

# **Evidence Brief: Genomics**

### Contents

Key publications – the big picture	2
HEE Star	3
HEE National Data Programme	3
Published Peer Reviewed Research	3
Practice, education, and training	3
Healthcare science	8
Nursing	9
Ophthalmology	11
Pathology	11
Primary care	12
Competency Frameworks	12
*Help accessing articles of papers	14

Produced by the HEE Knowledge Management team Evidence Briefs offer a quick overview of the published reports, research, and evidence on a workforce-related topic.

#### Date of publication: September 2021

**Please acknowledge this work in any resulting paper or presentation as:** Evidence Brief: Genomics. Jo McCrossan. (20/09/2021). UK: Health Education England Knowledge Management Team

There may have been an update to this Evidence Brief - to check you are reading the most current version please see the links below:

- <u>Complete Evidence Brief list link for HEE staff</u>
- Complete Evidence Brief list link for External staff

## Key publications – the big picture

The Topol Review: Preparing the healthcare workforce

to deliver the digital future 2019, Health Education England The roll out of genomics across the NHS will have major implications for the clinical workforce. The pace of change may differ by speciality but, ultimately, genomics will impact on the practice of most, if not all, health professionals. While some aspects of care, such as the management of rare genetic diseases will remain largely within the domain of specialised colleagues, many aspects of genomics, including risk prediction for common diseases and pharmacogenetics, will become 'mainstream' and their application embedded in routine healthcare delivery. As practice in genomics evolves, individual workforce training needs will depend less on traditional role demarcations and more on specific responsibilities related to 'real-world' implementation based on genomic information.

#### Interim NHS People Plan 2019, NHS England

We need to ensure that those providing care in the NHS, both now and over the coming years, are equipped with the knowledge and skills to keep up with scientific and technological advances and that we have the right specialist workforce to support the broader multiprofessional team in applying these advances. This will also create opportunities for more efficient and effective deployment of our most skilled people and new roles incorporating data, technology and clinical elements, such as clinical informaticians and genomic scientists.

The introduction of cutting-edge genomic technologies into the NHS Genomic Medicine Service, as signalled in the NHS Long Term Plan, will require enhanced capacity-building for both the specialist scientific and more general multiprofessional workforce. This will drive further workforce development and

new education and training approaches to help embed genomics and the more detailed understanding of the influence of the genome on health, disease and personalised treatment. There will be a critical relationship between 'real world' clinical evidence and insights from aligned industry and research collaboration for enhanced clinical interpretation of genomic information.

<u>Genome UK: The future of healthcare</u> 2020, HM Government This strategy sets out a vision for the future focused on three key areas:

- 1. Diagnosis and personalised medicine: Incorporating the latest genomics advances into routine healthcare to improve the diagnosis, stratification and treatment of illness.
- 2. Prevention: Enabling predictive and preventative care to improve public health and wellness.
- 3. Research: Supporting fundamental and translational research and ensuring a seamless interface between research and healthcare delivery.

#### See also: Genome UK: 2021 to 2022 implementation plan

Healthcare staff must be empowered to know when a patient might benefit from genomic testing and feel confident that they have the skills to communicate complex results to patients and their families in a simple way. In addition to their technical and medical complexity, genomic and genetic test results often raise difficult ethical questions and dilemmas for both clinicians and patients. It is therefore important that clinicians are provided with a developing framework and guidance on how to navigate these issues with their patients, and empower patients to make informed decisions for themselves and their families.

Developing a workforce with these skills will require training and development of existing healthcare staff. We need to ensure

that genomics knowledge and expertise is embedded in prospective education and training programmes.

#### <u>Genomics education for medical professionals – the current UK</u> <u>landscape</u> 2016, Clinical Medicine

Genomic science, incorporated into the national healthcare landscape, offers the potential of improved patient care and disease prevention that can be fully exploited only by an educated health professional workforce. Cooperation and coordination will be required both between the multiple strategic and delivery players outlined in this review, as well as with the biomedical research sector, to effectively nurture such a workforce. Furthermore, any national educational strategy will need both persistence and substantial sustained resource commitment.

## **HEE Star**

More resources and tools are available by searching for **Genomics** in the <u>HEE Star</u>

## **HEE National Data Programme**

HEE staff can look at the <u>National Data Warehouse (NDL)</u> SharePoint site to find out more about datasets and Tableau products.

