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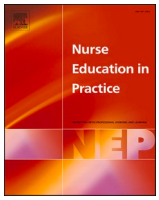

Empowering midwives with genetic knowledge: A systematic review of educational needs in genomics

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ABSTRACT

Aim: This systematic review aims to assess the level of genetics and genomics knowledge that midwives currently have and identify educational opportunities for them.
Background: With mainstreaming of genetics and genomics in medicine, it is necessary to upskill health care professionals to ensure the best medical care for patients. Midwives offer continuity of care to pregnant women, which now includes talking about genetic screening and testing in pregnancy.
Design: A systematic review was conducted, guided by the Arksey and O'Malley framework for scoping reviews.
Methods: A systematic searched of Embase, PubMed, CINAHL, Medline and Scopus databases was conducted in February 2024. Full text of included studies were analysed and synthesised, with themes relevant to the study identified via meta-ethnography and narrative synthesis.
Results: Sixteen studies were included, with diverse research questions and study types represented. Four themes emerged; 1) the low level of genetics/genomics knowledge of midwives, 2) the lack of educational opportunities available to them, 3) their understanding that genetics/genomics are critical to the care they provide and 4) their positive predisposition to further learning about genetics/genomics.
Conclusion: Extensive and comprehensive education in genetics/genomics is required for midwives to offer complete antenatal care to women and families and this should be embedded in midwifery educational programs.

1. Introduction

The use of genetics and genomics in health care has been one of the most significant medical advances in the last century. In 70 years, we have progressed from the discovery of the structure of DNA to understanding the role of genetic variation in human health and the provision of precision medicine at an ever-accelerating pace (Lander et al., 2001). While this has been an undeniably positive accomplishment for the millions of people who have benefited from genetics in medicine, healthcare providers have struggled to keep pace with the progress (Carroll et al., 2009; White et al., 2020). Genetic testing and genomics are now employed in myriad areas of health care, including cancer, neurology and rheumatology, with great variety in how they can help improve patient care (Kumar and Eng, 2014). Antenatal care is perhaps the sector where genetics and genomics have had the greatest impact; from pre-conception to the early years of a child's life, genetic medicine can offer reassurance and has expanded on the information available to prospective parents to aid in decision-making (Schluter, 2023). Genetic and genomic medicine in antenatal care has become commonplace. From preconception care to postnatal care and beyond, genetics and genomics are embedded in quality healthcare (Feero, 2013). There is a vast array of tests that a family can access before, during and after pregnancy, as outlined in Table 1. With an evolving landscape of antenatal care in Australia and globally, it is necessary to ensure that all healthcare providers in this space understand the basics of genetic medicine and how to best use it to improve care and outcomes. Midwives and nurses working in reproductive health are often the primary point of contact for families accessing antenatal care [77] and it has been shown that their level of confidence and understanding around genetic medicine is sub-optimal (Skirton et al., 2010; Saleh et al., 2019; Carpenter-Clawson et al., 2023). This knowledge gap undoubtedly has an impact on their overall confidence, the level of care they can provide and their ability to collaborate with other providers involved in antenatal care.

It is important to note that from this point, the words "woman" or "women" is used to identify the primary individual(s) in a midwife's or

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Table 1
Antenatal genetic and genomic testing (adapted from Feero (2013)).

Test	Abbreviation	Description	Implications for midwives
Reproductive genetic carrier screening	RGCS	Prospective parents can elect to have genetic carrier screening for a vast array of genetic conditions, e.g. cystic fibrosis and spinal muscular atrophy. These conditions can be autosomal recessive, meaning that both parents must be carriers for there to be a chance that a child might suffer from the condition. RGCS can also identify the carrier status of women for X-linked conditions such as haemophilia. Preconception genetic screening can provide valuable information to prospective parents.	1. May be unclear on chance of a genetic disease in a child with one or two carrier parents 2. May not know or understand inheritance patterns (dominant, recessive or X-linked), and which conditions fall under each category 3. May not feel comfortable discussing with prospective parents
Pre-Implantation Genetic Testing – Monogenic, Aneuploidies or Structural Rearrangement	PGT-M/PGT-A	Parents can elect to undergo in vitro fertilisation (IVF) with pre-implantation genetic testing of embryos for known conditions before deciding to proceed with embryo transfer	1. May not feel comfortable discussing with prospective parents on embryo selection 1. May struggle with explaining screening vs diagnosis of conditions detected in embryos
Non-Invasive Prenatal Screening	NIPT	A pregnancy can be screened and tested in many ways; non-invasive prenatal testing (NIPT) is a screening that can be conducted from approximately 10 weeks of pregnancy which involves only a blood test for the mother. DNA from the developing fetus is present in a pregnant woman's blood from late in the first trimester and can be tested to assess the risk of the fetus having a chromosomal abnormality such as Downs Syndrome (trisomy 21), Edwards Syndrome (trisomy 18) or Patau Syndrome (trisomy 13).	1. May struggle with explaining the nature (screening vs diagnostic) of the test and what is being analysed 2. May have difficulty explaining risk to parents based on screening results 3. For less common chromosomal abnormalities, may have trouble explaining positive predictive value and/or false positives/negatives
CVS/Amniocentesis		Diagnostic testing can occur later in the pregnancy via chorionic villus sampling (testing of the cells of the placenta) or amniocentesis (removing some amniotic fluid from around the baby and testing the cells found there). These tests can definitively diagnose a genetic condition in a fetus.	1. May struggle with explaining the nature of the test (screening vs diagnostic) and what is being tested 2. May not feel comfortable counselling prospective parents on their options post-testing
Newborn bloodspot screen	NBS	After birth, newborns can undergo a bloodspot screen for certain inherited metabolic conditions such as phenylketonuria, hypothyroidism, cystic fibrosis and congenital adrenal hyperplasia. If screening is positive, the baby may undergo genetic testing for confirmation.	May have difficulty differentiating between the NBS and subsequent genetic testing

