



# **STORIES FOR CHANGE**A QUALITATIVE EVALUATION

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# **EXECUTIVE SUMMARY**

### **STUDY AIM**

To evaluate the process of the implementation and the impact of NHS Horizons' approach to co-design and co-production using the Stories for Change project as a case study.

### STUDY DESIGN

This study was designed as a rapid feedback evaluation based on interviews with 3 of the project organisers, 6 co-design group members and 7 NHS professionals. It was also based on observations at different points of the programme, including the Skills Session, one Co-Design Group Session, the Learning Event, and the Debrief Session. The study was reviewed and approved by the UCL Research Ethics Committee (REC) (6862/008).

### MAIN FINDINGS

### **EXPECTATIONS OF THE PROGRAMME**

- In general, both the co-design group members and the project organisers expected that the sharing of stories would bring about change to maternity services and also lead to a wider movement.
- Project organisers expected the involvement of participants during the Skills Session to be on a spectrum, with the building of a safe, open space being their central focus.
- Co-design group members expected the audience to be engaged during the Learning Event, whilst project organisers hoped NHS professionals would be moved by the stories.

### THE MAIN FACTORS THAT ACTED AS POTENTIAL BARRIERS TO DIFFERENT STAGES OF THE PROGRAMME

- The main barriers that were shared by co-design group members and project organisers related to the way in which recruitment was done and the lack of time that was originally scheduled for them to meet.
- Co-design group members stated that stories were not shared early enough. This would have helped them to develop their stories, understand the similar themes arising from their stories and identify the changes they wanted to propose at the Learning Event.
- For the Skills Session, some perceived that a barrier was the lack of sharing their stories and development of their skills and some would have preferred the session to be based on role play and practice.

### THE MAIN FACTORS THAT ACTED AS POTENTIAL FACILITATORS TO DIFFERENT STAGES OF THE PROGRAMME

- The main facilitators were related to the formation of an open and safe space, the diversity among the project organisers, the way in which the participants were remunerated, and the design of the project.
- However, there were conflicting ideas in relation to the structure of the co-design process. Whilst some saw
  the non-hierarchical nature of the co-design process as a facilitator to creating the open and collaborative
  space, others saw it as impractical (at the beginning of the project). There was agreement that the planning
  session was useful.
- Additionally, views were conflicted in relation to the amount of time spent together, whilst some felt that there was sufficient time to discuss and plan as there were informal sessions outside of the scheduled sessions, others felt that there should have been more formal sessions.

### IMPACT OF THE LEARNING EVENT ON CHANGE

- The immediate impact of the Learning Event related to the use of stories, the empowerment of the co-design group members, the space for communication between service users and providers, and the facilitation of the event.
- In terms of long-term impact, participants believe the NHS will incorporate information from the event into their re-validation reports, everyone will reflect on how to incite behaviour change in a positive way and the stories will be shared beyond the Learning Event to reach broader audiences.
- Participants hoped that more service users will be involved in similar projects and that the culture of maternity care would shift.
- The Public Narrative approach impacted the co-design group members by empowering them and leading them to use the approach outside of the context of the project. NHS professionals were impacted by seeing the value of the approach and hoping future projects would use this approach.



### ADVICE & RECOMMENDATIONS MADE BY PARTICIPANTS

- The main areas for improvement of the project were related to recruitment, such as connecting with a variety of communities, and including fathers and partners, more individuals living in areas of deprivation and mothers from ethnic minority groups whose first language is not English.
- Participants also suggested more structure and an outline of the co-design process, an explanation of which aspects of the project will be co-designed and which will be co-facilitated to mark the roles more clearly and an increase in the number of scheduled sessions.
- In order to promote change, participants recommended creating a timeline to track changes, an action plan and to use social media to follow up on decisionmakers' promises and to keep the movement going.

# STUDY AIMS AND RESEARCH QUESTIONS

The aim of this rapid evaluation was to evaluate the process of the implementation and the impact of NHS Horizons' approach to co-design and co-production using the Stories for Change project as a case study.

The rapid evaluation was guided by the following guestions:

- 1. What is the programme theory guiding the Stories for Change programme? What are the expected outcomes?
- 2. What are the co-design group members, the project organisers, and NHS professionals' expectations of the project?
- 3. What are the factors acting as barriers and facilitators to the implementation of co-design and co-production?
- 4. What is the perceived impact of the Learning Event on creating change?
- 5. How is the Public Narrative approach perceived by the different groups involved?
- 6. What advice and recommendations do participants have for future similar projects?

# **METHODS**

### **DESIGN**

This study was designed as a rapid feedback evaluation with interviews as the main source of data (Vindrola-Padros, 2021). Using a rapid feedback evaluation allowed us to continually collect data and provide feedback within a limited timeframe (McNall et al., 2004: 288). We undertook iterative processes of data collection and analysis, carrying out the two stages in parallel in order to share emerging findings and to inform subsequent data collection (McNall and Foster-Fisherman, 2007). In addition to this qualitative study, a rapid review is being undertaken by members of the research team (see separate report). In the future, an economic evaluation will also be carried out, and we have developed a framework to help the project organisers identify the data they will need for a future evaluation (see Appendix 1).

### SAMPLE AND RECRUITMENT

Purposive sampling was used to recruit a sample of 16 participants, which included six members of the project's co-design group, three project organisers, and seven NHS professionals who attended the Learning Event. The project organisers included two co-facilitators and a project manager and administrator. The NHS professionals recruited were all stakeholders in maternity services, which included Maternity Voice Partnership (MVP) co-chairs, managers, consultants, those involved in their Local Maternity and Neonatal System (LMNS), and the sponsors of the project. Co-design group members and NHS professionals were invited to take part via one of the project organisers. Those who showed interest in participating in the study then were contacted by one of the researchers (SM) via email. Participant information sheets and consent forms were shared, and interviews were arranged.

### **DATA COLLECTION**

In-depth, semi-structured interviews were conducted with the project organisers, co-design group members, and NHS professionals over Zoom and Microsoft Teams from 14 February 2022 to the 23 May 2022. The interviews were conducted by two researchers working in parallel, using an interview topic guide, which was



created based on the research questions guiding the study. The interviews were audio recorded and interview data were entered into RREAL sheets, which helped to organise and summarise data in real-time based on key topics of interest (Vindrola-Padros, 2021). Organising data in this way allowed the researchers to maintain consistency throughout data collection and identify the key findings of the study in a short amount of time (Vindrola-Padros, 2021).

