement in care services or delivery for the cared for person
- We need a clear plan of action
- Everyone knows the problems but no-one comes up with the solutions
- All talk, no solutions
- Shift from care homes to care at home. Care and repair. Futureproofing
- People power is key

Agreeing Recommendations: Sessions 5 and 6

In the last two sessions the group prepared their set of recommendations. In session 5, participants were asked to reflect on the process so far and individually propose some draft recommendations that they would like to share and discuss with others.

These draft recommendations suggested to participants and facilitators a set of themes under which their recommendations could be grouped. In the table below we present a summary of these draft recommendations, slightly edited for clarity, to better share participants' reflections on what needs to change or be done.

The statements below contain rich detail, even if in a raw form, which we believe can help to extend the final recommendations. At times, [brackets] containing interpretation by the facilitators, have been added to aid clarity.

During session 6 the facilitators helped the group create more specific statements, which would be comprehensible to all. They then probed further as to why these statements were significant, and whether there were additional or specific ideas the group wanted to draw out.

The draft recommendations: raw thoughts or ideas were arranged into rough themes

Funding and Commissioning

No to privatisation... It doesn't work, end of... Ha ha!! Explore alternative models of social financing. Models for prevention purposes. Reinvest money back into the system. Commissioning according to a set price? Does the practice preclude individual approaches? e.g. Set price per hour? Commissioning practices are too rigid.

Valuing Care Staff

Career pathways for staff. Registration of care staff, CPD requirements, training met. Standardise conditions and training requirements in line with GMC/NMC. Avoids the race to the bottom. Improvements in the terms and conditions and wages of care workers; raise the status of carers is the best way to raise standards overall. Make it [care] an attractive career pathway.

Accommodation

Learn from experience outside UK; Need to look at other models of care and housing from outside the UK, such as group homes. Find out about funding and financing options; a range of options to meet the [varying] needs of individuals.

New builds need to be future proofed for life; old builds and privately owned homes also need adaption. New build regulations [need to be updated in light of changing care needs]. Homes will be fit for the future [and this will be more] cost effective. Review existing housing stock to ensure it is future proofed; legislate for future housing stock to be built as future proof [e.g. door widths].

Transport

Provides access to social groups, and health and medical services.

Technology

Technological monitoring options need to be discussed [more]. Technology leads to information sharing, working together, records and so secures service user wishes.

Early intervention and Prevention

Invest in prevention services. Reducing demand[s] on acute care will help people stay healthy, well, and independent longer.

Long term care planning made mandatory at retirement age. Will help people to stay in their homes, reducing costs on the state, maintain people's choice, help people in planning for retirement. Move towards planning of care and future proofing provision.

Because a crisis system is stressful and does not meet the needs of people, is expensive and depends on the availability of services at some unknown future time.

The draft recommendations: raw thoughts or ideas were arranged into rough themes

Unpaid Support

Involve family, friends and other unpaid carers with producing care plans. [Consider our] expectations on families. Support unpaid carers.

Working together

Coproduction and co-design of service provision. Nothing about me without me! Have a voice at policy and strategic level. Join up health and social care. Establish a care navigators bank. To make it easier to navigate [the system], to speed things up and to simplify the system. A wider definition of next of kin, and wider permissions to share information between agencies. Saves time and bureaucracy. A friend may know someone best. Gets over the problem that some people have with a distant or poor relationship with their families.

Informed Choices

Care navigation models will help to support people to get the right support at the right time from the right person. Will help people and communities to connect.

Social prescribing. Avoids crisis responses. Plans can be started quicker, with no delays or faffing about. Can identify who is the care navigator or support structure. Financial preparations can be made.

Allocate everyone a care navigator from 18+ years old. Help people to understand the system. Enable better choices. Prevention is better than cure. Increase [the] frequency of reviews as people get older. Support the [wider] community to care. Promote community [based care] champions. Because we need to harness the skills, creativity and compassion that is there already. Invest in [becoming a] wellbeing community, with 'low level' activities to build friendships. Cheap, keeps a person going for longer, and about fun and friendships. Promote positive images of later life and different models of support, such as extra care, circles of support, home-share and shared lives. People will be more informed of what's available and able to make positive informed decisions.

What's important

Cats, companion animals and babies and toddlers. Maintains identity, keeps people mentally stimulated, education about [the needs of] each generation. Accessibility to health services [is all about meeting] increasing health needs.

As stated above, within session 6 these initial recommendations were refined further.

Through more discussion, in pairs and in larger groups, new recommendations were produced and existing ones re-edited.

