

Panels “Narratives of consent and invisible women”, Northern Network for Medical Humanities 4<sup>th</sup> Annual Congress, 23<sup>rd</sup> April 2021, 12 – 16.00.

Session 1, 12 – 13.30, chaired by Sam Halliday

1. Jacqueline Nicholls: Consent – what mattered to me
2. Sandra Igwe: Black women – our voice matters
3. Rebecca Brione: “It wasn’t about what I wanted”: the experiences of consent of disabled women and women facing disadvantage
4. Emma Brooks: Choice and consent: communicative challenges faced in multilingual antenatal settings
5. Emma Milne: Alcohol abstinence and surveilling the ‘bad’ mother

Session 2, 14.30 – 16.00, chaired by Rebecca Brione

1. Livia Martucci: The central role of women and families when planning care in the perinatal period
2. Samantha Halliday: Risky women, risky decisions – birth planning in the context of serious mental illness
3. Louise Nunn: Supporting women in navigating complex choices through birth planning
4. Claire Murray: Abortion and reproductive choice: supporting decision-making in pregnancy
5. Anne Lanceley: BRCA 1 and 2 Preivors: Experiences of reproductive decisions

**Abstracts and speaker biographies:**

Rebecca Brione, Research and Partnerships Officer for Birthrights.

'It wasn't about what I wanted': the experiences of consent of disabled women and women facing disadvantage

Rebecca is Research and Partnerships Officer for Birthrights, the UK charity which champions respectful care during pregnancy and birth by protecting human rights. She is also a bioethicist and public policy expert in her own right, with a special interest in reproductive justice, autonomy, and understandings of harm. She has published on the human rights issues experienced by women facing multiple disadvantage during their maternity care (as Birthrights and Birth Companions), on non-consented vaginal examinations and on Court-ordered Caesareans. Rebecca has wide-ranging experience in UK and EU law-making, policy and project management through her previous career in the UK Civil Service, as well as experience working to improve front-line services in the maternity and criminal justice sectors. She has an MAs in Bioethics and Medical Law and in Natural Sciences and will be commencing a PhD in Philosophy and Medicine at King's College London in October.

Abstract: Choice and consent are at the heart of respectful maternity care. All women and birthing people have the right to choose what happens to their body; to be supported and given the information they need to decide whether to consent or decline any given aspect of

care. The law is clear that consent requires the person to understand the proposed care and to have the information they need about the risks and benefits that are important to them. Unfortunately, many women and birthing people find that their experience of care is very different. Those who are disabled or facing disadvantage are even less likely than the broader maternity population to be asked for consent, or to have their choices respected. This paper outlines the experiences of consent described in two studies carried out for and by Birthrights, into maternity experiences of people from these groups. In the first study, disabled women described being classified automatically as 'high risk', being denied the information they needed to make decisions and having their choices restricted as a result. Three quarters of women facing disadvantage in the second study had experiences in which their choices were not respected, or they were not supported to give informed consent. One quarter described explicitly non-consented interventions. This paper highlights the very significant gap between maternity policy rhetoric and experiences of women and birthing people in practice, and practical changes required to meet their nuanced and personalised care needs.

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[Dr Emma Brooks, Lecturer in Applied Linguistics, University College London](#)

Choice and consent: communicative challenges faced in multilingual antenatal settings

Dr Emma Brooks is a Lecturer on the Applied Linguistics and TESOL programme at UCL Institute of Education. Her background as an ESOL teacher working with asylum seekers and (un)settled migrant communities in the UK, informs her work on health communication in diverse populations. Holding a particular interest in linguistic ethnography, her research interests include translanguaging, superdiversity and the role of language in facilitating (in)equalities.

*Abstract:* This paper examines the complex considerations posed by multilingualism in contemporary healthcare environments. Taking as a starting point the fact that the linguistic, ethnic and cultural diversity of the NHS workforce mirrors the complex textured landscape of urban populations, I argue that a combination of institutional practices, and coping strategies, designed to facilitate communicative 'difference' hold the potential to invisibilise staff and patients alike and subsequently throw in to question what it means to give or gain 'informed' consent.

From the perspective of established literature, it is well-documented that migrants may encounter difficulties in accessing services, as well as clinical care that meets their complex needs. Indeed, professional interpreters are generally understood to be critical participants and the pivots around which information is shared, negotiated, digested and acted upon: skilled translation is understood as integral to patient understanding, experience and compliance with advice. On the other hand, mediation is not unproblematic. Triadic interaction increases the distance between medical practitioner and patient and the health literacy of interactants cannot always be assumed. Despite NHS guidelines, alternative methods of language facilitation are often utilised in lieu of professional mediation - in the form of family, friends or translation software: these too can result in unreliable, or inaccurate interpretation. Similarly, misunderstandings are obfuscated when negotiations take place in

a language not spoken by the health professional, therefore jeopardising notions of what constitutes 'informed' consent.

