

Keeping it Personal Evaluation Report



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Executive Summary

Keeping it Personal (KiP) sought to understand how health and social care partnerships can support more person-centred and integrated practice when working in a way that focuses on people first. The KiP project was managed by [Iriss](#). It formed part of the larger [People Powered Health and Wellbeing](#) (PPHW) programme delivered by the [ALLIANCE](#).

Over a 12-month period (Jan-Dec 2014) KiP brought health and social care practitioners and people who access services and support and their carers together at two sites. In North West Glasgow, the focus was on people with dementia and in the Motherwell area, people with heart failure.

Each group came together at six daylong workshops to: learn, plan and do together to improve person-centred care in their locale. The project set out to trial new ways of working (combining co-production and improvement methodology) with the expectation that these would help deliver on the following objectives. Learning about the processes used was also anticipated and that this would be shared beyond the life of the project.

The project set out to achieve the following outcomes:

1. Increased capacity and capability among people using services to be active partners at individual and service level to influence their own health and wellbeing by contributing to the design *and* delivery of more person-centred care and support, including peer support.
2. Increased capacity and capability among people delivering services to work collaboratively with people using support and services
3. Enhanced understanding/relationships/collaboration between statutory and third sector
4. Cultural transformation towards an asset-based, empowerment model.

Outcomes 1, 2 and 3 were realised by all to a certain extent in both groups. People felt more confident and capable in engaging and interacting effectively with one another, both across sectors and with others with lived experience. The majority of people with lived experience also described increased awareness of the supports that they could access, while everyone developed new knowledge and experienced learning - learning from each other about services and supports available; learning about themselves; learning how to work with others; learning about some of the challenges and barriers involved. The assets of all came to be more fully realised over the course of the project – with practitioners' awareness of peoples' ability to help themselves, in particular, increased (outcome 4).

By the end of the project, practitioners had a greater appreciation of how people with lived experience felt and the more preventative end of health and social care.

Some felt that this empathetic blurring of boundaries between professionals and those with lived experience a positive thing and that this would become more common and less likely to be seen as 'unprofessional.' Others remained more uncomfortable with this. Significantly, practitioners had come to understand the difference between consultation (their usual approach) and co-production, with some claiming to have already put this new knowledge into action. New networks had also been established which would be useful in future work.

In terms of improvements accomplished within the project time frame:

- Two dementia cafés and a carers café were created by the KiP dementia group with improvements made to people's health and wellbeing, with the hope that this could be grown to support more people. An overview of these outputs can be found at: <http://s.iriss.org.uk/1JKyNHe>.
- In the KiP heart failure group, plans were that the information resources created by the group would be shared on screens in local GP waiting rooms (to support earlier diagnosis so that people were better able to self-care and prevent their condition worsening). By the end of the project this had happened in a few instances but their impact others was not known. For an overview of these outputs: <http://s.iriss.org.uk/1J3bpDQ>

The full report goes into more detail about the learning that took place at *project level* and the aspects that can help or hinder progress. Key achievements, challenges and learning points are discussed and summarised in the report's conclusion.

Further information about the different steps and processes used during the project are captured in the [KiP blog](#).

1 Introduction and Background

As Health and Social Care Partnerships start to integrate, there is a concern that differences in professional interpretations of the provision of care and support may impede its effective implementation.

[The People Powered Health and Wellbeing Programme](#) (PPHW), delivered by the [Health and Social Care ALLIANCE Scotland](#) is responding to this concern by exploring how a person-centred approach to care may support integration.

[Iriss](#), is one of the PPHW programme partners and ran a project called 'Keeping it Personal' (KiP).

1.1 Aims of Keeping it Personal

- To provide the opportunity for people accessing services and carers/family members to influence their own health and wellbeing by contributing to the design *and* delivery of more person-centred care and support, including peer support
- To build the capacity of health and social care practitioners and people/family members by trialling new ways of working informed by the principles of co-production/design and improvement methodology
- To share the learning from the project with others - although this aspect is outwith the scope of this evaluation report

Further information about the project can be found in the KiP blog at: <http://blogs.iriss.org.uk/keepingitpersonal/>. This includes the different steps and processes used during the workshop activities.

1.2 Approach

- Partnering with two test sites (North West Glasgow and Motherwell area) as part of a situated and place-based approach¹;
- Focusing on conditions that are supported by health and social care practitioners: dementia in North West Glasgow and heart failure in the Motherwell area;

¹ In North West Glasgow, the post diagnostic support (PDS) team for people receiving a diagnosis of dementia was a fairly new development. It was established as a multi-disciplinary team, including health link workers and social work staff, with the aim of providing a minimum of one year post-diagnostic support to people with dementia and their families. This includes a dedicated link worker. The team already had established working relationship with Alzheimer Scotland and with a carers group. The team is supported by a Dementia Support and Development Lead and their wider management stakeholders.

In North Lanarkshire, health and social care professionals had some experience of working together, primarily through multi-disciplinary locality planning group meetings. They already had some links with third sector organisations. Their main ambition was to work more closely with people with heart failure.

- Recruitment of people with lived experience of these conditions (9), their carers (7), and health and social care practitioners who provide support (12). The KiP blog contains further information about membership for the [dementia](#) and [heart failure](#) groups in both sites.
- Iriss provided a framework of six facilitated sessions (each 10am-3.30pm) in a neutral venue over a twelve-month period to the two partnership sites (Jan-Dec 2014) – and encouraged people to do some 'homework' in between.

Group activities followed three steps: 1) learning together 2) planning together and 3) doing together.

The approach was informed by the principles of both [co-production](#) and [improvement methodology](#). Within this framework, people were supported to plan, do, study and act to *improve* person-centred care and support in their local area, taking an appreciative approach.

- People with lived experience received a fee for attending workshops in recognition of the time and contributions they made; it was a key principle that they were paid for their time just as professionals are paid for theirs.

The KiP project blog provides further information about:

- The background to this project (<http://s.iriss.org.uk/1FTQFOq>)
- A review of literature about co-productive and improvement methodologies (<http://s.iriss.org.uk/1b3jcXO>)
- Evidence about the use of these methodologies in practice (<http://s.iriss.org.uk/1E2kvD5>)
- The approach applied in KiP (<http://s.iriss.org.uk/1awbHr4>)
- How the project was set up (<http://s.iriss.org.uk/1DiWpjL>)
- The project costs (<http://s.iriss.org.uk/1CKkvla>)
- How the KiP: Dementia (<http://s.iriss.org.uk/1Bfky7E>) and KiP: Heart Failure (<http://s.iriss.org.uk/1D1Tl2R>) groups were run and what people did

1.3 Report structure

Part 2 of the report explains the evaluation process.

Part 3 discusses whether and in what way the aims of KiP have been realised. Learning that may support the realisation of this aim, should this approach be replicated, is also shared in this section.

Finally, part 4 presents: the findings from each of the evaluation questions; learning and ideas in response to these findings; and a discussion of these findings in relation to the anticipated project outcomes.

2 Evaluation Methodology

2.1 Methods

Two groups took part in the KiP projects, each comprising those with lived experience, family carers and practitioners who provide support, related to heart failure for one group and dementia for the other. Over twelve months each group attended six workshops facilitated by Iriss. Participants provided feedback about their experiences in a reflective group session in the final workshop. People were also asked to share individual reflections by choosing to talk to the Iriss facilitators using face-to-face and/or telephone interviews, or in small groups.