### **Published Peer Reviewed Research**

#### Practice, education, and training

Measuring physician practice, preparedness and preferences for genomic medicine: a national survey 2021, BMJ Open This national snapshot of medical specialists' current practice in genomic medicine provides the first detailed insight into the continuing genomics education needs of a broad group of subspecialties. It includes some specialties, such as emergency medicine, palliative medicine and infectious disease, for the first time internationally. The findings will also be helpful to genetics services and other clinical services implementing models for genomic medicine delivery. Further data analysis will provide insights into any differences between early adopters of genomic medicine and those who have not yet engaged, enabling the development of targeted, tailored genomics education and other capability-building strategies for optimising the adoption of genomics by medical specialists.

Ensuring best practice in genomics education and evaluation: reporting item standards for education and its evaluation in genomics (RISE2 Genomics) 2021, Genetics in Medicine Abstract only\*

These Reporting Item Standards for Education and its Evaluation in Genomics (RISE2 Genomics) are intended to be widely applicable across settings and health professions. Their use by those involved in reporting genomics education interventions and evaluation, as well as adoption by journals and policy makers as the expected standard, will support greater transparency, consistency, and comprehensiveness of reporting. Consequently, the genomics education evidence base will be more robust, enabling high-quality education and evaluation across diverse settings.

#### <u>Genomics Education for Medical Specialists – A Blended</u> <u>Learning Approach</u> 2021, Twin Research and Human Genetics *Athens log-in required*\*

[Abstract, p. 68] We developed four self-directed, interactive online modules, e-book and infographic that introduced foundational genetics content and clinically-relevant concepts, processes and skills for germline and somatic genomics. Workshops (pediatric, adult and somatic/cancer) then focussed on clinical cases presented by clinicians with genomics expertise and small group discussions. Participants completed evaluation surveys at baseline, post-online modules and post workshops. Participants rated online modules helpful for learning more foundational and pragmatic concepts, and facilitated workshops more helpful for learning about clinical aspects such as identifying the right test for the right patient, interpreting reports and genetic counseling, yet the major gains in knowledge and confidence were seen after online modules.

#### <u>Teamwork in clinical genomics: A dynamic sociotechnical</u> <u>healthcare setting</u> 2021, Journal of Evaluation in Clinical Practice *Abstract only*\*

Challenges to teamworking that arise in the elongated adaptive context do not always fit traditional ways of working, and innovative strategies will need to be adopted to ensure the diagnostic advances of clinical genomics are realised. Provision of time and permission for team members to share knowledge and evolve, promoting capacity building, nurturing trustful relationships and establishing boundaries are amongst the practice recommendations for organisational and team leaders, even though these activities may disrupt existing ways of working or hierarchical structures.

#### Social and behavioral science at the forefront of genomics: Discovery, translation, and health equity 2021, Social Science & Medicine *Abstract only*\*

Social and behavioral sciences should play a leadership role in identifying best practices for effective clinical and community translation of genomic discoveries. Inclusive research that engages diverse populations is necessary for genomic discovery and translation to benefit all.

## The genomics workforce must become more diverse: a strategic imperative 2021, American Journal of Human

Genetics Athens log-in required\*

The new NHGRI strategic vision features a set of guiding principles and values that provide an ethical and moral framework for the field. One principle emphasizes the need to champion a diverse genomics workforce because "the promise of genomics cannot be fully achieved without attracting, developing, and retaining a diverse workforce, which includes individuals from groups that are currently underrepresented in the genomics enterprise." To build on the remarkable metamorphosis of the field over the last three decades, enhancing the diversity of the genomics workforce must be embraced as an urgent priority. Toward that end, NHGRI recently developed an "action agenda" for training, employing, and retaining a genomics workforce that reflects the diversity of the US population.

