Annual review 2017
20 years of making science work for health
Future thinking

We believe the right health innovations, implemented in the right way, can provide more personalised healthcare and deliver improvements in health to all. We’re a non-profit think tank working to help this happen through shaping the conversation, providing the evidence, analysing policy and advocating for change.

- 8 consultation responses
- 68 opinion pieces
- 21 knowledge products
- 3 oral evidence sessions of parliamentary committees
- 500+ new followers
- 27,000+ website users since the relaunch of the website in June 2017

Our 20th anniversary year has been an exciting one. We’ve brought together industry, NHS clinical, scientific and policy professionals, patient groups and charities to explore the future of genomics and personalised healthcare at our conference. We’ve given evidence at parliament on artificial intelligence and genomics and genome editing. We’ve released new reports on ctDNA testing services, data anonymisation, linking and sharing routine health data and variant classification and interpretation. And our work on the importance of genomic data sharing has informed the National Data Guardian’s recommendation on encouraging genomic data sharing in 2018.

Our mission remains the same as it was in 1997, making science work for health; what is changing is the science. Genomics is emphatically here to stay, but we are also embracing other ground-breaking technologies that can help to deliver more personalised healthcare. Inevitably, these pose fresh policy challenges, including legal and regulatory concerns, ethical dilemmas, societal questions, and issues around clinical implementation.

In 2018, our multidisciplinary team will continue to ask, what next to ensure health innovations deliver better health for all? What health innovations should be implemented now? What infrastructure needs to change? And what regulatory issues and ethical questions should be addressed?

Do visit our website or follow us on Twitter.

Director
Dr Mark Kroese

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Healthy futures: genomics and beyond

What will the future of healthcare look like and how will we get there? How do innovations get into clinical practice? Which technologies are set to transform healthcare? We brought together international experts to unravel these questions at our conference.

Over 100 delegates, from industry to patient groups, joined us in Cambridge to hear from Prof Dame Sally Davies (Chief Medical Officer for England), Prof Sue Hill (Chief Scientific Officer), Dr Robert C. Green (Director, Genomes2People), Carla Deakin (NICE Office for Market Access), Claus Nielsen (Data for Good Foundation) and many more. We also saw the transformational potential of four health-related technologies pitched to us in our interactive session – biosensors, digital health, 3D printing for drugs and ctDNA testing technologies.

Get insights into the future of healthcare with our speaker video clips or catch up with what happened by reading our storify.

Visit our events page - phgfoundation.org/events
Making healthcare better

Harnessing innovations to help patients

Personalised healthcare in action

New circulating tumour DNA (liquid biopsy) tests can help non-small cell lung cancer patients access targeted therapies that treat their tumour with greater precision - a great example of personalised healthcare in action.

However, our report (released in September) found that increased awareness of this novel technology is needed to ensure that patients are not missing out on testing and access to targeted therapies - see report and full recommendations at phgfoundation.org/reports

We’re continuing our advocacy work on ctDNA technologies in 2018, partnering with the Cellular Molecular Pathology Initiative and Cancer Research UK to hold a meeting on liquid biopsies in March 2018.

We continued to provide leadership for the Joint Committee on Genomic Medicine Working Group on Mainstreaming Genomics, publishing five new genomic factsheets for specialties from public health to pathology.

PHG Foundation also brought together mainstream clinicians and clinical genetic scientists to develop principles for the practice of mainstream genomic medicine. Our resulting report identifies gaps in critical skills needed in relation to patient referral for genomic testing and test interpretation and urges more support for clinicians - read Genomics in mainstream clinical pathways
Informing policy

Helping to improve healthcare policies

Engaging with decision makers

In 2017, we have provided expert comment on topics including artificial intelligence, genomics and genome editing, life sciences and the industrial strategy, General Data Protection Regulation and the rare disease strategy via consultation responses.

Our specialists have given evidence to government committees on topics such as artificial intelligence and genomics and genome editing, as well as fulfilling invitations to speak on genomic data sharing across the globe from Belfast to Washington DC to Hong Kong.