When engaging with people who have dementia, their experiences were discussed verbally and by using visual materials. Carers also supported their partners and family members to engage with their reflections. The visual materials included words describing different feelings and emotions printed on separate pieces of paper that were spread out in front of people, as well as a wall chart that documented what people did at each session using photographs and words. These reflections were conducted at a pace that suited each individual, and time was taken to talk about each workshop to support recollections.

One facilitator had been involved all through the project, the other had joined at the final stage and for the evaluation. It was anticipated that people would feel freer to express honest opinions to the evaluator, who had not been heavily involved in the design and delivery of the project.

The project lead and facilitators involved in this work have helped to provide some of the context and narrative for this report.

2.2 Questions

All participants were asked:

1. What has been your experience of working on this project?
2. Have you learned anything, and if so what?
3. What do you hope will change as a result of taking part?

Additional questions for professionals included:

4. Do you work differently now, and if so, in what way?
5. Have you experienced any changes in relation to integrated working that derive from this project?

All participants were asked:

6. What would you like to have been different about this project?
7. What aspects of the project do you think should remain the same if it was to be repeated?

2.3 Sample

KiP dementia group

Seventeen people provided reflections at the final group workshop.

Sixteen people provided individual reflections, as one professional did not respond to the request to meet again. This meant five carers and five people with lived experience of dementia took part in individual reflections. Only one of the people with lived experience of dementia was able to provide reflections about the project itself. Others were able to provide reflections about the dementia cafés they were taking part in. Consequently feedback from people with dementia was limited.

KiP heart failure group

Eleven people provided reflections at the final group workshop.

Nine of a possible eleven people provided individual reflections. Two people did not take part in the individual reflections for health reasons. This meant there was limited feedback from people with lived experience of heart failure and carers.

2.4 Consent

Consent to share people's views within the project had already been sought; however, informed consent was verbally reaffirmed at this stage. It was explained that what was shared during the evaluation would not be attributed directly to any individual, and that participants would not be identified in the report.

The consent of people who had dementia was sought from them at the same time as consent was sought from their carers. This enabled time to be taken to explain to both the implications of their consent and to repeat information where necessary.

2.5 Data handling and analysis

Interviews and small focus groups were recorded, reviewed and data extracted. Notes were made during telephone interviews. The reflections that participants shared have been thematically analysed.

3 Improvements Achieved

This part of the report discusses to what extent people accessing services and carers/family members were able to influence their own health and wellbeing by contributing to the design *and* delivery of more person-centred care and support, including peer support. It focuses on the achievements of *all* group members (professional and non-professional) in terms of the improvements they were able to make in their given locale.

This section also provides points of learning that may support the realisation of these achievements should the approach taken in KiP be replicated.

3.1 Project outputs and impacts

KiP dementia group

Two dementia cafés and a carers café were created by the KiP dementia group. An overview of these outputs can be found at: <http://s.iriss.org.uk/1JKyNHe>.

The outputs from this group clearly indicate that the first project outcome was realised. As people were able to identify where they could make a positive difference, and, in response, successfully set up and ran cafés and carers' groups, they 'contributed to the design, delivery and improvement of support and services, including peer support'. Furthermore, the process of engaging in this work led carers to describe positive influences on their own health and wellbeing and for their loved ones. They also expressed pride in their achievements.

The three cafés have celebrated a year's anniversary, with health and social care professionals confident about referring new people to them.

The carers who run the cafés have documented the number of people attending (and any additional events run) and have taken stock of how long people stay and noted the general atmosphere. Evaluation of their impact on personal health and wellbeing (or personal outcomes) is based on asking people for their thoughts and listening to what they have to say. People are also invited to provide any comments or reflections in a guest book.

If time frames had allowed, KiP would have provided further input on how to capture data measuring impact on personal outcomes and how this can be used as part of an ongoing cycle of learning to drive further improvement through iteration.

KiP heart failure group

The plans were that the information resources created by the group would be shared on screens in local GP waiting rooms (to support earlier diagnosis so that people were better able to self-care and prevent their condition worsening). By the end of the project this had happened in a few instances. An overview of these outputs can be found at: <http://s.iriss.org.uk/1J3bpDQ>

However, the outputs from this group were not fully realised or tested within the project time frame therefore. This meant the first aim of this work 'to contribute to the design, deliver and improvement of support services, including peer support' was only partially realised.

In terms of *future* (potential) impact, the group hoped for an increase in public awareness of, access to, and engagement with the information that they had created about heart failure. Ultimately, they hoped for a change in attitude towards the condition so there was 'better public understanding', that people with the condition 'did not feel so sad about it' and that services have a 'holistic view of the patient both inside and outside the home'. Again, if there had been more time and things were further forward, the KiP project would have supported them to evaluate the impact of what they had created on other peoples' lives as part of an ongoing cycle of learning and improvement. Having said that, the group were evidently clear about the personal outcomes that they wanted to achieve for others.

In terms of the impact of being involved in the project, people with heart failure and their carers described learning more about living with their condition which 'influenced their own health and wellbeing'. It is also fair to say that there was some frustration within the *whole* group. It was not within their power during the time frame of the project to deliver, test and trial the information resources created. See 3.2.3 and 3.2.5 to explore some of the reasons for this. Whether their ambition was too large (or not feasible in the time frame and with the people involved) is something to consider? Nevertheless, the group kept returning to the issue of earlier diagnosis and identified this as the key issue to address and the one from which other improvements could flow for *others* whose condition had not yet worsened.

This suggests that the approach taken enabled people to achieve or work towards the first project aim. However, aspects of interaction and engagement were identified, which either supported or hindered this.

3.2 Aspects that supported or hindered achievement

These aspects included:

- 1) people's readiness to engage in this kind of work
- 2) their responses to the design and communication of this project
- 3) how readiness, responses and communication affected the group engagement and group dynamic
- 4) the ability of individuals to engage with this work
- 5) group membership and influence.

This section continues by discussing each of these aspects in turn.

3.2.1 Readiness to engage in this kind of work

People with lived experience: KiP dementia group

People with lived experience were easily recruited through the Post Diagnostic Support Service by a link worker or other practitioner that they knew well and trusted. The majority of participants knew about dementia (albeit to varying degrees) and understood it from their own experience. This meant that most of the group were ready to build on their understanding and learn from others' perspectives – both peers and practitioners.

Some carers had ideas about what was needed in their communities before engaging in this project and were motivated to 'take the seed [offered by Iriss] and nurture it and make it [cafés] grow [happen]'. These key members embraced others who were a little unsure about their abilities at the start of the project, and galvanised, encouraged and supported action.

There was mutual and sustained consensus in the group about the value of everyone's voice and people openly expressed their support for others who were trying out something new. For example, in response to a group member voicing uncertainty, phrases such as 'we are all learning how to do this together' were commonly used. This understanding, agreement and supportive atmosphere enabled the group to: better understand the issues they faced locally, identify ideas they wanted to realise, and test these ideas within the project time frame.