Resulting in agreed wording for each recommendation, which the group could then prioritise.

After the discussions were complete, all 12 recommendations were displayed on a wall.

The facilitators read out the recommendations again, so that participants could check their understanding before they voted.

The recommendations were then prioritised using anonymous voting sheets. Participants each had seven equally weighted votes.



Recommendations for Care at Home

Before finalising their recommendations the Inquiry participants were reminded of the Inquiry question:

What would it take to help people to have a good life at home for as long as they choose?

Every participant was given an individual alphabetised voting sheet to confidentially choose their top seven recommendations out of the final twelve recommendations.

Due to the highly deliberative and iterative nature of the process it would be unwise to only focus on the top recommendations.

All were considered important by the group, and based on many hours of deliberation. It was stressed to all the participants that every single recommendation would be recorded irrespective of how many votes it might get.

Recommendations are listed in the table below. *[Italics in brackets are clarifications added by the facilitators.]*

Theme	Recommendation and Detail on the What and the Why	Rank
Funding and Commissioning	<p>Commissioning practices are currently too rigid to accurately reflect a personalised approach.</p> <ul style="list-style-type: none"> • Stop commissioning “time and task” services, that fuel a one size approach; • Time to build relationships needs funding as it leads to greater independence in the long run; • Co-design/co-production in all tenders; • Investigate other financial models to bring back cash into the <i>[care]</i> sector; • Incentivise providers to facilitate independence outcomes; • <i>[The current model]</i> Stops small or local providers. <i>[We]</i> need a diverse market; • <i>[Move towards an]</i> Approved provider list, meeting the criteria <i>[described elsewhere in the recommendations]</i> instead of a preferred provider ‘closed shop’. 	1st =

Theme	Recommendation and Detail on the What and the Why	Rank
Informed Choices	<p>Care navigation models to be developed and available from 18+.</p> <ul style="list-style-type: none"> • Information is necessary to enable choices; • Information can be held <i>[delivered]</i> anywhere (e.g. in pubs, community centres and supermarkets); • Believe strongly in a social prescribing model that supports mental, physical and emotional health; • Prescriptions need costs attached to it, so that provider services aren’t at risk. <i>[Funding follows the prescription].</i> 	1st =

Theme	Recommendation and Detail on the What and the Why	Rank
Early Intervention and Prevention	<p>Earlier intervention.</p> <ul style="list-style-type: none"> • An earlier investment in prevention services will reduce long term costs. 	2nd =

Theme	Recommendation and Detail on the What and the Why	Rank
Valuing Care Staff	<p>Consider creating a professional body for social care workers, similar to General Medical Council or Nursing Medical Council.</p> <ul style="list-style-type: none"> • Improve morale, improve recruitment and retention; • Maintain regulations and continual professional development; • Workers more valued and respected. 	2nd =

Theme	Recommendation and Detail on the What and the Why	Rank
Accommodation	<p>Suitable, safe, reasonable accommodation for all.</p> <ul style="list-style-type: none"> • To remain independent; • reduces need to move; • More likely to want to remain in home for longer; • Safety <i>[improves]</i>. 	2nd =

Theme	Recommendation and Detail on the What and the Why	Rank
Transport	<p>Good public transport remains essential to a good life at home.</p> <ul style="list-style-type: none"> • Integrated transport system to support infrastructure; • Improve access; • Reduce cost; • Public transport free at 60 London, Scotland and Wales. 	2nd =

Theme	Recommendation and Detail on the What and the Why	Rank
Valuing Care Staff	<p>Improve terms and conditions for the contracts of Social Care Workers, and ensure these meet legal requirements.</p> <ul style="list-style-type: none"> • Improve recruitment and retention; • Workers feel valued and respected; • providers save money; • Abides by the law! • Raises status and professionalism of workers. 	2nd =

Theme	Recommendation and Detail on the What and the Why	Rank
Working together	<p>Greater integration of Health, Social Care, Housing, Voluntary Services and service uses, to share information and resources, and <i>[improve]</i> care planning.</p> <ul style="list-style-type: none"> • Information should be managed by the individual rather than the service; • Permission held in a single technological record; • Break down boundaries between services and <i>[reduce]</i> institutional hierarchies; • Move towards one file per person that's owned by them; • Make co-production mandatory in the commissioning cycle. 	2nd =

Theme	Recommendation and Detail on the What and the Why	Rank
Valuing Care Staff	<p>Introduce banding structure for care workers based on experience and qualification.</p> <ul style="list-style-type: none"> • Improve recruitment and retention; • Provide career pathway and opportunities for progression; • Feel more valued and respected. 	3rd =

