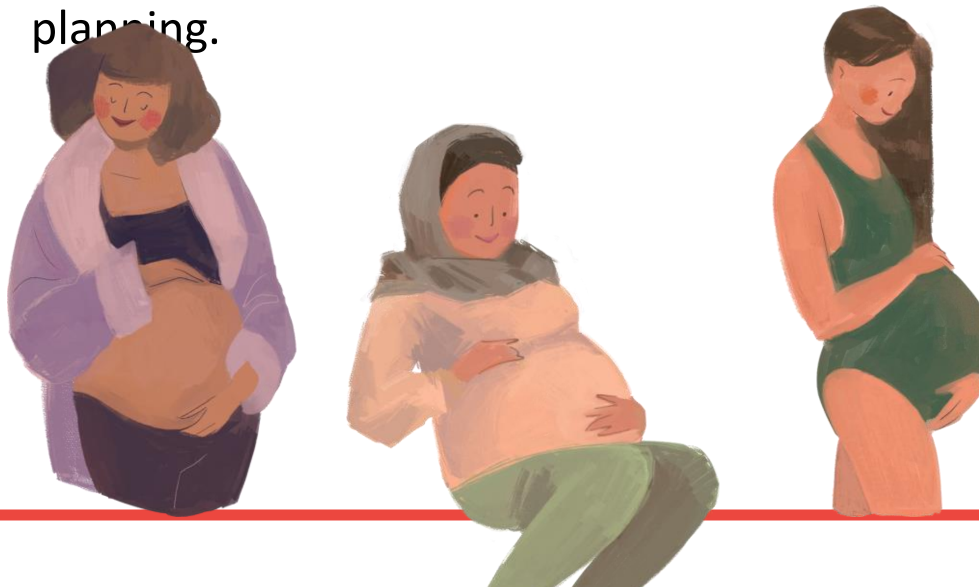
Personalised care

How midwives can personalise care and women's choice, including when those fall outside clinical recommendations?

Intro from the RCM chair

This webinar for midwives and student midwives highlights the RCM's publication Care outside of guidance and how it will support them in practice.

The webinar will cover the research and clinical core principles of personalised care and support planning.



Introducing the speakers

New publication:

- Find out how to personalise care and women's choices when they fall **outside clinical recommendations**
- Learn how to develop a personalised care plan and support women-centred care in practice
- Understand the role of duty of care, informed decision and consent in the context of personalised care planning

care outside guidance

Caring for those women seeking choices that fall outside guidance

Royal College of Midwives

Acknowledgements

RCM Expert Clinical Advisory Group (ECAG)

Independent Advisory Group:
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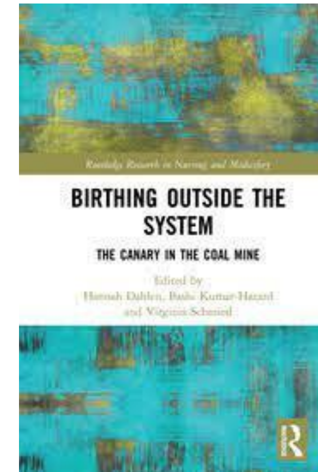

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Policy

Legal framework

Evidence

Clinical care

Road map to support: women's centred, personalised care

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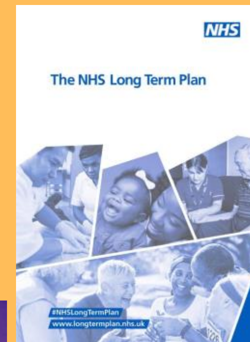
Woman-centred care

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.**

Maternity policy in the UK focuses on provision of safe and personalised care across the perinatal period.

The NHS Long Term plan sets out a vision for Universal Personalised Care with the implementation of the comprehensive model for personalised care across health and care system.



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Midwives have a key role as advocates and facilitators of women and childbearing people's choices.

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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.