The interviews were conducted in two stages in order to capture the process of co-designing and co-producing the programme from beginning to end. The first stage was carried out with nine participants, who were co-design group members and project organisers. The interviews captured their role in the project, their expectations, their experience of co-design and co-production, and any barriers and facilitators to the co-design and co-production process. The second stage of interviews was carried out with 12 participants, which included co-design group members interviewed in the first stage in order to capture their experience of the overall process over time, and NHS professionals who attended the Learning Event. These captured their views of the Learning Event and what change they hoped the project would lead to. The interviews in both stages captured participants' views of the Public Narrative approach and recommendations for future similar projects.

Documentary analysis and observations were carried out to ensure triangulation through the use of different data collection methods. This also allowed us to include information that was not brought up in the interviews, addressing any knowledge gaps, and to analyse the intended objectives of the programme compared to what is happening in practice (Vindrola-Padros, 2021).

### **DATA ANALYSIS**

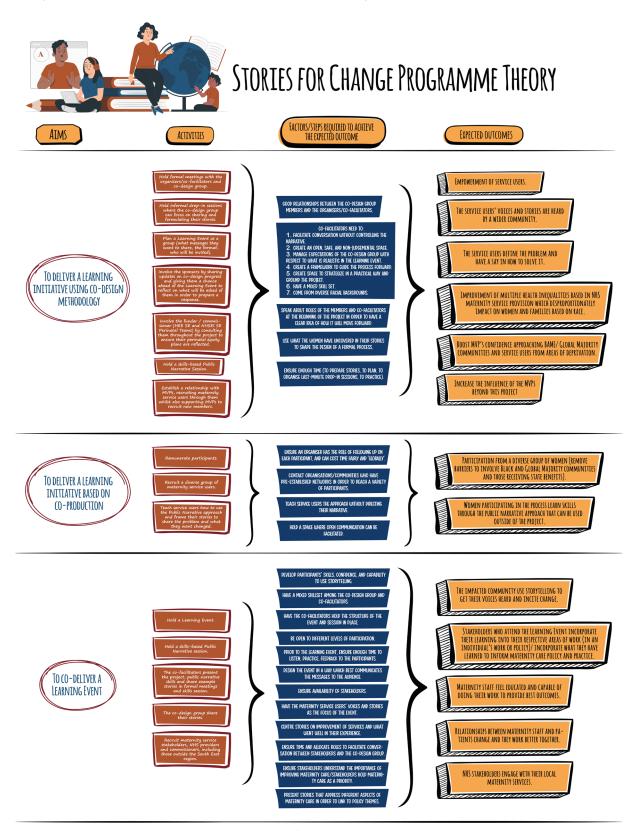
Following rapid qualitative data analysis approaches (Vindrola-Padros, 2021), RREAL sheets were reviewed by the research team to identify recurrent topics across study participants. A list of key findings was generated, and interview notes and recordings were reviewed to create detailed descriptions of these findings and identify illustrative quotes.



# **FINDINGS**

### PROGRAMME THEORY

Based on interviews, observations and documentary analysis, we developed a programme theory that outlines the aims, expected outcomes, and the activities and factors required to achieve these outcomes.







### **EXPECTATIONS OF THE PROJECT**

The main **expectations** of different elements of the project, shared by the project organisers, co-design group members and NHS professionals could be organised into the following categories:

### **GENERAL EXPECTATIONS OF THE PROJECT:**

### **CO-DESIGN GROUP MEMBERS**

- To help make change by using their experiences and stories, but some hoped for the project to also bring them personal benefit.
- Some believed that their voices may be heard but they expected that for change to actually occur, time would be needed.
- Many stated that they expected the movement to go beyond this project.

### PROJECT ORGANISERS

- Their main expectations were to have the voices of mothers at the centre of the project in order for the NHS to gain a deeper understanding of patients' perspectives and thus deliver improved healthcare.
- At the core of their expectations was the hope that this project starts a wider movement, starting with NHS workers to create a long-term plan for change, which is something that the co-design group members echoed.

### **EXPECTATIONS OF THE SKILLS SESSION:**

### **CO-DESIGN GROUP MEMBERS**

 Many hoped to gain skills and emotions that they could then use to develop their own personal stories, adding depth and more intensity to their experiences.

### PROJECT ORGANISERS

- That involvement of participants would be on a spectrum, project organisers did not expect that the group members would deliver the whole session but also did not expect them to simply passively participate.
- Similarly, they had no expectations regarding the involvement of participants as there was no hierarchy, just an open space.
- Organisers focused on building a sense of safety, bravery, and courage together, in efforts to prepare everyone for the Learning Event.
- There was a strong hope that everyone felt as if they were gaining something, and that this was worthwhile use of their time.

### **EXPECTATIONS OF THE LEARNING EVENT**

### **CO-DESIGN GROUP MEMBERS**

- They hoped to create change through the sharing of their stories and that by the end of the event they would leave with the hope that maternity services might get better.
- Expectation that the audience would ask questions to show their appreciation for the women sharing their stories but also to demonstrate that the stories meant something to them.
- For the audience to appreciate that this project is a lot of work, time, and energy for the group members.
- A few women hoped that the co-design group members had the confidence to effectively share their stories, especially in front of the NHS leaders.
- Some anticipated that they would be more of a listener than an active participant, as they felt as if they had more to gain from others than to share.

### PROJECT ORGANISERS

- That the women would tell their stories and bring about some form of change to policy, to an individual's
  work that attended the Learning Event, or to the work of people they manage because they have heard,
  understood, and been moved by their stories.
- Some of the co-design group members expected that everyone would share their stories, but the project



organisers made it clear that this was not effective, so, there was hope that aspects of different stories would be shared that linked to different policy themes.

- That the NHS professionals would be engaged and moved by the stories shared by the co-design group members and that everyone would be seen as a person rather than by their professional roles or positions.
- A core hope that change would be made but not in the vague sense. For example, for MVPs to make changes locally based on what they heard at the event.
- Expectations that mothers would feel empowered during and after the event.
- To create a feedback loop about 9 months after the Learning Event to showcase the changes that have been made.

### NHS PROFESSIONALS

- They anticipated that the proposed length of time of the event would lead to a lack of focus.
- However, someone stated they had no expectations, which was helpful as no presumptions were made.
- The co-design group members sharing their stories was expected but the discussion, reflections and pledges were a nice surprise.

