

care outside guidance

Caring for those women seeking
choices that fall outside guidance



Royal College
of Midwives

RCM Professional Briefing: Caring for those women seeking choices that fall outside guidance

The aim of this publication is to provide guiding principles and support midwives in facilitating personalised care and women's choices, including when those fall outside clinical recommendations.

Background

Maternity policy in the UK focuses on provision of safe and personalised care across the perinatal period (NHS England 2016; Scottish Government 2017; Welsh Government 2019). The concept of woman-centred care is at the core of midwifery care and midwives have a key role as advocates and facilitators of women's choices. Personalised care accounts for individuals' values and preferences and is based on choice and control through genuine partnership with health professionals to improve care outcomes. The NHS Long Term plan (NHS England 2019a) sets out a vision for Universal Personalised Care (NHS England 2019b) an ambitious target for the implementation of the comprehensive model for personalised care across health and care system. This includes the implementation of Personalised Care and Support Plans (PCSP) in maternity. The PCSP model enable clinicians to follow an evidence-based typology of care planning easily adoptable in different context and clinical settings (Burt et al 2014).



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Role of guidelines

In clinical practice the terms 'policies', 'guidelines' and 'protocols' are often used interchangeably, creating confusion for women, families and clinicians on the definition and role of each of those and their relations with personalised care provision (Frohlich & Schram 2015). The table below provides a definition for each term:

Term	Definition
Policy	Refers to a way of doing something that has been agreed by an organisation. They tend to be more prescriptive and implemented through HR (they can be contractually obliging such as uniform policies).
Protocol	A protocol is an agreed method of carrying out a certain procedure or treatment. It tends to be task oriented and give specific and focused instructions. For example, managing an eclamptic fit or major obstetric haemorrhage.
Standard Operating Procedures (SOP)	Refers to an outline of detailed, written instructions describing how to complete a procedure. They are designed to ensure consistency and standardisation for defined processes and eliminate variation (e.g. community on call SOP).
Guideline	A systematically developed tool that describes a condition, or care pathway and makes recommendations about treatment and care based on best evidence available. It should be used to assist decision making.