Role of guidelines

Understand the role of each and their relations with **personalised care provision**

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Role of guidelines

Guidelines bring together the evidence available on a certain topic aim to address care **variation**.

National and local guidance differs, so does the **definition** of ‘out-of-guideline’.

Sets of recommendations based on the trade-off between benefits and harm.

Guidelines do not supersede **women’s human rights** to **bodily autonomy.**

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- 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 PSCP 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
- Those conversations constitute the foundations of the holistic assessment which leads to the agreed personalised care and support plan

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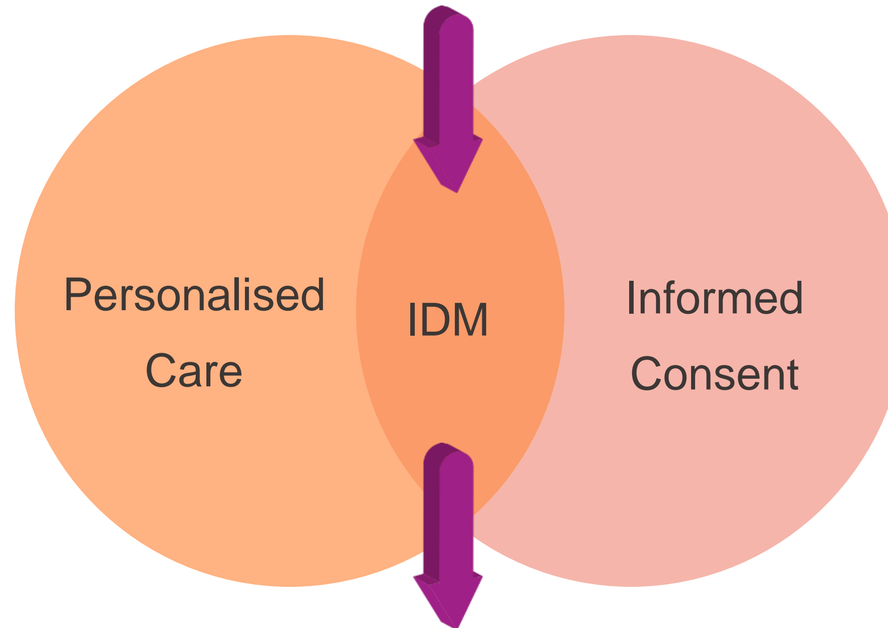
Readiness to participate in informed decision making (IDM)is determined



A decision about care is documented, implemented & shared with MDT

Personalised Care

Care options take into consideration individual values, preferences and perception of risk

Informed Consent

Midwives/ HPs provide the best available evidence for range of options including risk and benefits of each

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Research & evidence

@drfeeleyrm

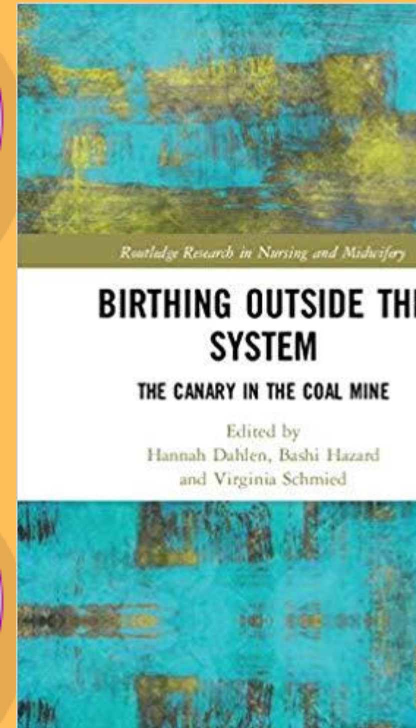
What do we know?