nurses' care. The word 'woman' is used in the context of 'women's health' as a field of medicine interested in issues affecting the female biological sex. It is acknowledged that this reflects traditional western gender norms of 'man' and 'woman' and sex characteristics of 'male' and 'female' assigned at birth. Identifying as a 'woman' has a significant impact on reproductive health in many societies. Sociocultural factors affecting a woman can negatively impact on the quality of care received and outcomes for the individual and her children (Musgrave, 2023).

At every stage, from preconception to postpartum, it is highly likely that a midwife would be involved in the care of that family (Nursing and Midwifery Board, 2024). A midwife will only be able to provide comprehensive prenatal care if they are confident in their understanding of tests involved in that care and in the delivery of meaningful results for the women and families they care for.

The primary statement in the Australian Health Practitioners Regulation Agency's Nursing and Midwifery Board Scope of Practice is that Midwives "work in partnership with women" (Nursing and Midwifery Board, 2024). Under examples of core midwife activities, the first listed is "(midwives provide) antenatal care including abdominal palpitation, performing clinical observations on mother and unborn baby, reviewing and ordering diagnostic and/or screening tests and risk assessments from a clinical, health, lifestyle and psychological perspective" (Nursing and Midwifery Board, 2024). Furthermore, the Pregnancy Care Guidelines (2020 Edition) (Department of Health and Aged Care, 2024), which provides high-quality evidence-based guidance to maternity service providers, contains a dedicated section of fetal chromosomal abnormalities and the tests that can diagnose them. The regulatory bodies governing the policies (Nursing and Midwifery Board, 2024; Department of Health and Aged Care, 2024) of midwifery agree that the genetic screening and diagnostic testing described previously fall within the scope of a midwife and/or nurse/midwife's practice.

Beyond the stated scope of practice, a midwife is also increasingly the practitioner who will have the most contact with a woman during her antenatal care; indeed, they are often selected by families for the continuity of care they can provide. In Australia, midwives work in the public and private health care systems and a variety of maternity care models. Just under half (46 %) of all models of maternity care in Australia have a midwife as the designated or lead maternity carer, which is the health care professional coordinating the care for the woman during the antenatal, intrapartum and postnatal periods (Australian Institute of Health and Welfare – Australian Government, 2023). The other models of care practiced in Australia all have midwives involved, but not as designated or lead maternity carer. Regardless of the model of care chosen by a pregnant woman or a woman planning pregnancy, midwives are highly likely to be present and actively involved in the care of the mother and baby. Midwives scope of practice is to work with women and families to facilitate an empowered and informed pregnancy, birth and post-natal period (Nursing and Midwifery Board, 2024). Organising, delivering and contextualising genetic testing and the delivery of genetic results for women and babies is now firmly within the domain of midwifery practice (Carpenter-Clawson et al., 2023).

Although the need for midwives and nurse/midwives with a comprehensive understanding of genetics and genomics is clear, research has shown that their perceived confidence and literacy in this area are low (Benjamin et al., 2009; Wright et al., 2019; Metcalfe and Burton, 2003; Crane et al., 2012). A recently published systematic review of genomics education for American nurses confirms previous findings, that nurses are provided with insufficient educational opportunities in genetics and genomics and that this should be a priority in the design of new nursing school curricula (McLaughlin et al., 2024). Moreover, the depth and breadth of genetics and genomics taught in midwifery programs is insufficient to meet the demands increasingly placed on midwives in their practice (Schluter, 2023; Metcalfe et al., 2008). While there is a framework for genomics policy more broadly in healthcare in Australia which has a well-trained workforce as a strategic priority (National Health Genomics Policy Framework, 2017; Department of Health and Aged Care, 2017)), no framework exists for the education of midwives specifically. In the United Kingdom (UK), Tonkin et al (Tonkin et al., 2018). published the first competency-based framework in genetics/genomics specifically for midwifery education and practice, using a consensus panel made up of midwives (both practicing and managing), educators and genetic counsellors in the National Health Service. This research established seven competencies in genetics/genomics with associated learning outcomes. Although there are well-defined overlaps in the care provided by midwives in the UK and Australia (Kennedy et al., 2020), there are aspects of midwifery care in Australia that are not covered by the Tonkin et al (Tonkin et al., 2018). competency-based framework. Australian midwives and midwifery students require increased literacy, competency and training in genetics and genomics (Wright et al., 2019) and this need can only be addressed by first assessing what is known and unknown by midwives currently and exploring the most effective ways to upskill midwives.

To initiate the development of a genetics and genomics education program tailored for midwives and student midwives, it is essential to first identify their specific needs. This program should be designed to cater to midwives at different stages of their careers, ensuring accessibility and relevance. A collaborative project (Nisselle et al., 2019a) developed and reviewed a Program Logic model of genomics education, followed by testing of the model in the UK and Australia in different contexts, serving four different healthcare workforces with genetics and genomics as a relatively recent addition to their profile. The same collaborators established the Reporting Item Standards for Education and its Evaluation in Genomics (RISE2 Genomics), which is an evidence-based set of standards offering a solid foundation for creating and evaluating a genetics education program targeted at midwives (Nisselle et al., 2021). These previously implemented education programs and associated evaluations may be able to be adapted to education programs specifically for midwives. This will ensure that genetics and genomics education for midwives aligns with the offerings provided to other healthcare practitioners, ensuring consistency and the potential for effective collaboration.