People with lived experience: KiP heart failure group

In contrast to the dementia group, the majority of people with lived experience of heart failure or for caring for someone with this, felt that they knew little/not enough about the condition or how to manage symptoms in order to live well. Existing information was either hard to find or inaccurate and often contradictory. Some people were still trying to make sense of their diagnosis, and others were unhappy about aspects of their experience of services. This was primarily due to late diagnosis, with them feeling let down by the diagnostic process and late access to specialist help and support.

Giving people space to express their feelings and respond to the perceived lack of knowledge and information meant that it took time before the group were ready to move together towards constructive and responsive ideas. Consequently, it took longer for this group to identify and develop ideas that may influence their own health and wellbeing and contribute to the design, delivery and improvement of support and services.

Practitioners in both groups

The practitioners in the KiP dementia group had stronger links with each other to begin with although the practitioners in the KiP heart failure group had worked together via multi-disciplinary locality planning group meetings.

Practitioners in both groups had *not* worked in a co-productive way before; however a small number from health services had some experience of using improvement methodology. For these practitioners, transferring the experience of using this approach in a health context was difficult at times due to the particular focus on personal outcomes within the KiP approach. This emphasised how they felt this impacted on their health and wellbeing and included *all* relevant aspects of their lives and how these connected (not just their experience of services). There were tensions between the drive for a rigorous process within the testing and improvement cycle and the more fluid, person-centred values of the co-production approach. For some, the two approaches did not seem compatible and resulted in a lack of confidence in the value of the KiP approach.

The lesser readiness of people with heart failure to move from sharing feelings and experiences to form and agree ideas and plans for improvement had an impact on others in the group. Some professionals who felt that they already had an overview of issues and knew 'what needed to be done' consequently felt frustrated and wished to move to action more quickly.

3.2.2 Responses to the design and communication of this project

It was identified during the evaluation that the majority of people experienced difficulties understanding the project's aims, goals and intended outcomes, particularly in the first three workshops.

In terms of aims, these was explained broadly as:

- Learning together - to explore what person-centred care is and work in a co-produced way to build knowledge and understanding;
- Improving together- identifying and realising real improvements in the local area
- Sharing the learning with others

Group activities across the six workshops were intended to follow three stages: 1) learning, 2) planning and 3) doing together- although this did not prevent learning from taking place throughout.

The difficulties experienced by the group members may represent the challenge of working in equal partnership with people who are more used to being led through a structured process. Traditional project management approaches, for example, often identify explicit outcomes or 'outputs' to be realised from the outset. This is different to exploring and arriving at what improvements to health and wellbeing can be achieved together, with the group taking ownership of these. Initial workshops introduced new ways of working together ie key principles of 'co-

production' without dwelling on the term. People in each group produced their own ['working together agreements'](#) to support this. They also explored what person-centred care and support meant or could mean for them based on their own experiences locally (or the journey of a fictional persona in this landscape) and took time to map what services and supports were already in existence in their community.

This was quite challenging as the new ways of working outlined were unfamiliar to most group members. Practitioners in health and social care also had different understandings of person-centred care and support, and people with lived experience were generally unfamiliar with this term at all. Again, it took time to explore and build a more shared understanding that was: inclusive of every aspect of a person's life (not just their experience of a service); that focused on their personal outcomes and desires; that used their strengths (or assets) and those of their family and community.

There were two different responses to this perceived lack of clarity.

- Some practitioners from the health sector in both projects became disillusioned with the project process and tasks, particularly when they felt 'out of their comfort zone', 'unsure about the purpose of tasks and activities, and 'not sure how this relates to the outcomes of our work'. This resulted in some intermittent engagement with the project and therefore lack of continuity. In the KiP heart failure group this was a particular difficulty, and led to a slower development of ideas when compared to the KiP dementia group.
- However, as well as a small number with variable engagement, others chose to 'ride the uncertainty out' and had 'hope' in the process. For these group members, deciding to engage and continue to discuss and share their knowledge and different points of view, allowed some difficulties to be resolved. This process also supported the group to build connections and bond.

3.2.3 Group engagement and dynamic

KiP dementia group

Nineteen people took part in the KiP dementia group. During the project three people (a professional, person with dementia and their carer) stopped attending, and another professional chose to engage intermittently.

There were various reasons for this. One professional moved on from their job just over half way through the series of workshops. In this instance a colleague was invited to take their place. A carer and a person with dementia chose not to return to the second workshop as they were not convinced the project was a good use of their time. They later returned, however, after hearing what happened in the second workshop and in particular about the visit to the Dementia Services

Development Centre in Stirling which took place between workshops 2 and 3 as 'homework.' They felt they might be 'missing out'. One professional who chose to engage intermittently regretted this choice at the end of the project. As, once the approach 'contributed to the design, delivery and improvement of support and services', they wanted to better understand how they could replicate this process.

Participant involvement in this group was steady and the group bonded quickly, particularly after getting together for the visit the Dementia Services Development Centre as mentioned. Some carers in this group were also clear and confident about what would help in their local areas, meaning leaders emerged at an early stage, which helped to galvanise this group.

KiP heart failure group

Fifteen people took part in the KiP heart failure group. During the project four people ceased to engage, and two chose to engage intermittently.

There were various reasons for this. Sadly two group members died during the course of the project: one person with heart failure and the wife (carer) of another member with heart failure. The latter's husband left the group due to this bereavement. Another person with heart condition only attended the first meeting because he felt too shy to work in a group setting and did not feel that he had enough to contribute. He also considered the full day (10am-3.30pm) too long for him. A professional left due to a long-term illness approximately half-way through, and two professionals from the same service decided to take turns attending, being unsure how well the project fitted with their work.

Understandably, these changes to the group membership affected the other members in terms of morale, continuity and critical mass. The group discussed recruiting more participants with lived experience; however as this discussion took place half-way through their work together it was decided this might not be helpful.

Additionally, this group's ideas hinged upon knowledge of and interactions with GPs. However, despite many approaches from different members of the group, no GPs took part either as a fully-fledged member or visitor to the group. (See 3.2.5 for further details of this.) Arguably, this made it more difficult for them to better understand the issues they faced locally and slowed the pace of progress. This meant that testing the information resources developed for use in GP's waiting rooms was not possible within the project time frame.

3.2.4 The ability of individuals to engage with this work

KiP dementia group

People with dementia: Only one person with dementia was able to clearly articulate the opportunities this work offered them, explaining it was 'good to be able to get together people regularly' as she liked to socialise.

Carers: To the surprise of most professionals, family carers had the capacity to take on more work, as well as the responsibility for establishing and running the cafés.

Practitioners: Had a desire to make something happen during this project but generally had a limited capacity during and in between sessions. During the workshops some practitioners described choosing to work with people who had dementia so carers could devote themselves more fully to the activities during the sessions. The majority of practitioners also said that they could only engage with the project during working hours due to other commitments. However a minority, generally the Link Workers and the Clinical Care Improvement Co-ordinator, worked with carers outside of the project and their working hours.

KiP heart failure group

People with heart failure and carers: Were motivated by the opportunity to support people like themselves. This motivation increased once they had ideas that they could focus on.

Practitioners: There was a commitment from the majority of practitioners to the project and to the ideas for improvement that the group developed. Similarly to the KiP dementia group, the majority of practitioners said that they could only engage within project hours due to other commitments; a small minority worked outside of the project hours.