#### <u>A family systems approach to genetic counseling: Development</u> of narrative interventions 2020, Journal of Genetic Counseling *Athens log-in required*\*

To what extent are family systems approaches relevant in the genomics era? What difference does it make to remember the wider social context within which 'problems' associated with a genetic diagnosis reside? How does this influence the conversations we have with our patients? These questions will be considered in relation to systemic approaches to genetic counseling practice. Narrative therapy with an emphasis on people's strengths, wishes, and ways of resisting the effects of a problem may be a particularly useful framework for genetic counselors. Narrative practice views people as multi-storied and is concerned with the question of how we encourage people to tell their stories in ways that make them feel stronger. Increased uptake of genomic testing and the number of people seeking genetic counseling present opportunities to consider new ways of working, particularly around support following a new genetic diagnosis. One option is to realize the potential of group interventions. Family therapy and narrative practices have the potential to encourage communication and for families to learn from each other.

Development of a novel, online training platform for genomics education in cancer care; preparing healthcare professionals for "Generation Genome" 2020, European Journal of Human Genetics Athens log-in required\* [Abstract, p. 511] We developed an online platform (Nucleus) to address this need across for cancer healthcare professionals in

our region. Modules in basics of cancer genomics, cancer genomics susceptibility, and precision oncology (technological and clinical applications) have been developed. Podcasts and blogs are currently in development. Initial user testing has been very positive with users rating the platform as relevant to practice, with appropriate length and pace.

# The leadership behaviors needed to implement clinical genomics at scale: a qualitative study 2020, Genetics in Medicine Athens log-in required\*

Entrepreneurial leadership is needed to promote innovativeness, risk-taking, and proactivity, essential in these early stages of clinical genomics. Shared decision-making is required from a wide range of clinicians, calling for both clinical and distributed leadership. Sharing leadership, and the potential loss of positional status from formal senior positions, may prove challenging to genomics "migrants," who are essential for nurturing genomic "natives." Clinicians will need support from their organizations and professional bodies to manage the transition.

#### Preparing Medical Specialists for Genomic Medicine: Continuing Education Should Include Opportunities for

Experiential Learning 2020, Frontiers in Genetics Athens log-in required\*

Our findings show that motivations to engage with continuing education about genomic medicine appear to be driven by a combination of: individual characteristics (interest in genomics, career stage, and medical specialty); perceptions of relevance to practice (current and future); and prior experience, such as that gained in research settings. We have shown that medical specialists contextualize their knowledge gained through formal education by engaging with their peers and seeking out opportunities for experiential learning. In fact, participants described how most genomics learning occurs outside of attendance at continuing education activities, which have been the previous focus of workforce development (Burton, 2011; Talwar et al., 2017).

# From helices to health: undergraduate medical education in genetics and genomics 2019, Personalized Medicine Athens log-in required\*

Integration of genetics and genomics into the clinical years can help students learn genomic medicine skills, and requires genomically literate teaching faculty. Genomic champions in different clinical specialties can be recruited to teach medical students and promote genomic literacy among their peers.

#### Ensuring Best Practice in Genomic Education and Evaluation: A Program Logic Approach 2019, Genet.

The program logic developed in this paper is a versatile and useful tool for developing education interventions in different settings. Despite a "call to action" over a decade ago (Gaff et al., 2007), few papers published since have described use of program logic in their design or evaluation. This program logic model can be used to inform program development and redesign; it is not intended to be linear, but as with all program logic models, can be used through cycles, with the outputs and outcomes informing inputs and activities at different stages. As not all education providers will be familiar with a program logic model approach to developing interventions, we are developing a set of companion documents to support the use of the tool, including a "how to" guide, a glossary of terms, useful resources for both education and evaluation, and detailed definitions and examples throughout. Readiness of clinical genetic healthcare professionals to provide genomic medicine: An Australian census 2019, Journal of Genetic Counseling Abstract only\* This is the first national audit of clinical genetic healthcare professionals, revealing the Australian workforce is motivated and prepared to embrace new models to deliver genomic medicine but consideration of education and training is required to meet demand. The majority of respondents (89.9%) were satisfied with their job and 91.6% planned to work in genetics until retirement. However, 14.1% of the genetic counselors in clinical roles and 24.6% of the clinical geneticists planned to retire within 10 years.