More recent research conducted in diverse settings demonstrates a shift in institutional practices, i.e. where multilingual professionals draw on their personal linguistic and semiotic resources in order to communicate as effectively as they can across language and medical discourses. On close inspection of situated dyadic encounters, interactional analysis reveals a distinct advantage to language concordance as it appears to enhance a sense of alignment, boost feelings of ethnocultural acceptance and improve understanding, thereby mitigating asymmetries. Yet, as with interpreters, the ability to utilise shared language(s) does not provide a panacea for (mis)understandings. Linguistic concordance may not always be sufficient to navigate the epistemic comprehension so central to notions of patient-centred care and informed consent. More saliently perhaps, as ad-hoc interventions by health workers are more likely to go unrecorded, linguistic resourcefulness may have the unintentional effect of glossing workforce multilingualism and masking community demand for interpreting provision. With institutions neither aware of the demand, nor their own internal 'resource(s)', responses to linguistically diverse populations are not only stifled but remain structurally unaccountable.

Existing interpreting and translation guidelines (NHS, 2018) would benefit from revision in the light of a more nuanced reflection on contemporary communication and a heightened awareness of the role of language in health inequalities. It is only when assumptions are disrupted and conventions reimagined, that we can begin to understand what we mean by adequate facilitation of informed consent.

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Dr Samantha Halliday, Associate Professor in Biolaw, Durham University.

'Conceiving Better Birth Plans: Mental Illness, Pregnancy and Court Authorised Obstetric Intervention.'

Dr Sam. Halliday is an Associate Professor in Biolaw at Durham University. Her research focuses upon comparative medical ethics and law at the beginning and end of life and she has published widely in these areas. She is the author of *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention*, Routledge, 2016. This research monograph is part of the prestigious Biomedical Law and Ethics Library and focuses upon the permissibility of encroachment on the pregnant woman's autonomy in the interests of the foetus. It adopts a comparative approach, drawing on the law in England and Wales, the United States of America and Germany in analysing the tension between a pregnant woman's autonomy and obstetric intervention undertaken to protect the foetus.

*Abstract:* Choice is a central tenet of maternity care, its importance is emphasized in policy documents; however, the lived experience is often rather different. In the twenty-first century, birth is framed as a medical procedure, rather than a natural process. The medical discourse is powerful and has successfully constructed pregnancy and birth as risky, as a procedure to be managed by experts using technology to ensure that nothing goes wrong. In

the case of a woman with a serious mental illness (SMI) both she and her pregnancy are regarded as risky. Whilst policy documents speak of patient choice, not all childbirth options are available to all women, nor will all options be considered valid, or even responsible options. This is particularly the case when a woman has an SMI. Her choices are easily dismissed, attributed to her SMI, or a more general lack of insight, extending beyond her SMI into her pregnant state.

This paper will interrogate the use of an advance decision to plan for labour and the later stages of pregnancy in cases of serious mental illness where it is likely that the woman will lose capacity during the pregnancy. An advance decision can be a useful instrument, bridging the occurrence of incapacity by providing a clear statement of how the individual wants to be treated, or more usually what treatment she does not want to be afforded. Although there is a wealth of literature concerning advance decision-making at the end of life, significantly less attention has been paid to the use of precedent autonomy in the psychiatric context. The use of advance decisions in the obstetric (and psychiatric) context is primarily addressed within the more aspirational birth plans' literature. Typically, in cases where a pregnant woman lacks capacity to make her own decisions, her best interests are construed in terms of ensuring the safe delivery of the child and upon a hypothesis of what the woman would have wanted, had she been well enough to decide for herself. The women are represented only by the Official Solicitor (representing her best interests, rather than her wishes) and her refusal of consent to obstetric intervention is easily dismissed. This paper will review recent case law from the Court of Protection, arguing that advance decisions could place women at the centre of these decisions, ensuring that their wishes, rather than their best interests, determine the way in which delivery proceeds and shifting away from the framing of women with SMI as objects, as recipients of care; as risks to be managed.

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Sandra Igwe, Founder of The Motherhood Group  
'Black women – our voice matters'

Sandra Igwe is a speaker, black maternal advocate and is the Founder of The Motherhood Group, a social enterprise and a platform to share the black maternal experience; through events, workshops, peer-to-peer support, professional support and through advocacy. The organisation also offers free doula support and counselling to black and ethnic minority mothers whilst understanding the health inequalities and disparities that this community faces. Through The Motherhood Group, Sandra pioneered the UK's first awareness week highlighting black women's maternal mental health whilst amplifying the voices of this group - Black Maternal Mental Health Week UK. Sandra also delivers culturally competent training workshops to organisations and individuals who want to better understand the black maternal experience.

