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Learning from the Experience-based Co-design Demonstrator Sites

Evidence and Evaluation for Improvement Team

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Executive summary

This report summarises the learning from three service areas that were supported by Healthcare Improvement Scotland's Improvement Hub (ihub) to demonstrate the use of Experienced-based Co-design (EBCD) in Scotland, including the factors that were identified as being important for success.

EBCD is different to other service improvement approaches in that it emphasises the importance of active involvement of patients and carers in collaborating and working in partnership with staff to design improvements in services. The five stage cycle or process brings together service users, carers and staff to reflect on their experiences of a service (gathered through filmed interviews and observations), and then work together to identify and co-design priority improvements.

Through this improvement work, EBCD has shown to enable staff and people using services to come together to share their experiences about what matters when receiving and delivering services and work together in new ways to improve the experience of care. These improvements also expected to have a greater impact over time as new ways of working become embedded.

A key challenge when using EBCD is the extent to which active involvement and participation of service users, carers and families can be sustained through to the co-design stages. Flexible and creative involvement opportunities and a focus on building relationships were described as being important for sustaining participation, particularly when patients may move on quickly from a particular service or unit.

Introduction

This report summarises the learning from three service areas that were supported by Healthcare Improvement Scotland's Improvement Hub (ihub) to demonstrate the use of EBCD in Scotland. This includes the factors that were identified as being import for success when using and adapting EBCD.

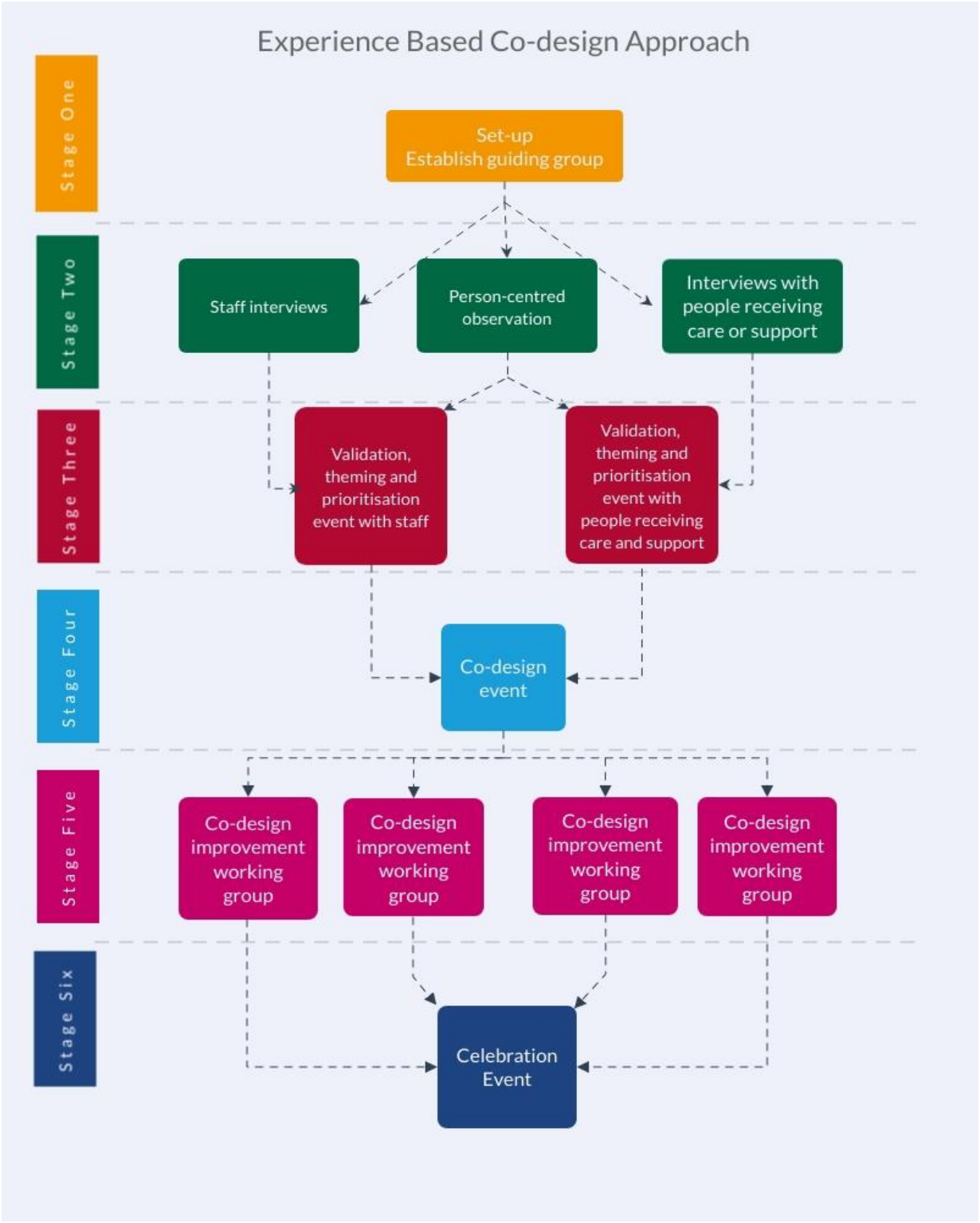
EBCD is different to other service improvement approaches in that it emphasises the importance of active involvement of patients and carers in collaborating and working in partnership with staff to design improvements in services. Having been developed from methods used in service design and participatory action research, the six stage cycle or process brings service users, carers and staff together to reflect on their experiences of a service (gathered through filmed interviews and observations), and then work together to identify and co-design priority improvements.