# <u>Current conditions in medical genetics practice</u> 2019, Genetics in Medicine *Athens log-in required*\*

New genetic discoveries are creating new opportunities in prevention, health maintenance, and the management of heritable disorders. To fully realize the potential of these medical breakthroughs and to ensure that all Americans have access to genetic services will take new practice models, new residency training models, and better reimbursement. Longterm investments are also needed to encourage students to join the genetics profession, so that ten years from now patients and families affected by genetic conditions are more quickly diagnosed and more easily able to access the primary, secondary, and tertiary care services they need. Genetics professional capacity within the health-care system will need to be substantially expanded and wait times for nonemergency appointments greatly reduced.

#### Delivering genomic medicine in the United Kingdom National Health Service: a systematic review and narrative synthesis 2019, Genetics in Medicine *Abstract only*\*

Mainstreaming genomic medicine into routine clinical practice requires actions at each level of the health-care system. Our synthesis emphasized the organizational, social, and cultural implications of reforming practice, highlighting that demonstration of clinical utility and cost-effectiveness, attending to the compatibility of genomic medicine with clinical principles, and involving and engaging patients are key to successful implementation.

#### Interdisciplinary learning on a postgraduate genomic medicine course – help or hindrance? 2019, Archives of Disease in

Childhood Athens log-in required\* [Abstract] Participants reported being affected in different ways

and to different extents by social, individual and course factors related to interdisciplinary learning. These mirror the behavioural, personal and environmental determinants of Bandura's social cognitive theory. Several advantages and disadvantages identified by participants show parallels with adult learning theory and the interprofessional education literature. These results may be used to inform strategies for optimising the experience of participants on future interdisciplinary learning courses.

#### <u>Genomics in Clinical Care: Preparing Non-genetic Health</u> <u>Professionals</u> 2019, Twin Research and Human Genetics *Athens log-in required*\*

[Abstract, p. 411] Melbourne Genomics has an upskilling strategy to meet education needs of practising non-genetic medical professionals: (1) internships; (2) blended learning short courses in clinical genomics; (3) workshops.

#### Driving the precision medicine highway: community health workers and patient navigators 2019, Journal of Translational Medicine

Low levels of health and genomic literacy render the American public ill-equipped to make informed decisions, use and interpret genomic information, or appreciate the benefits afforded by genomics-based technologies. We propose that coordinated expansion of the roles of community health workers and patient navigators within the precision medicine space can be effectively used to disseminate the knowledge required for the public to benefit from precision medicine advances in healthcare. A well-organized and trained community health worker and patient navigator workforce will provide a voice for the disadvantaged, especially among recent immigrants likely to be experiencing social isolation, language barriers, and economic deprivation. Armed with this knowledge, community health workers and patient navigators can advance the precision medicine agenda and empower disadvantaged communities to take advantage of major advances in the precision medicine era.

Building a learning community of Australian clinical genomics: a social network study of the Australian Genomic Health Alliance 2019. BMC Medicine

Social processes and self-directed modes of learning were shown to be powerful influences on members' genomic practice, underlining the significance of the strategy of building relationships to form a genomic learning community.

#### The 2019 US medical genetics workforce: a focus on

<u>clinical genetics</u> 2019, Genetics in Medicine *Athens log-in required*\*

To address the current shortfall and expected capacity needs of genomic medicine, a substantial increase in clinical genetics trainees will be necessary. However, there have been persistent deficiencies in filling training slots. Potential solutions, such as increasing the recruitment of clinical genetics trainees into the field, improving workforce diversity, and enhancing collaborative practice are a start, but will require a concerted effort and innovations across many stakeholders to fully realize. Salary enhancement and increased funding support for trainees will be integral in achieving this goal. If the workforce is successfully enhanced, genetics patients will benefit more from cutting edge research and therapies, in addition to a more collaborative approach to medical genetics care.

#### Using the Findings of a National Survey to Inform the Work of England's Genomics Education Programme 2019, Frontiers in Genetics Athens log-in required\*

For those NHS staff that need to understand genomics and apply this to their practice, our findings suggest there are two levels of education and training resources required. The first is general information targeted to professional groups and the second is cross-professional resources on specific areas or activities that form part of the clinical pathway. However, the results from these surveys also emphasize the need for

#### **Evidence Brief: Genomics**

ongoing awareness raising about genomics in general, as there are still healthcare professionals, as well non-clinical NHS staff, who do not know what genomics is, let alone how it can be applied to healthcare.