*Abstract:* The birth of both my daughters were under two years apart, in the same hospital, different staff, but I had the exact same inkling that I was not being listened to on both occasions. That my words were not taken seriously, that I had very little choice and above all I was missing the dignity, kindness and respect I had thought would accompany the life

changing experience of bringing life into the world. Robbed of the 'joyous' experience of giving birth. Ignored, pains dismissed. Silenced.

My concern has been echoed by several black women that have shared similar experiences through The Motherhood Group that I set up to share the black maternal experience. Like many other black women, I chose to struggle on my own and in silence rather than seek care, just for my words to be carelessly taken out of context, to be judged, shown no empathy. Our voice matters.

Structural racism and black women accessing care had a massive impact on my journey.

A system where public policies, institutional practices, and cultural representations work to reinforce and perpetuate racial inequity.

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Dr Anne Lanceley Associate Professor in Women's Cancer, UCL EGA Institute for Women's Health.

BRCA 1 and 2 Preivors: Experiences of reproductive decisions

With a background in English literature with nursing and health care Anne is Head of the Women's Cancer Research Department at UCL. Anne's research focuses on examining the patient experience dimension of developments in the field of women's cancers in the era of genomic medicine. Anne has a life-long interest in language and patient and health professional communication.

*Abstract:* Mutations of BRCA1 and BRCA2 genes are associated with an increased risk of breast and ovarian cancer. Female carriers of the mutation have a 65-80% lifetime risk of breast cancer and a 20-45% risk of ovarian cancer. Risk reducing salpingo-oophorectomy has been associated with a significant reduction in breast and ovarian cancer and is recommended to BRCA carriers by the age of 40 or after completion of childbearing. Recent literature suggests that that BRCA mutations are associated with a decreased ovarian reserve and earlier menopause.

Expanded genetic testing of BRCA mutations has led to identification of more previvors – women of reproductive age who test positive for the mutation, have a limited reproductive window and face potential risks to their fertility which might impact attitudes and decisions about relationships, parenthood and the use of preimplantation genetic diagnosis (PGD) and prenatal diagnosis (PND).

Using two patient cases this talk spotlights the potential complex reproductive options and decision-making for this group of previvors. The sensitive nature of these topics indicates a need for more counselling regarding reproductive choices alongside cancer risk focused guidance.

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Dr Livia Martucci, Consultant Perinatal Psychiatrist, Clinical Lead for Community Perinatal Psychiatric Services in SLaM.

‘The central role of women and families when planning care in the perinatal period.’

Dr Livia Martucci is a consultant in perinatal psychiatry working in SLaM. After graduating from medicine, she obtained a PhD in genetics of major psychosis, and specialised in psychiatry after this. During her training she developed a keen interest in training and education and completed a postgraduate diploma in medical education as part of her academic clinical training. In her work as a perinatal psychiatrist, she developed an interest in mental capacity and has been part of trust wide working groups, collaborating with research groups on advance decision making, and providing training through HEE and the Royal college of Psychiatrists on mental capacity and the law in the context of perinatal psychiatry.

*Abstract:* Each pregnancy and early postnatal period are a unique time in a family’s life. Pregnancy is also a time when most health risk factors manifest themselves and can have an impact on women’s health. This includes mental disorders, and the perinatal period is characterised by having a window of predictably increased risk of illness or relapse. This knowledge offers the rare opportunity to work towards prevention of a relapse, or early detection and treatment. When untreated, maternal mental illness has a significant impact on women, their children, partners and families. Knowing in advance that there is a higher risk of illness allows us to help women and families plan their care in a thoughtful and comprehensive fashion when they are well. However, we also need a framework for ensuring appropriate care when women are ill and lose their capacity to make decisions about their obstetric or psychiatric care. This can be a complex process that can often bring together families, health care professionals and law experts to ensure that medical, ethical and legal issues are considered whilst incorporating women’s and families’ wishes.

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Dr Emma Milne, Assistant Professor in Criminal Law and Criminal Justice, Durham University  
‘Alcohol abstinence and surveilling the “bad” mother’

Dr Emma Milne is Assistant Professor in Criminal Law and Criminal Justice at Durham University. Her PhD in Sociology from the University of Essex was funded by the Arts and Humanities Research Council. Emma’s research is interdisciplinary, focusing on criminal law and criminal justice responses to newborn child killing and foetal harm. The wider context of Emma’s work is social controls and regulations of all women, notably in relation to pregnancy, sex and reproduction. Emma’s monograph *Criminal Justice Responses to Maternal Filicide: Judging the Failed Mother* (Emerald Publishing) is being published in autumn 2021. She co-authored *Sex and Crime* (SAGE, 2020), and co-edited *Women and the Criminal Justice System: Failing Victims and Offenders?* (Palgrave, 2018).