Theme	Recommendation and Detail on the What and the Why	Rank
What's important	<p>Individualised approach for everyone that incorporates their personal wishes.</p> <ul style="list-style-type: none"> • Everyone has different needs and wishes. 	3rd =

Theme	Recommendation and Detail on the What and the Why	Rank
Technology	<p>Appropriate use of technology to enable people to remain independent, connected and safe.</p> <ul style="list-style-type: none"> • Facetime, Skype and WhatsApp <i>[More use of]</i>; • Voice controlled assistance (echo/alarm); • Assistive technologies / healthcare technology; • Buddy GPs; • Welfare checks. 	3rd =

Theme	Recommendation and Detail on the What and the Why	Rank
Unpaid Support	<p>Recognising and valuing the contribution of unpaid carers.</p> <ul style="list-style-type: none"> • Improve their support work and improve support for their own health and wellbeing; • Prevent burnout and crisis intervention; • Reduce carers own use of health and social care services in the future; • Carers save the system £11bn a year. It will not cope without their support, so they need to be supported. 	4th



What Happened Next

The launch event on Wednesday 12th December brought together agencies and Inquiry participants to hear the recommendations. They began the process of identifying commissioner and agency responses, and started to think through what would be needed for greater service user and staff influence in policy-making.

Around 40 people participated. As those present introduced themselves, they expressed both professional and personal lived experiences. Appendix 3 lists the range of attending organisations.

Fundamental transformations in Living Well at Home in Greater Manchester

Mark Fitton, speaking in his role as chair of the Greater Manchester Health and Social Care Partnership's 'Living Well at Home' Transformation programme and as a Director of Adult Social Services for Stockport Metropolitan Borough Council, acknowledged a tendency to think about care in "just statutory" terms.

Mark explained how commissioners hope to build a relationship with care providers that is more than merely contractual. He identified alignment between the inquiry findings and that of the Living Well at Home Transformation programme.

Highlighting the importance of recognising the role of unpaid carers, individualised approaches, and support for the workforce, Mark finished by pledging ***"The work you have been involved in is valued and will contribute significantly to the work we have undertaken to date"***.



Grouping recommendations: 4 Key Themes

The recommendations were introduced by Inquiry participants, and grouped thematically, enabling those present to opt for a focused discussion of their choosing.

In the spirit of our process, this was not just a typical launch event—those present became part of the endeavour, taking the ***"What"*** and ***"Why"*** and working together in small groups to consider ***"How"*** the different recommendations might be achieved.



Commissioning and Service Reform

Participants were asked to consider how to make commissioning practices less rigid and move away from "time and task" services, to prioritise early intervention, and to identify ways to recognise the contribution of unpaid carers.

Informed Choices and Patient Involvement

This group brought together the recommendations for long-term planning (such as Care navigation models available from 18+), cross-sector integration for better sharing of resources and information, and attention to individuals' personal wishes: "the loss of people's life stories undermined their wellbeing and sense of identity".

Valuing Care Staff

This theme included establishment of a professional body for social care workers, improving terms and conditions, and creation of a banding structure that would reward experience and qualification, rather than simply age and long service.

Infrastructure and Technology

This embraced the wider necessities to provide safe and suitable accommodation, good public transport, and appropriate technology. Frequently mentioned was how personal data could be shared more effectively if it was owned by the individual and not by discrete and often poorly-integrated services.



Next Steps

Discussions were very focused, with one participant describing how their group *“gelled... quickly became a think tank”*, and another group reporting back *“a desire to keep thinking and talking further, to get the recommendations put into action.”*

Others in the room pledged to share what they’d heard with colleagues who couldn’t make it, and to look again at the models used to value work in healthcare and homecare.

Project teams next steps will be to deliver the final report at the January 2019 meeting of the GMHSCP “Living Well at Home” Transformation group.

Alongside considering how the recommendations might influence service transformation work, we will ask their views on whether the model might be repeated within other service areas.

We will also be forwarding this report to senior elected leads across the GM area, and to stakeholders involved throughout the process.

A number of people are asking for the establishment of ongoing implementation groups. This will depend on funding being obtained to service that activity, unless they can become self-supporting.

