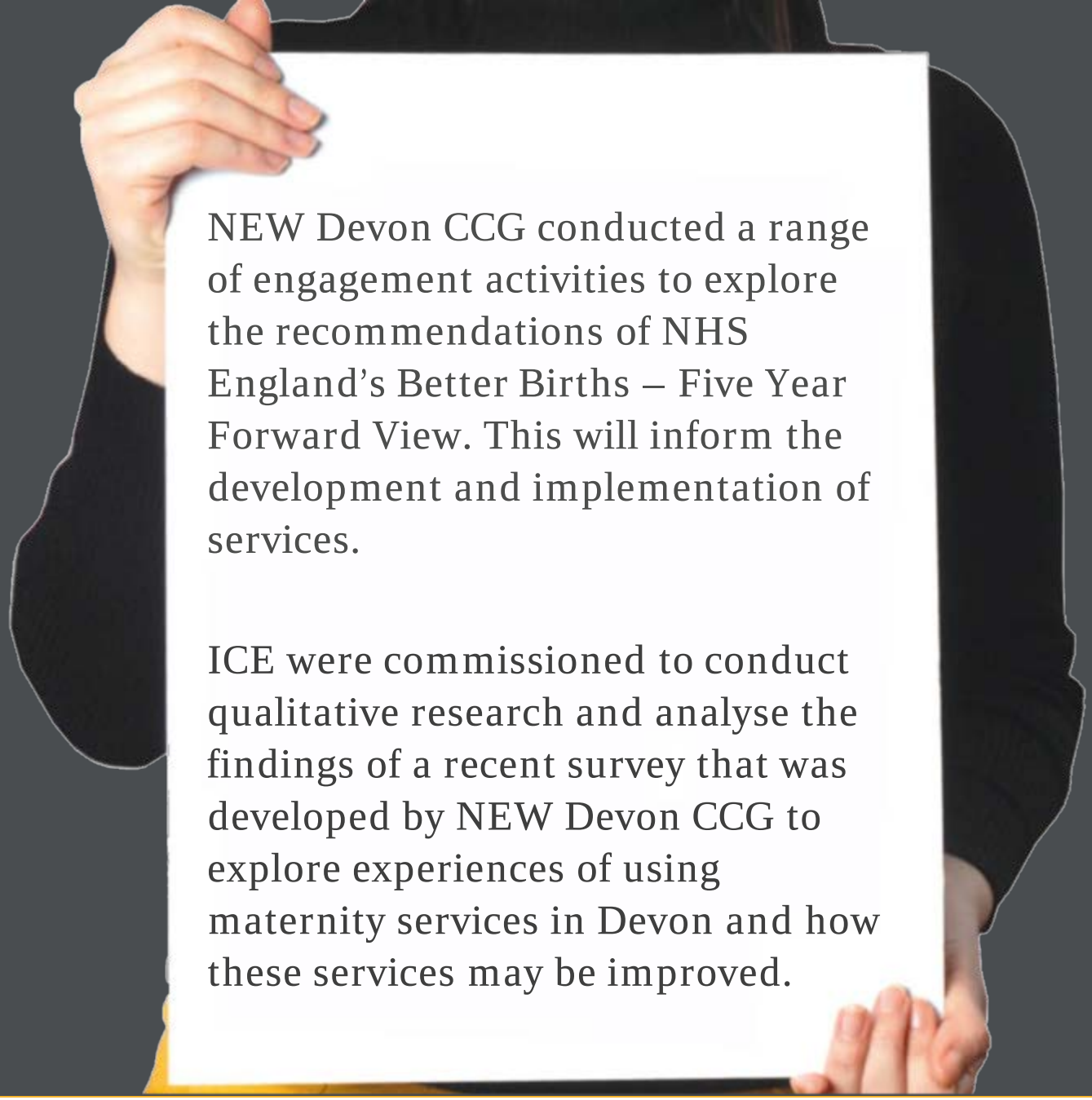
NHS
Northern, Eastern and Western Devon
Clinical Commissioning Group

BETTER BIRTHS

Research into expectations and experiences of maternity services in Devon

Specially prepared for you by team ice

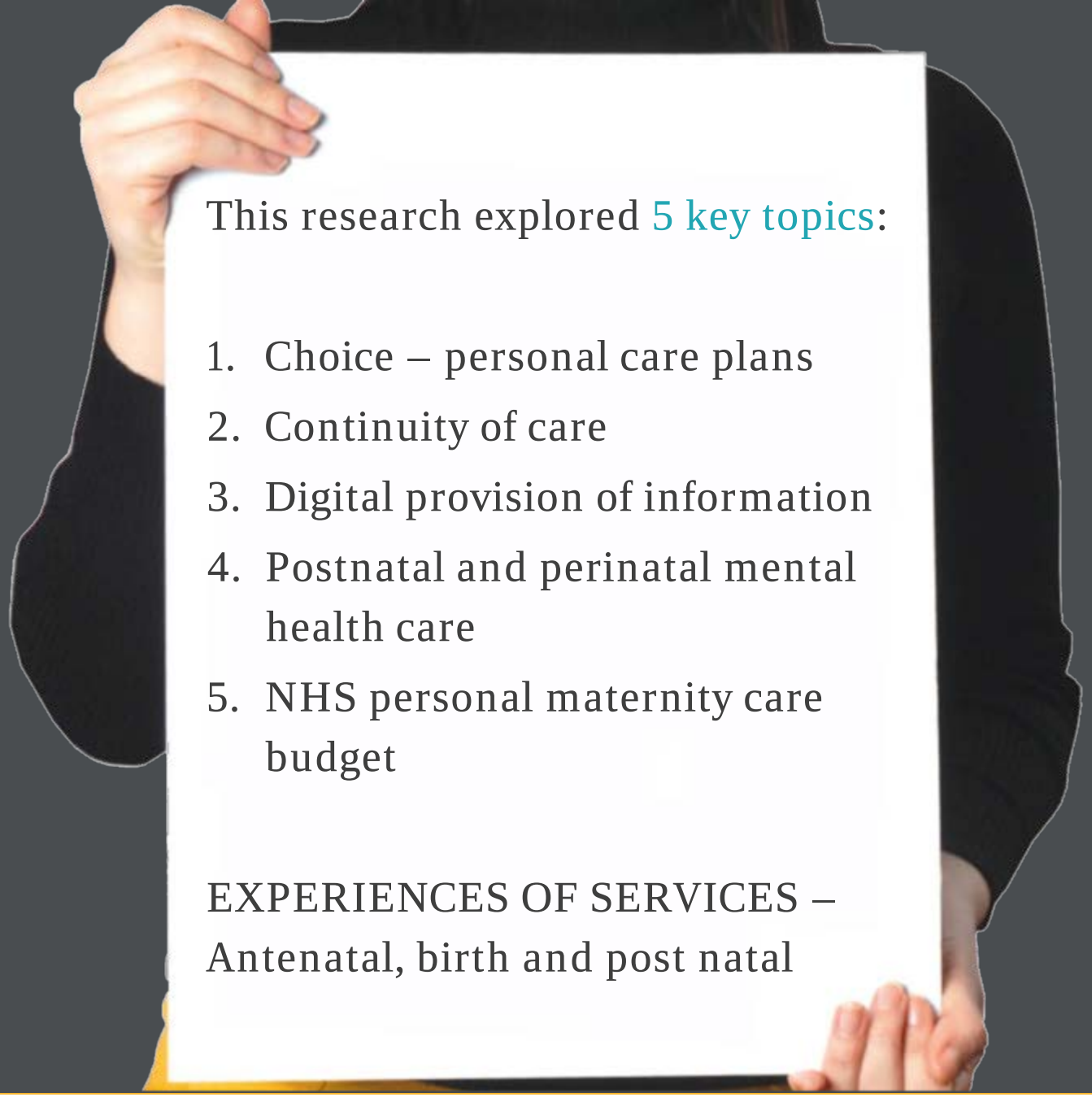
Background



NEW Devon CCG conducted a range of engagement activities to explore the recommendations of NHS England's Better Births – Five Year Forward View. This will inform the development and implementation of services.

ICE were commissioned to conduct qualitative research and analyse the findings of a recent survey that was developed by NEW Devon CCG to explore experiences of using maternity services in Devon and how these services may be improved.