To keep up with the pace of providing genetics and genomics-inclusive care to childbearing women, it is important to understand how midwives are currently being trained to provide this care. This systematic literature review aimed to provide answers to the following questions: (1) What are the depth and breadth of knowledge held by midwives and student midwives regarding genetic testing and genomics? (2) What are the educational needs of Australian midwives and student midwives regarding genetic testing and genomics?

2. Methods

A systematic review was conducted, guided by the Arksey and O'Malley (Arksey and O'Malley, 2005) framework for scoping reviews, adapted for this research project. The Covidence™ systematic review software was used to screen and extract data. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses for reporting of systematic reviews (PRISMA) (Page et al., 2021) was used to organize and report results. The systematic review process was informed by general information and guidance provided by Boutron (Boutron et al., 2023) and Curtin University (Curtin University, 2023). With the support of a UTS Graduate School of Health research librarian, a literature search of 5 databases (Embase, PubMed, CINAHL, Medline and Scopus) was conducted in February 2024. These databases have been selected because they cover a range of education and health-related peer--reviewed literature.

To develop the research question and context for this systematic review, a Sample – Phenomenon of Interest – Design – Evaluation – Research type (SPIDER) framework was used, as opposed to a Population – Intervention – Comparison – Outcome (PICO) framework which is the standard for reviews (Cooke et al., 2012). This was chosen because

no single intervention or outcome is being researched or sought in this study and because a SPIDER framework can be more appropriate when predominantly qualitative studies are likely to be reviewed (Cooke et al., 2012).

2.1. Search strategy

Internationally, antenatal care varies greatly and is delivered by a range of practitioners. The role of a midwife is highly variable and in many countries nurses or nurse practitioners will perform practices that fall within the scope of midwifery (Kennedy et al., 2020). As such, it is necessary to include nurses and student nurses as search terms in this review to ensure that all relevant evidence is gathered. Although there is a clear distinction in Australia between nurses and midwives as independent professions, this is not the case worldwide. In this review, we aimed to cast a wide net to gather all information that may be relevant. Additional search terms used included education, training, genetics and genomics (see supplementary file).

2.2. Inclusions/exclusions

Research included in this review is based on the following criteria: Included

- Publications in English
- Studies published in the last 10 years (2014–2024), to ensure research is focused on a current cohort of midwives and nurses and to ensure the context is contemporary genetics and genomics-based healthcare
- Only articles where the full text is available
- Qualitative or mixed methods research sampling nurses and midwives at any level of experience (including student nurses and midwives), because of the use of meta-ethnography in data synthesis and analysis
- Studies must be focused on nurses (involved in antenatal care/obstetrics) and midwives' knowledge and understanding of only 'genetics', 'genomics' or 'genetic counselling', with or without qualifiers