Birthing women and people's perspectives

Feeley et al (2015) **Why do some women choose to freebirth? A meta-thematic synthesis** Evidence Based Midwifery

Holten & Mirenda (2016) **Women's motivations for having unassisted childbirth or high-risk homebirth: An exploration of the literature on 'birthing outside the system'** Midwifery

Madeley (2022) (under review) **Challenging norms: Making non-normative choices in childbearing**…A meta-ethnography



@drfeeley

Key messages

- Rejection of medical, and for some, midwifery model of care
- Previous birth experiences ~ positive - traumatic
- Challenging dominant risk discourses
- Philosophy, beliefs, and desire to retain autonomy

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‘I felt ashamed, the only other thing I have ever felt ashamed of uh through the whole process, I was ashamed that I sounded like a pig that’s being slaughtered.’
(Cat- Feeley & Thomson p.6).

‘The obstructive behaviour by the community midwives, the lottery of who would turn up at the birth… I actually became fearful that they would turn up in time for the birth as **they seemed more scared of attending a home birth than I felt about having a home birth.**’
(Feeley, Thomson, p.6).

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Supporting choice, midwife perspectives

- Feeley et al (2019) **Caring for women making unconventional birth choices: A *meta-ethnography* exploring the views, attitudes, and experiences of midwives**. Midwifery
- Westbury & Einion (2021) Matricentric or Medically Responsible: **An Exploration of Midwives' Attitudes Towards Caring for Women and Birthing People Who Choose to Birth Outside of Guidelines.** The Practising Midwife

(and more from international perspectives)

@drfeeleyrm

‘Willingly facilitative NHS midwives’…

45 UK NHS midwives
Diverse sample (different practice settings, levels of experience, seniority
Two types of data collection
n=65 pieces of data
Three levels of analysis

How do NHS midwives self-defining as facilitative, support alternative physiological birth choices (what they do, how they do it, and the rationale for their chosen actions)?

What were their **experiences** in delivering such care?)

What and how do sociocultural-political factors influence the midwives’ practice? (the micro, meso, and macro working contextual influencing factors upon their practice).

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Table 2 Examples of birth decisions

Birth decisions otherwise 'healthy' pregnancy	Birth decisions 'complicated' pregnancy
Declining vaginal examinations during labour	Vaginal birth after caesarean (VBAC) homebirth, birth centre or at hospital without usual monitoring
Declining postdates induction of labour (IOL)	VBAC (after 2 or 3 caesareans) homebirth/birth centre
Declining all monitoring during labour and/or freebirth	Waterbirth – VBAC or gestational diabetes or twin pregnancy or breech presentation at home/birth centre or at hospital without usual monitoring
Declining recommended medical interventions (not emergency)	Raised BMI (>35-50) homebirth or birth centre
Declining antenatal screening/scans	Breech homebirth or birth centre or at hospital without usual monitoring
Declining antibiotics and/or augmentation for GBS+ or PRSOM	Medical conditions such as epilepsy, diabetes, blood clotting disorder, hypothyroidism, blood borne virus- homebirth or birth centre

When we know **what has been achieved** (in the NHS) we know what **can…**

What midwives need to practice - the ASSET model

A
- Autonomy
- Access, assess, & apply evidence-based information to individual women

S
- Skills- physiological birth experience and skills in a range of settings
- Skill development- ongoing CPD

S
- Systems approach that supports woman-centred care/full-scope midwifery
- Support (accessible, timely, restorative ~psychological safety)

E
- Empathy and compassion (for women and from colleagues)
- Emotional intelligence

T
- Trusting relationships; with women, colleagues, employers

Feeley, C. (2022) The ASSET model: What midwives need to support alternative physiological births (outwith guidelines). The Practising Midwife. 25(2):26-30.