Objectives

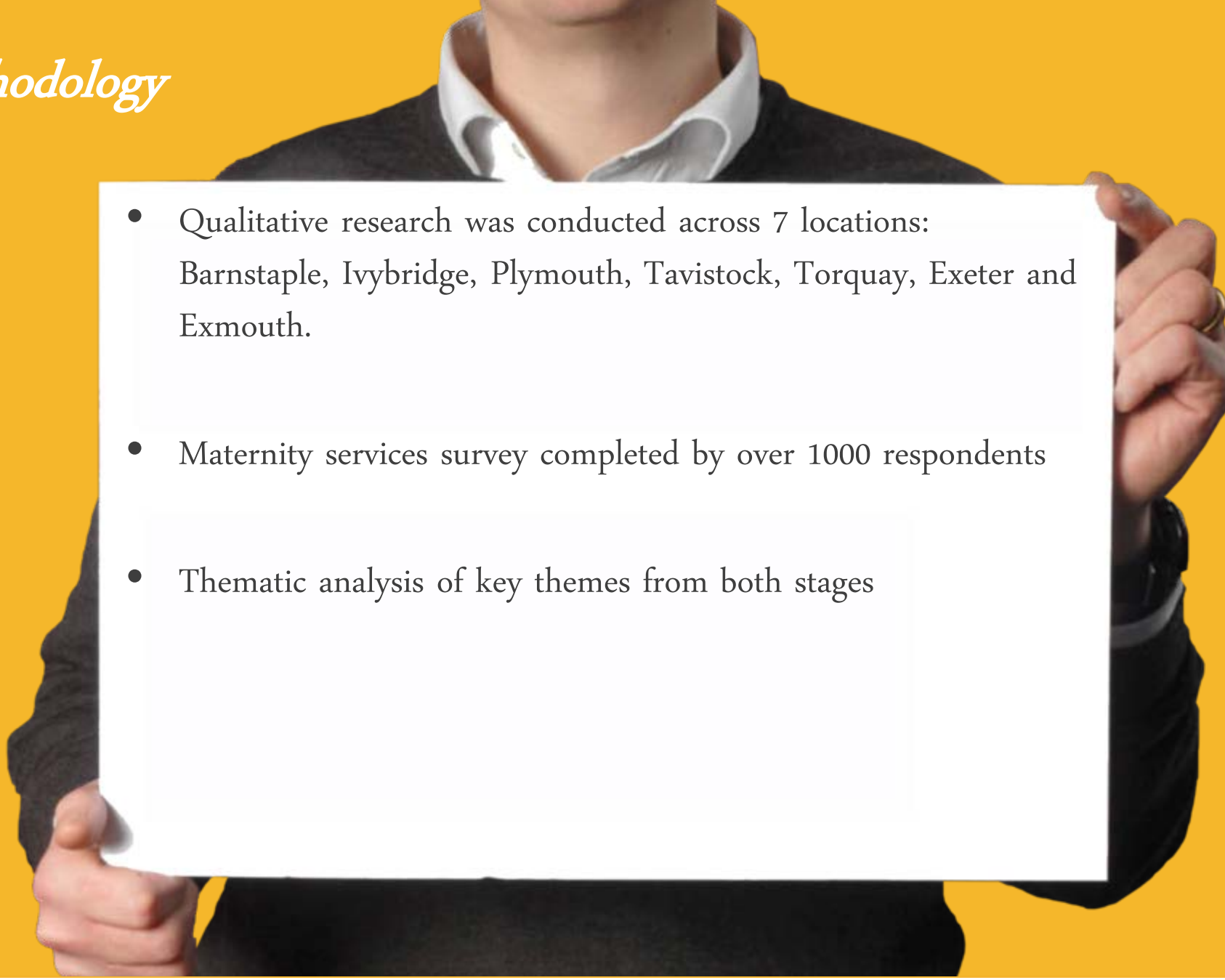


This research explored 5 key topics:

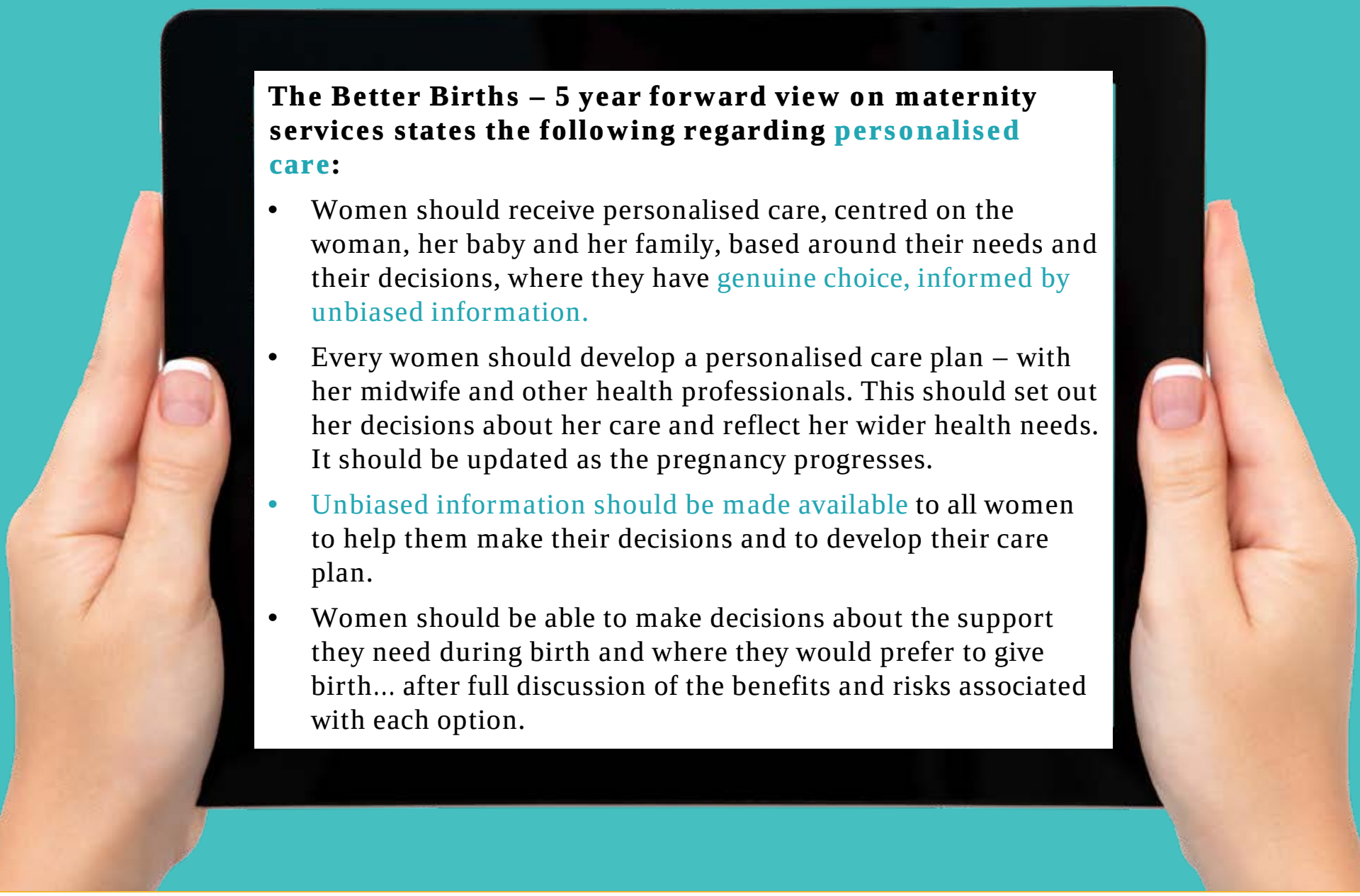
1. Choice – personal care plans
2. Continuity of care
3. Digital provision of information
4. Postnatal and perinatal mental health care
5. NHS personal maternity care budget

EXPERIENCES OF SERVICES – Antenatal, birth and post natal

Methodology



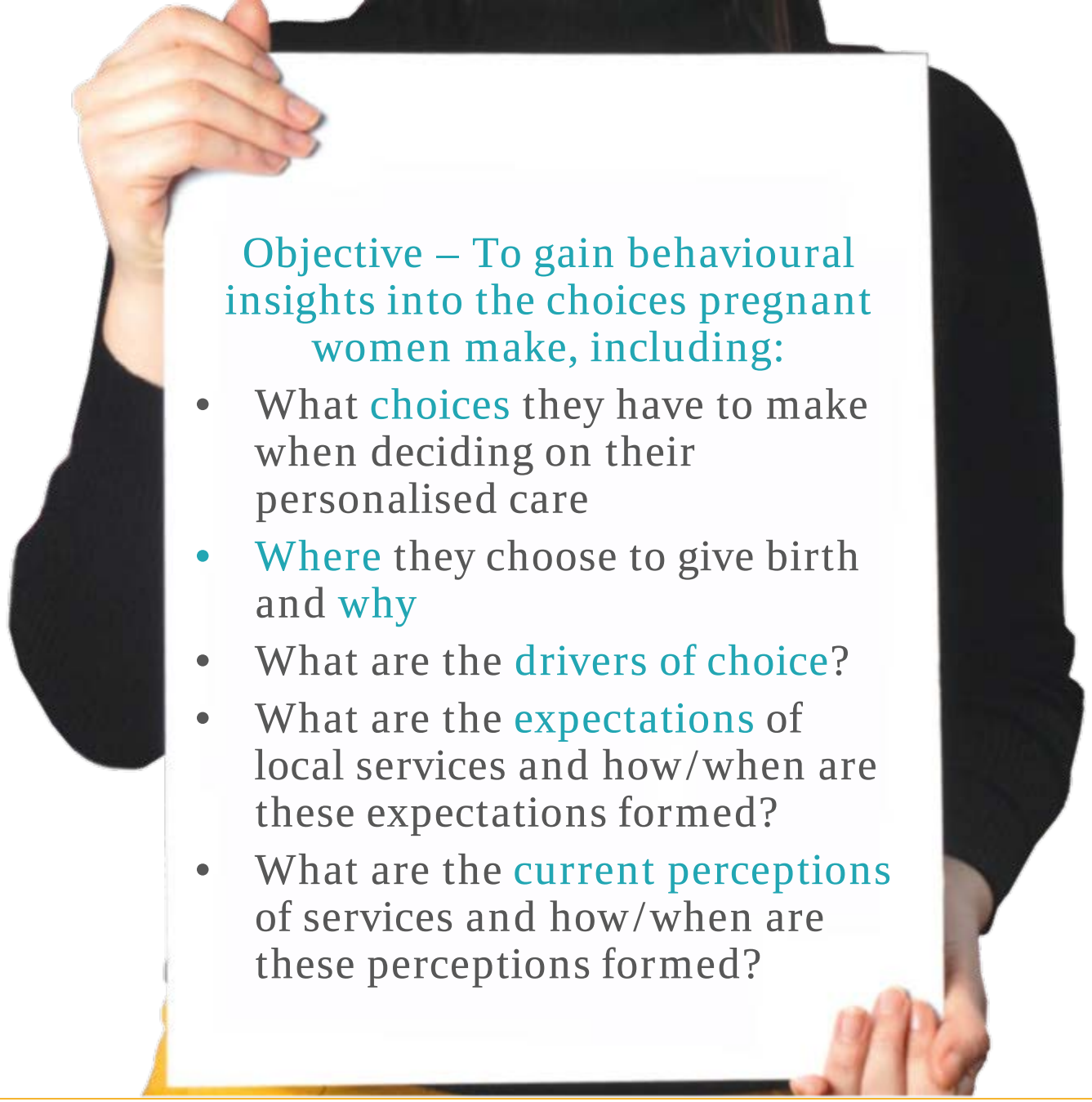
- Qualitative research was conducted across 7 locations: Barnstaple, Ivybridge, Plymouth, Tavistock, Torquay, Exeter and Exmouth.
- Maternity services survey completed by over 1000 respondents
- Thematic analysis of key themes from both stages