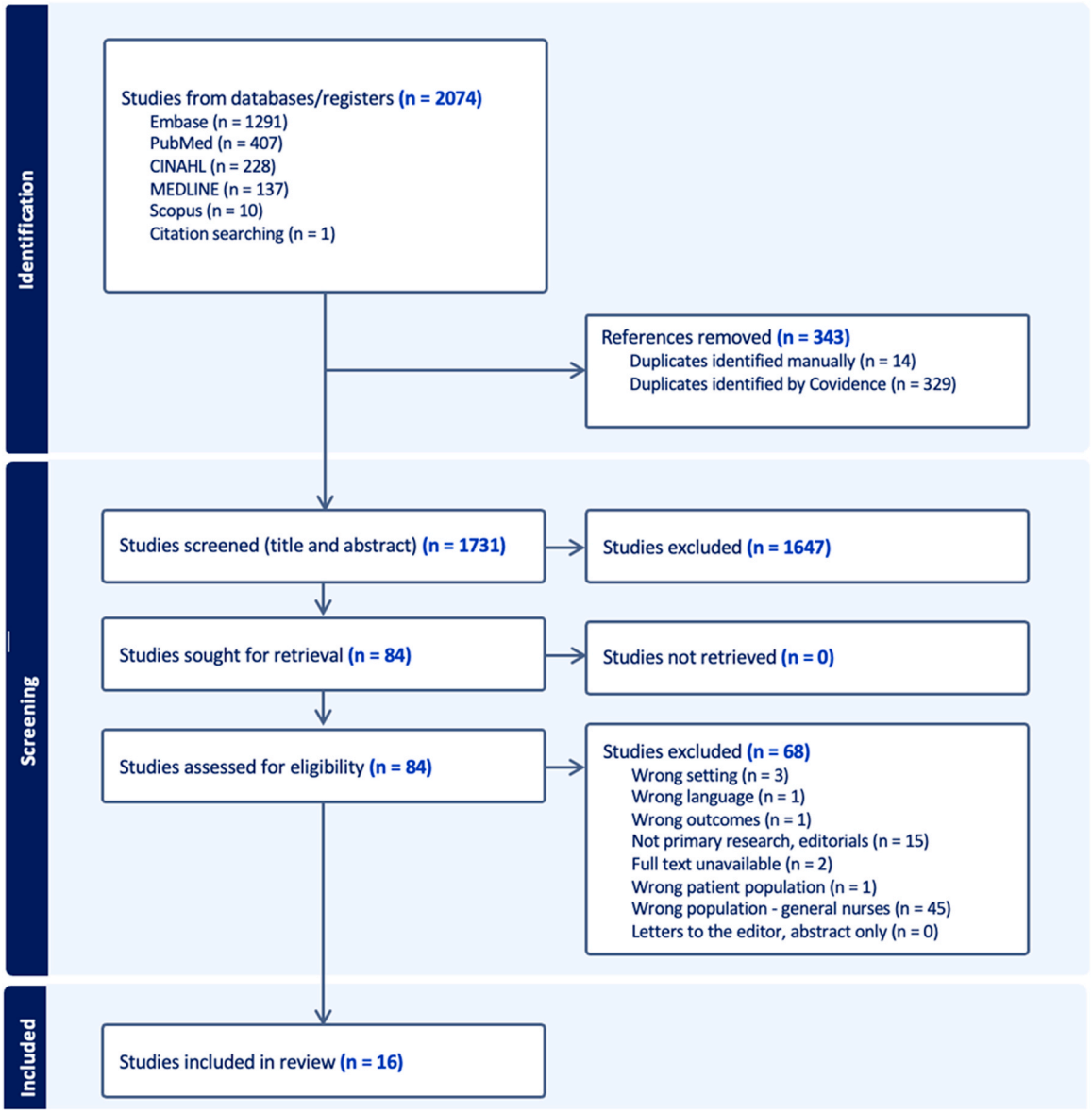

Fig. 1. PRISMA flow diagram.

- Published conference presentations may be included if they make a significant contribution to the body of research being reviewed and meet the other inclusion criteria

Excluded

- Letters to the editor, abstract only, editorials
- Studies which are strictly quantitative as they are inappropriate for the method of data analysis/synthesis we have selected. Although quantitative studies can provide evidence and rigour in a systematic review, they do not provide the required context for a meta-ethnographical analysis.
- Randomised controlled trials
- Studies that do not include nurses/midwives who practice in maternity care settings
- Not in English

2.3. Identification and selection of the relevant literature

Studies retrieved from the literature search were imported into Covidence™ (Covidence systematic review software,.) for screening. After removal of duplicates, studies underwent title and abstract screening by two reviewers (TG and LM) and discrepancies were resolved by a third reviewer (LF). Following this, the remaining studies underwent full text screening by two reviewers (TG and LM) and again discrepancies were resolved by a third reviewer (LF). The JBI Systematic Review Critical Appraisal checklist tool for qualitative studies was used to ascertain quality and assess bias in included papers (Lockwood et al., 2015). The assessment of included papers is presented in a risk of bias table. Inter-rater reliability was assessed by Covidence™ according to the methodology set out by McHugh in 2012 (McHugh, 2012), using the kappa statistic (see supplementary file for inter-rater reliability reports for title and abstract screening and full text screening).

2.4. Data extraction and analysis

Data from included articles was extracted using Excel. Data synthesis and analysis of the extracted data was done via meta-ethnography - the comparison, analysis, interpretation and translation of the findings of individual qualitative studies for a systematic review (Britten et al., 2002). This is an approach that (1) translates the findings of different primary research studies into each other to generate overarching themes, concepts, or metaphors; (2) identifies and explains contradictions and differences that exist between the numerous studies; (3) develops a picture of the whole phenomenon under study from studies of its parts (Noblit and Hare, 1988). This is consistent with and an adaptive expansion of the framework for scoping reviews proposed by Arskey and O'Malley (Arksey and O'Malley, 2005). As this study contains elements of a systematic review and elements of a scoping review, a combination of approaches in data analysis was required and strictly quantitative studies were excluded to remain true to the nature of the analysis.

3. Results

The initial search strategy yielded 2074 articles. Removing duplicates left 1731 articles for title and abstract screening. Screening excluded 1647 articles, leaving 84 articles for full-text review. Subsequently, 16 articles were retained for data extraction and analysis. The PRISMA flow diagram depicts the review process and reasons for exclusion Fig. 1.

3.1. Study characteristics

Sixteen included studies had representation from eight countries (Australia, USA, UK, Israel, Korea, Sweden, the Netherlands and Japan), with Australia (n = 6) and the USA (n = 4) having the highest number of included studies. Publication dates spanned the 10 years included in our search (2014–2023), with the most heavily represented years being 2019 (n = 4) and 2023 (n = 4). There is heterogeneity in study types and methodologies represented in our included studies, with the type seen most frequently (n = 9) being surveys of midwives with open-ended questions, qualitatively analysed. Notably, there are three included studies which describe competency frameworks or educational initiatives delivered in Japan, Korea and the UK and measure the success of their implementation. See Table 2. for the full list of included studies including important demographics and characteristics.

3.2. Quality assessment of included studies

The quality analysis was difficult due to the heterogeneity of the included papers, but the quality assessment aimed to use a consistent approach and set of criteria.

3.3. Thematic analysis

Analysis and synthesis of the included literature identified four major themes related to the aim of this systematic review. These were: (1) Genetic/genomic competency of midwives is low; (2) midwives understanding of the importance of genetic and genomics in their scope of practice; (3) the inadequacy of educational opportunities for midwives in genetics and genomics; and (4) midwives' positive perception of the use of genetics/genomics in their scope of practice. Finally, three of the included studies investigated and assessed new or adapted educational/competency frameworks for midwives, so these have been added as an additional theme (5).