3.2.5 Group membership and influence

Some of the challenges faced by the KIP heart failure group highlights key issues around group membership and influence and how to target people early enough, so that more preventative approaches can be made. In other words, WHO do you need to take the work forward effectively and make the biggest difference?

Early on, the KiP heart failure group experienced key challenges around recruiting people with heart failure at an *early enough* stage to help them self-care and prevent their condition worsening. People with 'mild' heart failure were not easily identifiable: either because they had not received a diagnosis, or had it not been explained to them what future implications would be if 'suspected' or 'mild' (stage 1 or 2). Terms like 'mild' or stage 1 and 2 were also confusing and not universally used. In younger people in particular, heart failure was often masked by other symptoms delaying diagnosis. As such, those we wanted to work with were managed in primary care and known only to GPs. GPs were also missing from the KiP group.

As such, attempts were made to get people to self-identify with invitations to join the group promoted in the local press, through a local poster campaign and via specialist organisations like Chest, Heart and Stroke, British Heart Foundation and Cardiomyopathy Association. This failed (perhaps for reasons already outlined). Other attempts were made to recruit via local GPs who were asked to identify and

send letters out to individuals. This also failed. At this stage the existing members of the group decided to change their focus to target those whose condition had worsened, but was currently stable. These people were eligible for the additional support of the Heart Failure Nurse, and were known to her. She was able to speak with individuals and recruit to the group this way.

Earlier diagnosis and prevention, interestingly, emerged as the key priority for those who did come on board. However, failure to recruit a GP to the group was problematic given that they were key in helping to action and deliver the improvements the group wanted to make. That GPs need to 'backfill' any time spent out of practice (with associated costs) makes their involvement in this type of work particularly difficult. The group thought about targeting GPs who had recently retired or were semi-retired, but this did not yield results either. Representatives from the group finally found their way into a local GP planning meeting as their solution to this. From this, they got agreement that information resources developed could be shown on screens in GP waiting rooms

Unlike the KiP dementia group, it was not within their power to deliver the intended improvements on their own. (The carers in the KiP dementia group led with creating and delivering the dementia and cares cafés themselves). Furthermore, the loss of key members- due to three members passing away (two with heart failure and one who was a carer) clearly affected this group, both in terms of morale and its ability to deliver.

3.3 Discussion and points of learning

Historically people have not been asked about their experiences in order to support the improvement of services, and traditionally people tend to be asked or consulted, rather than collaboratively involved in the identification and design of improvements. Furthermore, traditional project management approaches also start with the end outputs and work backwards from these to derive an action plan – not the other way around. The approaches used in KiP challenge people's expectations and cultural norms.

This may also relate to the uncertainty expressed about the aims and purpose of the project. This involves making clear to group members that they drive and own the improvements (so set their own outcomes and objectives.) Repetition of this message may be required. Added complexities included communicating and modelling new ways of working together (co-production) and building more shared understandings of 'person-centred care and support'. Stressing that the project seeks to build *new capacity* as well as deliver real outputs and impacts needed to be given extra weight as people's natural inclination is to focus on the latter. This also needs to be stressed at the recruitment stage so everyone fully understands.

When people come together they will seek to find a joint purpose, with the hope that they will be able to say of any output: 'I helped to make that.' The challenge is to keep everyone motivated during the process when they are still forming as a group, building knowledge and trust, and are at different points of readiness to

move from sharing experiences and building common understandings to planning and action.

Learning (1): Time may need to be built into a project plan for a project manager to understand people's readiness to engage in this kind of work at the very start.

Learning (2): Sharing experiences and building bonds and trust needs to be given adequate time. However, efforts may be needed during sessions to identify and respond to the need for a shift in thinking amongst group members, from a focus on personal experiences to broader implications for services and support if this starts to become an issue.

Project tools such as [experience maps and personas](#) can be created and sensitively used to help achieve this along with raising the issue with the group and trying to agree a way forward.

Learning (3): Group members should not be prescriptive about their outcomes, which may develop depending upon people's readiness, approach and needs during the project.

Although working with a co-productive approach, where aims, objectives and intended outcomes are derived by the people who take part, there were other intended outcomes around building new capacity. This was testing-out how co-production and improvement methodology could be used to help deliver more person-centred care and support. These parameters need to be clearly understood by all.

Learning (4): The host organisation (in this case, Iriss) should be clear about the aims and objectives of the project and ensure that those recruited to it are fully signed up to and understand these. This may need to be stressed at several points of the work to remind group members of this; people can easily fall into more familiar ways of working.

Learning (5) Any uncertainties or questions need to be brought out into the open and any disconnect or ability to contribute explored. These should be viewed as opportunities to learn. See Learning (8) also.

Finally,

Learning (6): Sometimes peoples' priorities easily align and key members of a group lead and galvanise a group. There can be a dose of luck involved in this process. However, having 'the right people' in the group who are empowered to drive forward (or at least make the connections to those who are) is also critical.

Learning (7) While it may be helpful to understand the limitations on people's ability to contribute (and factors affecting this), focus should be on what people CAN do.

4 Building Capacity

This section presents the findings from the evaluation questions as set out in 2.2. of this report. Questions 1-3 focus on people's: experiences of being involved; their learning; and hopes for what will change as a result of taking part. Practitioners (only) were also asked if they work differently since KiP and whether they have experienced any changes in integrated working as a result? (Questions 4 and 5)

All participants were asked to reflect on the project and say what aspects should stay the same or change if it were to be run again? (Questions 6 and 7)

Points of learning are offered in response to the findings and the section concludes by summarising whether, and in what way, the project helped to build the capacity and capabilities of the people involved to: work collaboratively; develop relationships and understandings; and move towards a more asset-based approach.

4.1 Experiences of being involved

Three key themes arose in response to this question about experiences of being involved in KiP. Findings were mirrored across both groups. These relate to how people felt and how this had changed (4.1.1), communication (4.1.2), and project design (4.1.3).

4.1.1 People's feelings as part of the journey

In the KiP dementia group in particular, the majority of people reiterated that they had developed a network of 'friends' and 'fantastic relationships', which were described as 'family' [friends + family]. New relationships, connections and networks had increased their capacity to care and self-care. Practitioners in this group also described seeing carers and people with lived experience develop during the projects as 'inspirational'.

People in both groups experienced a range of emotions before, during and after the project. Prior to its start, perceptions ranged from being: 'reluctant to take part', 'looking forward to meeting people', 'open minded' and 'cynical that co-productive work was tokenistic'. By the end of the project, most participants reported positive and enjoyable experiences of the work. They described it as 'therapeutic', 'really interesting', 'uplifting' and 'one of the best things I've been too, worth its weight in gold'. It was 'pleasurable', 'a real laugh' and a 'great buzz'.

Those who did not enjoy the project found the work 'very difficult' and carers mentioned it could be 'tiring' for people with dementia. However, at the end of the project the majority of people described feeling 'excited' and 'proud' of what they had achieved, but 'sad the project was ending'.

The collaborative aspect of this approach was deemed very important to the majority of people in both groups, with them describing 'feeling like equal partners',

and that they were 'informing others', 'making friends' and 'connecting' with one another as individuals with different knowledge and experiences. Clearly, the assets of different people in the group came to be realised and understood.

However a small minority described negative feelings, for example, having to 'bite their tongue' and being 'not able to engage collaboratively'. For a few, there was too much value placed on lived experience rather than larger sample sizes and traditional research reports. This example is indicative of the tensions that can exist between responses to health and social care provision and what people consider as the most valuable or credible evidence.