The Better Births – 5 year forward view on maternity services states the following regarding personalised care:

- Women should receive personalised care, centred on the woman, her baby and her family, based around their needs and their decisions, where they have genuine choice, informed by unbiased information.
- Every women should develop a personalised care plan – with her midwife and other health professionals. This should set out her decisions about her care and reflect her wider health needs. It should be updated as the pregnancy progresses.
- Unbiased information should be made available to all women to help them make their decisions and to develop their care plan.
- Women should be able to make decisions about the support they need during birth and where they would prefer to give birth... after full discussion of the benefits and risks associated with each option.

CHOICE (Personal care plan)



Objective – To gain behavioural insights into the choices pregnant women make, including:

- What choices they have to make when deciding on their personalised care
- Where they choose to give birth and why
- What are the drivers of choice?
- What are the expectations of local services and how/when are these expectations formed?
- What are the current perceptions of services and how/when are these perceptions formed?

Choice – Personal care plan

KEY FINDINGS

- **38%** reported that their birth went to plan, meaning **3 in 5** do not go to plan - "it's not a plan, we don't have full control" → Birth preferences
- **17%** almost **1 in 5** not sure if they had a birthing plan – Qualitative research demonstrated that birth plan conversations were not overt, with choices not fully explained (or individuals not signposted to appropriate additional information at the right time)
- To be **active partners in choices (share decisions)** regarding their care patients need to have knowledge of the choices available to them.
- Qual findings demonstrated that participants were not aware of the full range of choices they have available to them

RECOMMENDATIONS

- **Do not recommend use of the term 'plan' – Preferences was preferred**
- **Adopt the principles of shared decision making within maternity services – Will require shared decision making training – a STP wide shared decision making campaign is planned**

Better births: "*Unbiased information should be made available to all women to help them make their decisions and to develop their care plan*"

KEY BARRIERS TO SHARED DECISION MAKING

- No time to prepare/conduct independent research: Choices discussed without prior notice meaning that the women were unable to do independent research or access information to make informed decisions.
- NHS antenatal classes perceived poorly (free source of info): Many dropping out after only one session → Knowledge gap.
- Midwives asking leading questions, making assumptions regarding choices before a discussion has taken place.

Shared decision making - informed, empowered choice requires:

Knowledge

- Information provision to increase knowledge – signposting to support
- Time to prepare for meetings – independent research
- Know what questions to ask to gain further information regarding choices

Confidence

- Feel confident to ask questions and challenge if required

Collaborative relationship with HCP

- Open questioning from HCP
- Discussion of benefits and risks of options – balanced discussion

Better births: "*Unbiased information should be made available to all women to help them make their decisions and to develop their care plan*"

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RECOMMENDATIONS

- **Signposting to information is crucial – need to define the information exchange eco-system → Who, where, what, when. Information exchange must begin at earliest opportunity**
- **Signpost to both free and paid for sources of information → individuals choose what to engage with**
- **Develop decision aids/signpost to decision aids**

*Feedback on **NHS** antenatal classes*

- Not accessible to mum and birth partner - Inconvenient times – birth partners unable to attend.
- Too much teach – not interactive enough, too directive and not conversational.
- Content not tailored/personalised – Owing to the significant amount of choices available, the women wanted (expected) tailored advice based on their needs (personal and medical) and did not believe they got this at NHS antenatal classes.
- Content that could have been viewed at home shown during group sessions (e.g. videos) → wasted time that would have been better spend discussing choices.

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"There was 15-20 of us the first day and then the next week there were 4, so people really don't go on these free courses." –Plymouth

"They need to look at the feedback forms." – Exeter

"The NHS classes were just talk talk talk, needed to be more interactive like the NCT classes." – Plymouth

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*Feedback on **Private** antenatal classes*

Private classes are overcoming the knowledge gap:

- Perception that a greater depth of information was delivered → more informed choice and able to fully participate in birthing plan discussions
- Content delivered more interactively - conversational
- Birth month cohorts – Enabled shared experiences and peer support beyond birth
- Smaller class sizes – more personalised discussions
- More accessible - convenient times (evenings)
- However, many had to independently find out about these classes or heard from others – as opposed to signposted by midwife. Therefore a number of participants were unaware they had this option.

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“You had conversations, you engaged, you could ask questions, you could explore ideas for yourself, whereas the NHS ones you couldn’t even ask questions at the end.” Exeter

“The lady that runs it is an ex midwife…You felt like she was your friend, you could ask her anything and she would say well this can happen and this could happen…she was very passionate about helping people.” –Exeter

“It was only because my mum told me to go through NCT classes, had I not done that and just went through the system I would have been totally oblivious to some of the decisions that needed to be made.” - Barnstaple

“I’m glad I knew everything I knew before that appointment (birthing plan) because otherwise I don’t think I would have had enough time to make an informed choice” – Found out everything through NCT classes. – Plymouth

”

Personalised care plan – barriers to informed choice… Ambiguity effects

Knowledge gap – incomplete information. Developing due to inconsistent or limited information regarding the range of available choices

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Ambiguity effect - individuals avoid decisions wherein incomplete information (or inconsistent information) makes a decision feel risky

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Select less risky/safer options – default/perceived normal options or those experts recommend

Why is it difficult to make informed choices?

Cognitive limitations

- Choice is often difficult so individuals choose to maintain current behaviour
- The status quo or what is perceived as normal often requires less mental effort

Informational limitations

- Outcomes of a decision are rarely certain (will this result in a safe birth?)
- Errors can be costly – individuals want to avoid loss
- Individuals stick with what worked for others, normal options are considered the safe option

EXPECTATIONS vs EXPERIENCE - ANTENATAL

EXPECTATIONS

- First time mums had no expectations whilst mums who had previously given birth were still unsure of the choices available to them – assumed they would know because of their previous experience.
- 1st midwife appointment: expected to be provided with more information regarding what they should/shouldn't do and what choices they would have to make.
- Expect individuals they interact with to understand their story (demonstrate that they understand their story) – reduce need for repetition.
- Be provided with information - Access to jargon free information that will support them to make choices. Signposted to content by experts they trust. (balanced and unbiased)
- To hear about positive stories – not just risks and what may go wrong.
- If choose hospital birth - To be given clear practical information about the hospital (visiting hours, food, parking).
- To be able to build a relationship with their midwife.
- Emotionally – expect feelings of excitement to be matched/empathised with by individuals they interacted with.

EXPERIENCE

- 91% felt antenatal care was provided in the correct place
- 84% reported that they felt informed during pregnancy, 69% stated that they felt information was given at the right time.

Participants in the workshops reported...

- Not receiving enough personalised/tailored information
- Repeating their story on numerous occasions due to changes in the midwives they saw.
- Receiving competing information from midwives when meeting with different midwives during this period.
- Given lots of information at one time (bounty packs) but perceived as a marketing opportunity by many as opposed to access to important information – providing so much information at once is creating a choice blindness - individuals to ignore the information.
- Not accessing antenatal classes or stop attending after too few sessions to be fully informed.
- Personalised care plan – women reported not being prepared for this discussion and that their midwives asked closed questions, made assumptions and expected them to know what they wanted.
- Many, not building relationships and excitement not reciprocated

Experiences of care during birth

- 91% of participants in the survey reported that birth was in the right place for them.
- The panels below provide an overview of key factors that defined good/bad experiences across the survey and workshops:

Good experiences

- Continually updated of what was happening (even during emergency situations) → reduced anxiety.
- Choices were explained as situation evolved – e.g. regarding pain relief, birthing positions and procedures.
- Mum felt listened to/feedback was taken into consideration and actions were changed.
- Mum felt empowered to change their birth plan during labour based upon evolving needs.
- Open and honest care - empathy was shown during and after.
- Facilities/staff were comforting and personable.

Bad experiences

- Deviations from birth plan were not explained.
- Felt 'done to' as opposed to an active part of the experience.
- Unable to use equipment such as birthing pools (due to availability at hospital wards) despite significant demand being identified for such options.
- Staff change over during delivery – leading to uncertainty what had been happening and what was next → Mum having to repeat information.
- Privacy not given during vulnerable times.
- Poor communication/lack of empathy during emergency situations
- Individual not asked what they may need to help make them more comfortable – e.g. change of birth position.

