# Preparing for Genomic Medicine Nurse Training in Africa

#### INTRODUCTION

Recent advances in high-throughput sequencing and genotyping technologies are helping unravel complex relationships that exist between health, genetics and genomics<sup>1</sup>. Genetics is the study of inheritance and focuses mainly on understanding the function and composition at a single gene level while genomics addresses all genetic information of an individual, and attempts to identify their collective influence on an individual's growth, development and responses to the environment<sup>2</sup>. Progress in the genomics and genetics field is driving the boundaries of medicine and healthcare into the "Genomic Medicine" era<sup>3</sup>. Genomic Medicine is defined as "*an emerging medical discipline that involves using genetic/genomic information about an individual as part of their clinical care (e.g., for diagnostic or therapeutic decision-making) and the health outcomes and policy implications of that clinical use.*"<sup>4</sup>.

Several examples of Genomic Medicine exist and are currently being used in healthcare systems for cancers, rare diseases, clinical microbiology and pharmacogenetics<sup>3</sup>. Mutations genes e.g. BRCA1 or BRCA2 known to be associated with breast cancer are now routinely screened for by some centers to identify genetically at-risk individuals and provide the necessary counselling<sup>3</sup>. In our own environment, a set of four genes is routinely tested in individuals developing colorectal cancer under the age of 50 years, so that their relatives may benefit from 'predictive' testing, in the event a disease-causing mutation is identified in the proband/patient<sup>5</sup>. In some USA institutes, prospective screening of patients with variants in genes responsible for metabolizing pharmaceutical drugs is conducted and results deposited into electronic medical records to inform prescription of drugs such as cloxigel<sup>3</sup> and carbamazepine<sup>6</sup>. However, the transferability of most existing Genomic Medicine examples to the African population is questionable given the high levels of genetic diversity and rare variants in these populations<sup>7</sup>.

Africa has a high disease burden fueled by a range of infectious diseases (in particular HIV & AIDS, malaria, tuberculosis)<sup>8</sup> and an increasing prevalence of non-communicable diseases<sup>9</sup>. Given the promise of Genomic Medicine in addressing continent specific health challenges, there is a need to increase genomic and genetic knowledge of African populations through research. To this end, several initiatives are currently underway aimed at increasing research capacity and knowledge of African genetics and genomes, these include the Human Heredity and Health in Africa initiative (H3Africa) which has 26 research projects/networks spread across Africa<sup>10</sup>; MalariaGen<sup>11</sup> and The African Genome Variation Project <sup>12</sup>.

Increased understanding of African genetics and genomics could facilitate the development of genetic/genomic tests for diagnoses, prognoses and for personalized drug treatments (pharmacogenetics/genomics) tailored for African populations and pathogens<sup>13</sup>. While healthcare workers are key to the anticipated successful inclusion of Genomic Medicine into routine healthcare procedures, African health practitioners seem to have little or no genetics/genomics knowledge<sup>14</sup>, thus reflecting shortcomings of current curricula. Continued failure to incorporate genetics and genomics into curricula in Africa will result in healthcare workforces incapable of keeping up with their evolving role in the Genomic Medicine era – thereby amplifying the already existing gap in healthcare and research.

H3ABioNet (Pan African Bioinformatics Network - www.h3abionet.org) in collaboration with the University of Cape Town's Division of Human Genetics, are coordinating the development of an African Genomic Medicine Curriculum for personnel involved in genetics/genomics research and healthcare workers. To avoid reinventing the wheel, a formative assessment was conducted aimed at:

- a) Analyzing and learning from existing Genomic Medicine training initiatives, b) identifying free genetics and genomics online courses or resources, c) documenting competencies which could help guide and possibly fast-track our curriculum development, and d) mapping of stakeholders.
- An abridged version of the formative assessment is presented in the sections below.

### **GENOMIC MEDICINE TRAINING INITIATIVES**

The development of technologies pertinent to genomics is paralleled by developments in the arena of pedogogics (i.e. the science or art of teaching/education). Several institutions are offering Genomic Medicine training ranging from workshops, Massive Open Online Courses (MOOCs), short courses, diplomas and Masters Programs, however such training initiatives are still under-represented in Africa. A list of programs provided in the Table 1 is not exhaustive but rather aimed at highlighting examples. Noteworthy, is the Genomic Medicine training which is supported by the National Health Service England (NHS) – a model Africa could learn from, this training is offered across several universities across the United Kingdom in a coordinated manner. These include the University of Birmingham; Newcastle University; University of Manchester; University of Sheffield; Imperial College London; Queen Mary University of London/University College London; St Georges, University of London/King's College, London; University of Cambridge; University of Southampton and University of Exeter.