*Abstract:* Despite there being no evidence to support the claim that small amounts of alcohol causes harm to a foetus or breastfeeding baby, public health messages continue to promote abstinence only, stating there is no safe limit of alcohol consumption for pregnant or breastfeeding women. In previous research, I, with Professor Betsy Thom and Dr Rachel Herring, have conclude that official messages from government and health sources employ popular tropes of the ‘good’ mother and urge women to act in the best interests of the foetus.

Furthermore, official guidance and advocacy sources have become increasingly consistent regarding the way in which alcohol consumption during pregnancy is framed in terms of risk to the foetus, whereas research studies indicate more diverse and nuanced views among midwives.

This paper will expand on our previous work, considering the implications of messages of alcohol abstinence in the context of representations of motherhood. The findings will be contextualised within a risk framework and feminist analysis of idealised motherhood. As such, the concept of 'consent' by women to receive and adhere to such messages will be considered.

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Dr Claire Murray, lecturer in law, University College Cork

['Abortion and reproductive choice: supporting decision-making in pregnancy'](#)

Dr Claire Murray is a lecturer in the School of Law, University College Cork and is the Principal Investigator on the Wellcome Trust funded Ethics, Law and Pregnancy in Ireland Network (ELPIN) project. Her current research focuses on capacity and maternal and reproductive rights.

*Abstract:* ['Abortion and reproductive choice: supporting decision-making in pregnancy'](#)

This paper will begin by highlighting the range of barriers to accessing termination of pregnancy services where capacity is an issue, with a particular focus on other people as a barrier to accessing services. It will then move on to consider the role of support in overcoming these barriers, the importance of independent advocacy, but also the limitations of these supports. Finally, the paper will interrogate the extent to which will and preferences are being engaged with in the context of access to abortion services.

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Dr Jacqueline Nicholls, Associate Professor in Health Law at the Institute for Women's Health, University College London.

[Consent – what mattered to me.](#)

Dr Jacqueline Nicholls is an Associate Professor at the Institute for Women's Health at UCL. As a qualified solicitor and clinician with a PhD in psychology Jackie's interests are rooted in healthcare practice with a particular interest in beginning and end of life care. Jackie's research is interdisciplinary focusing on autonomy, medical negligence and consent and shared decision-making in a range of women's health contexts. Most recently she has published on consent in ante-natal contexts and on mental capacity assessment. The wider context of her work is woman/patient-professional interaction including patients and citizens experiences of communication and information-sharing. Jackie has wide-ranging experience in UK healthcare practice and law has been at UCL since 2006 having previously held a range of academic posts and professional posts in legal practice and, as a clinician, in the NHS.

*Abstract:* Choice and consent are cornerstone principles of respectful woman-centred maternity care in which autonomous decision-making is maximally supported. Every woman has the legal right to choose what happens to her body and to be adequately supported in

sharing in the decision of whether to consent or reject any care intervention offered to her. The law is clear that consent requires the person not only to understand what the proposed care involves including its risks and benefits and reasonable alternative option, but also for the process of decision-making to be a genuinely shared dialogue in which a woman's individual values and preferences are addressed.

Unfortunately, many women find that their experience of being asked for their consent is very different. This paper will draw on previous research carried out at UCL looking at women & healthcare professionals experiences of consent. Despite women's desire to share in decisions about their care via individually tailored dialogues many women do not experience the consent process as one of genuine choice-making in which they are equal partners in their care. Information provision is often considered to be the panacea to a woman's spoken or unspoken concerns. Yet women do not always receive information in a way that is supportive to them in making a truly autonomous and personal choice, for example, because it is overwhelming in amount or complexity, difficult to apply to their circumstances or it omits to tell them what they not what they want to know. Too often consent consultations frame women as risks to be managed rather than as autonomous individuals with choices to make within their own nuanced personal contexts. This paper will expand on our previous work considering the implications of what matters to women alongside what healthcare professionals think is important in the context of the realities of day to day practice. It will interrogate the assumptions that may underpin these findings and highlight the gap between the law and rhetoric of consent and the experiences of women in practice.

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Louise Nunn, Consultant midwife.

[‘Supporting women in navigating complex choices through birth planning’](#)

Louise is a consultant midwife with a special remit as mental health lead for the maternity service as well as complex pregnancy lead. She spent several years as a Perinatal Mental Health specialist midwife and in a public health consultant role prior to her current post. She has been the co-chair of the NW London PMH Clinical Network since 2018 and is the midwife lead on the Pan London Network.

*Abstract:* This session will explore how ‘choice’ is framed in clinical practice:

- Recognising the unconscious bias and power exchange between health professional and patient to create meaningful dialogue
- What does choice, control and safety mean to women?
- The importance of a trauma-informed approach to understand choices
- Do women make ‘unwise decisions’?
- Navigating complex plans in practice – challenges in the absence of evidence with examples