Experiences of care after birth – Postnatal ward – Qualitative feedback

- The care received on postnatal wards was perceived very negatively. Participants stated that they felt like a number and not supported during their most fragile time → not supported or empowered regarding choices.
- A number of participants who had a traumatic birth reported that staff had made them feel like it's normal "oh everyone has c-sections" → disempowered them from asking for support (mental, physical and regarding feeding).
- Many women were unable to access support from their partners/family that they believed would have reduced the burden on staff – visiting hours are not flexible enough for families/partners to support – this made participants feel extremely anxious and lonely.

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"I asked if the midwife could take care of my baby for a while whilst I had a sleep but they said they couldn't (Exeter Hospital)." – Exeter

"It seems like they just think, 'oh come on, everybody has c-sections'.. Yeah but I had been in labour for 5 days before." - Exeter

"The only reason he stayed (partner) the first night is because I said, if you're going to make him go, I'm going too and I don't care if I gave birth two hours ago." – Exeter

"They would have so much less work to do if they let your partner stay, you would recover quicker." – Exeter

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Experiences of care after birth – Postnatal ward – Qualitative feedback

- The participants believed that they were not given enough practical information about the care provided on the ward – e.g. food stops being served after 24 hours → unable to prepare. This led to numerous women reporting they were left to go hungry (A number reported that staff had not proactively addressed some of these challenges and that some catering staff were rude).
- A number of participants stated that they felt staff were unhelpful and/or unapproachable – they also didn't feel empowered to challenge (didn't know what to expect)
- It was accepted that staff were busy – however a number of women reported that it wasn't a busy period during their instance of poor care.

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Experiences of care after birth – out of hospital

- 7 in 10 of those who attended hospital believed hospital was the right place for care after birth
- 42% who had postnatal care at the Community Centre felt this wasn't the right place
- Across locations, the experience of postnatal care at home following the birth of their child was variable

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"She asked my friend to make her a drink so that she could ask me alone if I was okay, I broke down. (she could tell there was something wrong)" – Plymouth

"I told her (midwife) that my family and I was very nervous after having a previous miscarriage but she wrote on my notes "mum and dad excited and looking forward to it'." – Barnstable

"You need a consistent person that knows you that can tell something isn't right." – Exeter

"

Experiences of care after birth – out of hospital

- Positive experiences were characterised by a continuity in care that enabled relationships to be built and challenges to be identified and overcome
  - For example, one woman reported how a midwife (who had done each of her visits) identified that she was experiencing mental health impacts and signposted her into services – despite her stating that she was ok when being asked.
- Conversely, negative experiences tended to occur when there was a lack of continuity of care – women reported that they were unable to build a relationship with their health visitor or midwife because they saw different individuals each time. They also reported that they felt that there were poor quality or no handovers between staff, leading to significant repetition and challenges going unnoticed.
- Closed questions and assumptions that things were going well despite limited discussion and/or observation were also characteristic of bad experiences – Worryingly, this was even said to occur during screening for mental health issues.

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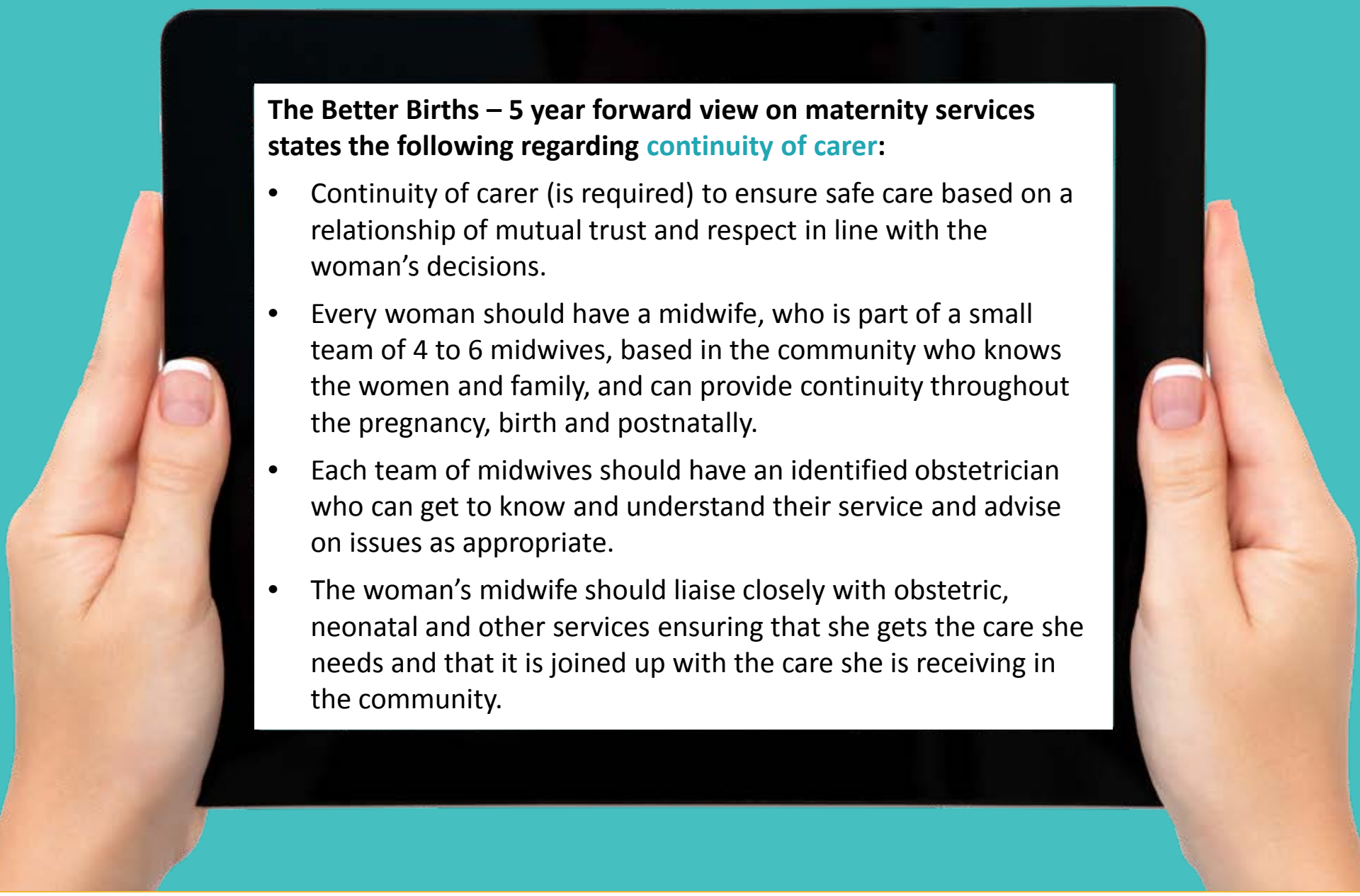
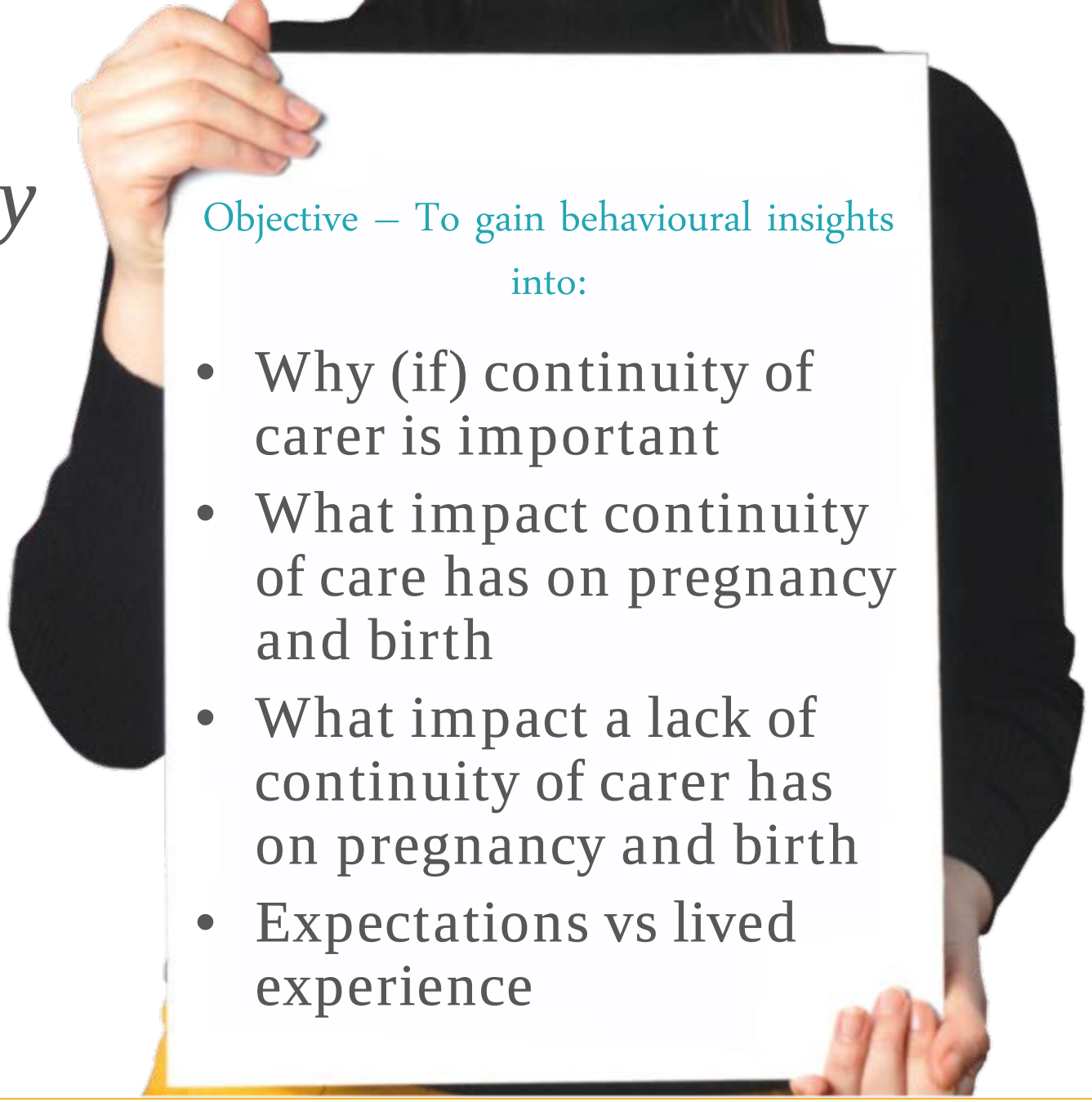
HCP behaviours are a key driver of perceptions of care