(1) Genetic/genomic competency of midwives is low

Of the included studies, seven established through primary research or reported on the findings of other studies which described the genetic and/or genomic competency of midwives as low.

Some of the studies included nurses and midwives (Carpenter-Clawson et al., 2023; Wright et al., 2019; Dagan et al., 2021) and typically the representation of midwives in the sample population was relatively low, but the findings were clear that for midwives and all clinical nurses, their confidence and understanding of genetics and genomics were low. A study based in the Netherlands focused on Non-Invasive Prenatal Testing (NIPT) (Martin et al., 2018) and a study based in Sweden focused on prenatal testing for Down Syndrome specifically (Ternby et al., 2015) and both identified that midwives' understanding of these tests and their ability to deliver results has improved over time, but is still inadequate to meet the needs of the population they serve. A study based in the USA focused on the provision of NIPT by certified nurse-midwives (CNMs) (Dettwyler et al., 2019) found that very few CNMs had experience in this area and relied heavily on the input and collaboration of genetic counsellors to provide this service. Two studies investigating the literacy (Wright et al., 2019) and the competence (Wright et al., 2018) of nurses and midwives in genetics and genomics both found that they had made minimal progress towards achieving identified goals set by their governing bodies in this domain.

(2) Midwives have a clear understanding of the importance of genetics and genomics in their scope of practice

Reporting on midwives and obstetric nurses' perception of the importance of genetics and genomics to their practice was the focus of five included studies. In most cases (n = 4), this was linked to their desire to learn more and increase their confidence in this area. Overall, it was reported that midwives understood genetics and genomics to be an important part of their role and well within their scope of practice. The studies conducted in the Netherlands (Martin et al., 2018) and Sweden (Ternby et al., 2015) which investigated midwives' feelings about prenatal genetic testing, both included questions in their design which assessed midwives' perception of the importance of these tests in their practice. In both studies, midwives found these tests and genetics more broadly, to be very important. Three studies that assessed Australian

Table 2
Included studies.

Author and Year	Title	Country	Research Question(s)	Study Type	Findings	Conclusions
Best et al., (2023) (Wright et al., 2018)	Supporting healthcare professionals (HCP) to offer reproductive genetic carrier screening: a behaviour change theory approach	Australia	This paper aimed to identify and prioritise implementation strategies to reduce barriers and enable HCPs particularly those in primary care, to routinely offer RGCS.	Behaviour change theory intervention study	The top ranked barriers to offering RGCS in primary HCPs are: low HCP skill, knowledge and awareness; time available in consults; patient receptivity and HCP attitudes/beliefs	Regular professional development activities for HCPs will address the biggest perceived barrier in the provision of RGCS
Carpenter-Clawson et al., (2023) (Saleh et al., 2019)	Competencies needed by the frontline clinical workforce for genomic mainstreaming	UK	This study investigated the level of competence/ confidence of practicing nurses and midwives to support mainstreaming and their perception of the importance of genomics in delivery of patient care	Literature review and qualitative study - semi structured interviews and thematic analysis	1. The confidence scores regarding genetic competency in all cohorts were overall very low. 2. Uptake of genetics education by nurses and midwives is poor relative to other HCPs	These professionals (nurses and midwives), although recognising the importance of genomics for their patient care, do not currently have the basic subject knowledge, understanding and confidence that would enable them to integrate genomics into their service
Dagan et al., (2021) (Noblit and Hare, 1988)	Integrating Genomic Professional Skills Into Nursing Practice: Results From a large cohort of Israeli Nurses	Israel	To explore the association of genomic knowledge, self-epistemic authority (SEA; i.e., subjective perception of knowledge expertise), perceived importance of genomics in nursing, and the integration of genomic skills into nursing practice.	Cross sectional study, quantitative analysis	1. The mean genomic knowledge was low 2. Nurses reported a low integration of genomic skills in their practice although their overall perceived importance of genomics was positive 3. Obstetric nurses had more genomic knowledge, more positive perceptions about genomics, and performed more genomic skills in their nursing practice.	Although nurses realised the importance of genomics to their practice, and genomics is part of the Israeli nursing core curriculum, we found disappointingly low levels of knowledge and performance of genomic skills in nursing practice.
Dettwyler et al., (2019) (Ternby et al., 2015)	Certified Nurse-Midwives' (CNM) Experiences with Provision of Prenatal Genetic Screening (GS): A Case for Interprofessional Collaboration	USA	(1) What do midwives know about prenatal GS? (2) What factors influence prenatal GS use in midwifery practice? (3) How do midwives discuss and offer prenatal GS in practice? and (4) How do midwives and genetic councilors (GCs) interact with each other?	Qualitative study using grounded theory	1. Midwives in this study had a good understanding of prenatal GS that was appropriate to the CNM scope of practice 2. At the time of this research study, few CNMs had experience with NIPT 3. Additional research is needed regarding interactions between CNMs and GCs	Midwives in this study, like GCs, offered prenatal GS in a nondirective manner, based on individual risk assessment and practice-based guidelines, while placing high value on patient education, informed consent, and autonomy
Founds, (2014) (Murakami et al., 2020)	Innovations in prenatal genetic testing beyond the fetal karyotype	USA	–	Analysis	Obstetric, gynecologic, and neonatal nurses will continue to routinely participate in genetic/genomic care with increasing availability of noninvasive screening and test options	Educating clinicians with updated genomic knowledge has been outpaced by new technologies and direct-to-consumer marketing of prenatal tests
Martin et al., (2018) (Dagan et al., 2021)	Introduction of non-invasive prenatal testing as a first-tier aneuploidy screening test: A survey among Dutch midwives about their role as counsellors	Netherlands	This study investigated midwives': 1. knowledge about NIPT; 2. perceived competence with counseling women about NIPT; 3. attitudes towards NIPT as first-tier prenatal aneuploidy screening; and 4. behavior and experience with NIPT.	Qualitative study, online survey of midwives	1. Midwives knowledge on NIPT and genetic screening is strong, with some identified areas of misunderstanding 2. Perceived competence in genetic counselling is high - actual competence may be overestimated 3. Attitudes towards prenatal screening are neutral or positive	Concludes that midwives demonstrated solid knowledge about NIPT that may still be improved in some areas. Dutch midwives overwhelmingly support the integration of NIPT as a first-tier screening test
Murakami et al., 2019 (Nisselle et al., 2019b)	Developing competencies in genetics nursing: Education intervention for perinatal and pediatric nurses	Japan	The aims of this exploratory study were to: 1. develop an entry-level competency-based genetics nursing seminar about chromosomal abnormalities for nurses and student nurses, 2. evaluate learners'	Exploratory study on an educational intervention - qualitative and quantitative data	1. Participating in a single seminar on genetics/ genomics increased confidence of participants 2. Importance of family decision making was identified as it relates specifically to genetic conditions	The findings indicate that existing genetics nursing education does not adequately prepare nurses for the contemporary clinical environment in which genetics knowledge has