Learning (8): *Fully* encourage and explore different perspectives during a project to build new learning, knowledge and understanding. It may also be symptomatic of tensions that exist, voiced or unvoiced. Therefore, finding ways to bring out any disagreement, uncertainty or disaffection may be beneficial to the aims, outcomes, and outputs of the work.

Workshop activities and tools can be used to help achieve this, but it may also be beneficial to follow up with individuals out with sessions.

Learning (9) Alternative approaches could be considered. One practitioner suggested that were this project to be replicated it may be beneficial to start the work by bringing together a large group of people with lived experience of a condition, their carers and practitioners. In this group a range of evidence could be sought about experiences, needs and difficulties. This evidence could then be used to support a smaller group(s) to respond to these difficulties. This would allow people to move between a large evidence base and specific interventions and would enhance the robustness and representativeness of this work whilst also building support.

Also see points of learning in 3.3 of this report.

4.1.2 Communication

As already discussed under 3.2.2, many people did not feel that communication which described the project, the project aim, objectives and intended outcomes was clear – particularly in the first three workshops.

This led to feelings of frustration for some, with some practitioners only engaging because they were expected to by their managers. People with lived experience who were also uncertain, were motivated to return due to other incentives- this included coming together to share experiences with people in a similar situation first and foremost, followed by the hope of making real improvements and, perhaps, the fee received from Iriss for their time.

Feelings changed, however, once people 'started to feel part of a group' and as part of this group came to a mutual understanding as to 'what we wanted to get out of it [working together]'.

Some of the challenges and complexities for the project lead around communicating project 'aims, objectives and outcomes' are explored more fully in 3.2.2. In brief, however, this involves the importance of making sure that group members realise that they drive and own the improvements (so set their own objectives and outcomes) - beyond the general aim of improving person-centred care. Communicating and modelling new ways of working together (co-production) and exploring what is meant by 'person-centred care and support' and coming to a more shared understanding also takes time.

Nevertheless, the majority still stated at the end of the project that they would like to have known the aim and anticipated outcomes at the start and *prior* to their engagement. This may suggest that they were co-opted onto the group by their managers (if practitioners) or link workers (if people with lived experience) without being fully aware of, primed or willing to trial and learn about new ways of working. Building new capacity and improving person-centred care were given equal weight in this project, with co-production being the vehicle to try to deliver this. This was non-negotiable.

Learning (10): Iriss and the PPHW's objectives in this work needed to be given extra weight and stressed to all group members at the recruitment stage and beyond. Building new capacity (and learning about how effective these approaches are in practice at the junction of health and social care) was given equal weighting to improving person-centred care in this project. Co-production was the vehicle for delivering the latter, with this non-negotiable and not co-produced by the group. (See Learning (4) also).

4.1.3 Project design

Despite the majority of people feeling unclear about the purpose of the first three workshops, people generally described the workshops as 'working well', 'well structured', friendly, open and relaxed', and 'creating a vibe that lent itself to everyone there'. A minority described the approach as being 'a bit drifty' and 'too touchy feely'.

There was a general consensus that the workshops could have taken place more often than bi-monthly, and that several breaks are needed when working with people who have dementia. The need for more breaks was highlighted during the first workshop and was built into future sessions.

Some practitioners in the KiP dementia work were surprised that so much was achieved and at such a fast pace over six sessions altogether. However, more time was needed in the KiP heart failure group as it took longer to focus on an idea. This meant that the end of the project felt rushed to some in the KiP heart failure group.

There were also some strong views about the 'homework' that people were asked to do in between workshops, designed to support momentum and learning, planning and doing. Sometimes this was set by the project facilitators (most often in the

earlier workshops) and sometimes by group members themselves. Some practitioners did not believe it was realistic to ask them to work outside of the project hours. Carers and people with lived experience were not used to doing homework (in the traditional sense, writing down thoughts and reflections). However, when homework included people getting together between workshops, some in the group that had bonded (including practitioners) enjoyed the experience. 'Homework' may also not have been the best term to use as, although meant playfully, it carried connotations of school for some. This may not have helped people to feel empowered and equal partners.

Learning (11): During project planning, allow for extra workshop days if a group is finding it difficult to identify and develop their ideas. (However, this assumes: that you have a flexible enough budget to cover this if, like Keeping it Personal, you pay for a neutral meeting space; you pay all people with lived experience for their time; peoples' timetables are flexible enough to accommodate this. Running more, but shorter days may be a solution to this.)

Learning (12): Check in with people how often they would like to meet, and about their experiences of the timing of workshop activities and breaks. Find the 'best compromise' if you have to, if there are constraints on the hours people are prepared to work.

Learning (13): Check out people's capabilities to engage with certain 'homework' tasks before prescribing anything and perhaps avoid use of this term. One approach is to discuss people's availability to engage with tasks outside of project hours, or make the timing of these activities explicit (along with size and shape) when recruiting participants. Alternatively, let people determine themselves through discussion at workshops what they can 'offer' to do in between sessions.

4.2 What participants learned

Everyone who took part in the evaluation was able to say that they had learnt something. This learning fell under three themes. In relation to co-productive practice, people described learning more about themselves (4.2.1), about the value of community (4.2.2) and about what is achievable in a co-productive project (4.2.3).

4.2.1 Personal learning

Some people described learning about themselves and others about how they work in relation to a particular condition and in a co-productive group.

Reflections about personal learning included 'learning about my condition in ways I wasn't aware of before', carers becoming aware that 'other people are dealing with the same frustrations I am', and practitioners recognising 'I don't need to push so much to get results from people'.

Learning derived from working with others in a co-productive group included being reminded of the value of listening and hearing. Learning from others' experiences and knowledge supported people to have 'lightbulb' moments that have affected: their approach to their condition, the support they recognise they need, and the way they practice. For example, carers from the dementia group identified learning to 'respect my own view', 'respect the views of others', and recognise the power of 'being open about your experiences'.

For practitioners from both groups there was a tension surrounding their professional and public boundaries. One practitioner described previously thinking that there was 'no place for empathy in professional practice'. However, when she chose to engage with people in this project, she experienced a 'breakdown of some barriers' between herself and other group members. She described the result as 'improved engagement and connections'. Others wholeheartedly embraced a blurring of these boundaries and met outside of working hours for project and social reasons. This was something that these practitioners had not done before. Conversely, other professionals were not keen to test such boundaries, some recognised they were 'working outside of my comfort zone', others described themselves as not being 'all that suited to this work' and 'didn't see the project as a learning experience'.

People also recognised on reflection that it will 'take time to do this kind of work'.

Learning (14): There can be a desire to focus on creating outputs at each meeting and figuring out how these relate to improving person-centred care in the local area. However, finite outputs, such as information resources or dementia cafes, should not be prioritised over the learning and changes people experience themselves. These are outcomes in themselves. (Furthermore, co-produced outputs can only emerge once a co-productive group has fully formed).

Learning (15): Working in a co-produced way takes time and cannot be rushed.

4.2.2 The value of community

People with lived experience, carers and practitioners all described learning, or being reminded, that community is important. Carers in particular described the 'connections', 'camaraderie', and 'support' as giving them a sense of belonging, a sense which reminded them that they 'are not alone' and that they 'need it to fight the isolation they feel'.