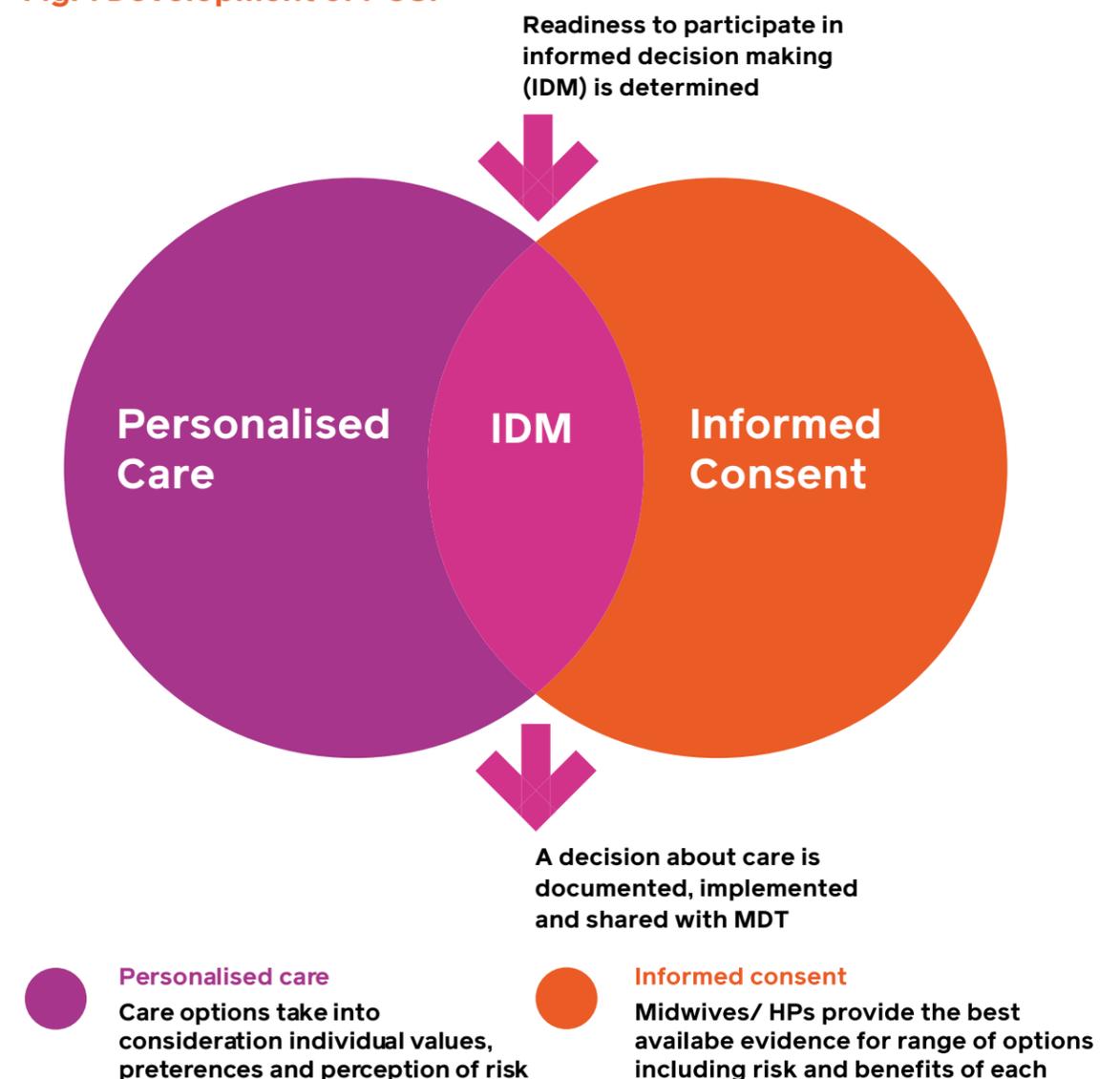
The defined role of guidelines, policies and protocols needs to be considered when they are used to inform consultation and care planning. Guidelines bring together the evidence available on a certain topic and play an important part in avoiding variation of care, however, frequently national and local guidance differs, so does the definition of 'out-of-guideline' (Feeley et al 2020). Guidelines include sets of recommendations based on the trade-off between benefits and harm; some are made with more certainty than others based on the quality of the underpinning evidence. Moreover, guidelines do not supersede women's human rights to bodily autonomy. Therefore, even where they may be strong evidence in favour of a course of action or treatment, information giving should not unduly persuade or coerce and maternal decisions should be respected.



Personalised Care and Support Plan (PCSP)

Personalised care requires a relationship of mutual trust and good multi-disciplinary involvement and can be facilitated by models of midwifery continuity of care (MCoC). The development of a PCSP requires a series of facilitated conversations centred on active participation of the person in exploring how to best manage their health and wellbeing, accounting for their preferences, values, needs and individual and family circumstances (NHS England 2021). Those conversations constitute the foundations of the holistic assessment which leads to the agreed personalised care and support plan (Fig 1).

Fig. 1 Development of PCSP



Informed decision making and Informed consent

Informed decision making is based on individuals being supported to understand the care, management, and support options available to them as well as the potential associated risks, benefits, and consequences of those options. The best available evidence should be presented in an accessible way, including personalised and holistic risk assessment which takes into consideration what the individual wants to know, rather than what clinicians think the individual should be aware of. Assumptions must be avoided and safety considered through a holistic lens including physical, mental, emotional, spiritual and cultural considerations. The term “shared decision” making has been superseded by informed decision making, as although the process is collaborative, the final decision rests with the individual: my body, my baby. It is also important to note that some women may decline extensive information giving by the maternity professional. This is their right to do so and should be respected and documented accordingly. The development of a PCSP is based on personalising care provision that is founded on individual preferences, values and level of risk tolerance. Personalised care and support plans should be developed collaboratively with the woman and once agreed, they should be clearly documented and accessible to the woman. PCSP should include the decisions made by the woman on her care and what support will be made available to enable those choices. Ideally, conversations

should start with that the woman wants (if known), including benefits, risks and alternatives. Additionally, the care planning discussion should include contingencies in line with the woman's preferences and values, so all possible scenarios are considered. It should be remembered that care planning is an iterative process, should new circumstances develop, the woman maintains control and preferences are recorded in the event of a changing peripartum situation.