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Table 2 (*continued*)

Author and Year	Title	Country	Research Question(s)	Study Type	Findings	Conclusions
			awareness of genetics knowledge and confidence in providing nursing care for patients and families who have genetic issues and evaluate this using a presurvey and postsurvey instrument, and 3. explore the reflections of learners following exposure to the stimulus materials to evaluate understanding			an increasingly critical role
Niselle et al., 2019 (Best et al., 2023)	Lessons learnt from implementing change in newborn bloodspot screening processes over more than a decade: Midwives, genetics and education	Australia	To explore midwives' roles and education requirements in newborn bloodspot screening (NBS) for genetic conditions, as programs and supporting education evolve.	Retrospective cross-sectional study, quantitative analysis	The study found midwives' NBS knowledge improved in 8/18 areas after 10 years, mostly related to process changes, but there was also an increase in misconceptions regarding which conditions are screened	As NBS programs evolve through the addition of conditions screened for or changes to technology or consent processes, multiple strategies should be applied to upskill midwives to ensure they can best support parents to make informed choices.
Peterson et al., (2023) (Founds, 2014)	Genetic counseling practices among outpatient obstetric providers in the Northeast	USA	This study aimed to describe how patient, provider, and practice demographics influence the offering of diagnostic prenatal genetic testing by outpatient prenatal care providers.	Survey with quantitative analysis	No provider group universally offers diagnostic testing. Providers who serve populations from a racial and ethnic minority, those with public insurance, and those whose primary language is not English are less likely to universally offer diagnostic genetic testing.	This multicenter survey study highlights the gap between best practices and clinical practice and the disparities in prenatal genetic counseling and testing
Saleh et al., (2019) (Skirton et al., 2010)	Scoping the Scene: What Do Nurses, Midwives, and Allied Health Professionals Need and Want to Know About Genomics?	Australia	To identify the perceived genetic knowledge and education needs for AHPs, nurses and midwives	Qualitative, semi-structured interviews with thematic analysis	The results show that this is a diverse group that is keen to know more about genomics and genetic services but unsure of reliable sources.	Australian allied health professionals, nurses, and midwives are aware of the importance of up-skilling in genomics but remain unclear about how it applies to their practice
Schluter, 2023 (Schluter, 2023)	Understanding the application of genomics knowledge in nursing and midwifery practice: A scoping study	Australia	To explore how Queensland nurses and midwives are applying genomics knowledge in clinical practice to understand how best to support the workforce to meet patient needs in response to increased genomic testing rates.	Scoping review followed by interviews for review interpretation	Nurses and midwives are working in partnership with their patients and families to support genomic decision making. The emerging needs of patients to understand their diagnostic and treatment pathway is forcing nurses and midwives to self-educate. This approach to upskilling is not adequate for those nurses and midwives currently who are regularly exposed to patients requiring genomic support.	There is a need to address the emerging genomic workforce and education requirements to ensure nurses and midwives are capable of supporting patients undergoing genomic testing.
Shin et al., (2020) (Peterson et al., 2023)	Key competencies for Korean nurses in prenatal genetic nursing: experiential genetic nursing knowledge, and ethics and law	Korea	The study aimed to determine competencies for Korean nurses needed in prenatal genetic nursing and nursing education	1. a survey and classification of the findings, and the design of a PGNEP. 2. a quasi-experimental study. 3. consultation with an external expert	78 competencies established, in 10 categories - experiential prenatal genetic nursing knowledge was the most significant	This study identified competencies for prenatal genetic nursing and nursing education in Korea. There is a need for nursing instructors and researchers to improve the competencies of nurses in the identified experiential nursing knowledge and on ethics and law related to prenatal genetic nursing. areas.
Ternby et al., (2015) (Martin et al., 2018)	Midwives and information on prenatal testing with focus on Down syndrome	Sweden	The aim of this study was to investigate the knowledge midwives have of prenatal	Cross-sectional prospective study	1. More education about prenatal tests and Down syndrome was desired by 94 % of midwives	It is important to ensure that midwives in antenatal care have sufficient knowledge to