### BARRIERS AND FACILITATORS

The main barriers that were shared by co-design members and project organisers related to the way in which recruitment was done, the lack of time that was originally scheduled for them to meet and the lack of early sharing of stories (see Table 1 for more in-depth explanation of the barriers). The main facilitators to the implementation of co-design and co-production that were shared between the project organisers and the co-design group members related to the creation of an open and safe space, the diversity among the project organisers, the way in which the participants were remunerated, and the design of the project (see Table 2 for more in-depth explanation of the facilitators).

However, there were conflicting ideas in relation to the structure of the co-design process. For instance, whilst some saw the non-hierarchical nature of the co-design process as a facilitator to creating the open, collaborative space, others saw it as impractical. However, after the planning session, it was clear that all co-design group members felt that a session dedicated to planning was necessary to ground their ideas for the preparation of the Learning Event. Another conflicting idea related to the time spent together. Whilst some felt that there was sufficient time to discuss and plan as there were informal sessions outside of the scheduled sessions, others felt that there should have been more formal sessions.



**Table 1. Barriers** 

	PROJECT ORGANISERS		CO-DESIGN GROUP MEMBERS
	RECR	UITMENT	
Participants were primarily recruited through social media and through MVPs, which acted as a barrier to working with people that the healthcare service hasn't worked with before.	"We were recruiting people primarily through social media, obviously with social media you are finding the people you are already connected with."	Potential barriers to participation due to systemic factors that may make it difficult for some to participate, including: Those who do not speak English well. Those who do not have access to technology. Those who do not have childcare options.	"I wonder in terms of the aims the project in terms of parity of outcomes and parity of care, I wonder if actually some of the people who suffer the most from less effective care, less compassionate care, are people who don't speak very good English, people who don't have access to being able to join online groups, people who don't have the childcare support to be able to come join in those online groups."
Did not know that providing remuneration would interact with state benefits, potentially leading to the exclusion of participants from more deprived backgrounds.	"We really want to make sure that we remunerate people for their time, which is great in practice but in reality [] the majority of the time if someone is in receipt of any state benefit they are unable to claim this money which then feels inequitable among the women taking part."		
	LACK OF SCHEDU	LED TIME TOGETHER	
Less time spent together than needed due to funding that limited the sessions to three co-design sessions and one Learning Event. This also led to unscheduled meetings having to take place.  "For funding reasons, we have three co-design sessions and then we have a Learning Event. [Co-facilitator] is using quite a lot of discretionary effort to coach and support in between, but it's never enough."		Led some participants to feel that the meetings could be quite repetitive which slowed down the co-design process.	"On Zoom [] the time together isn't a lot [] I wonder if a whole day together of co-designing, whether that be a day together or online, to accelerate the momentum of things, rather than having to constantly check back in."  "We need to collaborate a little bit more, but being able to do that would mean that we need more time."
		Planned to spend less time together than was actually needed, which led to many unscheduled meetings.	"If they were to do something like this again I think it needs more time, initially it was advertised as can you commit to five or six days but actually there was a lot more commitment needed."



OTHER FACTORS RELATING	TO THE CO-DESIGN PROCESS	
	Lack of sharing stories during the co-design pro- cess, which meant that:	
	It was difficult to know what the underlying themes between their stories were, which made it more difficult to formulate their asks for change at the Learning Event.	"What I would see as more useful is using some sessions to share our stories with each other so that we can become more familiar with each other around what each person is bringing."
	Some did not receive feedback early enough, which would have helped them develop their stories.	
	Interacting online made communication less coherent.	"In an ideal world, if it were face to face, co-design would be a lot more co-herent [] It's very much jarred in some ways, it doesn't flow as naturally as it would if it were face to face."
	For some, the practicalities of the co-design process were vague as there was no one who was leading the project. Some felt that there was a lack of defined roles at the beginning, which meant that the co-design approach did not feel practical.	"The practicalities of the co-design process are still a bit vague [] If everyone is brought to the same level, as in if the facilitators are really putting the power back to the group, that's a really nice idea but sometimes you need someone to guide it [] there needs to be some sort of concrete steps."  "Sometimes you lose the sense that there's someone driving this forward in a practical way [] I don't know if roles need to be more defined and marked out, and at the beginning setting the boundaries of what will be co-designed and co-delivered, and what aspects will be facilitated and delivered by the professionals."



	SKILLS	SESSION	
The lack of co-facilitator to facilitate a breakout room meant that not all the maternity service users got to share their stories.	"It had become a discussion about one person's story [] and that was the group of the three that was not led by either [co-facilitator]. If I had my time again I would do it differently and I underestimated the need for [co-facilitators] to hold the space to ensure that people were kept safe."	They were not as organised as they could have been in advertising the Skills Session which meant they did not get as many participants as they thought they might.	"I thought more people would attend, so I don't know whether we left it a bit late in the day to advertise to get the word around, I noticed my local MVP hadn't shared anything [] that's one thing we could have been a bit more organised with."
		For some, the session did not build on their skills as they expected.	"When you hear 'skills session' you think that you will come out of it feeling like you've gained something, or whether you've come out with a bit of food for thought [] I don't think that that's labelled quite appropriately."
	LEARN	ING EVENT	
		Some felt that the variety of ways in which the stories could be shared was not clarified enough, which led to fewer people participating than there could have been.	"They only clicked later, much much later, much too late, that they could have shared their story in the smaller break rooms which weren't recorded [] I think if that message had been clarified earlier there might have been a bit more participation."
		Lack of childcare meant that one member had to balance entertaining her child and being present at the event.	"I had my daughter with me as well, as I don't have childcare yet, so that was a bit of an obstacle as I was kind of rattling her whilst also trying to engage in the event."



