

The Emergence of Clinical Genomics and Genomic Medicine Across India: The Role of the UK-India Genomic Medicine Alliance

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Abstract

Genomic applications in precision medicine and healthcare are now globally recognised with huge public and private investments. The United Kingdom (UK)-India Genomic Medicine Alliance (**UKIGMA**) offers a unique opportunity for clinicians and scientists from UK and India, to work together and develop comprehensive genomic medicine and healthcare programmes through a series of genomic education and training courses, raising awareness on genomic applications for health and supporting the necessary infrastructure build-up for the benefit of the vastly heterogeneous people of India and South Asia.

Introduction

Genetic and genomic applications in healthcare are now globally acknowledged and considered as one of the most powerful and pertinent developments in the history of medicine. The practice of medicine is now for the first time, truly personalized, precise and evidence-based. India has made significant progress in this field and is one of the established leaders in South Asia. Education and training in all formats are the key for successful implementation. The successful movement for genetics-led medical education steered by the **Indo-UK Genetic Education Forum**, has generated much needed enthusiasm and direction across India and neighbouring regions. This forum has set its vision for genomic education and training aimed at medical and healthcare practitioners.

There are several unknown and undiagnosed rare diseases prevalent across India that are awaiting genomics input for precision diagnosis, novel therapeutic inventions, and precision prevention. It is extremely important that India takes the lead and develops a coordinated and comprehensive genomic medicine and healthcare programme. The Genomic Medicine Foundation (UK), offers a unique opportunity for the UK and

Indian clinicians and scientists to work together and develop the genomic medicine and healthcare programme through a series of genomic education and training courses, raising awareness on genomic applications for health and supporting the necessary infrastructure build up for the benefit of vastly heterogeneous peoples of India. This is appropriately named the '**UK-India Genomic Medicine Alliance**' referred to as '**UKIGMA**'.

Aim of the UKIGMA

"To organise and lead a professional group of like-minded clinicians and healthcare professionals for promoting and supporting the genomic applications and translations in medicine and healthcare in India and across the Indian subcontinent"

Objectives of the UKIGMA

- Identify and enrol organisations and institutions engaged in scientific and applied research in genomics relevant to medicine and healthcare
- Encourage collaboration with individual genetic/genomic clinicians and scientists, and other professionals in anthropology, population genetics, bioethics, social sciences and bio-economics
- Develop a programme for training and skills development through series of structured courses, workshops, and webinars in the key areas of applied and translational genomic medicine
- Plan and carry out specific audit on the outcomes of investments in institutions and laboratories as part of the current strategy for capital and infrastructure scientific developments for genomic medicine and healthcare
- Develop and steer through individual or group research projects related to utilization and the delivery of genomics-led medical and healthcare, specifically in laboratory genomics, functional

genomics, metabolomics, and computational genomics.

- Encourage dedicated genomics-led research programme for new drug discovery and development through clinical trials in specific genetically distinct ethnic population groups
- Identify disease-associated founder genome variants in different population groups for developing community based genomic healthcare

Some of the education driven activities are already included in the current **Indo-UK Genetic Education Forum** that continues within the objectives of UKIGMA. Since 2010, many academic institutions and hospitals across India and Sri Lanka have participated in this programme. The forum continues and would remain an integral part of the UKIGMA that plans to focus on a number of areas for working together and develop clinical, educational and applied research projects through mutual collaboration (**Table 1**).

Professional and Scientific links

The alliance plans to work closely with related international organisations, specifically the Global Genomic Medicine Collaboration (G2MC) and Genomic Alliance for Global Health (GA4GH). The alliance expects to establish close working links with the Indian Government's genomic medicine initiatives led by the CSIR Institute of Genomics and Integrative Biology (IGIB), Department of Biotechnology (DBT) and the Indian Council of Medical Research (ICMR). It is anticipated that this major joint activity will have active input by members of the Indian Society of Human Genetics (ISHG) and the Society for Indian Academy of Medical Genetics (SIAMG). Some of the Indian genetic and genomic scientists are internationally renowned experts in Indian population genetics and genomic variation. The alliance welcomes genetic and genomic organisations, units, institutions, academic units, and laboratories to join and strengthen India's regional genomic leadership. It could be in the form of an informal 'expression of interest' or through a formal '*Memorandum of Understanding*' (**Figure 1**).

Table 1 Selected work streams of the UK India Genomic Medicine Alliance

1. Genetic and Genomic Education
2. Birth defects (congenital anomalies)
3. Rare genetic diseases including inherited metabolic diseases
4. Cancer genetics and genomics
5. Cardiovascular genetics and genomics
6. Neurological and psychiatric genetics and genomics
7. Genetic and genomic eye diseases
8. Genetic and genomic kidney diseases
9. Infectious diseases (tuberculosis, malaria, dengue, human immunodeficiency virus (HIV) infection, COVID-19, and others)
10. Adult metabolic diseases (obesity, hyperlipidemia, diabetes mellitus)
11. Genome laboratory technologies (chromosomal microarray analysis; next-generation sequencing; whole-exome/genome sequencing; bioinformatics)
12. Ethical, legal and social issues (ELSI) in genomic medicine and healthcare

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UK INDIA GENOMIC MEDICINE ALLIANCE

UK INDIA GENOMIC MEDICINE ALLIANCE “To organise and lead a professional group of genetic and genomic scientists, clinicians and healthcare professionals for promoting and supporting the genomic applications and translations in medicine and healthcare in India and across the Indian subcontinent”

Figure 1 Join UKIGMA.

Table 2 Institutes and organizations associated with UKIGMA'

Department of Cardiovascular Medicine, Postgraduate Institute of Medical Education and Research (PGIMER), Chandigarh.

Department of Cardiology, All India Institute of Medical Sciences, New Delhi, Delhi.

The Centre for Precision Medicine, King George's Medical University, Lucknow, Uttar Pradesh.

Department of Biochemistry and Medical Genetics, JSS Higher Academy of Education and Research, Mysore, Karnataka.

Department of Clinical Genetics and Cardiology, Christian Medical College, Vellore, Tamil Nadu.

Department of Human Genetics, The University of Colombo, Sri Lanka.

The alliance is guided and supervised by an independent International Advisory Board. Other interested genetic and genomic clinicians, specialist genetic and genomic units and governmental and non-governmental organizations/ institutions are encouraged to join the alliance. For all enquiries please contact- d.kumar@qmul.ac.uk md@genomicmedicine.org genomicmedicineuk@gmail.com