Key finding across survey and workshops…

- Good care (quality of care) was always associated with positive behaviours: Caring, friendly, supportive, compassionate, helpful - Even when preferences/choices were not possible due to circumstances (if explained why)


The Better Births – 5 year forward view on maternity services states the following regarding continuity of carer:
- Continuity of carer (is required) to ensure safe care based on a relationship of mutual trust and respect in line with the woman's decisions.
- Every woman should have a midwife, who is part of a small team of 4 to 6 midwives, based in the community who knows the women and family, and can provide continuity throughout the pregnancy, birth and postnatally.
- Each team of midwives should have an identified obstetrician who can get to know and understand their service and advise on issues as appropriate.
- The woman's midwife should liaise closely with obstetric, neonatal and other services ensuring that she gets the care she needs and that it is joined up with the care she is receiving in the community.

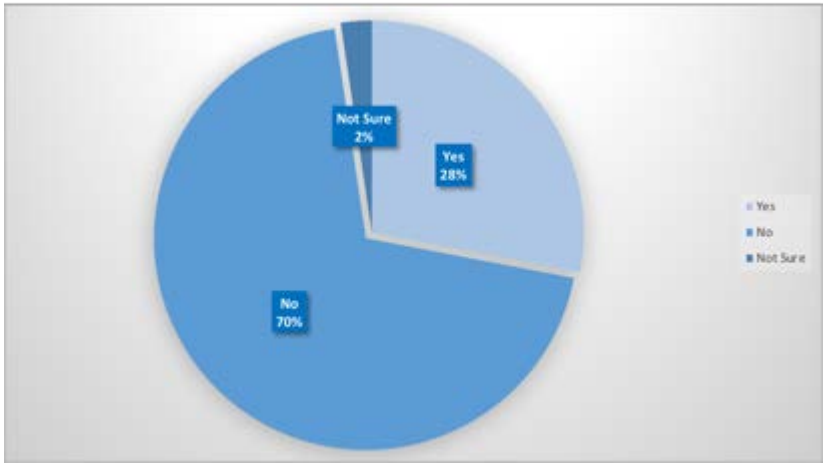
Continuity of carer



Objective – To gain behavioural insights into:

- Why (if) continuity of carer is important
- What impact continuity of care has on pregnancy and birth
- What impact a lack of continuity of carer has on pregnancy and birth
- Expectations vs lived experience

Continuity of carer

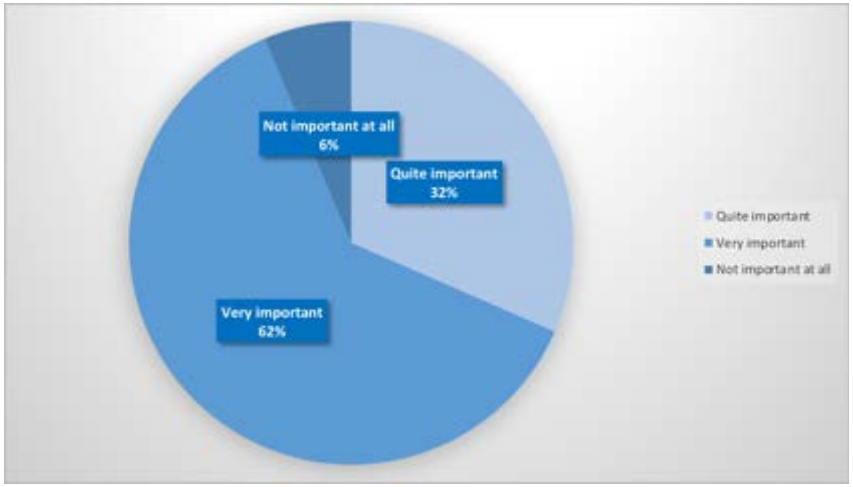


SURVEY FINDINGS:

- Only 28% had one HCP throughout pregnancy and birth
- 94% stated it was "quite" or "very important" to have a continuity of carer
- Pregnancy (54%) and Labour (35%) were reported as the most important times for continuity of carer

QUALITATIVE FINDINGS:

- Happy if care provided by small team of HCPs – allows for different perspectives but a consistent message
- Not essential to have same midwife for pregnancy and birth – but important throughout pregnancy → Personal care, no repetition, understand me any my needs – build relationship, plan together
- Postnatal continuity of care important factor in identifying mental health needs



***BETTER BIRTHS**: "Every woman should have a midwife, who is part of a small team of 4 to 6 midwives, based in the community who knows the women and family, and can provide continuity throughout the pregnancy, birth and postnatally"*

PERCEIVED BENEFITS OF HAVING A SMALL TEAM OF MIDWIVES

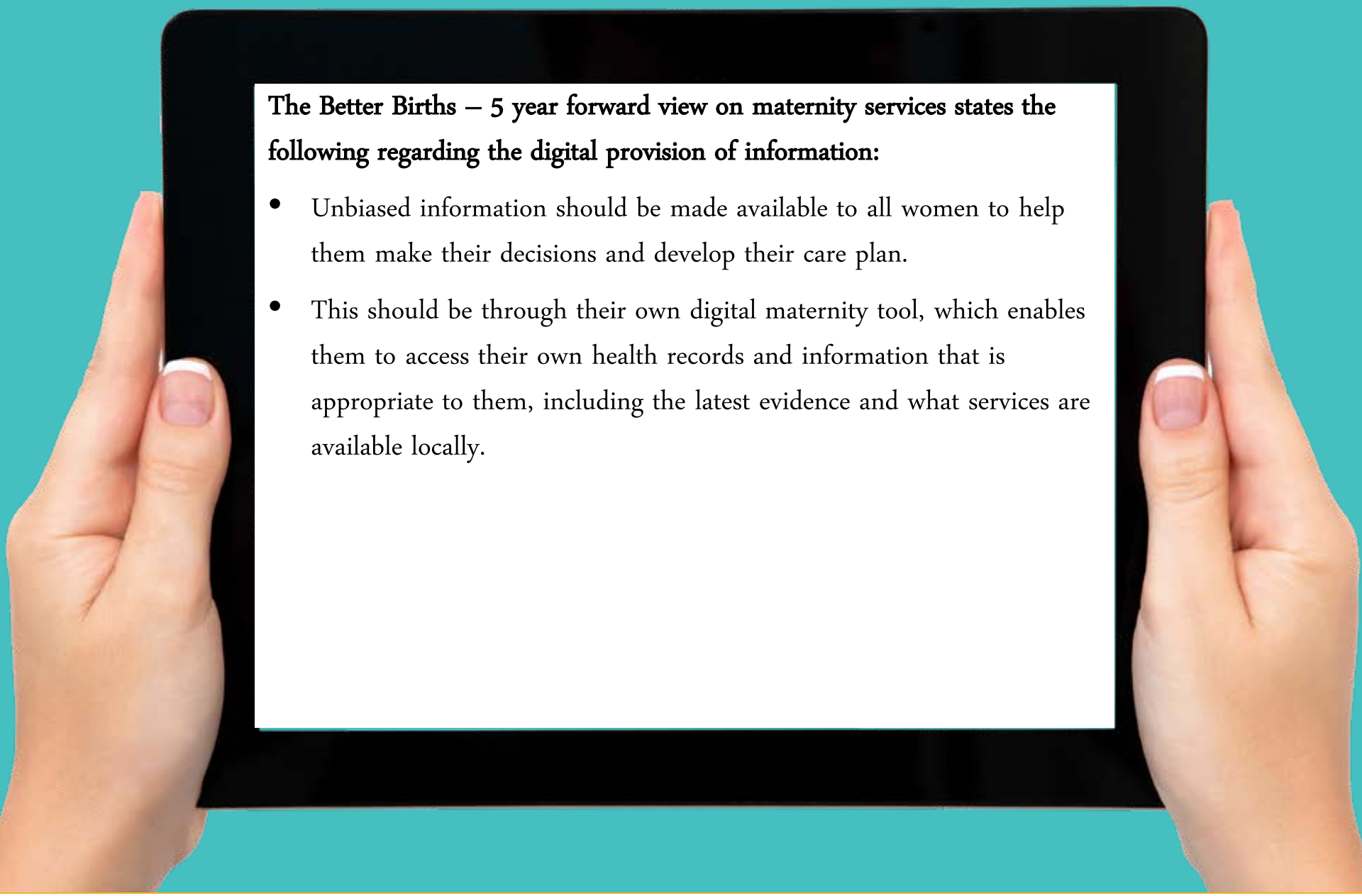
The majority of women reported that they would accept receiving care from a small team of midwives, as outlined in the better births 5 year forward view. They stated that this would:

- Allow for a number of opinions and preferences to be shared without it being overwhelming – they would expect to have consistency in information from a small team but acknowledged that different midwives may provide different perspectives.
- Stop repetition across meetings and allow them to build rapport.
- Improves chances of risks/mental health support needs to be identified.