### **Table 2. Facilitators**

	PROJECT ORGANISERS		CO-DESIGN GROUP MEMBERS
	CREATION OF	AN OPEN AND SAFE SPACE	
The project organisers believed in their capability to create change; commitment and passion created an open and safe space.	"The facilitators, there is a lot of optimism, we believe in what we are doing, we really see the capability of this for change."  "I found it really interesting that we hadn't talked about 'oh, we are creating a safe space' or anything like that, we didn't know how it was going to go, you know we are bringing people together [] and I was really touched when one of the mums spoke about how safe they felt [] that really stood out to me."	Supported by project organisers who:  Recognised the challenges the maternity service users had been through.  Were active listeners.  Made co-design members feel actively a part of the group.  Used language focused on collaboration and cooperation.  Made mothers feel they could express sensitive issues, such as racial bias and consent.  Were aware that the co-design group are mothers and made mothers feel welcome to feed and take breaks in the meetings.  Facilitated discussion in a productive, yet not decisive, way.	"I feel like I am actively part of a group because it is reciprocated, so [the project organisers] are active listeners, they actively contribute, it doesn't feel like it is another thing for them to do on their list for that day."  "The language that is used is all about collaborating, cooperating with one another, being part of this journey with us."  "You can even express anything that is sensitive, like racial bias, like lack of consent [] but you forever feel supported while discussing it which is great."  "They were very good at prompting discussion without necessarily leading it."  "[The project organisers] should receive multiple accolades for this [] the energy, the organisation, the direction, the support that as a team, the three of them do [] they felt like management without feeling like management."
The project organisers valued mental wellbeing in order to empower the women and not re-traumatise them.	"The wellbeing of the mums, ensuring that it's really clear that we didn't want any re-traumatisation."	The space was open, safe and non-judgmental, which was conducive to sharing their stories and ideas.	"We all felt quite safe, a very safe space to discuss whatever we wanted to maternity related."  "Open-ended flow of discussions and thoughts around what we are thinking."
The project organisers ensured that the boundary between the private and the personal was established from the beginning to ensure that people were sharing what they were comfortable with.	"We are very clear about the distinction between the private and the per- sonal."	Keeping the personal and private separate was a boundary that was set from the beginning.	"There is a difference between the personal, which we want to bring the personal to this storytelling event, but don't necessarily bring the private. It's been very nice to have that acknowledged that there are going to be boundaries."



		Lack of pressure to share during the process.	"There's no pressure, no expectation, there's an expectation to share, but even with that, you share what you feel like sharing."
		Felt that they were in the same boat allowed them to share and learn from each other.	"With birth trauma, it can feel very isolating [] and so being around other parents who had actually gone through, not even necessarily similar stories but had faced difficulties within their labour and birth and through pregnancy, that has been [] the opposite of isolating, reassuring that I am not the only one."
			"We've got a lot to learn from each other, but we're all in the same boat. It's quite a strange situation."
	DIVERSITY AMON	NG THE PROJECT ORGANISERS	
Diverse project organisers represented the inclusion they want to embody in the project, both racially and in terms of including service users.	"[Co-facilitator] is both a service user, a kind of mentor and coach and support. I think we've deliberately positioned me at one step removed as the facilitator of the workshops [] I am white [] and one of the key things, not the only, but one of the key things in this programme was race and racial equity. It's appropriate that we have a balance and a blend of leadership and voices within the sessions."	Mixed skillset of the project organisers created a balanced and dynamic group:  A project organiser who was practical and created the structure for the sessions, with a clear plan and objectives.  A project organiser that brought helpful and realistic lived experience, and emotional support.  A project organiser who provided administrative and additional support.	"[Project organiser] has been really hands on with encouraging us to share and to be involved [] [project organiser] is chairing the meeting she's coming at it from a different way where she had to get objectives covered and outcomes [] [project organiser] is there in the background providing additional support to all of us, but [project organiser] is on the other side providing emotional support [] quite a good dynamic of people."
REMUNERATION			
The funding was designed in a way that would remunerate participants for their time.	"We were going to be valuing in a range of different ways, Including remunerating for their time. And [the project organiser] is just amazing in working together to create a business case of sort to get the funding that we needed to make sure that that was covered."	Covering childcare cost was part of remuneration which helped participation in sessions.	"It's a lot easier for me to be more present in the meetings [] to offer to cover childcare is a really positive aspect."



		Showed they are being appreciated for their time and expertise and helped to prioritise the project.	"I think it helps as well with commitment of time because everybody is so busy it helps to prioritise it."  "If I came on as a consultant for a project, I would expect to get paid for that, so why should we treat service users with less than that."
		Influenced some participants to join the project.	"It did influence me to get involved in the start."
	DESIG	N OF THE PROJECT	
A meeting was organised that grounded the ideas into a plan.	"That's when our thinking comes into contact with the structure of an agenda."	Sufficient time to learn the approach, share their stories and ideas, and plan ahead; this allowed for the balance between the emotional and the practical.	"We had three sessions to get everything out, talk, bond, pass ideas around, and then it was, 'okay, what are we going to do moving forward, let's put a plan into place', and that I think was really good."
The approach was organic rather than instrumental, without pre-decided content, but co-facilitators provided a structure to guide the process.	"The approach was far more organic than instrumental and deliberately designed to be almost devoid of content at the start and work with what the women chose to bring in terms of shaping what happened next."  "That approach to agency only works if it has a place to dock into in terms of the structures."	For some, the open way in which it was structured made them feel more in control of the process and build trust.	"I was expecting it to be a lot more structured [] in that I would know exactly what to do in regard to my story, what I should be putting forward [] it's nothing of the sort, it's really like we've walked in to a group and everybody's been really open with us taking control with what we want to share."  "There's a lot of structure there, but it's not to the point where we're ticking boxes [] it's very open and free flowing, which makes me feel that there is a lot of trust there, we've been trusted to share what we think is best."



Project organisers ensured power sharing.	"Power sharing is the norm, we recognise everyone's expertise that they bring, there's no competition."  "We were in it together, so no hierarchy, just openness really."	Power sharing was established:  Power was given back to the service users as service user expertise was recognised.  Co-facilitators did not decide what was happening, participants felt listened to and that the process was not being decided for them.	"This is important because the power balance is right, whereas other groups and feedback requests and things like that you often feel like actually it's not real, you're going to say your thing but then the people running it are going to do their thing anyway, whereas this feels more like everyone's voice is important and they actually want to hear what needs to change rather than they've already decided."
The holistic design of the project meant that co-production was ethical.	"We mean business, we are not just ticking boxes [] we designed it holistically, you know, ethics was at the heart of this."	Sharing stories with each other and feeding back to each other helped construct their stories.	"Telling each other stories, which is really interesting and really valuable."
Congruence ensures that the participants adhere to the co-design methodology throughout the project.	"Congruence is really important at this point. In other words, having started with an intention, having carried that intention through in every aspect of the design, having worked with them in a particular way, that we don't then flip into a different mode which becomes more about an event and a presentation [] and becomes less about the authentic, messy, relational work that we have done."	The informal drop-in sessions between the service users:  Provided flexibility which fit the mothers' schedules (e.g., after their child's bedtime).  Acted as peer support.  Helped co-design group members develop their stories.	"Drop-in sessions [] tell our stories in [] a peer support way which, it's been really lovely to have that informal side of things."
		The WhatsApp group with the service users was helpful and made the co-design group members feel supported and less alone as they took the time to write to each other and share.	"The WhatsApp group that has gone on behind the scenes has been really useful, I think if we didn't have that it might have been more challenging emotionally."