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Table 2 (*continued*)

Author and Year	Title	Country	Research Question(s)	Study Type	Findings	Conclusions
			diagnosis, especially DS, when informing expectant parents		2. The majority (83–89 %) had insufficient or no education regarding different prenatal tests.	inform expectant parents about the conditions screened for.
Tonkin et al., (2018) (Department of Health and Aged Care, 2017)	The first competency-based framework in genetics/ genomics specifically for midwifery education and practice	UK	This paper details a competency framework to help address the need for structured guidance around genetic and genomic education and training for midwives.	Consensus panel	All original competencies were found to be valid but required amendment in order to focus specifically on the role of the midwife and the needs of the mother, child, and wider family	Devised a set of learning outcomes and practice indicators which sit beneath an existing competency framework to provide a useful tool for educators considering where/how to fit genetics and genomics into practice.
Wright et al., 2019 (Wright et al., 2019)	Genomic Literacy of Registered Nurses and Midwives in Australia: A Cross-Sectional Survey	Australia	The aim of this study was to measure the genomic literacy of Australian registered nurses and midwives by assessing participants' understandings of genomic concepts most critical to nursing and midwifery practice	Cross sectional survey	1. Majority of practitioners reported that genetics was relevant to practice 2. Genetics knowledge was poor, GNCI scale	Genomic literacy in midwives is poor
Wright et al., (2018) (Dettwyler et al., 2019)	Nurses' competence in genetics: An integrative review	Various	The aim of the present review was to ascertain the extent to which nurses are achieving the core competencies in genomics appropriate for nursing practice	Integrative review	1. Respondents' poor confidence in collecting a family history and three-generation family tree was reported by the authors of several studies 2. The limited genomics education could be responsible for the low genomic knowledge 3. many nurses are unaware whether a genetics/ genomics course is available to them	Nurses' confidence in using genomic knowledge and/or skills were low

midwives' competence, literacy and understanding in genetics (Schluter, 2023; Saleh et al., 2019; Wright et al., 2019) included assessments of the perceived importance of genetics to practice and all reported that midwives understood its relevance and were keen for upskilling in this area. One study (Wright et al., 2019) analysed this quantitatively, with 97.2 % of midwives in Australia reporting that genetics was relevant to their clinical practice.

(3) There are inadequate educational opportunities for midwives in genetics/genomics

Of the included studies, eight identified a lack of educational opportunities for midwives, both at the level of their initial training in tertiary studies and as continuing professional development opportunities. In Australia, several studies (Schluter, 2023; Saleh et al., 2019; Best et al., 2023; Nisselle et al., 2019b) identified that genetic advances were outpacing educational opportunities for midwives and nurses, with one study (Best et al., 2023) specifically discussing reproductive genetic carrier screening (RGCS) as a significant achievement in reproductive medicine, but identified that there was inadequate professional development available for upskilling in this area. Another study (Nisselle et al., 2019b) focused on newborn bloodspot screening (NBS) and suggested that multiple strategies including mentoring, on-site training and online educational modules should be available for midwives to keep pace with new genetic conditions added to the testing profile. Internationally, the landscape appears similar, with midwives in Japan (Murakami et al., 2020) and the USA (Wright et al., 2018; Founds, 2014; Peterson et al., 2023) reporting inadequate or ineffective opportunities to meet their educational needs.

(4) Midwives have a positive perception of the use of genetics/ genomics in their scope of practice

Of the included studies, three found that midwives had a positive perception of the use of genetics and genomics, which is essential for the uptake of any new educational initiatives. Studies from Israel (Dagan et al., 2021), the USA (Wright et al., 2018) and Australia (Nisselle et al., 2019b) reported that midwives felt positive about the integration of genetics and genomics into their practice, despite feeling unprepared. In particular, the Israeli study (Dagan et al., 2021) included a questionnaire given to obstetric nurses that contained questions specifically aimed at assessing the feelings, positive or negative, towards the integration of genetics into obstetric nursing practice. The evidence showed that nurses felt positive (average importance rating M=2.88 on a 1–4 Likert scale), despite low levels of knowledge in genetics and this positive inclination led them to seek out more educational opportunities.

(5) Suggested educational/competency frameworks for midwives

Three of the included studies outlined educational or competency frameworks currently used or suggested for midwives. A Japanese study (Murakami et al., 2020) included the development, use and evaluation of an entry-level, competency-based genetics nursing seminar. The seminar was found to be moderately effective but inadequate to meet the needs of the nurses who undertook it. A Korean study (Shin et al., 2020) established 78 competencies in genetics across 10 categories through consultation with paediatric genetic nurses and genetics experts. There has been limited further exploration of the utility of these competencies. Finally, a UK study (Tonkin et al., 2018) detailed a competency framework to assist in streamlining the education of midwives in genetics and identified specific learning outcomes related to these competencies that midwives should aim to achieve throughout their training and in continuing professional development.

4. Discussion

This systematic review investigating the education needs of midwives in genetics and genomics yielded some important insight. Of most importance was the finding that midwives' understanding of genetics and genomics is generally low and that educational opportunities in this area are limited. Two additional findings across the included literature were that midwives have a good understanding of the importance of genetics and genomics to their practice and that midwives are generally positively disposed towards the use of genetics and genomics within their scope of practice. Additionally, three educational frameworks in progress (a list of competencies and a competency-based framework) were captured in our search and provide a potential starting point for the development of an educational framework for Australian midwives.

