Genomic medicine: core principles for nursing and midwifery pre-registration education (March 2022)

Area/principle	Foundation	Intermediate	Resources	Learning outcome(s)	NMC standard: platform (P) and outcomes (O)
Genomic fundamentals					
Describe the structure and functions of DNA, genes, chromosomes, exomes and genomes.			NHS England (NHSE) National Genomics Education Programme (GEP): Image library	3	P 3: O 3.2
			North Thames (NT) Genomics Laboratory Hub (GLH): Genomics Now podcast series		
			NHSE GEP: Bitesize genomics: What is genomics?		
			NHSE GEP: Genomics 101: From Genes to Genome		
			NT GLH: Facilitator's toolkit		
Demonstrate an understanding of how variations in genetic/genomic structures contribute to human development and wellbeing.			NHSE GEP: Rare disease education hub	3	P 3: O 3.1, 3.2
			NHSE GEP: Cancer genomics		
			NHSE GEP: Genomics 101: From Gene to Protein		
			NHSE GEP: Genomics 101: Genomics in Healthcare		
Demonstrate an understanding of autosomal recessive, autosomal dominant, X-linked, mitochondrial and chromosomal rearrangement inheritance including the factors which influence these patterns of inheritance.			NHSE GEP: Genomics 101: Dominant, Recessive and Beyond	3, 4	P 3: O 3.2
			NHSE GEP: Genomics 101: Inheriting Genomic Information		
			St George's University of London (SGUL): Genetic Inheritance for the Pregnancy Pathway: A Practical Guide for Clinicians		
Demonstrate a general understanding of the different types of genetic/genomic tests available and the scenarios they are used in.			NHSE: National Genomic Test Directory	2, 3	P 2: O 2.9
			NHSE GEP: Genomics 101: Investigating the Genome Part 1: The Process		
			NHSE GEP: Genomics 101: Investigating the Genome Part 2: The Tests		
			NHSE GEP: Genomics 101: Genomics in Healthcare		
Describe how genetic variation can influence a person's response to medicines.			NHSE GEP: Pharmacogenomics glossary entry	5, 6	P 3: O 3.3, 3.5; P 4: O 4.5, 4.14, 4.15, 4.17
Describe how pharmacogenomic testing can be used to enhance medicines' safety and efficacy.			NHSE GEP: What is pharmacogenomics?	5, 6	
			NHSE GEP: Rapid genomic test helps prevent newborn hearing loss		
			Royal College of Physicians: Personalised prescribing: using pharmacogenomics to improve patient outcomes		

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Ethical, social and psychological issues					
Evaluate the ethical and legal issues surrounding informed consent, insurance (including relevant legislation), non-disclosure (including information to at-risk relatives) and information sharing in genomics.			Genetic Alliance UK: Insurance and genetic conditions	1, 8	P 1: O 1.2, 1.9, 1.14
			NT GLH: Training and resources catalogue		
			PET: ABC v St George's: exercising judgment without fear		P 2: O 2.7, 2.9, 2.10
			NHSE GEP: Ethical, Legal and Social Issues in Applied Genomics		P 4: O 4.2, 4.3
			PET: Whole Genome Sequencing at Birth – Genomic Data, A Resource from Cradle to Grave?		P 3: O 3.5, 3.15
Explore the ethical, social and cultural issues associated with genetic/genomic testing, including those that cover non-disclosure, termination of pregnancy and obligate carriers.			BPAS: Termination of pregnancy for fetal anomaly	6, 8	P 1: O 1.2, 1.9, 1.14
			Antenatal Results & Choices (ARC): Patient stories		P 2: O 2.8, 2.9, 2.10
			National Library of Medicine: Ethics in genetic counselling		P 3: O 3.5, 3.6, 3.15
			Current Genetic Medicine Reports: Ethical Issues in Genetic Testing for Inherited Cancer Predisposition Syndromes: the Potentially Conflicting Interests of Patients and Their Relatives		P 4: O 4.2, 4.3
			NHSE GEP: Public Health Masterclass in Genomics: Ethical and Legal Considerations		
Understand the complexities of family communication and examine strategies to the issues, such as non-disclosure.			National Library of Medicine: Sharing genetic test results with family members of BRCA, PALB2, CHEK2, and ATM carriers	6, 7, 8	P 1: O 1.9, 1.11, 1.13, 1.14
			National Library of Medicine: Enhancing family communication about genetics: ethical and professional dilemmas		P 2: O 2.9, 2.10
			National Library of Medicine: How communication of genetic information within the family is addressed in genetic counselling: a systematic review of research evidence		P 3: O 3.5, 3.15; P 4: O 4.2, 4.3
Critically evaluate the potential psychological impact of genetic/genomic test results for patients and their families.			NHSE GEP: Nursing educator's toolkit	5, 6, 7, 8	P 1: O 1.9, 1.11, 1.13, 1.14
			Rare Disease UK: Patient experience videos		P 2: O 2.9, 2.10
			NHSE GEP: Let's Talk About…The Impact on Families		P 3: O 3.5, 3.15; P 4: O 4.2, 4.3
			SWAN UK: What does getting a genetic diagnosis mean?		
Critically evaluate the ethical issues of patient participation in genomic research, including the use of biobanks.			NHSE GEP: National Genomic Research Library: information for clinicians	8	P 1: O 1.2, 1.7
			Genomics England: How your data is used		