SKILLS SESSION			
Gave a variety of options with how the co-design group members could contribute, without pressurising them.	"How much or little of the Skills Session do you want to deliver. The spectrum went from no- thing, to [co-facilitators] say nothing, and they do the whole thing, so that was the choice open to them."	Helped participants gain confidence and skill of the Public Narrative approach.	"I came away from that feeling that if I had to pick one of those meetings to attend that would have been the one, I would've chosen [] I came away feeling that it had been a skills training session [] it gave me more confidence."
		Introduced the group to more service users. Following the session, they discussed the inclusion of other mothers and invited them to join.	"There was a couple of ladies that joined that Skills Session that we invited to join the group because it just felt right."
		The co-design members were not pressured to deliver the session and were given options relating to their participation.	"We were asked, again no pressure, if anybody wanted to lead a breakout room."
	LE	ARNING EVENT	
Project organisers worked together with the co-design group to organise the event. It was important to give the co-design group space to lead, whilst not leaving them responsible to uphold the structure of the event.	"Not to assume that they have more facilitative experience than they do in the way that we design that event [] I want to put them in spaces where they lead, but not where they are responsible for holding something that is material to the structure of the event."	The presence of facilitators in the breakout rooms helped the co-design group members with the conversations that took place in the breakout rooms, helped the event run smoothly and feel collaborative.	"I really appreciated having a facilitator in the room, I thought he was very good at leading the conversation wi- thout directing it, which I think is a very underrated skill."
		The use of a WhatsApp group with all the facilitators and co-design group members involved helped with the delivery of the event.	"I really liked that [the project organiser] set up a WhatsApp group for all the facilitators and the breakout room hosts and things, and that was really helpful because it then, when things were happening, and I was a bit confused or having some technical issues I could send a quick note on my phone and was also getting support from there."



The openness of ways in which people could contribute made the collaboration process feel natural, as co-design group members contribu-	"I've got a scrapbook and I did that when I was struggling to put my story together in a way that I thought would be useful enough, so when someone suggested using that
ted in ways that they felt comfortable.	I felt like 'okay, well I've done my bit now'."

### PERCEIVED IMPACT OF THE LEARNING EVENT ON CHANGE

Participants highlighted different levels of impact generated by the Learning Event. There was the immediate impact on those who delivered and attended the event, the potential long-term impact on changes in maternity services.

When reflecting on the impact of the Learning Event, the NHS professionals and co-design group members interviewed unanimously believed that the event was powerful. The event itself was seen as a catalyst for creating change, although, this was believed to only be the start of a whole movement, with changes to maternity services being at the centre of this process. The initial impact on those involved has already led to some changes and is hoped to lead to additional changes, which are expanded on in the following section.

### **IMMEDIATE IMPACT**

1. The use of stories: When reflecting on the impact of the Learning Event, both co-design group members and NHS professionals expressed the power of the use of stories. The NHS professionals felt that the use of stories was eye opening, and it was considered a method that was conducive to learning and to creating change when staff were overworked. NHS professionals enjoyed the variety of stories that were shared throughout the event, and some reflected on specific stories that stuck out to them.

On the other hand, when speaking about their impressions of the use of stories in the event, co-design group members reflected on how the event and the sharing of stories was emotional, and they needed to process the event over the following days. Although participants believed that the wider goals of the project were not yet achieved, as this was just the start of a long journey toward creating change, they felt that the short-term goal of impacting service providers through sharing their stories had been achieved. Some reflected on how they had expected the Learning Event to be the end of their work, but they realised it was just the beginning. Perceptions and impact of the use of stories relating to the Public Narrative approach are further discussed in the section below 'Impact and perceptions of the Public Narrative approach.'

- 2. Empowerment of co-design group members: Co-design group members reflected on how the event left them feeling empowered, due to having the opportunity to share their stories and the fact that they were presenting to key stakeholders. Some participants highlighted how frontline workers may hear service users' stories, but those who have the power to drive change in the system do not. This is why this event was so important as it provided the service users with a platform to share their experiences with powerful stakeholders. The participants felt that there was a good turn out and were grateful as they acknowledged the shortage of maternity staff in the NHS. One co-design group member decided to share her story through the use of artwork, which caught the attention of the head of midwifery from her trust. As a result of seeing her story, the head of midwifery wanted to help her navigate through her recovery as well as to have the co-design group member help develop their maternity services. However, some participants were disappointed that no one from their local trust was present to hear about their experience. The event also led to some of the co-design group members to consider becoming midwives themselves.
- **3. A space for communication between service users and providers:** The NHS professionals interviewed reflected on how the event created a space for service users and service providers to communicate with each other directly. Some NHS professionals compared the telling of stories to the use of posters or reports, such as the Ockenden report, to transmit service users' experiences, and believed that the direct communication was a superior approach. Participants highlighted that it was important to listen to the mothers in order to know how they experience maternity services and to be informed of the changes that they would like.



The variety of stakeholders present meant that staff in different roles were impacted. In an interview, a co-design group member stated that a midwife in the breakout room admitted to never thinking about the emotional side of caring for maternity service users, and that she would change her practice from that moment on to consider the mother's perspective. An MVP who was interviewed shared that the event made her reflect on how to speak and listen to maternity service users. In line with the observations of the Learning Event, these reflections indicate that the sharing of stories led to honest reflection and conversations between the service users and providers.

The facilitators who were midwives reflected on how important this event was in the timeline of midwifery, as this type of conversation had never been had before. [Observation of the Debrief Session]

**4. Facilitation of the event:** For all the participants, an important aspect of the event was the way in which it was facilitated. Although the NHS professionals interviewed acknowledged that it would be hard for the service users to tell their stories, and for the service providers to hear their experiences, they felt that the event created a supportive space for productive conversations. For the NHS professionals, the use of breakout rooms and facilitators who prompted conversation made the event feel like a safe learning space, and made them feel engaged, involved, and supported. On the other hand, for the co-design group members, the presence of facilitators was reassuring and helped them facilitate conversation in the breakout rooms. Although the majority of participants believed that the audience was involved and engaged, one co-design group member felt that not everyone was present, as not everyone actively participated in the breakout rooms.

