Genomics and midwifery

George F Winter explores the benefits and challenges of genomics in the context of midwifery practice

In an editorial published almost two decades ago, midwife Tekoa L King noted that genetics – traditionally defined as the study of single genes – 'has been replaced by genomics, which is the study of the function and interactions of all the genes in the genome' and predicted that 'the genomic revolution in health care is the real paradigm shift that will influence every patient encounter' (King, 2005). By 2018, Tonkin et al (2018) reported that a UK one-day expert panel consensus meeting involving 15 midwives and three genetic counsellors had produced 'the first competence-based education framework that defines the knowledge and skills in genetics/genomics required specifically by midwives'. The framework did not require midwives to practice outside of Nursing and Midwifery Council standards, but provided 'a means for individuals and organisations to consider midwifery practice through a "genetic lens"' (Tonkin et al, 2018).

To what extent can midwives apply genomic knowledge for the benefit of their patients, as this aspect becomes a part of normal midwifery practice? In an Australian study, Schluter (2023) undertook a literature review and interviewed 32 Queensland-based nurses and midwives who were applying genomics knowledge in clinical practice, to understand how patient needs were being met in response to increased genomic testing. Schluter (2023) found that 'the emerging needs of patients to understand their diagnostic and treatment pathway is forcing nurses and midwives to self-educate to keep pace with current practice demands'. It was found that the self-education approach was insufficient for those nurses and midwives who had to address the concerns of patients requiring genomic support.

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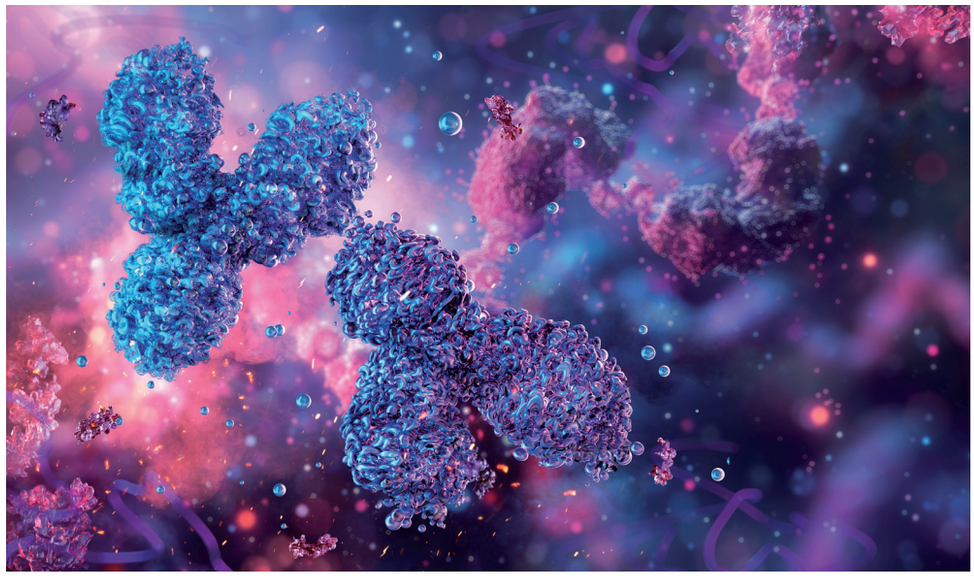

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Whoe genome sequencing for newborns could provide a wealth of data on possible health concerns, but raises questions regarding interpreting the data and the ethics of informed consent

Given the time constraints, staff shortages and other ongoing demands on midwifery practice today, one might infer that Schluter's (2023) findings could be applied to territories beyond Australia. In which case, recent developments in a UK context might herald further genomic-related challenges to midwifery practice. Consider an editorial that asked why 'do we not screen the whole genome of all newborns, given the wealth of information and potential benefits it could provide?' (Anonymous, 2023). The editorial drew attention to the Newborn Genomes Programme, a £105 million UK-based project intending to sequence the genomes of up to 100 000 newborn babies. Although details of the project are incomplete, 'the aim is to provide information to parents on between 200 and 400 rare diseases. The exact figure will be revealed when experts from different specialities can finally agree on whether acceptable treatments are currently available for the individual conditions' (Anonymous, 2023).

However, the editorial acknowledges that challenges deriving from this approach include first, the difficulty of interpreting whole genome data, in that some mutations known to cause recognised childhood diseases might only arise later in life or not at all. Second, whole-genome sequencing can generate significant numbers of false negative results, compared with present-day conventional screening using mass spectrometry and other laboratory tests. Third, the ethics of obtaining informed consent from parents to participate in such screening programmes, especially when outcomes might be of questionable importance, 'is difficult enough in the

short term. For the longer term, parents cannot give consent, nor can they know the wishes of their grown-up child about participating in such a programme' (Anonymous, 2023).

Given the diverse range of genomic-related challenges, one might wonder whether midwives have received, or are equipped with, sufficient ethical preparedness to address some of the concerns that may arise. It might be that midwives at an individual level are competent to cultivate, trust and assert their moral character, but this might place an undue moral, and possibly distressing, responsibility on individuals, when it is a responsibility that the managerial system within which midwives work should be shouldering.

Should a specialist genomic-trained ethicist be embedded in reproductive health teams? It seems a reasonable consideration, but on the other hand who is to say that such an individual, no matter how well-trained and academically proficient, would necessarily have a more finely tuned moral compass and sense of empathy than, for instance, a student midwife? Nevertheless, technological advances mean that there is an interface between midwifery and genomics that needs to be negotiated. As Sahan et al (2024) pointed out, 'since 2001, the UK Genethics Forum has been a national case-based forum for discussion of ethical and legal issues arising in genetic/genomic medicine'. The Forum's main goal is both to help genomics professionals ensure that ethical considerations inform day-to-day practice 'and promote the sharing of experience and good practice in addressing ethical questions' (Sahan et al, 2024).

To what extent can the midwifery profession hope to develop and accommodate the expertise to address confidently genomic-related matters with patients? Grimwood et al (2023) conducted a thematic analysis and review of midwifery education and training in England that included the participation of 181 focus groups. One of the dominant themes identified was that adequate staffing in maternity teams should allow 'dedicated time for feedback, discussion of cases, and space for reflection … All regions advocated protected time for students and practice supervisors/assessors to work together, to ensure time for reflection and reinforcement of learning' (Grimwood et al, 2018).

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Advances in genomics should be matched by adequate staffing levels that allow progress in genomics to be translated into patient care. **BJM**

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