Evaluations received at the Launch event

As participants left the launch event they added comments on how they felt. These included:

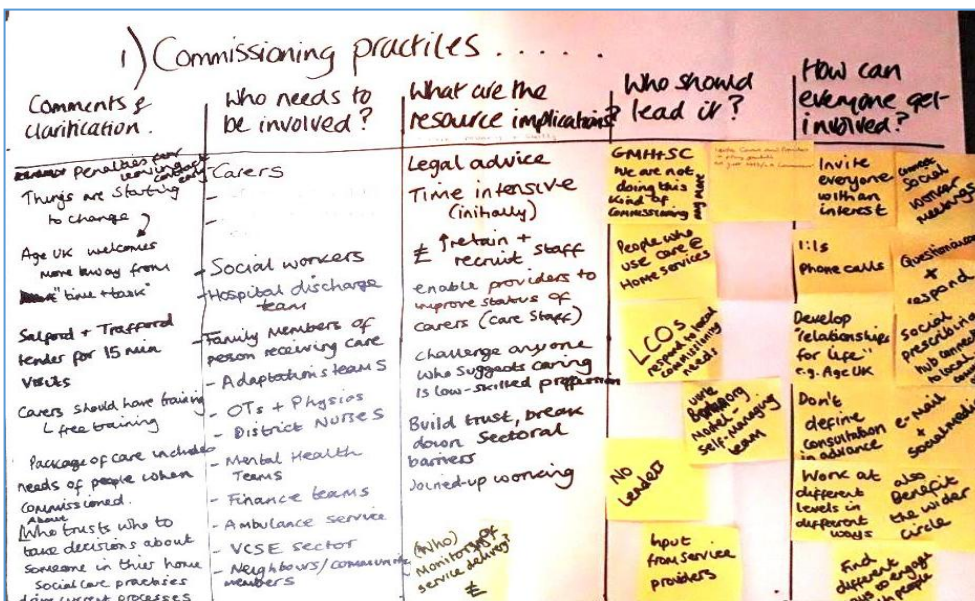
- *“It felt empowering”*
- *“A wonderful evening”*
- *“I’m glad that I came. It feels a meaningful conversation that can change the future of people’s lives. Thank you.”*

They also completed a written evaluation form, and statements included:

- *“Spending time discussing the findings with people challenged me, inspired me, taught me.”*
- *“I was very impressed by the way it was all put together. I [also] feel there should have been more care providers.”*
- *“Co-production! Co-production! Coproduction! is so important. Always good to have that reminder.”*

➤ *As a member of the inquiry team, it was good to re-connect and see our “outcomes” are only the beginning of the conversation...”*

➤ *“I’ll continue to be involved; put the person first. Nothing about me, without me.”*



Appendix 1: Commentators Questions



Bob –

Shared his experiences of being involved in a carers support organisation, and as someone caring for an elderly relative.

1. Can you tell us more about social prescribing? And.. are there any other solutions?
2. How has your experience as a carer influenced your work at Crossroads Together?
3. Did you and your mum ever consider a direct payment? If not, why not?
4. What one thing do you think is the most important to consider?
5. What are your priorities and what would you mum's priorities be? To keep mum at home and to have a good life?
6. What was the self-managing model called? Can you tell us more about how it works?
7. How can we help people feel less isolated?

Joanne –

Talked about her experiences of receiving care at home as a disabled person, especially her challenges with moving into adapted accommodation.

1. What could be done to help people speak up if they experience poor care?
2. Have you been offered the opportunity to have direct payments?
3. How can we improve arranging care for you?
4. Do you have any worries about the future?
5. You said you moved from the first to the ground floor, did you get any support to move?
6. What do you think would improve your quality of life, anything you like?
7. Your current carers, are they self-employed? (trying to determine safety)

Muriel –

Spoke about her role both as a coordinator of volunteer-led community care and as a member of the Inspired People's Older Persons advocacy group

1. What do you think policy makers should focus on, what is important to you?
2. How could this be achieved?
3. How recent are some of your experiences?
4. Could you explain your previous role?
5. You still sound actively involved?
6. What is Inspire? (what is social eating?)
7. Do you have any examples of good care?
8. Is it your job that has kept you so active and able to help and support others?

Mark –

Provided the commissioners' perspective, and the challenges of managing without adequate resources within a complex and fragmented system.

1. Are there conflicts between your professional decision making and personal values?
2. Do you think standardising working conditions for care providers i.e. level of training, pay, perks, can be implemented to help the workforce feel valued and help retain carers?
3. If so, how? If not, why not? [e.g. fixed contracts for social care providers]
4. Why don't we do something different?
5. What plans/ideas are there to re-direct money from acute services to preventative services?

David –

Shared his experiences of caring for an elderly relative at a distance, including using live-in carers.