Based on observations and interviews with co-design group members, the delivery of the event was successful and engaging due to the teamwork between the three groups delivering the project, the co-facilitators, the facilitators and the co-design group members. The co-design group members felt that the co-facilitators had confidence in them, and this helped everything run smoothly. What felt like teamwork for the co-design group members, was perceived as collaboration by the NHS professionals, who were impressed by the power balance in the co-production approach of this project.

NHS professionals shared that it was useful to have a set of questions to help them reflect on their pledges during the event, which made the event feel very practical. However, although co-design group members valued the sharing of pledges at the end of the event, some participants questioned whether enough attention was paid to setting out clear pledges. All participants agreed that the setting of pledges was just the start of creating change, and felt that creating action plans, tracking changes proposed, and reproducing similar events was necessary to ensure long-term change.

Facilitators reflected on how the event made them feel invested in change and how due to the context off the event being based on stories, the conversation in the breakout rooms felt more human and were thus easier to facilitate.

[Observation of the Debrief Session]

Breakout rooms opened up a space for everyone attending to reflect on the stories, their work, and what changes can be made moving forward. The variety of NHS stakeholders present shared their impressions of the stories, shared their own stories, and conversed between each other, the co-design group members and the facilitators present in each breakout room. [Observation of the Learning Event]



Table 3. Quotes relating to the immediate impact of the Learning Event

IMMEDIATE IMPACT	CO-DESIGN GROUP MEMBERS	NHS PROFESSIONALS
		"There is nobody more invested in the safety of their baby than that mother who is sitting right in front of you" and a truer word was never said."
The use of stories	"The stars of the show were the ladies that read their stories."  "I'd thought of the Learning Event as kind of the end, of 'this is what we are aiming for,' but actually it's become almost just the start."	"I think it's just hearing some actual women and seeing that raw emotion [] it's the fact that they used their own words [] and I think that's so impactful, you can read things and think 'oh that's sad' and it doesn't impact you but it's very different when it's coming from the actual person."
		"The "stories" bit in the title made it right, we hear stories all the time [] but to actually have an event that was focused in that with other key stakeholders there was really important."
	"I really enjoyed the event, I felt empowered after it, and will definitely be using what I have learned from the whole experience."	
Empowerment of co-design group members	"With maternity being quite short sta- ffed at the moment, it's quite impres- sive that that many people attended."	
members	"The people who do have that power to make a change don't have the opportunity to hear what's going on in the frontline, that is a helpful use of events like these."	
A space for com-	"One of the ladies talked about how she felt the moment the baby's born and how you can never get that mo- ment back, and the midwife said 'I've	"Especially is coming through the same audience of those who have suffered, what I am saying is what the Ockenden report reflecting? She only hears it by herself and then she analysed it and put in a report, I prefer straight away to allow the mother to talk with us. There is no point in a [] middle person [] we are not meeting each other."
tween users and providers	never considered that, in all these years I'd never considered that from the mothers point of view and I will be taking that into my work'."	"It was a very good event, I think most of the time we think we are providing a servi- ce but we never accepted to sit down with the patient or mother and say how much they accept it from us."
		"That really important point of power sharing and giving that power back to the mothers and not thinking that you're the one that's sitting there with all the power."



# Facilitations of the event

"I really appreciated having a facilitator in the room, I thought he was very good at leading the conversation without directing it, which I think is a very underrated skill."

"[The project organisers] had so much confidence in us to do what we wanted to do [...] and that's a huge risk to take on us and I'm glad it paid off, I'm 110% sure."

"The pledges made at the end of the session seemed vague, so, is this actually going to turn into something?"

"It felt like a very safe learning space, and it was made like that I think by the facilitators and especially in the breakout rooms."

"They tried to make the session so that you feel like you were involved and you're not just sitting there listening to these stories."

### **LONG-TERM IMPACT**

Participants shared changes that are already occurring as a result of the project, as well as those they hoped would occur. However, they also acknowledged factors that could act as barriers to the implementation of these changes. Many participants voiced the concern that lack of accountability in committing to the pledges could lead to a lack of change. Others believed that the lack of resources, including staff, would limit change. One of the overarching themes shared by all participants was how important it was to use stories to promote change, however the need to reach a wide audience was seen as crucial, and with staff shortages in the NHS, some questioned how staff would ever have the time to hear the stories. Even after hearing the stories, some participants believed that it would be difficult to get midwives to change their pre-established way of working. Buy in from senior leaders in adopting this approach was also seen as a barrier, as the co-productive approach and Public Narrative use in this project sought to question a hierarchical system, a process that might not be accepted by some staff members. Participants also acknowledged that without social media use and similar events, the creation of change would be hindered.

The following list presents the changes that are already taking place or that participants hope will take place.

### **CHANGES TAKING PLACE**

- Incorporation of findings into maternity services:
  - ♦ NHS stakeholders will include information from the event in their re-validation report.
  - ♦ The midwife will use her position in midwifery to develop maternity care.
  - ♦ Led MVPs to reflect on their role and to recognise the importance of getting to know the different cultures in their region.
  - ♦ Maternity service users are being involved in the development of training programmes in maternity services.

    The annual training on cultural competency and cultural safety e-learning 2 (which is a training programme designed to provide safe care for every woman) is being updated with the involvement of maternity service users.
- Stories are being used as a result:
  - ♦ Co-design group members' stories have been shared in other meetings.
  - ♦ MVPs have started using stories using the Public Narrative approach to create change. They have decided to use stories as a part of the data they present.
  - ♦ Led to reflection in a perinatal equity steering group on how to use stories to mobilise people and bring about change, including recognising the emotional investment and how to translate this into actions.
  - ♦ Recording of the Learning Event has been uploaded onto the NHS South East Clinical Delivery and Networks website, which can be accessed by service providers and users.
- Similar projects are being planned:
  - ♦ MVPs have decided to plan an event similar to the Learning Event.



- Feedback loops are being planned:
  - ♦ A call to action feedback loop with MVP chairs for the region's 'you said, we did' is being arranged by the Stories for Change organisers.
  - ♦ 3- and 6-month check-ins after the Learning Event for any needed support.
  - ♦ A 'share and learn' webinar 9 months after the Learning Event for MVPs to share their 'we dids'.