EBCD as a method or approach has evolved in response to the challenges that it presents in different service contexts and systems. Adaptations to the EBCD process are common in practice[1] and an accelerated version has evolved that utilises archive film instead of conducting patient interviews. The co-design focus of EBCD has also been found to vary in practice, with challenges being encountered in achieving the active involvement of service users in co-design as partners in the process[2].

To understand how EBCD was used and adapted across different service areas supported by the ihub and the lessons learned across these examples, a case-based qualitative evaluation was conducted. The findings summarised in this report address the following questions:

- How have different service areas used and adapted the EBCD approach to implement service improvements?
- What lessons are there about the factors important for success when using EBCD across different settings, including the challenges and opportunities?

Figure 1. EBCD approach



What does EBCD as an improvement approach involve?

EBCD brings staff, patients and carers together to share their experiences of a service, work together to identify and prioritise improvements and then implement these using co-design principles.

The six stages of the EBCD process can on average take between 9-18 months to complete (stages shown in Figure 1)[3]. It combines the use of observation and in-depth interviewing to collect staff, patients and carers experiences and explore various touch points in the care journey. Touch points are defined as 'the key moments or events that stand out for those involved as crucial to their experience of receiving or delivering the service'.

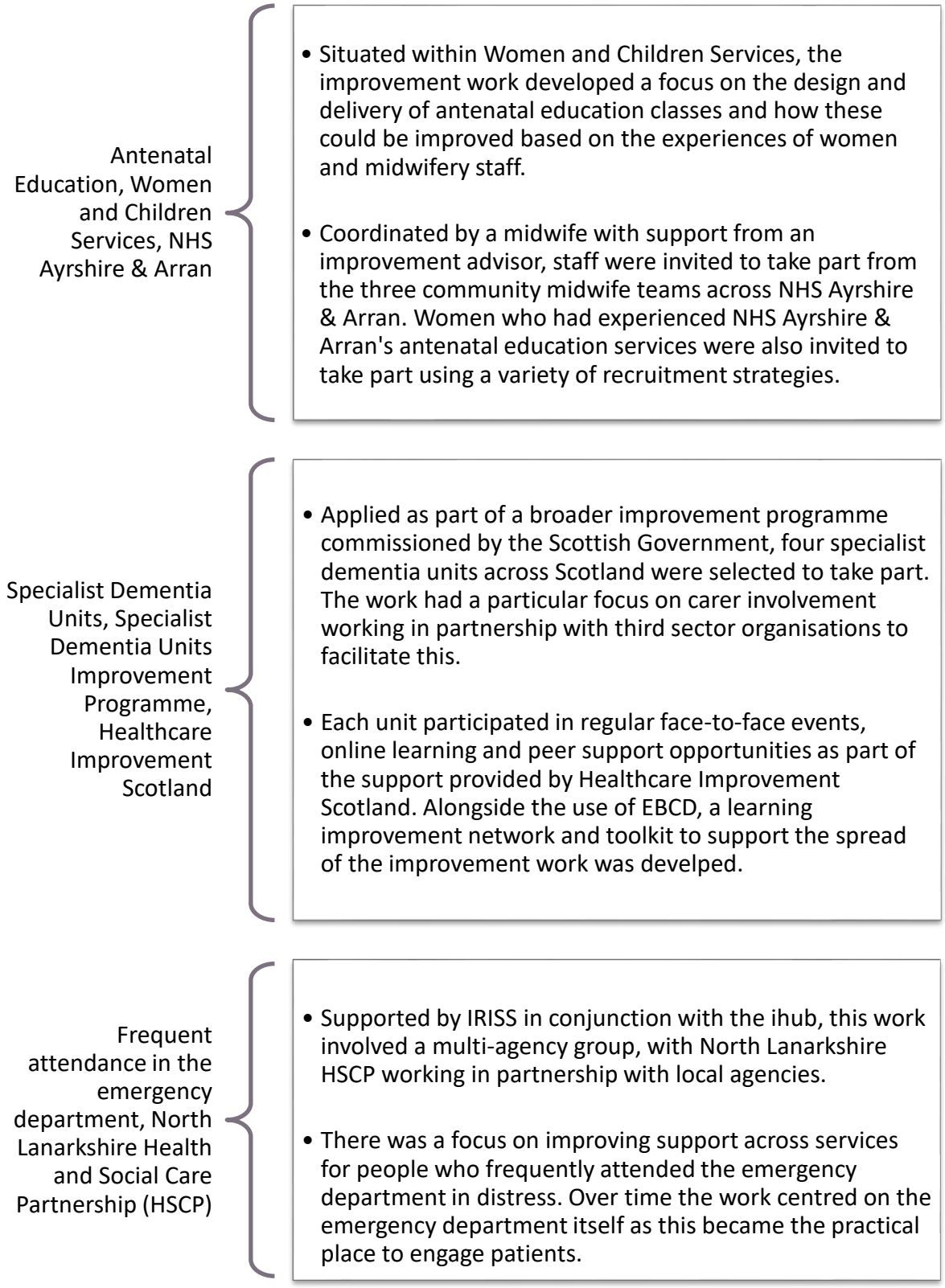
Filmed patient interviews are also edited to form a trigger film that acts as a prompt when staff, patients and carers are brought together in an event structured to identify shared priorities for improvement. Staff, patients and carers then work in small groups to co-design and implement improvements.

Where was EBCD used?

Three service areas were supported to use EBCD to implement service improvements in priority areas according to their local circumstances (see Figure 2 for the main features): Specialist Dementia Units participating in the Specialist Dementia Improvement Programme; Women and Children Services in NHS Ayrshire & Arran focusing on antenatal education; and a multi-agency project in North Lanarkshire Health and Social Care Partnership (HSCP) focusing on the issue of frequent attendance of people in distress in the emergency department.

All areas received introductory training in EBCD methodology which was delivered by the Point of Care Foundation[3] and methodological support and coaching was provided as part of Healthcare Improvement Scotland's work with each site.

Figure 2. Features of each service area using EBCD



How was the use of EBCD evaluated?

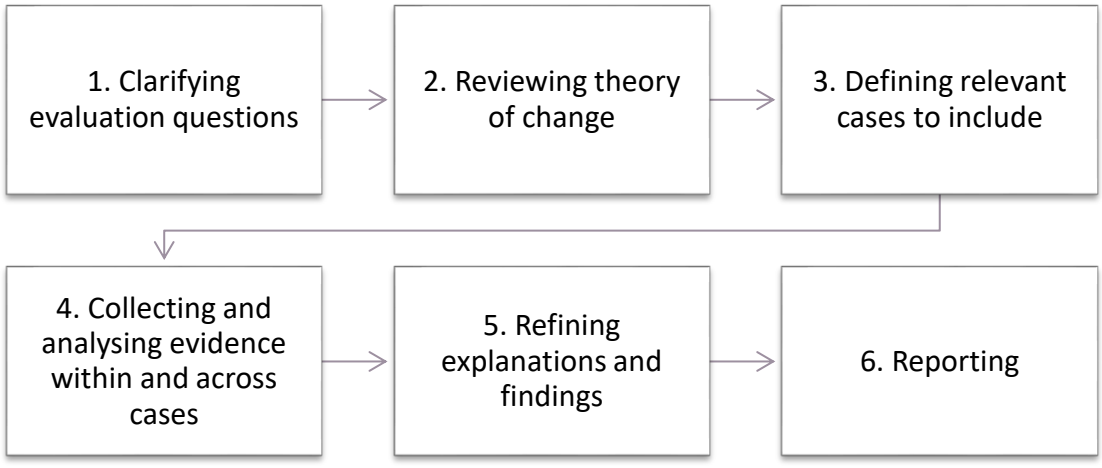
A case-based qualitative evaluation approach was used which is suited to examining complex change across different service contexts (see figure 3 for the key steps taken). As an approach, it focuses on the analysis of small number of relevant cases or stories of change to understand how change has taken place in particular circumstances. Similarities and differences within and across cases then provide a basis for identifying lessons learned about the factors that are important for success.