"I think it's fine to have a different midwife as long as they connect with you on those first few interactions." - Ivybridge

RECOMMENDATIONS

- Implement better births recommendations related to continuity of carer
- Explore ways in which handovers between members of a maternity care team may be improved to enable the next individual within the care team to have quick, easy access to information regarding the individual they're seeing → quickly establish rapport. Patient passports are often used in children's hospitals to support the development of rapport and relationships.
- Link in with planned care workstreams related to personalised care plans – tell my story once
- Ways in which the provision of conflicting information may be reduced must be explored – defining the information exchange eco-system.



The Better Births – 5 year forward view on maternity services states the following regarding the digital provision of information:

- Unbiased information should be made available to all women to help them make their decisions and develop their care plan.
- This should be through their own digital maternity tool, which enables them to access their own health records and information that is appropriate to them, including the latest evidence and what services are available locally.

Digital provision of information

Survey findings

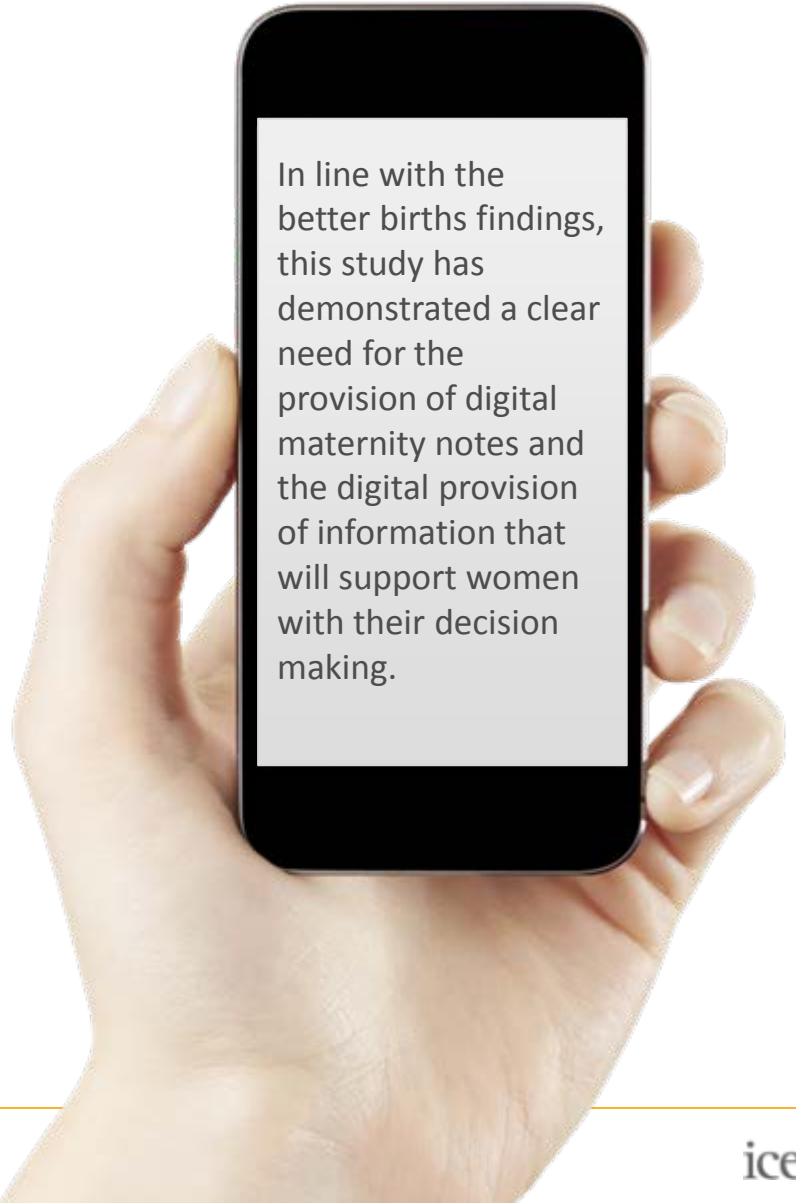
- **85%** believed digital notes would be "extremely" or "very" helpful - **The majority of workshop participants were also in favour**

Qualitative findings –Perceived benefits of digital

- More convenient to transport with me (wouldn't forget them – "you always have your phone")
- Easier for staff to access key information - The medical team should have instant access to the individual's notes.
- Privacy – Expected to be more private compared to carrying the notes folder.
- Easier to read – don't have to rely on being able to read HCP's handwriting.
- Opportunities to link out to other online content – would signpost to trusted content that would support them with their decisions.

RECOMMENDATIONS

- A **review of available digital solutions** is conducted to identify if existing solutions will meet the needs of local women as identified herein – If they do, then individuals should be signposted to this digital solution at the first midwife appointment.
- Chosen solutions must be able to **signpost to local services** (including antenatal classes, mental health support, social prescribing opportunities).
- Key challenges regarding the **integration of IT systems** will need to be overcome. NHS England are said to be working on a digital maternity tool that will provide interoperable digital maternity records
- Breast feeding support was identified as a key need – explore and review available digital solutions and consider developing a **Breast Feeding digital solution**



A good digital solution is…

- Secure – Their data is protected and only accessible with their consent.
- Doesn't require an ID/password to be remembered and input each time need access – The participants wanted ease of access whilst maintaining security like they are used to with PIN access to phones.
- Can provide reminders – They wanted the solution to integrate with calendars and remind them of appointments.
- Information is in a format that's easy to navigate and easy to view – They wanted to have access to information (including about local services) that was relevant to their stage in the journey – don't need it all at once.
- Includes options to print – They wanted to be able to print content if required.

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"It would be good if you could have the option to print certain pages." – Plymouth

"If it actually showed local services that you could choose for different needs, that would be useful." – Exeter

"I'm always forgetting my password, I don't want or need another one." – Ivybridge

"Would be good to get reminders of appointments and stages of pregnancy." – Barnstaple

"It would be good to signpost to antenatal classes through the app, as it's not something widely pushed by midwives." –Plymouth

"

A good digital solution is…

- Must provide detailed and practical information about each hospital – maps, parking, visiting hours.
- Must be accessible at all times (reported that access to Wi-Fi and mobile signal can be challenging in Devon) - an app may enable both online and offline accessibility.
- A number of women stated that they would have liked to keep their maternity notes – if a digital version offered the opportunity to print a folder that can be kept as a memento, this would be valued. Information regarding baby such as growth and weight was considered particularly important – as opposed to clinical and health information regarding mum.

“

”It would be nice if they slightly commercialised it so that you can put baby scans and everything in and pay £5 at the end you get it sent to you in a book or something, yeah fine.” Ivybridge

“If you still have the option to have them printed (paper/printed version of notes).” – Plymouth

“Needs to be easily accessible, signal isn’t the best around here.” - Tavistock

“If they tailored it to your area signposting to services, that would be really useful.” – Exeter

“It’s good to have something that reminds you of the journey you are on.” (discussing a timeline) – Ivybridge