Consent is a fundamental right of individuals, who should be involved in decision making regarding their care and making informed decisions. Consent is required by health professionals when making recommendations of care, before carrying out interventions or administering treatment; consent is not required when a woman opts for a care pathway or makes a decision concerning place of birth, for example in the instance of a planned home birth with risk factor/complexities. In such circumstances clinicians are not seeking consent but are required to support the woman in making an autonomous, informed decision with care and contingency plans.

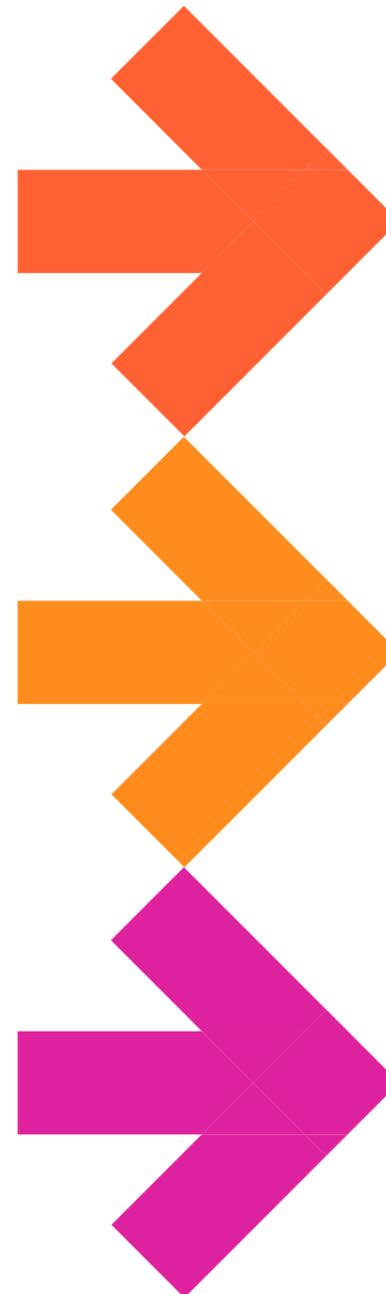
The ruling Montgomery v Lanarkshire, that is based on a court case on intrapartum care, underpins UK law on informed consent. Serious harm and both short- and long-term unintended consequences can result from women not being listened to and not being able to have the time and information necessary to make a truly informed decision about their care.



Seven principles of informed consent

The General Medical Council (GMC 2020) guidance on consent sets seven principles of informed consent.

1. All individuals have the right to be involved in decisions about their treatment and care and be supported to make informed decisions if they are able.
2. Decision making is an ongoing process focused on meaningful dialogue: the exchange of relevant information specific to the individual patient.
3. All individuals have the right to be listened to, and to be given the information they need to make a decision and the time and support they need to understand it.
4. Clinicians must try to find out what matters to patients so they can share relevant information about the benefits and harms of proposed options and reasonable alternatives, including the option to take no action.
5. Clinicians must start from the presumption that all adult patients have capacity to make decisions about their treatment and care. A person can only be judged to lack capacity to make a specific decision at a specific time, and only after assessment in line with legal requirements.
6. The choice of treatment or care for individuals who lack capacity must be of overall benefit to them, and decisions should be made in consultation with those who are close to them or advocating for them.
7. Individuals whose right to consent is affected by law should be supported to be involved in the decision-making process, and to exercise choice if possible.





Duty of care

Midwives are obliged by the NMC code (NMC 2018) to 'put the interest of people needing or using nursing or midwifery services first'. This is achieved by prioritising their care and safety, treating women with kindness by listening and preserving their dignity and human rights. Midwives are legally required to uphold duty of care for the women they care for. This concept applies to individual clinicians and maternity services, which are required under human rights laws to respect individuals' decisions concerning their care.