Three service areas being supported by the ihub to use EBCD were purposefully included as cases. Data collection involved documentary analysis, two semi-structured group discussions with the EBCD national steering group and three semi-structured interviews with improvement advisors involved with each area. The group discussions and interviews were audio recorded and transcribed. The data was brought together using qualitative data analysis software (Nvivo) and analysed using thematic analysis[4].

Limitations

A case-based approach made it possible to identify common lessons learned across different instances of use and adaptation of EBCD. However, as the findings are based on a small number of cases and limited to the perspectives of members of the EBCD steering group, the lessons are only applicable to service contexts with similar features.

Figure 3. Key steps in the evaluation



Findings

Improving the experience of care using EBCD

A range of improvements have been implemented as result of the work across each area to understand what matters in the experiences of patients, staff and carers in their local context. These improvements reflect the small scale and practical nature of change expected as result of using EBCD but which is also expected to develop and spread over time as new practices and ways of working together become embedded.

In NHS Ayrshire & Arran, through the process of nine co-design meetings, the use of EBCD resulted in a new approach to booking antenatal education classes including electronic booking and improved use of social media to increase awareness of the availability of classes.

At the Specialist Dementia Unit sites*, the insights gained through the EBCD process, particularly from their use of observational techniques, identified stress and distress and mealtimes as being key priorities for improvement. Improvements were made in how carers are involved and how communication is conducted with one unit developing an information pack to support admission to the ward. The learning from using and adapting EBCD in Specialist Dementia Unit sites is also being brought together in a toolkit.

In the case of North Lanarkshire, progressing to the co-design stages was not possible due to challenges specific to involving a short-stay patient population with complex needs in co-design events and in maintaining ownership and leadership for the project across a multi-agency group. However, a useful approach to working with information governance was established during this project that enabled digital recording to take place across other EBCD projects sites.

The learning and improvement themes from this co-design project have now been embedded or have influenced other key improvement programmes in Lanarkshire that aim to improve the experience for this same group of patients. This includes the Distress Brief Intervention Programme (DBI), which aims to build connected compassionate support for people who present to front-line services in Scotland in distress (www.dbi.scot).

*Specialist Dementia Units webpages: https://ihub.scot/improvement-programmes/focus-on-dementia/specialist-dementia-units/

Improving practice and ways of working

Across the sites, changes in practice were understood to have arisen from the use of EBCD, as staff have come together with patients and carers to work in ways that have not happened before.

> *"It might not be the hard tangible stuff but it gets the team working as a team and its actually really engaged and brought people together in a way that they haven't been brought together before to work this way"* Improvement advisor, Specialist Dementia Units

There was an understanding that using EBCD had provided the opportunity to be involved in co-design for the first time and to drive a culture of improvement based on these practices and ways of working that support this.

> *"One of the things that has come out of this work, is the shift in culture. There are more opportunities for staff to be involved in co-improving for the first time really"* Associate improvement advisor, Healthcare Improvement Scotland
>
> *"Anecdotally they felt more confident using QI methods, they felt it has helped to drive improvement, it's almost like it has helped to drive a culture of improvement. In the two wards I've been working with I can definitely see that, so we've had medics, AHPs, nursing staff, care support workers, so I've been able to work with quite a range of staff"* Associate improvement advisor, Specialist Dementia Unit sites

Lessons learned about the use and adaption of EBCD

A number of lessons learned were identified across three service areas that reflect the challenges and opportunities this approach presents in the context of different care settings. The following learning themes were identified which are also summarised in Table 1 as key challenges and opportunities.