Ways to achieve this were also highlighted. Carers and practitioners commented about the importance of sharing information, thoughts and feelings and how this is important to 'help people gel and come together' and 'get people on the same page'. They recognised the value in some of the approaches, process and tools used during KiP. Each workshop, for example, started with an icebreaker type activity designed to help people get to know each other beyond their profession, illness or caring role and help bring the breadth of their into the open. A 'working together agreement' also established key principles of working, such as the need to respect

and listen to others (without rushing to agree or disagree). Personas were also used to allow people to bring in their experiences with greater anonymity before trust had been built up in each KiP group.

Community can therefore be understood in terms of building those connections and trust within the group. However, it can also be understood in terms of growing the group's understanding of their local community and context to identify room for improvement and associated actions. Practitioners and carers alike valued the [community mapping exercises](#) which used the knowledge of all group members to establish and assess existing services and supports in their local area from their perspectives. The KiP dementia group also extended this to bring in others through their networks to add to the map. Practitioner in particular, planned to use this tool again in their work.

Learning (16): Take time and make the best use of tools available to build relationships and trust to form your community of learners and improvers and bring their assets out into the open. Tools that map local supports and services (as defined by the group) are also a useful tool for valuing existing assets and seeing where improvements can be made.

4.2.3 What is achievable in a co-productive project

With respect to the KiP dementia group, some people were not convinced at the start of the project that co-productive practice would yield anything. However, people were surprised that 'a lot' could be achieved and practitioners were 'taken aback at the pace of development of the ideas' and sometimes felt that they needed to 'pull on the reins'. Other practitioners remarked that the speed at which ideas were developed 'put public services to shame' as the ideas could 'never have been developed so quickly in our system'. The speed of this work was attributed to the carers in the group and practitioners described being shocked at how much 'energy and dedication' carers had for this work, whilst also being dedicated to their caring role and other aspects of their lives.

However, practitioners also caveated what could be achieved in a co-productive project, explaining that ideas needed to be realistic and must come from within the group. Some believed that within this project, supporting the development of ideas took up too much of their time, and that unless an idea related to their practice they could not justify this use of time during working hours. Work with the KiP heart failure group also revealed other factors that could limit achievement, certainly within the time frame of the project. In 3.2.1 the 'readiness' of those with heart failure and carers to move beyond sharing their experiences to action is discussed as slowing the pace. They were also missing key players in the group, such as a GP with the influence to help them implement their plans, and so had to find ways to go to them outside the group (3.2.5); plus the loss of other group members due to ill-health and bereavement affected the progress of this group (3.2.3).

The role that people assumed during a workshop could also affect what was achievable. With respect to the KiP dementia group, some practitioners explained

that they had chosen to work directly with people who had dementia in the workshops 'as it can be difficult to truly involve them in the process'; they did so to enable carers to engage more fully. Practitioners felt that this impacted on the contribution they were able to make themselves. It is also fair to say, however, that most carers from this group said that they would have been unable to take part in the project at all if they had been unable to come along in pairs— so with their husband, wife or mother with dementia.

Learning (17): Be ambitious, but consider the limitations of what is feasible to achieve with the 'people assets' and other resources that you have, including time. Consider at the outset if you have all the key members you need to move this work forward; continue to ask this question throughout and take action if you do not. If key members cannot come to you, find ways to go to them.

Learning (18): It may be useful to check how involved people feel they are able to be during workshops, particularly when there are people involved that rely heavily upon support, such as people who have dementia.

4.3 Changes post-project

Earlier sections of this report have dealt with the outputs of the project (dementia and carers cafés for the dementia group, and information resources for the heart failure group); their impact (and hoped for impact) on people's health and wellbeing. See 3.1.

This report has also discussed the personal and group learning that has taken place. See 4.2.

Consequently, this part of the report will focus on the potential future impact on practice and the lives of people with dementia and heart failure.

4.3.1 Changes to practice

Some practitioners said they did not now work differently; others did and in the following ways:

- Practitioners had a greater appreciation of how people with lived experience feel and were more aware of the 'preventative end' of health and social care.
- Practitioners said that they are now able to distinguish between 'working for' and 'working with' people. Managers involved in the KiP dementia group described gaining a better understanding of the difference between consultancy (their usual approach) and co-production and wanted to replicate this model of working in the future.
- Some practitioners from the KiP heart failure project said they were now collaborating more widely with other practitioners and were ensuring that

people with heart conditions and carers were involved, rather than consulted in the work they do.

- In the KiP dementia group, practitioners said there was a 'better connected network' between 'diagnostic centres', and a 'greater awareness between services' which had led to an 'increase in referrals to carers' and respite services'.
- Some professionals involved in the project intend to use the capacity building approaches learned through KiP.
- Some professionals hoped that it would become more common in professional practice to be empathetic, without this being seen as 'unprofessional'.
- Practitioners reported a better knowledge of services and supports, particularly those involved in the KiP heart failure group as people were less well connected than the KiP dementia group to begin with.
- Beyond the life of the project, they also felt that they had gained a new network of support, explaining 'I now have a wider, trusted and helpful network I can contact to better support the people I work with.'

4.3.2 Growth, development and sustainability of improvements

- The KiP dementia group had established and were developing their cafés before the project ended (December 2014); they celebrated a year's anniversary in October 2015.
- The KiP heart failure group had not tested the information resources for people with heart failure to be used in GPs surgeries before the end of the project. It was hoped that this group would not become despondent, and would continue to work together.
- Project timescales and design did not allow for the development and sustainability of the improvements developed to be well explored. There is much still to learn in this respect from those who took part in KiP.

It was the aspiration of carers from the KiP dementia group, for example, to continue to 'support people to get perspectives on their problems' and also 'figure out how they could be supported financially' to continue. They also hoped that attendance at these would increase 'so 'people who are suffering, come out of their homes and to our cafés', 'so people can get some relief and get away from their problems'. Other future lines of enquiry to explore might include: how do they maintain old members/ attract new ones; how do they ensure responsibilities are spread so that the loss of 'do-ers' or leaders is not fatal?

- Spread or replication of cafés (or other developed resources) post-project is another area that cannot be fully reported upon.

Some carers and people who have dementia wanted to share what they had gained from the KiP project around running the cafés so that people in a similar position were able to learn from their experiences. The local carers centre is in discussion with the carers group to explore how carers' learning may be shared.

4.3.3 Changes in relation to integrated working?

Practitioners were asked if they had experienced any changes in relation to integrated working as a result of being involved in KiP?

There was a mixed response to this question. The majority of practitioners said they had not experienced changes to integrated working as a result of taking part in this project; some described changes that suggested improvements in integrated working; and some were able to provide examples of improvements.