### CHANGES PARTICIPANTS HOPE WILL TAKE PLACE

- More service user participation:
  - ♦ Co-design group members and service providers expected that the Learning Event will lead to similar projects across England.
  - ♦ Some co-design group members desired to be involved as experts by experience in future projects.
  - ♦ NHS professionals recognised this project as an opportunity to replicate the model, including using the Public Narrative approach with seldom heard communities.
  - ♦ NHS professionals hoped to see the Public Narrative approach used in their regional LMNS system to skill up more maternity service users to create change.
  - ♦ The Learning Event led to reflection on co-production approaches, including regional MVPs being more motivated to use co-production approaches than before. Participants believed future service user involvement should be carried out like in the Stories for Change project, where service users are involved from the design stage in order to define the issues and identify the solutions together.
- Change in maternity care culture:
  - ♦ Co-design group members and service providers hoped that the event would lead to the retraining of midwives within the NHS.
  - NHS professionals expected that the event would make staff more aware of their actions and the language they use.
  - ♦ NHS professionals hoped that a system can be created where more time is given to each mother in order to care for them holistically.
  - ♦ Co-design group members and service providers desired for this event to lead to behaviour change in the service providers who attended by embodying a more compassionate approach, as well as lead to a culture of respect that provides good care irrespective of the under-resourced NHS.
  - The Learning Event led to reflection on how to promote behaviour change in a positive way, which included the importance of supporting staff who are not providing compassionate care. Participants voiced that, like in the Stories for Change project, future change should be conducted through positive and productive conversations.

### IMPACT AND PERCEPTIONS OF THE PUBLIC NARRATIVE APPROACH

The Public Narrative approach also had an impact on those involved in the design of the project, and those who attended the event. The main perceptions of the Public Narrative approach could be organised into the following categories:

### **CO-DESIGN GROUP MEMBERS**

- For MVPs, it gives them the ability to use the approach in their role and to showcase to the service users how the project is actively trying to improve maternity services.
- The approach provides co-design group members with the confidence to speak to more people, as well as to address the theme of perinatal equity during these conversations.
- Participants believed that through the diversity of those who shared their stories in the co-design group, themes of race were accessed implicitly in their stories. The diversity of those who shared also addressed the fact that improvements need to be made in maternity care for all women, which was thought to be inclusive.
- Concerns were raised regarding how far the approach can go in inciting change as different stories resonate with different people. Some found that people from the same areas had similar themes in their stories. Therefore, perhaps it would be better if it was kept on a small, regional scale in order to be impactful and effective. In addition, they found that receiving feedback from a large array of people makes it more difficult



to incorporate into their stories, so splitting up groups based on experience, could give more relevant and targeted feedback.

- After the Learning Event, co-design group members believed that the approach allowed stories to be shared with enough time, keeping the interest of the audience.
- The approach, compared to standard data sharing, allowed the group members to impact the audience as they connected with people on a more personal level, gaining more respect, which was their short-term goal.
- One participant explained how the Public Narrative approach works with human psychology, as it captures attention, whilst telling them what to do in manageable chunks.
- The approach made members feel empowered, hopeful and invigorated and it was deemed a silver lining of their birthing experiences, as speaking about it and producing change is something constructive that came from a bad experience.
- The process of learning to tell their stories through the Public Narrative approach acted as a way for the co-design group members to own their stories.
- The approach had a good impact on their communication, with one participant having local services finally respond to her once she'd started using this approach.

"It's all about taking the listener on a journey with you" [Co-design group member].

"People were given enough time to share the stories and keep people's interest without the audience losing momentum or getting distracted by something else" [Co-design group member].

### PROJECT ORGANISERS

- Project organisers believed that the co-design group members would gain confidence from the approach, as well as the skills and capability to use storytelling in a way that will incite the change they desire.
- The emotion from the stories created the motion which will then lead to change and action.
- However, it was acknowledged that some professionals may view the approach as using the women as instruments for advertising and marketing.
- A barrier to storytelling creating change is not so much in the act itself but the skill, knowing how and in which context to use it, sticking to a short timeframe; the approach has a skeletal structure that provides flexibility, calls to the head and the heart.

"If you've got the tools and the skills, then you are better placed to work with the sharing of power amongst decisionmakers" [Project Organiser].

"How do we, despite the overwhelming urge in the human condition toward inertia, towards the path of least resistance, towards maintaining and protecting where we are, how do we move people to action?" [Project Organiser]

### NHS PROFESSIONALS

- Attention grabbing: many perceived that stories make people listen as they are told in a way that keep listeners alert. There's emotional resonance, that other methods of sharing information do not have.
- Themes of perinatal equity & race: one NHS professional stated their admiration for the women of different ethnic backgrounds speaking up for themselves in environments where their voices need to be heard the most. NHS professionals also believed that themes of race were addressed when service users of diverse ethnic backgrounds shared their stories, including ethnic minorities and white women, which highlighted the array of challenges and issues faced by women receiving maternity care.



- Approach should be used in future projects and events: NHS professionals hoped that more projects
  and events would use this approach, but it was acknowledged that it was important to allocate time to build
  trust and build relationships with the women.
- All the NHS professionals interviewed reflected on changes that should be made and how this could be done, indicating that they felt called to act as a result of hearing these stories.

"There's an emotional resonance there, that immediately you can connect with those people that you can't do by other means, you know a poster wouldn't have the same impact" [NHS professional].

"It made me feel that I am now in a position, a hot seat basically, to make a change with them" [NHS professional].

### ADVICE FOR FUTURE PROJECTS AND RECOMMENDATIONS TO PROMOTE CHANGE

The table below presents the main areas of improvement for future Stories for Change projects that were identified by the participants as well as recommendations of what can be done next to ensure change. The main areas for improvement of the project were related to recruitment, the inclusion of participants, the co-design process, the Skills Session and the Learning Event. The recommendations related to promoting change were focused on ensuring accountability of NHS professionals to create change, and to reaching a wider audience.

