

Press release

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PHG Foundation joins new Global Alliance to enable responsible sharing of genomic and clinical data

A new global alliance is setting out to ensure that the benefits of genomics sequencing for health are realised as promptly and efficiently as possible - whilst protecting patients and research participants.

Recent technological advances have created an explosion in genomic information and new opportunities for biomedical research and development as increasing levels of genomic and clinical data from individuals and populations around the world are amassed. Hopes are high that these data will pave the way for exciting medical advances in improved methods for diagnosis and prognosis, screening and risk prediction, treatment and monitoring.

However, at present there are no agreed standards for the best ways in which to share this invaluable data effectively and responsibly to optimise the potential for medical progress whilst simultaneously providing suitable protection for the autonomy and privacy of the people who have contributed their data.

To address this gap, the Global Alliance to Enable Responsible Sharing of Genomic and Clinical Data brings together more than sixty international organisations to develop and promote policy solutions including harmonised regulatory frameworks to facilitate genomic and clinical data integration in a responsible manner.

The PHG Foundation's specific contribution will be to forward the implementation of capabilities and processes to ensure that new and emerging knowledge from genome sequencing is put to good use delivering improved healthcare and public health services in a rapid and equitable manner around the world.

PHG Foundation Director Dr Hilary Burton said: *"We are delighted to join with other leading organisations in this new Global Alliance, working together to ensure that genomic data is optimally used to improve human health in a responsible manner"*.

The global partnership is inspired by the example and achievements of the World Wide Web Consortium (W3C) and the Human Genome Project (HGP). Partner organisations agree to adhere to the core principles of the alliance, which are based on principles of respect, transparency, accountability, inclusivity, collaboration, innovation and agility.

International partner organisations are drawn from healthcare providers, research institutions, disease advocacy bodies, life science and information technology companies. They include BGI-Shenzhen, the US National Institutes of Health (NIH), the American Society of Human Genetics (ASHG), the European Society of Human Genetics (ESHG) and in the UK, the National Institute for Health Research (NIHR), Cancer Research UK (CRUK), the Wellcome Trust Sanger Institute (WTSI) and the PHG Foundation. It is hoped that many more will join the alliance as it begins to lay the necessary foundations for a new era of genomic medicine.

For more information, please contact Dr Philippa Brice at the PHG Foundation press office +44 (0)7505092081 or philippa.brice@phgfoundation.org

ENDS

Notes to Editors

- The Global Alliance has supplied a fact sheet which can be downloaded at www.phgfoundation.org
- The PHG Foundation is an independent genomics and health policy think-tank based in Cambridge, UK
- Our mission is making science work for health – identifying the best opportunities for 21st century genomic and biomedical science to improve global health, and to promote the rapid, fair and effective translation of scientific innovation into medical and public health policy and practice
- We generate knowledge, evidence and ideas to inform, educate, and stimulate debate
- We also provide expert research, analysis, health services planning and consultancy services for governments, health systems, and other non-profit organisations
- The PHG Foundation is the working name of the Foundation for Genomics and Population Health, a charitable company registered in England and Wales, charity no. 1118664 / company no. 5823194. 2 Worts Causeway, Cambridge, CB1 8RN, UK. Tel: +44 (0) 1223 740200 Fax: +44 (0) 1223 740 892