- The majority explained that they could understand how this process could be a catalyst to support people to think from a lived experience, rather than a service-related, perspective. In particular, some said they no longer saw 'person-centred care' as a 'buzzword' and had 'bought into it'.
- Health and social care practitioners from the KiP heart failure group valued the inclusion of practitioners from the third sector, and third sector practitioners were pleased there was more than one third sector organisation involved. They interpreted this as not 'tokenistically involving the third sector', but reflecting the reality of variation in organisational focus across the sector.
- Practitioners from the KiP dementia group said they were not working with each other in a more joined up way since taking part, as the majority already worked well together. Nevertheless, practitioners described better connections and increased referrals between the two services practitioners worked for – and referrals to the dementia and carers cafés. The project had enhanced how they worked.
- Some practitioners from the KiP heart failure group described finding that their networks had improved. For example, being able to 'put faces to names, names to job roles, and understand the purpose of specific roles' and now knowing who to contact for trusted advice. They explained this has resulted in referrals not needing to be made to statutory services because practitioners have been able to work together in the best interest of a person with heart failure.

Discussion

'Integration is not an end in itself – it will only improve the experience of people using services when partner organisations work together to ensure that services are being integrated as an effective means for achieving better outcomes'

(Public bodies (Joint Working)(Scotland) Bill, section 5).

There was a general consensus from the people involved in KiP, particularly practitioners, that the design of the project focused on person-centred approaches to supporting people with lived experience and carers. Integration was therefore positioned as being effectively realised when the individual outcomes of people with lived experience and carers were prioritised and addressed (Petch, 2013). Due to the ideas each KiP group chose, the project design related to empowering and *building capacity* amongst people with lived experience and carers as well as practitioners. This was about working in different ways, with practitioners more able and prepared to 'share the power.' This meant that less time was spent exploring the cultural and service-based structures and systems that may lead to improved integrated care outcomes for individuals.

In the KiP heart failure group, people hoped for an increase in public awareness of, access to, and engagement with the information that they had created about heart failure. Ultimately, they hoped for a change in attitude towards the condition so there was 'better public understanding', that people with the condition 'did not feel so sad about it' and that services have a 'holistic view of the patient both inside and outside the home'. Concrete approaches to make inroads to this aspiration include this group informing GPs about their work at local planning meetings and getting information on the screen in GP waiting rooms. The challenges in working with GPs and engaging with them as (equal) partners is, arguably, a 'systems issue' which sought to address other systems issues- namely earlier identification of the illness and referral to support so those with 'mild' heart failure can prevent it from becoming worse as they are more able to make well-informed choices about their health.

It remains an aspiration that greater numbers of practitioners, particularly those in key roles like GPs, will adopt the new ways of working trialled in KiP and help build evidence of their impact on the health and wellbeing of individuals. With this we will begin to see a shift in power towards those who use services and supports and the carers who support them.

4.4 What should be different/ remain the same in KIP?

4.4.1 Suggested changes

People had many suggestions for changes if this project was to happen again. These include:

- **Time:** Most people felt the days were too long at the start of the project. Some suggested too much time was spent getting to know one another. However, most felt this time was needed, to be able to work together well, and that the length of the session was necessary in the latter stages of the project.
- **Frequency of sessions:** Most people would have liked the sessions to have run closer together, for example every two weeks. (Over the 12 months or would this have made it a shorter, more condensed project ie. lasting only 12 weeks?)
- **Group composition:** In the KiP heart failure work people felt that the composition of the group did not fully support their intentions. Despite the group deciding not to recruit new members after numbers fell, on reflection some people were of the view that more carers and people with lived experience needed to take part so this perspective was more fully represented. Also the involvement of GPs was needed, and some wondered if Consultants could have been involved also – albeit the group had tried and failed to recruit the former. (See 3.2.5 for discussion).

A future aspiration might be that once the value of working in co-produced ways is better known and proven, currently 'hard to reach' health professionals will become less hard to reach.

- **Communication:** People would have liked more of an overview of the project purpose and to have addressed this purpose earlier in the sessions. Some of the challenges, complexities and learning points around this are addressed in 3.2.2 and 4.1.2.
- **Homework:** Some people did not like the homework, particularly when it involved reflective writing. However, action-based homework was more popular with some, although generally not practitioners, due to a lack of time in their working week. As previously mentioned, some did not like the term 'homework' due its connotations with school.
- **Facilitation:** In the KiP heart failure group some people felt that the process 'did not get into the nitty gritty' quickly enough and that some sessions were 'too touchy feely'. People's reluctance and resistance to this personalised way of working together had not been discussed during the process. Rather it was assumed (perhaps wrongly) that they had joined the project as they wanted to and were ready try out new ways of working to support more personalised care. A more asset-based appreciative approach to working

formed part of the project approach, so focus was what could be done, not what could not. Arguably, this drew some focus and gave less weighting to the barriers - personal and systems based – although it did not exclude either from the conversations.

4.4.2 What should be kept

There were several suggestions about aspects of the project that people would like to see remain if the project was to run again. These include:

- **Timing:** The timing of being invited to engage in the KiP dementia project was identified by some as key, as some carers were aware that dementia and carers' cafés were needed in their local area.
- **Space:** The locations were perceived as lovely places to meet and provided good and neutral spaces in which to work together.
- **Lunch:** The informality of lunch, and that everyone ate together, was described by many as an important time in the sessions to get to know each other and bond.
- **Equality:** In the KiP dementia group people spoke about a sense of equality, 'everyone was the same', 'we all learnt together' and there was 'no ring leader in this group, we shared responsibilities'.
- **Specific activities:** In both groups, asset mapping was perceived to be a useful activity, providing a contextual and tangible aspect to conversations and opportunities for people to learn more about their local area.

In the KiP dementia sessions, the mirror activity used in the first few sessions was popular. This was designed to help people get to know each other (and build this over the first few sessions) by sharing their likes, dislikes and aspects of their personal life history. It was also about group members getting to know each other as 'whole people' – and not just 'service users' 'patients' 'practitioners' or 'carers'.

The introduction to leadership video and 'getting something started' was also popular- this used a video of a dancing man who inspired others to join him until the whole field was dancing! This example highlights the value of humour and having fun, which people reflected upon in the evaluation.

- **Facilitation:** Iriss was positioned by some as 'helping' get this activity started, and 'sowing the seed' which others could plant, nurture and develop. The facilitators were also complimented as creating a 'nice atmosphere' which was 'informal'.

5 Conclusions

Summary of key achievements

The project sought to understand how health and social care partnerships can support more person-centred and integrated practice when working in a way that focuses on people first. It set out to achieve the following outcomes:

1. Increased capacity and capability among people using services to be active partners at individual and service level to influence their own health and wellbeing by contributing to the design *and* delivery of more person-centred care and support, including peer support.
2. Increased capacity and capability among people delivering services to work collaboratively with people using support and services
3. Enhanced understanding/relationships/collaboration between statutory and third sector
4. Cultural transformation towards asset-based, empowerment model.

Learning about the processes used was also anticipated and that this would be shared beyond the life of the project.

Outcomes 1, 2 and 3 were realised by all to a certain extent in both groups. People felt more confident and capable in engaging and interacting effectively with one another, both across sectors and with others with lived experience. The majority of people with lived experience also described increased awareness of the supports that they could access, while everyone developed new knowledge and experienced learning - learning from each other about services and supports available; learning about themselves; learning how to work with others; learning about some of the challenges and barriers involved. The assets of all came to be more fully realised over the course of the project – with practitioners' awareness of people's ability to help themselves, in particular, increased (outcome 4).