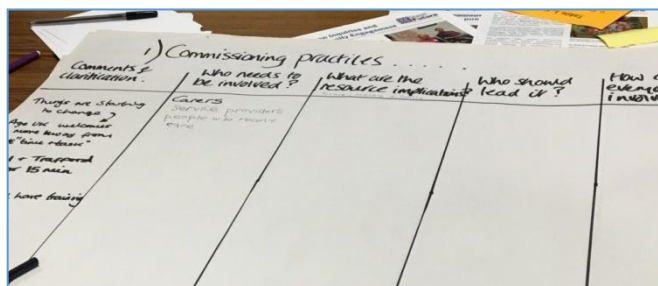
1. How is your dad with the live-in person, effectively a stranger?
2. Did you look at personal budgets?
3. Extra care schemes, retirement villages, did dad consider that and if not what would have attracted him to it?
4. How difficult was it to make care arrangements? What could have helped you?
5. Age Concern gave financial advice, was that sufficient?
6. With Homeshare, how does it work?

Appendix 2: Launch Event Attendees

On 12th December 2018 we held the multi-stakeholder workshop to launch the recommendations and identify forward actions. Below is a sample of the wide range of organisations represented.

Organisations

Age UK Manchester
Amity HCD
Crossroads Together
Greater Manchester Health & Social Care Partnership
Greater Manchester Mental Health Trust
Healthwatch Bury
Home Instead Senior Care
Levenshulme Inspire
Manchester Alliance of Community Care
Manchester City Council
NW Assoc. of Directors of Adult Social Services
Shared Future CIC
Stockport Metropolitan Borough Council
Strategy for Change
The Care Company Plus
University of Manchester
University of Salford
University of Sheffield
Wigan Council
Workers Education Association



Appendix 3: Researching a new model for Professional-led Citizens' Inquiries:

This work began as a research project, emerging from the Jam and Justice ARC's wish to explore new models for co-production.

It sat as one of a suite of interlinked co-design projects, all considering, given that devolution was happening in Greater Manchester, how new models of service reform and bottom up governance might be co-created.

ARC members wanted to explore a research project which focused upon co-production in health and social care. External stakeholders engaged in this arena have stated that they would be interested in a radically different way of exploring change. Given health and social care is an important element of devolution this appeared to fit with Jam and Justice.

Our suggested approach is a model of collaborative service redesign, using the principles of the Citizens' Inquiry, but inverting it.

We believe that professionals involved in Care at Home policy and practice, and indeed any area of multi-agency service provision could build on their existing professional and technical expertise if they had fresh insights from greater sharing of perspectives. This includes being sparked to re-connect with their own personal experiences.

We hoped to take people out of their current "programming" or view of policy solutions. We believed that technical and specialist knowledge has an equally valid and valuable role to play, and is useful in its own right.

However, the project is premised on the idea that the expertise in this policy area is "unbalanced" and needs re-balancing. Segmented by profession and hierarchy. That is sometimes called a silo mentality.

We saw a need for the professional, detached, specialist viewpoint to be balanced by a rounded, holistic, and emotionally connected perspective. Hence inverting the traditional process, with professionals acting as citizens, and those receiving services as "the experts".

Could (or would) we do this again?

Through running the project the facilitators observed:

- The particular demands on front-line professionals made attendance at consecutive sessions over a number of weeks challenging.
- Enabling participation is as important as incentivising it (i.e. a need for professionals to be released from work to co-produce policy, strategy and service models / delivery this way).
- The changing make-up of the group represented a facilitation challenge. This was responded to and accommodated throughout the process by more frequent check-ins, introductions and recaps from facilitators and fellow participants.

This raises various further questions:

- Does attending all sessions matter?
- What is the balance between consistency versus diversity of voice?
- Does a varied attendance enhance or diminish the take-up of the recommendations?
- How is this indicated by how participants report their feelings of engagement and their participation levels, and/or the number and nature of apologies received?

Overall, having facilitated a number of "citizen-led" inquiries, project lead Jez Hall felt that the quality of the deliberation and final recommendations was not markedly different within an "inverted" process. Further there were interesting possibilities, expressed by many of the participants, for this process to facilitate individuals' professional development and practice.

Despite limited funding for the pilot, resulting in lower attendance at times than we might have hoped, he feels this model could be rolled out into other policy areas and provides a useful addition to more traditional service planning processes.

The Inquiry into the Challenge of Care at Home

A new model of an Inverted
Citizens' Inquiry

Autumn 2018



Shared Future Community Interest Company

Registered as a Community Interest Company in
England. Company Number: 06919338

Web: www.sharedfuturecic.org.uk.