Duty of care is underpinned by informed decision-making and the principles of authentic and legal consent. Midwives need to counsel women using the very best evidence or options available to them in accessible format and document such conversations. Women can accept or decline such recommendations and develop personalised care and support plans, which are facilitated by continuity of care.

In some instances, midwives and health professionals may experience a personal conflict between their duty of care and the wishes of women in their care, particularly where the women's wishes fall outside best practice guidance. Perception of risk varies and midwives may have to negotiate their professional concerns sensitively while still providing compassionate care and attending women for an 'out of guidance' birth in midwifery-led settings (See Key Recommendations six and eleven).



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Midwifery and Human Rights

The Human Rights Act (HRA) 1998, protects individuals' basic rights and freedoms, including those 16 rights stated in the European Convention on Human Rights. The HRA protects women's choices regarding where and how they give birth and their rights to decline recommended care based on medical advice. The Midwifery and Human Rights guide developed by the British Institute of Human Rights (2016) in collaboration with the RCM covers the 16 rights protected by the HRA, however articles 2, 3 and 8 provide the framework for PCSP. Article 2.

Artical	Description
Article 2 Right to Life	Women should never be denied access to maternity services, and potential impediments in accessing care (such as lack of personalisation of care) should be removed
Article 3 Right to be free from inhuman or degrading treatment	Women should not be subjected to medical procedures they do not consent to nor should be denied pain relief
Article 8 Right to respect for private and family life, home, and correspondence	Women should be supported in any choice they make during pregnancy and childbirth; this includes care against medical recommendations

Wider context

The provision of personalised care can be facilitated on a practical level by midwives and midwifery models such as midwifery continuity of care (MCoC). However organisational culture, midwifery leadership and effective multi-disciplinary team working all influence the successful provision of personalised care. Women are more likely to access and engage with services when their physical, emotional, psychological, and social needs are met and when cultural safety is respected. Collaboration with local Maternity Voice Partnerships and Maternity Services Liaison Committees is key to developing locally appropriate pathways of care that enable women's views and attitudes to inform maternity care provision.



Key recommendations

1. Each maternity contact is an opportunity for women to make informed decisions. Ensure enough time and space is given to counsel women on care pathways and develop personalised care and support plans.
2. Each consultation between women and midwives should be based on the assumption that the midwife may suggest a set of clinical recommendations and care pathways that can be accepted or declined.
3. Evidence based information should be given and shared in advance where possible in accessible and easily understandable format (which considers language barriers and health literacy) and tailored to individual, social and cultural circumstances.
4. Conflicting clinical recommendations based on national or local guidelines should be clearly discussed if applicable and the terms 'guidance', 'policy' and 'protocol' should be used appropriately.
5. Advocacy considerations should be taken into account, particularly for women requiring interpretation services or women with social complexities and vulnerabilities that may require an advocate present for PCSP development.
6. Midwives should seek input and support from senior midwifery clinicians and members of the multidisciplinary team when developing PCSP for women with social and medical complexities.
7. Midwives should support the woman to make informed decisions and suspend judgements on those decisions; clinicians are not required to 'approve' women's informed choices.
8. Care planning should be recorded and made accessible to the woman, who should be able to suggest edits and modifications if necessary and agree to it. At the end of the consultation, the decisions made on treatment and care, timelines for review and next steps should be clearly discussed and documented.