Clinical Perspectives of 'Outside Guidance Care'

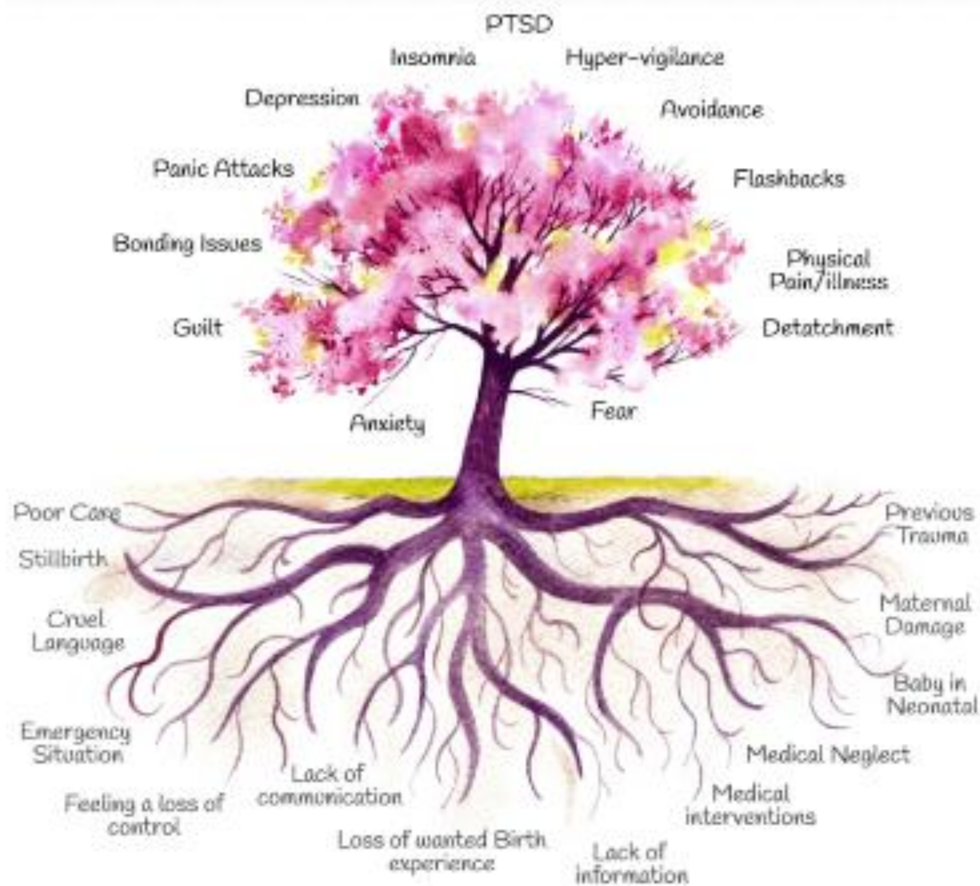
Julie Frohlich
Consultant Midwife
Guy's and St Thomas' NHS Foundation Trust

Complex pregnancy

Women with a more complex pregnancy – the so called ‘high risk’ women – may have had even more limited choices in our increasingly risk-averse NHS, with clinicians ‘struggling’ to reconcile women’s informed choices with their own perceptions of safety and, instead of facilitating meaningful discussions, ‘guiding’ (coercing) women to make a perceived ‘right choice’

Themes arising from care planning consultations

- Risk: over-emphasis and use of 'scary language'
- Impersonal care - in line with guidelines but 'on a conveyor belt'- lack of choice
- Emphasis on management of medical conditions and fetal wellbeing - mother's needs overlooked
- Lack of acknowledgement of anxiety / mental health
- Lack of effective multi-disciplinary team-working



Birth Trauma Tree
PTSD
Insomnia
Hyper-vigilance
Depression
Avoidance
Panic Attacks
Flashbacks
Bonding Issues
Physical Pain/illness
Guilt
Detatchment
Anxiety
Fear
Poor Care
Stillbirth
Cruel Language
Emergency Situation
Feeling a loss of control
Lack of communication
Loss of wanted Birth experience
Lack of information
Medical interventions
Medical Neglect
Baby in Neonatal
Maternal Damage
Previous Trauma
UnfoldYourWings.co.uk

The foundations of personalised care

- Every woman has a right to receive safe and appropriate medical care
- Every woman has a right to maternity care that respects her fundamental human dignity
- Every (mentally competent) woman is free to make individualised choices about her own body, pregnancy and childbirth, *even if her caregivers do not agree with her*