#### <u>Genomic Education at Scale: The Benefits of Massive Open</u> <u>Online Courses for the Healthcare Workforce</u> 2019, Frontiers in Genetics *Athens log-in required*\*

MOOCs are an excellent vehicle for reaching large numbers of learners from across healthcare professions. The use of frontline practitioners as course mentors was successful in this setting: these mentors enhanced the learning experience, while the model itself developed frontline staff as educators. Further research is needed to see if this model, which may offer a sustainable way to deliver healthcare MOOCs, can be replicated, both in terms of using different professional groups as mentors and in healthcare settings outside of the NHS.

#### Preparing Medical Specialists to Practice Genomic Medicine: Education an Essential Part of a Broader Strategy 2019, Frontiers in Genetics Athens log-in required\*

Findings from the very limited empirical studies conducted to date (largely in the field of oncology) suggest that medical specialists' perceptions of genomic medicine are likely to be complex. Mixed views on the clinical utility of genomic medicine currently exist, with perceived benefits frequently tempered by several concerns. At the same time, specialists generally consider the arrival of genomic medicine inevitable. Most do not feel prepared for this inevitability and perceive a lack of understanding and confidence. While little evidence exists, there is indication that CME in genomic medicine is likely to be broadly welcomed.

#### Genomics education for medical professionals - the current UK landscape 2016, Clinical Medicine Athens log-in required\* Genomic science, incorporated into the national healthcare landscape, offers the potential of improved patient care and disease prevention that can be fully exploited only by an educated health professional workforce. Cooperation and coordination will be required both between the multiple strategic and delivery players outlined in this review, as well as with the biomedical research sector, to effectively nurture such a workforce. Furthermore, any national educational strategy will need both persistence and substantial sustained resource commitment. Education will be the key if the full measure of health benefits from genomic science is to be achieved. Future work might involve contacting these groups and organisations to gather information on genomics initiatives that they have set up themselves, and to seek the involvement of those who are vet to develop policies in this area.

<u>Challenges and Opportunities for Genomics Education: Insights</u> <u>from an Institute of Medicine Roundtable Activity</u> 2016, Journal of Continuing Education in the Health Professions *Abstract only*\*

This commentary promotes continuing and graduate education – informed by an awareness of barriers, drivers, and best practices – as the most effective approaches for preparing the workforce for genomic medicine and ultimately improving patient care, and argues that the time for education is now.

#### **Healthcare science**

#### Evolving Careers in Genetics: Attitudes of Healthcare Scientists 2019, European Journal of Human Genetics Athens log-in required\*

[Abstract] Studying the specialist workforce in the Genomics Service, particularly in Cytogenetics and Molecular Genetics, offers potential insights into the nature and impact of the changes on their occupational boundaries. Both disciplines have evolved as separate occupations with their own professional bodies in the UK. Recently, the distinction between them has become increasingly 'blurred' through the advancement of shared technology; the need to decrease service costs and find efficiencies; and the Modernising Scientific Careers policy programme which merges two previously separate scientist education and training programmes. As a result, the two specialities are being merged and the services rationalised. This is leading to changes in healthcare science careers and scientists' future working roles and relationships in this clinical domain.

#### Nursing

#### <u>Current status and future directions of U.S. genomic nursing</u> <u>health care policy</u> 2021, Nursing Outlook *Athens log-in required*\*

Without necessary genomic health care quality performance measurement tools for clinicians, purchasers, regulators and policymakers; an adequately prepared nursing workforce; frameworks, planning, and know-how for rapid cycle performance improvement/quality improvement; it will be difficult to move precision health beyond research trials at academic medical centers. Similar to other performance measurement health care policy 'calls to action', we opened the dialogue to defining a precision health care quality measurement strategy that is evidence based, harmonized, and multi-stakeholder (Lamb & Donaldson, 2011; National Quality Forum, 2019). Strategic integration of health care quality performance measurement principles and federal benchmarking infrastructure including development of genomic outcome measures and nurse contributions to genomic health care will facilitate broader expansion of precision health into routine health care operations.