This is the first systematic review of the educational needs of midwives specifically in genetics/genomics, but there have been several studies and reviews that focused on the educational needs of general nurses, doctors and other health care providers in genetics (White et al., 2020; Talwar et al., 2017; Paneque et al., 2016). Using the Program Logic educational program (Nisselle et al., 2021) discussed previously, some aspects of these studies may inform future directions of this research. Niselle et. al., suggest an approach that navigates the following steps: planning (the stage this research contributes to), development, delivery and evaluation. An important area of future research is the development of an educational framework for midwives; hence their highly specific requirements must be considered. First and foremost, the relationship that exists between a woman and the midwife attending her pregnancy and birth is a unique one. The continuity of care in the midwifery model of pregnancy and birth brings with it opportunities and challenges, even within the realm of genetic testing. A midwife's confidence and competence around the genetic testing requested, the delivery of results and associated decision-making are essential for the maintenance of that relationship. Ultimately, the quality of care received by women in the care of a midwife is dependent on that midwife understanding all aspects of that care.

Most of our included studies confirmed that the knowledge of genetics and genomics of midwives is low and that they lack appropriate educational opportunities in this area. It is therefore clear that an opportunity exists for widening the scope of genetics and genomics teaching in Australian tertiary institutions which offer midwifery programs. With the collected evidence suggesting that midwives understand the importance of genetics and genomics to their practice and feeling positively disposed towards their use, there is reason to believe that educational opportunities for midwives would be well received. Identifying the appropriate learning outcomes, pedagogical practices and educational frameworks to best deliver this must be the focus of extensive further research.

The National Health Service in the United Kingdom offers some insight into a path forward, with a specific mention of genetics and genomics in the Nursing and Midwifery Council's (the UK's regulatory body for public health nurses and midwives) Standards of Proficiency for Midwives (Nursing and midwifery council, 2024) (Standard 6.18: Apply in-depth knowledge of anatomy, physiology, genetics, genomics, epigenetics and psychology to inform the assessment, planning and provision of care for the woman and newborn infant across the continuum (Nursing and midwifery council, 2024)). From an American perspective, a recent discussion paper (Dewell et al., 2024) offered a different perspective by mapping the American Nursing Association's Essentials of Genomic Nursing competencies (American Nurses Association, 2023) against the American Association of Colleges of Nursing Essentials competencies (American Association of Colleges of Nursing, 2021) so that nursing faculties can seamlessly integrate genomic education into their existing offerings.

Because of this explicitly stated requirement of in-depth knowledge of genetics and genomics, midwifery education programs are required to address it in their curricula. Additionally, post-credential training in genetics and genomics specifically for midwives is available from multiple sources; a yearly or bi-yearly multiday workshop on genetics and genomics education for midwives is offered by Wellcome Connecting Sciences (Wellcome Connecting Science, 2024) to upskill midwives and their educators and the NHS's Genomics Education Programme (Health Service England, 2019) offers short online courses and resources for midwives at any stage of their career. Australian student midwives and midwives would benefit from a version of these resources, adapted for our purposes, our competency framework and our standards of care.

This systematic review sets a benchmark for the knowledge and understanding of midwives around genetics and genomics and begins to investigate the landscape ahead of a potential introduction of new educational strategies. Further research in this area should focus on devising standards of proficiency for Australian midwives in genetics and genomics. This will require a more detailed investigation of current deficiencies in midwives' understanding, how this education can best be delivered and how the process can be evaluated. The evidence gathered from this systematic review and other research establishes clearly that upskilling midwives in genetics and genomics is well overdue.

Our systematic review has some limitations. First, we conducted a thorough search of major databases and adopted a broad search strategy to identify articles published in English, but we may have missed articles published in other languages. Second, there was a lack of consistency in the type and methodology of the studies included in the review, which made it difficult to analyse and evaluate them using a standard set of criteria. While the heterogeneity of evidence is not inherently negative in a systematic review of qualitative and mixed methods studies, it does require a wider scope of thematic analysis to ensure results from all included studies are given equal consideration (Mulrow et al., 1997; National Health and Medical Research Council, 2019). Although quantitative studies were deliberately excluded in the search strategy, there is the possibility that the inclusion of any strictly quantitative studies may have added evidence to our analysis. Finally, our search strategy and screening process were most limited by the different designations for obstetric health care professionals across different countries – there is a real risk that many relevant studies were excluded due to the population studied being nurses rather than midwives when these studies might have contributed meaningfully to the review. The reviewers were as meticulous as possible while screening to ensure all relevant studies were included, but this semantic difference contributed heavily to our low inter-rater reliability and consistent need for conflict resolution in screening.

5. Conclusion

Improving educational outcomes for the next generation of midwives and those currently practicing is an ongoing challenge. As genetic medicine is integrated into antenatal care, midwives are ill-equipped to address the needs of the mothers and babies they care for. The unique relationship between midwives and families throughout the antenatal journey is central to the well-established positive outcomes of midwifery care. Further research should focus on facilitating the upskilling of midwives in genetics and genomics so that they can feel confident in every aspect of the collaborative care they provide to women and families.

CRediT authorship contribution statement

Gusen Talia: Writing – review & editing, Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **Freeman Lucinda:** Writing – review & editing, Validation, Methodology, Conceptualization. **Musgrave Dr Loretta:** Writing – review & editing, Validation, Supervision, Methodology, Conceptualization.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.nepr.2025.104340.

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