Montgomery v Lanarkshire (2015)

- In order for a patient to make an informed decision, there must be a conversation between doctor and patient. The doctor must 'ensure that the patient understands the seriousness of her condition, and the anticipated benefits and risks of the proposed treatment and any reasonable alternatives, so that she is then in a position to make an informed decision.' The information cannot flow one way and the doctor's advice must be 'sensitive to the characteristics of the patient.'
- The Montgomery ruling has not radically changed the process of consent; it has simply given appropriate recognition to patients as decision makers.

https://www.bmj.com/content/bmj/357/bmj.j2224.full.pdf

NICE guidance

- Recent change of emphasis
- Not just clinical actions – focus on effective communication and woman's autonomy
- Clinician is information giver and facilitator
- Importance of multi-disciplinary team-working

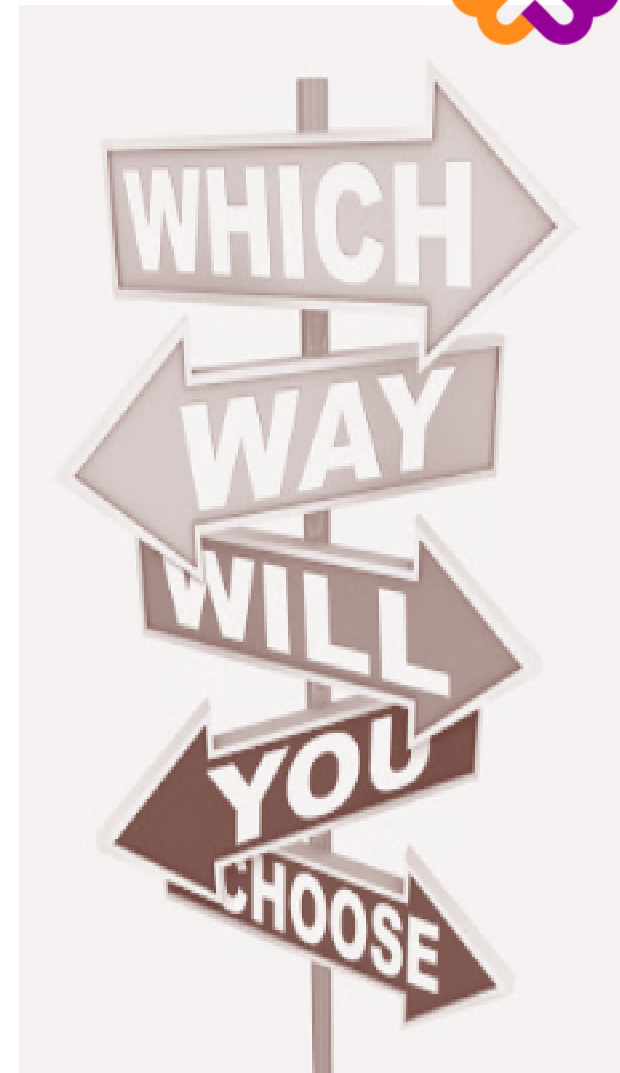
HOW care is conducted might be just as important as WHAT you do (Mobbs *et al* 2018)

Care planning clinic

- Individualised care planning clinic run by a consultant midwife at a large central London teaching hospital with 6800 births per year
- Women are offered 45 minute appointments
- The hospital has an obstetric unit (OU) for women with complex pregnancy or women who want epidural analgesia
- There is a co-located MLU which has around 1200 births per year.
- Home births account for around 2% of all births
- Community midwifery services offer caseload or traditional care depending on area and there is also a dedicated young persons' team and two 'complex care' midwifery teams

What happens during a care planning appointment?