			PET: Whose Genome Is It Anyway? Big Data and Your DNA		
Area/principle	**Foundation**	**Intermediate**	**Resources**	**Learning outcome(s)**	**NMC standard: platform (P) and outcomes (O)**
Mainstreaming genetics/genomics					
Identify the impact of and have the opportunity to discuss the principles of giving genetic/genomic results in a person-centred manner.			NHSE GEP: Genomics 101: Talking Genomics	4, 5, 6, 7	P 1: O 1.8, 1.9, 1.11, 1.13, 1.14
			NT GLH: Facilitator's toolkit		
			NHSE GEP: Facilitating Genomic Testing: Discussing Diagnostic Germline Genomic Tests		P 2: O 2,8, 2,9, 2.10
			National Library of Medicine: SPIKES-A six-step protocol for delivering bad news: application to the patient with cancer		P 3: O 3.5, 3.6, 3.15
			National Library of Medicine: The language of uncertainty in genetic risk communication: framing and verbal versus numerical information		P 4: O 4.2, 4.3
Demonstrate how to take a comprehensive family history from a patient with a genetic condition.			NHSE GEP: Genomics 101: Taking and Drawing a Genetic Family History	2, 3, 7	P 3.2
			NHSE GEP: Taking and drawing a family history		
			NT GLH: Training and resources catalogue		
			Journal of Genetic Counseling: Standardized Human Pedigree Nomenclature: Update and Assessment of the Recommendations of the National Society of Genetic Counselors		
Identify key clinicians who can be involved in patient support and decision-making.			NHSE GEP: Genomics in Midwifery	1, 5	P 1: O 1.18
			NHSE GEP: Nursing in the Genomic Era		P 5: O 5.4
			NHSE GEP: The Genomics Team		P 7: O 7.1
Apply knowledge of inheritance patterns to determine the chance of a patient or their offspring inheriting a genetic condition.			SGUL: Genetic Inheritance for the Pregnancy Pathway: A Practical Guide for Clinicians	2, 3, 4	
Explain the principles of informed consent for genetic and genomic testing.			PET: Informed consent to non-invasive prenatal testing: findings from a qualitative study in Lebanon and in Quebec	1	
			NHSE GEP: Requesting whole genome sequencing: information for clinicians		
Recognise professional limitations in terms of responsibility and have an appreciation of the role of genomic services in England (including the role of MDTs), the associate support organisations and sources of peer-reviewed information to be able to signpost accordingly.			National Library of Medicine: The new genomic medicine service and implications for patients	8	P 1: O 1.18
			NHSE: NHS Genomic Medicine Service		P 5: O 5.4; P 7: O 7.1, 7.8
Demonstrate an understanding of the implications of DTC genetic testing on clinical care as well as the ethical and social			PET: Policymakers advised to address problems with direct-to-consumer genomic testing	2, 3, 8	
			The BMJ: Direct-to-consumer genetic testing		

implications.			NHSE GEP: Direct-to-consumer testing: a clinician's guide		

Learning outcomes
1. Explain the importance and application of informed consent in the field of genomic medicine generally.
2. Explain the different purposes of genomic testing in patients with rare inherited diseases, cancer and infectious diseases.
3. Discuss the concepts of genetic and genomic predispositions to illnesses.
4. Explain genomic results in terms of diagnosis prediction and uncertainty.
5. Evaluate and apply the skills necessary to support individuals who have genomic results that affect their care, including the underpinning evidence base and patient perspective.
6. Discuss the consequences of genomic test results on the patient and the wider family, including incidental findings drawing on the published evidence base, and personal experiences of patients, carers and the wider family.
7. Evaluate and apply the communication and counselling skills needed to engage and communicate effectively in a compassionate manner with patients, their carers and the wider family.
8. Critically evaluate current and potential future ethical, legal and social issues (ELSI) of genetic counselling.
Nursing & Midwifery Council: 'Future Nurse: Standards of proficiency for registered nurses' mapped to core principles
2.2 Demonstrate knowledge of epidemiology, demography, genomics and the wider determinants of health, illness and wellbeing and apply this to an understanding of global patterns of health and wellbeing outcomes.
3.2 Demonstrate and apply knowledge of body systems and homeostasis, human anatomy and physiology, biology, genomics, pharmacology and social and behavioural sciences when undertaking full and accurate person-centred nursing assessments and developing appropriate care plans.