#### A Maturity Matrix for Nurse Leaders to Facilitate and Benchmark Progress in Genomic Healthcare Policy,

<u>Infrastructure, Education, and Delivery</u> 2020, Journal of Nursing Scholarship *Athens log-in required*\*

The essential elements that need to be in place for nurses to be able to deliver effective care that integrates genomics into standard practice are explicit within ASIGN. The tool provides the basic framework to guide further development in genomics, including guiding academic and continuing education. By using the matrix as a framework for assessment, groups, organizations, or countries can use ASIGN to benchmark themselves at a starting point to inform a plan for progress. The tool is nimble, as users can be a country or region within a country, or an organization such as a hospital, professional body, or government. Focusing on outcomes, users of ASIGN can capture both the current status and change over time. Comparisons between indicators and stage of maturity (i.e., high vs. low maturity) can help users identify areas where work needs to be focused. Individuals can identify the most appropriate measures (evidence) for each indicator, thus offering some flexibility, in recognition that there will be wide variations in resources, infrastructure, and service provision across countries, regions, or organizations.

#### <u>A Roadmap for Global Acceleration of Genomics Integration</u> <u>Across Nursing</u> 2020, Journal of Nursing Scholarship *Athens log-in required*\*

The model espouses five broad and synergistic principles. The first principle advocates that integration of context (in this case genomics) should also place emphasis on understanding the broader social and contextual influences. The second principle advocates for inclusivity, particularly for marginalized, minority,

and vulnerable populations. Complementary to this, the third principle focuses on ensuring accessible diffusion of innovations, and understanding the barriers and facilitators for this. Gaining stakeholder perspectives embeds communication as a dialog and further supports inclusivity. The fourth principle focuses on effective utilization of communication technologies to promote efficient sharing of information, inclusivity, and health equity. The fifth principle emphasizes the need to promote specialized training and continuing education that also encompasses cultural and linguistic competence. This set of broad guidelines can be used by teams to consider how their implementation plans address the issues of equity and inclusivity.

#### Exploring the genomic education needs within the NHS

workforce: a cardiac genetic nurse perspective 2020, European Journal of Human Genetics *Athens log-in required*\* [Abstract, p. 777] This study aimed to explore the education needs and support required for CGNs to fulfil their role. A key theme identified was the skills associated with managing the uncertainty of genetic information. The interviews highlighted that effective learning requires immersion in the clinical environment and the need for a CGN-specific competency framework to be developed. The study demonstrates the need to define the competencies required for the role of a CGN, to standardise practice nationally and ensure that nursing and genetic counselling resources are applied effectively.

#### <u>Measuring physician practice and preparedness for genomic</u> <u>medicine: a national survey</u> 2020, European Journal of Human Genetics *Athens log-in required*\*

[Abstract, p. 776] T wo-thirds of respondents felt genomics will soon impact their practice and, while a third recently completed CGE, only a quarter felt prepared. Respondents lacked confidence in genomic knowledge and ability to explain concepts to patients and incorporate test results in patient management. These data can inform genetic services (re test referral patterns) and support genomic education providers to best meet learner needs and develop a competent, genomic literate workforce.

#### <u>Genomic Literacy of Registered Nurses and Midwives in</u> <u>Australia: A Cross-Sectional Survey</u> 2019, Journal of Nursing Scholarship *Athens log-in required*\*

This survey measured the genomic literacy of Australian registered nurses and midwives. The findings indicate that the genomic literacy of Australian registered nurses and midwives is low, a finding similar to that reported in international studies where nurses' knowledge of genomics is largely reported to be poor or, at best, moderate. Poor performance across the GNCI© indicates that Australian registered nurses and midwives are not achieving the competencies outlined in the Essentials of Genetic and Genomic Nursing: Competencies, Curricula Guidelines and Outcome Indicators document (Consensus Panel on Genetic/Genomic Nursing Competencies, 2009). Since these competencies represent the minimum standards required to deliver competent genetic and genomicfocused care, it can be inferred that Australian nurses and midwives are not prepared to deliver such care. Australian nursing and midwifery authorities must act if they are to equip their registered nurses and midwives with the genomic literacy required to deliver genomic healthcare.