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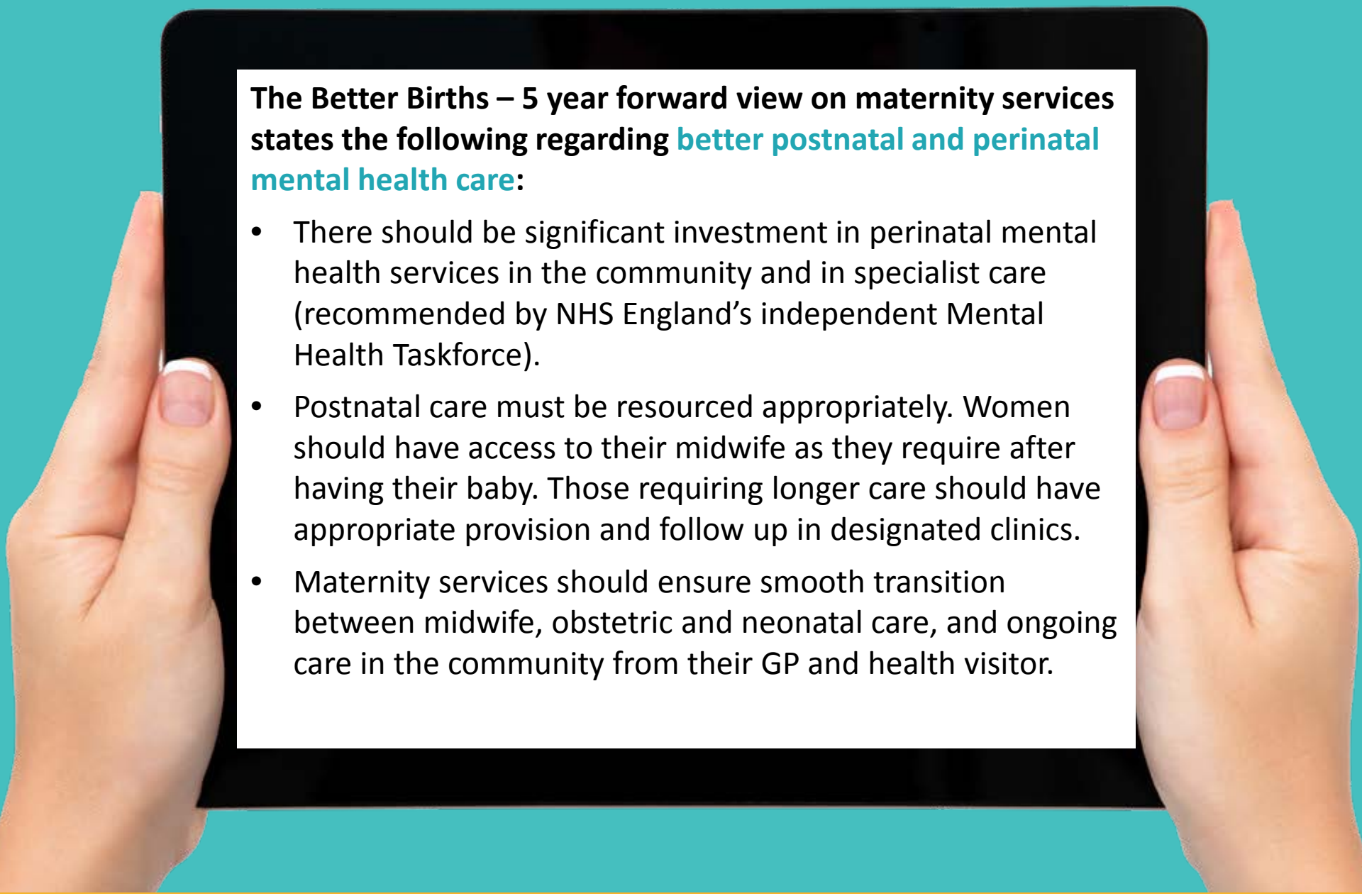
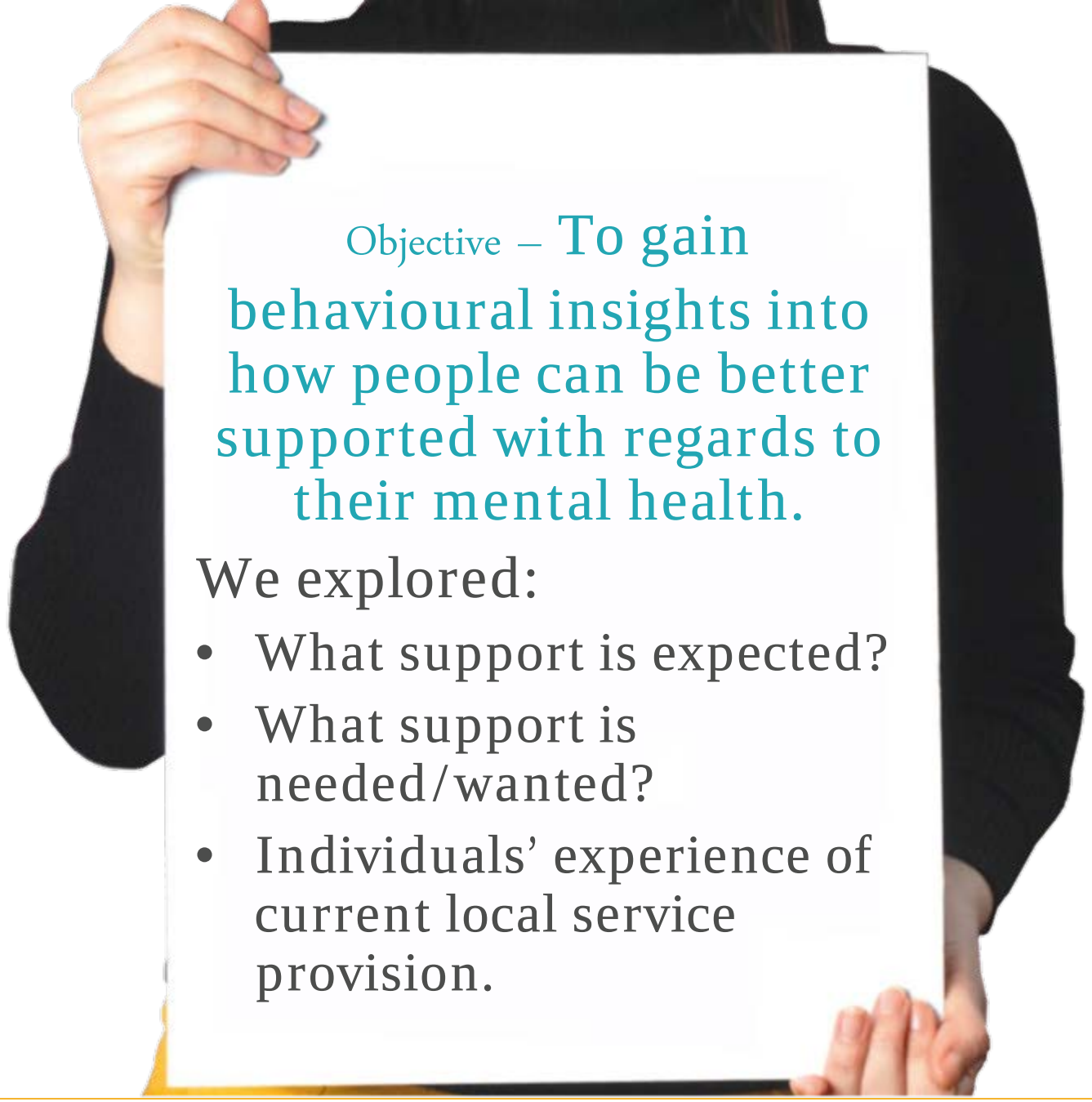

The Better Births – 5 year forward view on maternity services states the following regarding better postnatal and perinatal mental health care:
- There should be significant investment in perinatal mental health services in the community and in specialist care (recommended by NHS England's independent Mental Health Taskforce).
- Postnatal care must be resourced appropriately. Women should have access to their midwife as they require after having their baby. Those requiring longer care should have appropriate provision and follow up in designated clinics.
- Maternity services should ensure smooth transition between midwife, obstetric and neonatal care, and ongoing care in the community from their GP and health visitor.

Postnatal and perinatal mental health



Objective – To gain behavioural insights into how people can be better supported with regards to their mental health.

We explored:

- What support is expected?
- What support is needed/wanted?
- Individuals' experience of current local service provision.

Postnatal and perinatal mental health care – Key findings summary

- Clear challenges with identification of PTSD ("PTSD has made me struggle to care for my children, lose my job and threatens my marriage.")
- 41% of individuals who reported that their birth did not go to plan answered "no" to the question "Did you or your family receive support to cope with this?"
- Lack of support with feeding was a key cause of negative experiences and often resulted in mental health issues (anxiety, guilt → believe baby unwell).

Perinatal Mental Health Support – before birth

- Previous miscarriages → extreme anxiety: many said that every day they thought their baby may be gone. Fear of losing their child caused negative emotional impacts.
- They wanted empathy and understanding of their story however a number reported that their requests for support were not taken seriously and that their midwife lacked empathy.
- They reported that they wanted to hear positive birthing stories and for midwives to ask questions and provide options in a more positive light instead of discussing the worst case scenarios and risks.

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"I tried to talk to the midwife about my miscarriage quite a lot and my anxieties around it and she was not very helpful in what I needed from her." (participant changed midwives due to insensitivities) – Barnstaple

"I said to her, this is a big thing for me and she said 'oh you'll be alright! This one will be alright', I asked for any addition services but she insisted I didn't need them." – Barnstaple

"I told her (midwife) that my family and I were very nervous after having a previous miscarriage but she wrote on my notes "mum and dad excited and looking forward to it'." – Barnstable

"

Lack of relationship with midwife, caused by a lack of continuity in care, was a key barrier to receiving perinatal mental health support

Many participants reported that a lack of continuity in care prevented them from receiving perinatal mental health support. The **lack of continuity of care caused**:

- Many participants to feel like they couldn't build a rapport/relationship with their midwife which led to them feeling less empowered to speak up and share their thoughts and feelings – even causing them to answer dishonestly on screening questionnaires.
- Opportunities for the HCP to identify issues to be missed - Despite physical and mental health problems existing, the participants believed that midwives had been unable to identify their challenges due to a lack of continuity in their care - They were not able to notice that the patient wasn't feeling/acting their norm.
- A lack of empathy and understanding which was needed to calm their nerves and anxieties – they believed that the individuals they interacted with didn't understand their story and needs due to it being different individuals each time.

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"She asked my friend to make her a drink so that she could ask me alone if I was okay, I broke down. (she could tell there was something wrong)" – Plymouth

"You need a consistent person that knows you that can tell something isn't right." – Exeter

"It was only because I had the same health visitor that I was able to say some of the things I was feeling, whereas if I'd had the same midwife in the first month (after birth), perhaps I wouldn't have gone through the first 7 months of her life feeling how I did." – Exeter

"

Screening for mental health needs was not identifying issues

- Antenatal and postnatal midwife appointments felt very rushed. Many participants said their appointments felt like a tick box exercise.
- This was particularly apparent during the postnatal screening for perinatal mental health needs, which was typically conducted using a questionnaire administered in a paper based or digital format. The women reported that they didn't want to rate their feelings on a scale of 1-10 or fill in a questionnaire on a device. They needed to have a human to human conversation with a person they trust and have built rapport with. They wanted to be listened to and the closed questioning and checking boxes in a questionnaire that they received didn't enable them to raise issues.
- There were reported instances of HCPs making assumptions and filling in the questionnaire without really listening ("so everything is ok isn't it?) to the women. Instances of the women being given the questionnaire to complete themselves were also identified.
- Continuity of care was considered really important at this stage because if the participant didn't know the HCP conducting the screening ,it made them less likely to be open and honest when questioned.
- A key driver for dishonest/incomplete responses was a fear that their child may be taken away from them if a mental health issue was identified.