Level	Institute/s	Focus Area	Notes
Masters/Post graduate diploma/Certificate	Several	Genomic Medicine	Developed especially for National Health Services Healthcare professionals
Massive Open Online Course (MOOC)	George Town University	Genomic Medicine	MOOC no longer live but content is accessible
Modules	University of Florida	Pharmacogenomics	Specific to Pharmacogenomics/genetics
Workshops	Training Residents in Genomics (TRIG) Working Group	Genomic Pathology	The group runs training workshops and also provides a handbook and material for potential trainers
Masters of Science in Genomic Medicine	University of Miami, United States of America	Genomic Medicine	Provided concurrently with an MD degree.
Module (Master of Clinical Nutrition)	Ain Shams University, Egypt	Nutrigenomics	Module offered as part of Master
Workshop	Funded by the Wellcome Trust Foundation	Molecular Approaches to Clinical Microbiology in Africa	Advanced workshop and training
Short course	Genetic Alliance South Africa (GA- SA)	Congenital disorders and Counselling	Online course offered to South African nurses who care for those affected with congenital disorders

 Table 1: Examples of existing Genomic Medicine Courses

Nurses are pivotal to the realization of Genomic Medicine in Africa as they are frontline workers in most healthcare facilities in Africa and have access to in-depth knowledge of the patients, families, and communities. Development of the Genomic Medicine curricula and corresponding courses will be a lengthy process as with any other training initiatives. In the interim, interested nurses can access free online educational resources. H3ABioNet recently developed a community driven web-based portal, the "eGenomics Catalogue", aimed at aggregating free genomics and genetics training resources (books, courses, webinars, databases and software) (http://egenomics.h3abionet.org/). Users can search, upload and write reviews of resources aggregated by the eGenomics Catalogue. We highlight some resources found in the eGenomics catalogue which might be useful for nurses in Table 2.

Title	Link	Description	Creators
Telling Stories	http://www.tellingstories.nhs.u	Short stories from those affected by genetic	NHS National Genetics
	<u>k/</u>	disorders.	and Genomics Learning
			Center
DNA Learning Center	http://www.ygyh.org/	Site is devoted entirely to genetics education	Created and maintained by
		and includes information & short videos	the Cold Spring Harbor
		specific to a number of genetic disorders.	Laboratory
Genetics is Relevant	https://research.cchmc.org/gepn	Self-paced course. Includes interviews from	Cincinnati Children's
Now: Nurses' Views and	lect/c118/index.html	genetics/genomics nurses.	Hospital Medical Center
Patient Stories			
Global Genetics	http://g-3-c.org/en	Bilingual interactive cases that highlight	The G3C (Global Genetics
Community-Unfolding		links between genetics and genomics.	and Genomics
Interactive Case Studies	Case Studies		Community)
Journal of Nursing	https://www.genome.gov/2755	Nursing and medical expert sharing their	Journal of Nursing
Scholarship Genomic	2312/journal-of-nursing-	knowledge stemming from publications in	Scholarship Genomic
Nursing Webinar Series	scholarship-genomic-nursing-	the Genome Issue of the Journal of Nursing	Nursing Webinar Series
	webinar-series/	Scholarship.	
Genetics Home Reference	https://ghr.nlm.nih.gov/	A catalogue of genetic conditions,	National Library of
		explanations and a resource for learning	Medicine (NLM), which is
		basics in genetics and genomics. A free book	part of the National
		is also available.	Institutes of Health

### COMPETENCY AREAS

Competency based medical education (CBME) is growing in popularity for planning and developing curricula in the health sector as it promotes accountability; learner-focused skills; knowledge and attitudes<sup>15</sup>. We highlight one source of nurse competencies relevant for genetics/genomics, the Genetics/Genomics Competency Center (G2C2). The challenge is to merge nurse competencies from different sources, tailor them for the African setting in order to suggest essential genetic and genomic nursing competencies relevant for nurses in Africa. The lack of a community agreed-upon

minimum competencies list impedes efforts to educate nurses for genomics-based health care. Curriculum changes based on an essential list of competencies could facilitate nurse education in Genomics/Genetic <sup>16</sup>.

**The Genetics/Genomics Competency Center**: The Inter-Society Coordinating Committee for Practitioner Education in Genomics (ISCC) maintains the Genetics/Genomics Competency Center and the corresponding G2C2 website (<u>http://g-2-c-2.org/</u>). G2C2 stores 28 nurse competencies categorized into four areas:

- Family History
- Genomic Testing
- Patient Treatment Based on Genetic Results
- Somatic Genomics
- Microbial Genomic Information

## WAY FORWARD

Lack of or inadequate training in Genomic Medicine could delay the translation of emerging African genetic and genomics research output into quality healthcare. However, what is recognized is that investment of effort into a core curriculum which could serve the constituencies of genetic research scientists as well as clinical practitioners e.g. nurses, Genetic Counsellors and Clinical Consultants (including all of the clinical specialties) and would be effort well spent. We propose to develop an essential list of competencies in Genomic Medicine tailored for researchers, healthcare professionals and trainees in Africa. We also plan on using the Kern's six step approach for curriculum development<sup>17</sup>. Such an approach could help systematically map needs, stakeholders, resources and monitoring and evaluation plans necessary for the implementation and adoption of the curriculum across the continent. H3ABioNet will develop a portal for the African Genomic Medicine curriculum and related resources, however awareness and use of these resources requires strengthening. Linking the H3ABioNet portal to existing online curriculum management systems in training institutions within African Universities and Colleges and the provision of train-the-trainer initiatives in Genomic Medicine might increase awareness and adoption of the Genomic Medicine curriculum.

To increase the relevance of the curriculum, ready to use genomic/genetic tests relevant to Africa will be sourced and recommended as part of the curriculum. We propose using the environment of H3Africa i.e. amongst the 26 projects currently underway, to engage their staff in experimenting with the available education/training programs on offer in order to gauge their relevance and compatibility. We expect that there are at least 52 nurses already involved in the H3Aprojects.

We anticipate that the curriculum developed under the leadership of H3ABioNet and the University of Cape Town Division of Human Genetics will help pave way for the integration of Genomic Medicine into mainstream healthcare in Africa.

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