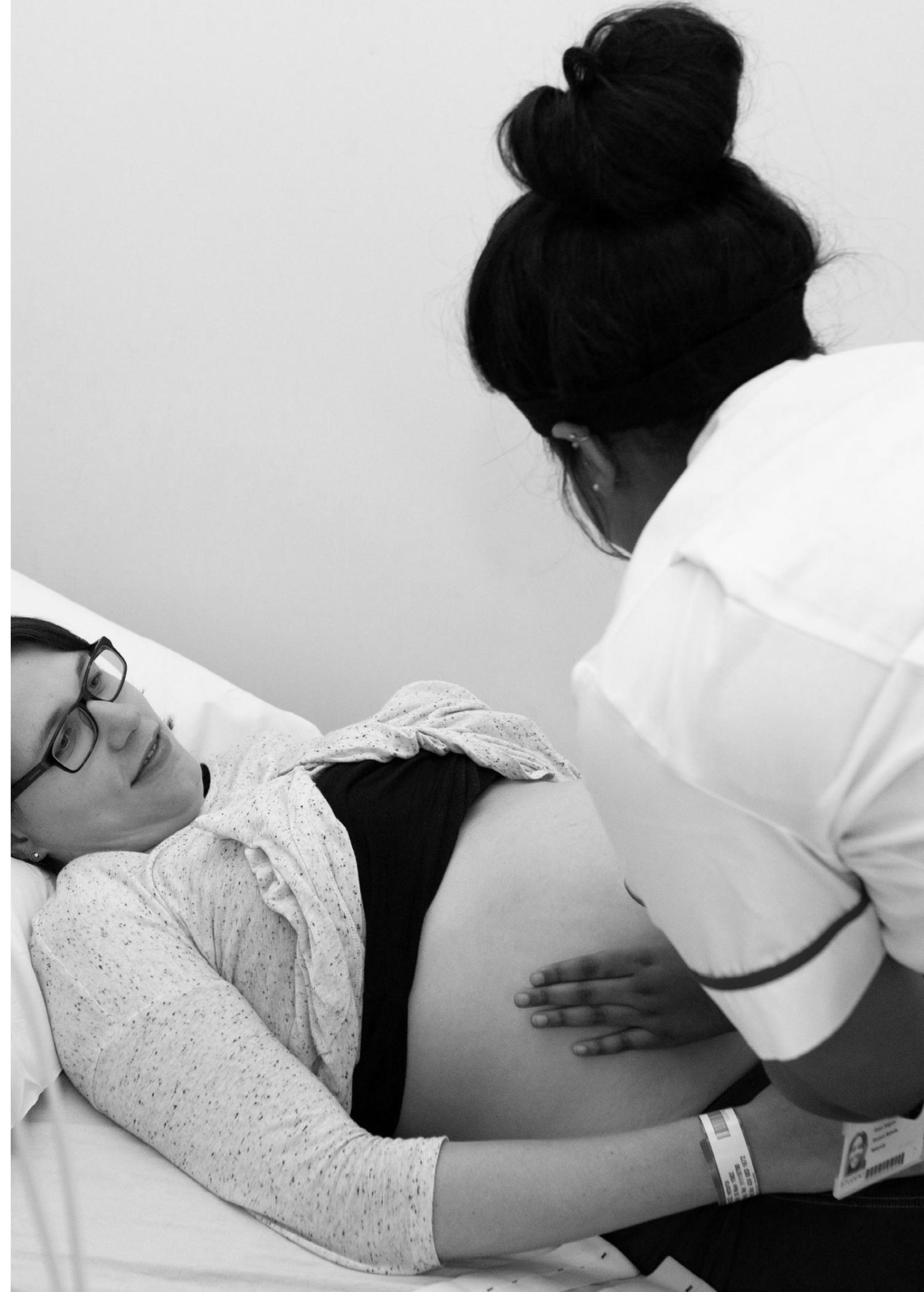
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9. In the instance of a women requiring some extra time to reflect on 'a PCSP', they should be given the opportunity to finalise any PCSP at a later moment including via remote consultation.
10. Every woman should be given the opportunity to review and change an agreed PCSP if circumstances change or if they change their mind.
11. Midwives should seek support and advice from their PMA/Supervisor of midwives or other senior midwife, if needed, to enable them to confidently facilitate PCSP in practice.
12. Senior midwives (service managers/ consultant midwives) should assess midwifery skills and competencies and provide support to midwives facilitating complex PCSP in midwifery-led settings, provide access to any training required, provide senior midwifery backup and liaise with MDT to develop appropriate escalation plans.



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