#### Hospital Nursing Leadership Led Interventions Increased Genomic Awareness and Educational Intent in Magnet® Settings 2018, Nursing Outlook Athens log-in required\* The

Precision Medicine Initiative is poised to accelerate genomic discoveries relevant to practice. Assuring the genomic awareness of nurses in the workforce is an essential step to

realizing the benefits of genomic discoveries on the public's health. Longer term interventions are required for successful practice integration. This necessitates an ongoing investment in leadership education, infrastructure, and policy development to enable genomic adoption enhancing healthcare safety and quality while reducing costs. Results provide policy makers and healthcare leaders a mechanism applicable to the interprofessional healthcare community for capacity building and integration of genomics to improve health outcomes.

#### Expanding RN Scope of Knowledge—Genetics/Genomics: The New Frontier 2017, Journal for Nurses in Professional Development *Abstract only*\*

A knowledge survey was used to assess nurses' knowledge following a yearlong genomics education initiative. Findings indicate that nurses benefit from repeated exposure to geneticsrelated content. Recommendations from this study include development and implementation of strategies that can be used to prepare nurses at all levels for the application of genetics and genomics. Clinical nurses with knowledge of genetics will be able to implement evidence-based interventions to manage acute and chronic illnesses. These nurses will then be able to engage patients more fully, thereby helping them to understand the relationship of genetics to healthy outcomes.

# A strategy for implementing genomics into nursing practice informed by three behaviour change theories 2016,

International Journal of Nursing Practice Abstract only\* The core philosophy of the strategy is that genomic nurse Adopters and Opinion Leaders who have direct interaction with their peers in practice will be best placed to highlight the importance of genomics within the nursing role. The strategy discussed in this paper provides scope for continued nursing education and development of genomics within nursing practice on a larger scale. The recommendations might be of particular relevance for senior staff and management.

#### Using clinical genomics in health care: Strategies to create a

prepared workforce 2015, Nursing Outlook Abstract only\* Benefits from genomic discoveries hinge in part on a prepared and knowledgeable HCP workforce who can access and apply these discoveries for individuals, families, and communities when the information is needed in clinical care. However, current graduate and continuing education is not meeting this need for HCPs across all health care settings.

#### Ophthalmology

#### Ophthalmic Services Guidance: Genomics Services 2020,

Royal College of Ophthalmologists

A long-term objective will be to work with the Training Committee, in conjunction with other Royal Colleges, to develop an appropriate curriculum to reflect on-going changes to clinical practice that result from the development of mainstream genomic medicine. While the move towards adoption of genomic medicine is imminent, it is likely that the speed of development of skills will differ between subspecialty groups, and objectives will be different for subgroups of clinical ophthalmology.

#### Pathology

#### Pathology workforce and training in genomic medicine 2021,

Royal College of Pathologists

This article briefly outlines the establishment of clinical whole genome testing in NHS England and describes the subsequent curriculum in development to train and upskill the pathology workforce. Although the model by which training needs will be addressed remains unclear, what is certain is that equipping the pathology workforce to integrate modern genomic analysis with traditional morphology is essential for the enhancement of patient care.

#### **Primary care**

#### Anticipating the primary care role in genomic medicine: expectations of genetics health professionals 2021, Journal of Community Genetics Abstract only\*

GHPs described a key role for PCPs in genomic medicine that could be enhanced if GHPs and PCPs worked together more effectively, making better use of GHPs as a scarce specialist resource, improving PCP knowledge and awareness of genomics, and increasing GHPs' understanding of primary care practice and how to provide PCPs meaningful education and support. Health system change is needed to facilitate the GHP/PCP relationship and improve care. This might include: PCPs ordering more genetic tests independently or with GHP guidance prior to GHP consultations, genomic expertise in primary care clinics or GHPs being accessible through buddy systems or virtually through telemedicine or electronic consultation, and developing educational materials and electronic decision support for PCPs. Our findings highlight need for change in delivering genomic medicine, which requires building the relationship between GHPs and PCPs, and creating new service delivery models to meet future needs.

Primary Care Genomics: A roadmap for curriculum change and educational resource development 2020, European Journal of Human Genetics Athens log-in required\* [Abstract, p. 140] Health Education England's Genomics Education Programme (GEP) has developed a roadmap for defining General Practitioners' (GPs) learning needs and identifying priorities for resource development, suitable for adoption by other specialties. The toolkit has become a go-to destination for GPs learning about genomics, and its development roadmap can be adopted by other specialties.