Table 4. Recommendations

Table 4. Neconinelidations			
THEME	RESPONDENT GROUP	RECOMMENDATIONS	
Recruitment process	Project organiser	Long-term networking is needed to connect with a variety of communities and established groups in these communities.	
		<ul> <li>Acknowledge the importance of building new relationships.         Outreach workers (separate to community midwives) could follow up with people who register their pregnancy in order to give them the opportunity to be included in the project from the start.     </li> </ul>	
		Ask what type of remuneration participants would want as state benefits may interact with remuneration and participants may not want to just receive money.	
	Co-design member	Local community outreach to include participants that would not hear about the event through social media or MVPs.	
	Drainat arganizar	Could include fathers and partners in future projects.	
Inclusion in the co-design group	Project organiser and co-design member	<ul> <li>Include more people living in areas of deprivation through im- proving recruitment and considering how to remunerate partici- pants.</li> </ul>	
	Co-design member	Could include someone that represents midwives as they would bring a different, more frontline perspective.	
	NHS professionals	Include mothers from ethnic minority groups who have English as their second language.	



	Project organiser	<ul> <li>Include daily themes (such as daily tips) in the WhatsApp group in order to create more connection between members of the group.</li> </ul>
		<ul> <li>At the start of the process, speak about which aspects of the project will be co-designed and which will be co-facilitated in order to mark the roles more clearly.</li> </ul>
		Spend a whole day together in order to accelerate the process and help keep the pace, either in person or online.
Co-design process	Co-design member	<ul> <li>Send hard copies of the slides to the co-design members in advance of the sessions to allow them to prepare. Share their stories with each other earlier to better understand each other's experiences, what improvements they want to call for, and how to present them.</li> </ul>
		<ul> <li>Increase the number of sessions that they hold from the be- ginning to have more allocated time to create and share their stories and plan the event.</li> </ul>
		Create an agenda before the meeting so they know in advance what would be discussed, and this would help them make a plan around what to do with their children during the event.
		Create a shared document to compile the notes that the co-design members make reflecting on the process of the project.
	Project organiser and co-design member	Provide more time to set up and practice the Public Narrative approach.
	Co-design member	Provide more time in breakout rooms.
Skills Session		Make the Skills Session more of a training and workshop as the co-design members had already learnt the skills; it would be better to role play and practice.
		Invite participants earlier on so that more people could attend.
		Encourage more service user involvement through more social media use and use a wider range of social media platforms (including Instagram).
		Hold more rehearsals before the event.
Learning Event	Co-design member	<ul> <li>Implement a structure where everyone is prompted to talk in breakout rooms in order to encourage everyone to be present and to hear everyone's views.</li> </ul>
		Encourage attendance from representatives from each co-design member's local trust.
		Spend more time in the breakout rooms focussing on the pledges the NHS professionals make.
		Invite more consultants to attend.
		Invite health visitors to attend.
	NHS professionals	Share more stories.
		<ul> <li>Hold in person Learning Events, where the audience does not sit behind a screen.</li> </ul>



	Co-design member	Create a timeline to track the changes.				
		Create an action plan that shows how the changes will be accomplished.				
		Use social media to follow up on the decisionmakers' promises and keep the movement going.				
In order to promote change: Accountability to commit to creating change		<ul> <li>Hold a meeting every 3-6 months to get an update from the decisionmakers to find out what has been done and how the stories have created change.</li> </ul>				
		<ul> <li>Involve service users at the local level, as this will ensure that they are listened to, that they can monitor the change, and keep the im- portance of the human experience on the service providers' minds.</li> </ul>				
		Hold a "you said, we did" board in order for the professionals to show commitment to their actions.				
	NHS professionals	Hold an annual event to review progress.				
		Constantly review progress through a health equity lens.				
	NHS professionals	Bring the project to every region and NHS hospital, or to individual provider trusts.				
In order to promote chan-		• Use eye-catching advertisement to publicise the project (needs to be different to critical analysis reports, like the Ockenden report, where one reads the content then moves on).				
ge: Reaching a wider audience		NHS employers should allow their staff time to attend and hear the stories.				
		Learning Events should be held at board meetings as a mandatory event in order to reach people who do not want to listen to these stories.				

# LIMITATIONS OF THIS STUDY

The findings of this study should be considered in relation to its limitations. The data collection started when the project commenced, which meant that the first interviewees approached had little time to reflect. This was overcome by interviewing some interviewees in the second round, but not all took part in a second interview. Furthermore, due to the rapid nature of the evaluation, there was a short data collection period following the Learning Event, which meant that the impact of the project could not be properly evaluated. Furthermore, there may be biased perspectives on the positive impacts of the project, as the NHS professionals interviewed may be those who are more likely to attend such events, and who are more invested in creating change in maternity services than other NHS stakeholders.

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# APPENDIX 1. FACTORS TO CONSIDER WHEN CALCULATING THE COST OF THE PROGRAMME

TO DELIVER A LEARNING INITIATIVE USING CO-DESIGN METHODOLOGY	Costs of manuals and hands out.	Unit cost per manual/ hand out	e.g. £17					
	Costs of manu	Number of manuals/ hands out used in the event	e.g.15					
	premises	Cost of premise unit used in the event (in £)	e.g.£150					
	Costs of premises	Number of premises used in the event	e.g. 1 room					
	Cost for co-facilitators group	Remune- ration (in £). (Please clarify if remune- ration is per session or per hour; S(ession) or (H)our	e.g. £25/ S					
		Number of participants	e.g. 15					
		Hours per day and total days delivering the session as co- faci- litators	e.g.4h/3 days					
		Hours per day and total days for training as co-faci- litators	e.g.5h/ 1day					
		Number of co-facilitators along with their salary band and their expertise (e.g. admin, nurse etc)	e.g. 2 nurses, band 5					
	Cost for organisers (including any costs for training purposes and setting up of the activity)	Hours delivering training before the activity	e.g. 5h					
		Number of trainers/ facilitators along with their salary band and their expertise	e.g. 1 researcher, band 6					
		Dura- tion of activity	<del>-</del>					
		Number of activities during the initiative	e. 4					
		Activity	Formal mee- ting	Informal drop-in session	Learning event	Activities with sponsors	Activities with the funder/commissioner	Skills-based Public Narrati- ve Session.





TO DELIVER A LEARNING INITIATIVE BASED ON CO-PRODUCTION									
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A LEAR									
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		ed in tment y band,	e.g. 2 ad- min, band 4					Total hours spent on recruitment	24
		Staff involv recruit (salar experi	e.g.						e.g. 24
								Staff involved in recruitment (salary band, expertise)	e.g. 2 admin, band 4
	Teach the use of Public Narrative approach		Recruitment of diverse group of ma-ternity service users		Skills-based Public Narrati- ve Session.	Project pre- sentation	Sharing co-design group's sto-ries	Recruitment maternity service stake- holders	