Allowing the focus for EBCD to emerge through the course of listening to and understanding experiences

EBCD works differently from other approaches because of how improvements that are based on experience only emerge through the course of listening to and understanding the perspectives of those that are receiving and delivering care in a particular place and context. Across the demonstrator sites, how the EBCD process was focused and specific objectives developed was important for success.

In the experience of using EBCD in NHS Ayrshire & Arran, although there might be improvement issues that are already of interest to explore such as access to services, specific aims for EBCD emerged from the process of engaging with participants and listening to their experiences.

> *"Often in quality improvement work it helps to draw a boundary around the thing you want to improve so that you know what to focus on. However, predefining an issue from the start draws a boundary around that thing so in future I would use EBCD to help staff and service users explore the area of concern they want to improve, what it is, what it means and through this let the boundaries emerge"*
> Improvement advisor, NHS Ayrshire & Arran, Antenatal Education demonstrator site

> *"We started off hoping to develop antenatal classes to be more accessible for hard to reach women. But these women were even less interested in becoming involved in EBCD meetings than in antenatal classes. It took us ages to work out that the aim of the EBCD project was emergent from the process – through reflective discussion of the service"* Coordinating midwife, NHS Ayrshire & Arran

Similarly, in the case of North Lanarkshire HSCP demonstrator site, although there was a desire to focus the co-design work around the whole service journey for people that experience crisis and emergency hospital admission, the work became defined around the location where people experiencing crisis were most likely to be reached, such as at the emergency hospital department.

Other challenges were described in terms of having clear enough ownership and leadership for the work when the focus for improvement spanned multiple NHS, third and independent sector service groups.

> *"The lead of the project group moved to a new post therefore the lead from the emergency department took over which meant the focus shifted to the emergency department and we lost some of the high level ownership and prioritisation at the Health and Social Care Partnership level. There was a need to continue momentum and for there to be a sense of ownership and influence over what needs to be improved"*
> National methodology support lead, Healthcare Improvement Scotland

Taking time to get started and develop capability

From a range of perspectives there was an understanding that progressing EBCD could be time and resource intensive. An important component for success relating to time was developing the understanding and capability to use EBCD and be in a position to work together in the new ways required for co-designing improvement.

> *"When they do come together they are ready to work together but the process has made that happen and I think we have to appreciate some of the important components of EBCD are actually helping to get people ready for the co-design part"*
> National methodology support lead, Healthcare Improvement Scotland

From the perspective of using EBCD in specialist dementia units, a collaborative approach was important for developing capability as it provided opportunities for specialist dementia staff to learn from each other.

> *"There were benefits from the collaborative and learning sessions because it gave the units an opportunity to come together to look at the issues. I think for them to get a sense of where they were in comparison with their peers I think that was quite important to them and it gave them an opportunity to learn together"*
> Associate Improvement Advisor, Specialist Dementia Unit demonstrator sites

From the perspective of improving antenatal education in NHS Ayrshire & Arran, developing the capability to use EBCD was an experiential process, requiring direct experience of facilitating and working actively with people using services.

> *"In my experience, experience-based co-design is not something that you can learn didactically in a classroom setting, it's something that is experiential…it is through practice that you are able to build your own capability"* Improvement advisor, NHS Ayrshire & Arran demonstrator site

Overcoming barriers to capturing people's experiences of care

Capturing the experiences of people using services is a key part of how improvement is grounded in what matters to people. The production of the trigger film from interviewing people is viewed as a powerful way to prompt the identification of shared improvement priorities. However, this can also be a barrier to using EBCD. Negotiating local governance requirements and the skills and technology required for filming were challenges encountered across the different services.

> *There were lots of roadblocks, resistance to doing things because of local information governance rules, but we were able to challenge this and work with them to enable us to move forward"* National methodology support lead, Healthcare Improvement Scotland

In the case of Specialist Dementia Units, although there was some success in interviewing carers and using talking mat picture boards to communicate with patients, observation became a crucial way of gaining insight into the experiences of receiving and delivering care in each unit when interviewing of patients was not possible. Adaptation of structured observation tools such as the Workplace Culture Critical Analysis Tool (WCCAT) became important in structuring and analysing the observations in the context of specialist dementia care delivery.

> *The bit that was really helpful, perhaps more than any of us had anticipated was observations to get the experience of people with dementia… people in specialist dementia units tend to have quite either advance dementia or quite acute symptoms so sitting down and having an interview or focus group or whatever is not going to work for them"* Improvement advisor, Specialist Dementia Units demonstrator sites

Finding ways of sustaining participation in improvement

The extent that sites felt they were successful in implementing improvements together with people involved in the co-design stages varied. There were a range of different circumstances that may have contributed to this but how participation was sustained was highlighted a being important for success.