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"It's a tick box exercise, they are ticking boxes for the sake of ticking boxes. They're (HCPs) not listening to what's being said." – Exeter

"My GP told me to ring my health visitor but I never did, I thought she's not going to help." – Exeter

"Just because I get up everyday and my house is clean doesn't mean there isn't something going on." – Exeter

"Services actually listening and saying yeah there is a problem and helping that way."(when asked what could be improved) – Tavistock

"You do sometimes feel like you're talking and people aren't actually listening." (when discussing care from HCPs)– Tavistock

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A lack of support with feeding caused negative emotional impacts for many participants

A lack of support with feeding caused significant negative emotional impacts that the participants believe could have been resolved if better support were available.

Individuals who initiated breastfeeding reported that:

- They were not properly observed or supported to breastfeed before being discharged.
- Instances of tongue tie were not picked up at hospital or when back receiving community support, this caused significant levels of anxiety and negative emotions for women who feared that their child was unwell or may need to be readmitted due to weight loss – in addition to feeling guilty and like a failure as they were struggling to breastfeed.
- There were instances of treatment for tongue tie that took longer than expected.
- That women needed further support to breastfeed if they were to be able to initiate (particularly after difficult or traumatic births) and maintain.

> ***"The midwife would say 'we recommend 6 months of breastfeeding' and that was that." – Barnstaple***
>
> ***"I found that breastfeeding was extremely pushed, that was the only downfall with NCT." - Exeter***
>
> ***"I really wanted to breastfeed but I couldn't, I had no clue I could combi-feed." – Tavistock***
>
> ***"It was 4 weeks before his tongue tie was removed. I couldn't breastfeed even though I really wanted to, I felt like a failure." – Tavistock***

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Individuals who formula fed or transferred to formula feeding as they were unable to initiate or maintain breastfeeding reported that:

- They were not supported to transfer to formula feeding even when necessary – including being discharged with no equipment at home if for example they had tried to breastfeed (so had not prepared anything for formula feeding) but were then unable to do so.
- Because they received (what they perceived to be) biased information from HCPs towards breastfeeding, they were unprepared for combi or bottle feeding.

The participants reported that they needed practical information that was balanced and unbiased regarding all of their options (including expressing and combi-feeding).

> ***"The midwife would say 'we recommend 6 months of breastfeeding' and that was that." – Barnstaple***
>
> ***"I found that breast feeding was extremely pushed, that was the only downfall with NCT." - Exeter***
>
> ***"I really wanted to breastfeed but I couldn't, I had no clue I could combi-feed." – Tavistock***
>
> ***"It was 4 weeks before his tongue tie was removed. I couldn't breastfeed even though I really wanted to, I felt like a failure." – Tavistock***

Postnatal depression vs post traumatic stress disorder – PTSD Missed by screening

NHS choices Your health, your choices

Post-traumatic stress disorder (PTSD)

Post-traumatic stress disorder (PTSD) is an anxiety disorder caused by very stressful, frightening or distressing events.

Someone with PTSD often relives the traumatic event through nightmares and flashbacks, and may experience feelings of isolation, irritability and guilt.

The symptoms of post-traumatic stress disorder (PTSD) can have a significant impact on your day-to-day life.

In most cases, the symptoms develop during the first month after a traumatic event. However, in a minority of cases, there may be a delay of months or even years before symptoms start to appear.

Some people with PTSD experience long periods when their symptoms are less noticeable, followed by periods where they get worse. Other people have constant, severe symptoms.

Postnatal depression

Many women feel a bit down, tearful or anxious in the first week after giving birth. This is often called the "baby blues" and is so common that it's considered normal. The "baby blues" don't last for more than two weeks after giving birth.

Signs that you or someone you know might be depressed include:

- a persistent feeling of sadness and low mood
- lack of enjoyment and loss of interest in the wider world
- lack of energy and feeling tired all the time
- trouble sleeping at night and feeling sleepy during the day
- difficulty bonding with your baby
- withdrawing from contact with other people
- problems concentrating and making decisions
- frightening thoughts – for example, about hurting your baby

Mental Health Support – Debrief/feedback offered for individuals who experienced traumatic births

- Difficult/ traumatic birth → wanted closure – they wanted to know what happened and why it happened At least two participants said that their experience was so severe that it would put them off having another child.
- A debrief with hospital staff was offered to a number of the participants – This offer was taken up by most and was said to have provided closure.
- However, for some this debrief took place in the same area of the hospital where the traumatic event took place, making the participant relive the experience and causing significant emotional distress.

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“I was walking down the corridor and I just had a panic attack, I was back where it all happened and it was horrible.” – Plymouth

”I’m so glad it happened with my third child because if it happened with my first, I definitely wouldn’t of had another child.” – Torquay

“It would be nice to know that something was being done about it so that it doesn’t happen to the next person or even me.” – Tavistock

“We got it sent out in the post quite out the blue…I don’t know why it was sent to us, it wasn’t something that I could interrupt other than how long they had to do CPR on him or that he was blue, yano that’s not what you want to be hearing about when you’re finally home.” - Tavistock

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Recommendations

- Many of the key issues related to mental health were related to issues with 1) Continuity of carer or 2) behavioural/relationship issues. Therefore, Implementing better births recommendations related to continuity of carer and embedding the principals of shared decision making may be expected to improve outcomes.
- Identify and address training needs related to the screening for mental health issues.
  - Screening must be more conversational – build rapport to identify issues
- Provide opportunities for feedback (debriefs) for all patients who suffer a traumatic birth → screen for signs/symptoms of PTSD both in the short (by midwives and health visitors) and medium term (in the community by GPs and health visitors).
- Identify and signpost to opportunities for social prescribing (e.g. peer support) – the women wanted empathy, understanding and to hear from individuals who had been through similar experiences. They wanted opportunities beyond the current anxiety and depression service


The Better Births – 5 year forward view on maternity services states the following regarding the NHS Personal Maternity Care Budget:
• Women should be able to choose the provider of their antenatal, intrapartum and postnatal care and be in control of exercising those choices through their own NHS Personal Maternity Care Budget.

The NHS Personal Maternity Care Budget – initial feedback

Participants' immediate reactions to the idea of having a NHS personal maternity care budget were all negative.

- This idea evoked fear in all participants and made them feel overwhelmed at the thought of having this responsibility.
- It was stated that monetarising decisions would actually have the impact of restricting control and choice, with many women stating that they would be worried about how they spent NHS money and that this would lead them to make choices that did not necessarily focus on their personal needs.
- Participants reported that based on their previous experience, they don't have enough knowledge/information to make key decisions at times when they are asked to and would be fearful of making the wrong choice and not being able to change their mind if the money had already been spent.
- They reported that they would be more likely to trust the experts to make these decisions regarding how budget is spent.
- They also questioned whether this would lead to providers with better reputations and availability of equipment becoming overcrowded, leading to poorer experiences.

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"You don't want to waste the NHS money." – Plymouth

"You should just have the service that is right for you." – Ivybridge

"You shouldn't have to choose between hospitals, all hospitals should be good enough." - Torquay

"The care that is appropriate for you at the time is what should be given to you." – Torquay

"I'm happy to be guided by the doctors for what is best for my baby." - Barnstaple

"

The NHS Personal Maternity Care Budget – A lot of questions need answering

The participants had a range of questions that they stated needed to be answered:

- When do you get given the budget? – participants reported that other elements during the antenatal process feel like they occur too late, they were concerned this would also be one of them.
- Will we know how much each option costs?
- What if I have no budget left for unexpected birth or after care?
- Previous experience might make more expensive options a must (e.g. a high risk pregnancy and/or need for c-section). How will this work?
- How can choice of provider be supported given that work commitments restrict where I am able to go and when? (”What if I want to drive to Exeter all the time, would work allow it?”)
- Can I change my mind? Once it’s spent, is it gone?

“

“That would be really hard.” – Exeter

“What if you run out of your budget…it seems silly.” - Tavistock

“There’s enough worry involved already without adding another issue.” - Barnstaple

“What if I have used all of my budget and then I have unexpected mental health care I need after the birth -how does that work?” – Exeter

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RECOMMENDATIONS

We do not recommend that a personalised maternity care budget is implemented. We recommend that decision aids regarding provider options are developed to support women to make informed choices.

- Participants want more choice and control when making decisions regarding their maternity care, but were unanimous in stating that attaching a budget would not facilitate this. In fact, they believed this would restrict their choice and control.
- Participants were visibly overwhelmed at the prospect of having control of a budget and having to select from a range of providers.
- Whilst a personalised maternity care budget may appeal to individuals who are activated and knowledgeable regarding their care options, for the majority of individuals this is unlikely to empower them. Significant changes in information provision (to increase patient activation levels), continuity of care (to build trusting collaborative relationships) and provider options (choice is already restricted with birth options and available equipment significantly limited in many locations) would need to be in place before the idea of a personalised maternity care budget is likely to resonate better with local women.
- Participants stated that decision aids that provided details regarding available choices, without monetarising the decision, would be more acceptable.

thank you

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