General practitioner attitudes and expectations for providing personal genomic risk information to the public 2019, Twin Research and Human Genetics Athens log-in required\* [Abstract, p. 448] GPs understand genomics-based risk as one of many factors that influence individual disease risk and, therefore, believe that genomic risk information could be explained to patients within the context of overall risk assessment. Although GPs perceive themselves to be future gatekeepers of genomic testing, they recommended a shared decision making approach. They believe that patients should: be able to interpret their genomic risk information, have the capacity to undertake relevant preventive behaviors, and not experience adverse psychological or emotional responses. GPs require clinical practice guidelines that specify recommendations for risk assessment and patient management, and evidence-based point-of-care resources and tools that incorporate genomic and traditional risk factors.

## **Competency Frameworks**

#### <u>Genomics Education Programme</u> 2021, Health Education England

Delivering genomics education, training, and experience for the healthcare workforce.

# See also: Facilitating genomic testing: A competency framework

This competency framework identifies the core competencies required to facilitate and consent patients for <u>germline</u> genomic tests. The <u>Genomics</u> Education Programme has developed this framework in collaboration with healthcare professionals from

across the health service. Each competency is provided with links to supporting evidence-based educational resources.

<u>Genomics in the NHS</u> 2021, e-Learning for Healthcare More healthcare professionals than ever before are likely to encounter genomics in their daily role. As it increasingly becomes a part of routine care, all healthcare professionals, not just those within specialist departments, will need some level of understanding of the impact genomics will have on the diagnosis, treatment and management of a wide variety of conditions. The e-learning courses have been developed for those directly involved in the GMS and the wider healthcare workforce.

#### <u>A nationally agreed cross-professional competency framework</u> to facilitate genomic testing 2020, European Journal of Human Genetics *Athens log-in required*\*

[Abstract, p. 767] The Genomics Education Programme has developed a nationally agreed cross-professional competency framework outlining the knowledge, skills and behaviours required to facilitate genomic testing. This framework can be used as a guide for best practice by clinicians involved in requesting genomic tests. For those delivering education, the framework provides a foundation to identify learning needs and structure training, such that consent conversations can be delivered in a consistent manner across specialties. In addition, these competencies can be used as a reference to evaluate how consent is facilitated in different specialty areas to enhance the delivery of genomic medicine.

The changing face of clinical genetics service delivery in the era of genomics: a framework for monitoring service delivery and data from a comprehensive metropolitan general genetics service 2020, Genetics in Medicine *Athens log-in required*\* Development of a standardized method of determining workforce adequacy in clinical genetics, based on average work RVUs or similar metrics, would assist in clarifying acceptable international benchmarks. Combining this with modeling on training program outputs, as well as physician retention and retirement timelines, will be important to guide strategic workforce planning. Cancer genetics and subspecialties with significant practice structure variation may require customized frameworks. This framework will capture areas of practice that require modification in response to shifts in technology and workload. Longitudinal data gained by implementation of this framework and publication of the outcomes will assist services worldwide in refining best practices.

# The first competency based framework in genetics/genomics specifically for midwifery education and practice 2018, Nurse Education in Practice *Abstract only*\*

This paper details a competency framework to help address the need for structured guidance around genetic and genomic education and training for midwives.

- Genomics is an integral component of the maternal and family health care pathway.
- Learning outcomes and practice indicators develop over time and with experience.

• Genomic competence can improve care, consistency and safety for women and families.

#### Methods of Genomic Competency Integration in Practice 2015,

Journal of Nursing Scholarship *Athens log-in required\** Champion dyads used creativity to design interventions that supported their staff to advance a new complex competency, genomics, within their facilities. They informed interprofessional colleagues about the value of nursing leadership in advancing genomic healthcare translation and supporting provision of safe, quality care delivery that integrates new knowledge. Developing policies to facilitate responsible translation of genomics into nursing practice is an effective strategy for nursing leaders who accept the responsibility to design systems and infrastructure that support the translation of genomics into health care.

### \*Help accessing articles of papers

Where a report/ journal article or resource is freely available the link has been provided. If an NHS OpenAthens account is required this has been indicated. It has also been highlighted if only the abstract is available. If you do not have an OpenAthens account you can self-register here.

If you need help accessing an article, or have any other questions, contact the Knowledge Management team for support KnowledgeManagement@hee.nhs.uk