> *"I wouldn't say that it felt like co-design at this stage, we co-defined the definition of what the improvement areas in all of the sites were but actually involving carers in taking forward the improvement bit we haven't been as strong with that"* Improvement advisor, Specialist Dementia Units demonstrator sites

Flexible and creative involvement opportunities were described as being important for sustaining participation, particularly when patients may move on quickly from a particular service or unit. Although the level of co-design that will be achieved was understood to depend on the extent to which patients and carers are in a position to continue their involvement.

> *"If people are going to use EBCD, they need to be creative in terms of how they engage with relatives and I think, we had a relatively easier time in a care home type environment as they are in contact with carers in the longer term, whereas in the other units there was higher turnover"*
> Associate improvement advisor, Specialist Dementia Units demonstrator sites

In the case of antenatal education, sustaining participation was understood to be a relational process, requiring an emphasis on flexibility and efforts to build rapport and trust. The use of a group chat tool, in this case the messaging app WhatsApp, helped to overcome barriers to participation by how it helped women to be more continuously involved.

> *"The other reasons why the project took so long, is that you can't build rapport by just meeting with someone, if you want them to come back and remain engaged then you have to invest in the relationship to do that"*
> Improvement advisor, NHS Ayrshire & Arran demonstrator site

Table 1. Challenges and opportunities identified across each case

Challenges	Opportunities
Specialist Dementia Units	
• Conventional interviewing was difficult to carry out with patients which acted as a barrier to understanding the experiences of people with dementia. • Co-design became less of a focus for the improvement work as challenges were encountered sustaining service user and carer involvement.	• Observational work was key for understanding more about what was being experienced by people with dementia in each unit and built care team confidence in their abilities to observe the experience of their patients. • Adaptation of structured observation tools such as the Workplace Culture Critical Analysis Tool (WCCAT) provided an opportunity to gain insight into how care was being experienced. • A flexible and creative approach to involving carers and families helped to mitigate against a lack of involvement in the process.
Antenatal education in Women and Children Services, NHS Ayrshire & Arran	
• The topic of antenatal education provided a pragmatic focus for improvement but limited the opportunity to understand more of what matters as part of the whole antenatal experience.	• Sustaining participation was identified as being a relational process, requiring an emphasis on flexibility and investment in relationships. • The use of a WhatsApp group helped to overcome barriers to participation by how it kept participants involved more continuously and facilitated discussion and ideas.
Frequent attendance in emergency care, North Lanarkshire HSCP	
• Engaging patients was a key challenge when trying to reach a short-stay population with complex needs. • A lack of ownership amongst the multi-agency group over time created difficulties sustaining the process.	• Filmed interviews provided insight into the journey across services for people frequently attending the emergency department in distress. • The development of clear information about how EBCD is carried out and governed within the project supported organizational approval and information governance requirements.

Conclusions and key lessons learned

Using EBCD as an improvement approach has enabled staff and people using services to come together to share their experiences and work together to develop a number of improvements across the participating services. The outcomes of this are also being experienced in terms of new practices and ways of working together.

A key challenge was the extent that participation in the co-design stages could be sustained but there was also the opportunity to find ways of involving patients and carers using flexible and creative approaches that emphasize the importance of building and maintaining meaningful relationships.

Overall, the EBCD process required tailoring to the context of the setting including how patients and carers are likely to be able to engage and communicate as part of the process. Further key learning points from the experiences shared across the national working group include the following:

- Readiness to adopt EBCD as an improvement approach is a key consideration, since this is a different approach to involving people in improvement and capability for this takes time to develop.

- The improvement focus for an EBCD project should be broad in the beginning so that specific aims and improvement priorities can emerge through the course of listening to and understanding people's experiences and so that there is ownership for taking these forward.

- Bringing staff, people using services and carers together to participate in a co-design process delivers a depth of insight into how services are being experienced that we would not otherwise have obtained. This however requires flexibility in terms of when and how people are brought together.

- Willingness and capacity of patients, carers and relatives to participate in what can be a lengthy process is important to consider. There is also opportunity to invest in relationships and develop new practices and ways of communicating and working together to ground improvement in shared experiences of what matters.

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