- Women are supported to articulate and understand their priorities for care – their goals
- Women's individual risk factors are discussed and any possible associated implications are explained, including the possible associated risks and benefits of a requested intervention or care package
- Women are asked about their own perception of risks and benefits in relation their individual circumstances
- A labour and birth care plan is agreed and documented
- The care plan is shared with other clinicians
- The care plan is iterative



Evaluation of the care planning clinic

- The benefits of shared decision making were highly valued regardless of transfer, mode or actual place of birth.
- Women perceived the culture of the OU as not conducive to normal birth and sought to improve their health, and that of their baby by labouring outside the OU
- Women wanted to be part of the decision making process and to receive support and information to enable this.

Using your **BRAIN**

- **B**enefits
- **R**isks
- **A**lternatives
- **I**ntuition (instinct)
- **N**othing

The language of risk

- We live in increasingly risk-averse times and obstetricians and midwives may be particularly cautious regarding risk
- We need to be wary of 'over-egging' risk: the baby doesn't turn into a pumpkin at midnight!
- We perhaps have a tendency to use relative risk rather than absolute risk – especially if it suits our 'purpose of persuasion'
- We shouldn't use population data to suggest that *every* woman with a similar characteristic has an *identical* risk
- Alternative risk words may be less scary and coercive: e.g. likelihood, chance, possibility

The woman's instinct

- Instinct (intuition) is unique to each individual.
- A woman's instinct is often right!
- A mother has the 'closest contact' with the unborn baby and often has a 'sense' of wellbeing or alternatively, 'foreboding' if something is wrong.
- When the potential benefits and risks of an offered intervention are 'similar' (benefit doesn't clearly outweigh risk), the woman's instinct is key: she must be supported to do what feels right for her and her baby.

Clinicians do not have to 'approve' of the woman's decision

"The ethical principle of autonomy gives women a fundamental right to security of person. The principles of beneficence and nonmaleficence are caregivers' duties to "do what is best," and "do no harm." Usually, women and caregivers agree on the best course of action and informed consent is straightforward. Occasionally however, a woman declines recommended treatment or requests treatment that a clinician believes is unsafe. When this occurs, the historical adage: "the doctor knows best" is no longer valid. Ethical tension between autonomy, beneficence, and nonmaleficence may cause conflict between a woman and her caregivers that can impede communication, compromise care, and contribute to poor outcomes. In these situations, negotiating informed consent or refusal can be challenging. By accepting a woman's refusal, caregivers commonly believe they incur ethical and legal liability. Accordingly, they may withdraw care or coerce women to accept intervention. However, coercion negates consent and abandonment is unprofessional."

Kotaska, 2017

The language of personalisation

Depersonalising terms:

'My lady'
The PET in bed 2
The 28 weeker in room 1
She's 6cm
You're 'high risk'
Failure to progress
Poor maternal effort

Always introduce yourself, use the woman's name, explain concerns in understandable language

#hello my name is…
Kate Granger
Founder

The language of choice

Avoid directive terms such as:

- We need to deliver your baby
- We will induce you at 38 weeks
- You'll need an epidural

Use instead:

- In your circumstances I would recommend / suggest / advise induction of labour at 38 weeks because…
- You may want to consider an epidural because…

Can personalised care improve outcomes?

"Women's positive and negative recollections of their birth experiences are related more to feelings and exertion of choice and control than to specific details of the birth experience"

COOK, K. & LOOMIS, C. 2012. The Impact of Choice and Control on Women's Childbirth Experiences. The Journal of Perinatal Education, 21, 158-168.

Measures of successful personalised care

- Every woman feels she has been supported to make informed choices that are right for her and her baby – whatever her complexities
- Every clinician has the knowledge, skills and desire to facilitate women's autonomous, lawful, informed decision making
- Every clinician feels supported to support women
- Improved quality / outcome measures
- Improved relationships
- Birth trauma avoided
- Healing from a previously traumatising birth

References

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- *Midwifery and Human Rights: A practitioner's guide* https://www.bihr.org.uk/midwiferyhumanrights
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Q&A Panel

Thank you!

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