By the end of the project, practitioners had a greater appreciation of how people with lived experience felt and about the more preventative end of health and social care. Some felt that this empathetic blurring of boundaries between professionals and those with lived experience a positive thing and that this would become more common and less likely to be seen as 'unprofessional.' Others remained more uncomfortable with this. Significantly, practitioners had come to understand the difference between consultation (their usual approach) and co-production, with some claiming to have already put this new knowledge into action. New networks had also been established which would be useful in future work.

In terms of improvements accomplished within the project time frame:

- Two dementia cafés and a carers café were created by the KiP dementia group with improvements made to peoples' health and wellbeing, with the hope that this could be grown to support more people. An overview of these outputs can be found at: <http://s.iriss.org.uk/1JKyNHe>.

- In the KiP heart failure group, plans were that the information resources created by the group would be shared on screens in local GP waiting rooms (to support earlier diagnosis so that people were better able to self-care and prevent their condition worsening). By the end of the project this had happened in a few instances but their impact on others was not known. For an overview of these outputs: <http://s.iriss.org.uk/1J3bpDQ>

Discussion of key challenges

Historically people have *not* been asked about their experiences in order to support the improvement of services, and traditionally people tend to be consulted, rather than collaboratively involved in the identification and design of improvements. Furthermore, traditional project management approaches usually start with the end outputs and work 'backwards from these to derive a plan – not the other way around. The approaches used in KiP challenge people's expectations and cultural norms.

This may relate to the uncertainty expressed about the aims and purpose of the project. This involves making clear to group members that they drive and own the work (so set their own outcomes and objectives.) Repetition of this message is probably required as people easily 'forget' and fall into old ways of being.

Added complexities included communicating and modeling the new ways of working together at the same time as building the group and building a more shared understanding of 'person-centred care and support'. Clearly, greater stress should have been given to the fact that the project was as much about trialing new ways of working as it was about delivering real improvements – although the premise was that the process used would be more effective in delivering person-centred care because it truly involves people in design and delivery. Knowing *how* to build the capabilities and capacities of the workforce more generally, is also the bigger ambition of the project.

We can expect (or certainly hope) that when people come together they will seek to find a joint purpose, with the hope that they will be able to say of any output: 'I helped to make that.' The challenge is to keep all people motivated during the process when they are still forming as a group, building knowledge and trust, and are at different points of readiness to move from sharing experiences and building common understandings to planning and action.

Furthermore, the extent to which this approach can respond to difficulties in the system and at the juncture of health and social care is hard to substantiate. Some of the challenges faced by the KiP heart failure group - around identifying and recruiting people with heart failure at an early enough stage in their illness and being unable to bring GPs into the group as equal partners – highlights key issues. The other key issue, of course, is the time commitment involved in doing this type of work, particularly for practitioners who are often 'time poor.' However, weighting the time invested (six workshops and some 'homework') to galvanise the improvements, needs to be balanced against the outputs and impacts. With respect

to the KiP dementia group, significant achievements were made, with carers taking the lead in delivering new supports for themselves and others, unpaid. The impact of the improvements introduced by the KiP heart failure group are unsubstantiated, but their ambition was large, around the difference they hoped to make.

Time is clearly a significant challenge, particularly if a project, like KiP, is finite. With outcomes determined by the group, foreseeing all the possible challenges and trajectory of the work is simply not possible. The KiP heart failure group encountered significantly more challenges than the other group around recruitment, group membership and readiness. However, another key difference between the groups, was that it was within the power of the KiP dementia group to take forward actions themselves. Carers led and delivered the cafés. It was *not* within the power of the KiP heart failure group to reach and support people with possible heart failure on their own. For this they needed the help of GPs. Consequently, they and the project 'ran out of time' to measure the impact of the information resources developed. Neither did we get the opportunity in both groups to test out improvement methods to 'test' and re-test' them as part of an ongoing process – or see whether initiatives could be sustained or would evolve over time.

The time invested, weighted against the longer-term impacts of KiP (and similar approaches) would be informative to future up take of co-production as a way of working. This should be an area of future investment.

Key learning points

- Time may need to be built into a project plan for a project manager to understand people's readiness to engage in this kind of work at the very start.

The host organisation should be clear about the aims and objectives of the project and ensure that those recruited to it are fully signed up to and understand these. In this case, trialling new ways of working was the vehicle being tested to improve person-centred care and building new capacity was as important as the outputs. This may need to be stressed at several points of the work to remind group members; people can easily fall into more familiar ways of working.

- Check in with people how often they would like to meet, and about their experiences of the timing of workshop activities and breaks. Find the 'best compromise' if you have to if there are constraints on the hours people are prepared to work.
- Take time and make the best use of tools available to share experiences and build relationships and trust to form your community of learners and improvers; bring their assets out into the open.
- There can be a desire to focus on creating outputs or rushing to action without exploring how these relate to improving person-centred care in the local area.

- Tools that map local supports and services (as defined by the group) are also a useful tool for identifying existing assets and seeing where improvements can be made.
- Efforts may be needed during sessions to identify and respond to the need for a shift in thinking amongst group members, from a focus on personal experiences to broader implications for services and support if this starts to become an issue.

Project tools such as [experience maps and personas](#) can be created and sensitively used to help achieve this along with raising the issue with the group and trying to agree a way forward.

- During project planning allow for extra workshop days if a group is finding it difficult to identify and develop their ideas. (However, this assumes: that you have a flexible enough budget to cover this if, like Keeping it Personal, you pay for a neutral meeting space; you pay all people with lived experience for their time; peoples' timetables are flexible enough to accommodate this. Running more, but shorter days may be a solution to this.)
- Any uncertainties or questions need to be brought out into the open and any disconnect or ability to contribute explored. These should be viewed as opportunities to learn. Time should be taken to explore this in between workshops with individuals as well as at workshops.
- Similarly, *fully* encourage and explore different perspectives during a project to build new learning, knowledge and understanding. It may also be symptomatic of tensions that exist, voiced or unvoiced. This may be beneficial to the aims, outcomes, and outputs of this work.
- Sometimes peoples' priorities easily align and key members of a group lead and galvanise a group. There can be a dose of luck involved in this process.
- However, having 'the right people' in the group who are empowered to drive forward (or at least make the connections to those who are) is critical. Consider at the outset if you have all the key members you need to move this work forward; continue to ask this question throughout and take action if you do not. If key members cannot come to you, find ways to go to them.
- Be ambitious, but consider the limitations of what is feasible to achieve with the 'people assets' and other resources that you have including time. Focus on what you can do, not what you can't.
- It may be useful to check in how involved people feel they are able to be during workshops, particularly when there are people involved that rely heavily upon support, such as people who have dementia.
- Check out people's capabilities to engage with certain 'homework' tasks before prescribing anything and perhaps avoid use of this term. One

approach is to discuss people's ability to do this at recruitment and be much more explicit about what would be involved (if you can). Alternatively, let people determine themselves through discussion at workshops what they *can* 'offer' to do in between sessions. Again, focusing on what people CAN do is best.

- Finite outputs, such as information resources or dementia cafes, should not be prioritised over the learning and changes people experience themselves. These are outcomes too. (Furthermore, co-produced outputs can only emerge once a co-productive group has fully formed).
- Working in a co-produced way takes time and cannot be unduly rushed. Flexibility is required and having fun along the way is a definite plus.

References

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Keeping it Personal is part of the
People Powered Health and Wellbeing
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<http://pphw.alliance-scotland.org.uk/>

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