“Of the range of issues that merit prompt attention, promoting effective genetic and genomic data sharing within the NHS, supported by proportionate security measures and appropriate consent would help deliver the greatest health benefit for patients”

Alison Hall - Head of Humanities
Speaking at second evidence session for House of Commons Science & Technology Committee’s inquiry on genomics and genome editing
Scanning the horizon

Exploring transformational technologies for better health

What’s hot or not?

As a horizon scanning organisation, we identified early the potential of genomics to improve health in the UK and we continue to accelerate the impact of healthcare innovations. Our healthcare futures research sets out for non-experts which technologies are ‘hot’ and which are not – from transcriptomics to virtual reality.

“As an enabling technology, transcriptomics is certainly one to watch. It is an important part of the ‘omics toolkit and will have a role to play in the development of more personalised approaches to healthcare.”

Dr Laura Blackburn - Senior Policy Analyst (Biomedical Sciences), PHG Foundation
What will health and social care look like to the next generation?

We're excited about our new flagship project which aims to visualise our healthcare in 20 years and explore the path to responsibly and effectively get there.

Bringing together experts and enthusiasts from diverse backgrounds, we're gathering essential insight into the opportunities and issues in the future for people across four life stages where their health needs and personal approaches to health may differ – pregnancy, teen years, the ‘healthy’ adult and older age.

Ask questions, suggest solutions
Join the conversation on Facebook, Twitter and LinkedIn #myhealthyfuture
Experts and enthusiasts can also take part in My Healthy Future workshops
Providing the evidence

Advocates on genomic data sharing

We believe responsible sharing of data by NHS clinical genetics / genomics services is essential for patient safety and service quality. Our advocacy work on the need for national agreement on the legitimacy of genomic data sharing built momentum in 2017.

- National Data Guardian’s (NDG) 2017 report listed ‘to encourage proper data sharing in genomic medicine’ as one of the top 8 priorities for 2018
- The NDG’s office published a paper to help build consensus on data sharing for NHS clinical genetics and genomics services. This paper drew heavily on an evidence session, which along with the ACGS, we collaborated with the office of the NDG to deliver
- Our Head of Humanities Alison Hall gave oral evidence to the House of Commons Science & Technology Committee’s inquiry on genomics and genome editing
- We published a paper in the British Medical Bulletin arguing for concerted efforts by policy makers to increase understanding among both public and health professionals of why data sharing is essential to improving healthcare
- We presented on genomic data sharing at conferences in Washington DC (Curating the Clinical Genome conference) and Warwick (Public Health England annual conference)

2017 also saw us release a report and recommendations for policy makers on improving the linkage and sharing of routine health data for important insights for health research. Read Linking and sharing routine health data for research
Advocating for change

We published Identification and genomic data, a report highlighting the challenges and deficiencies in the current regulatory regime.

View our series of blogs on data regulation and ethics by our humanities team.

Creating a responsible regulatory framework

Changes in EU legislation on data protection and in vitro diagnostic devices (IVDD) mean that new Regulations will now be directly enforceable on Member States. Meanwhile Brexit negotiations have added extra complexity requiring that UK plans for implementing these EU Regulations also take account of a range of possible post-Brexit scenarios.

In 2017, as a member of the MHRA IVDD external stakeholders group, we have consulted on various national processes associated with implementation of the EU IVDD Regulation. The IVDD Regulation was legally signed off this year, with a concession that genetic tests be proportionally regulated, taking account of the prevailing laws in individual member states. This concession was achieved after the significant negotiation led by the UK, in which PHG Foundation played a major role.

We also worked as part of NHS England’s GDPR Research Group to assess the nature, scope and wording of the flexibilities and special conditions devolved to Member States of the EU General Data Protection Regulation. This group also has oversight of key guidance that will be produced to support the implementation of the Regulation.

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Strengthening networks

In 2017 PHG Foundation has:

• Signed a memorandum of understanding with Hughes Hall, Cambridge
• Partnered with Cambridge University Health Partners for our flagship My Healthy Future project
• Continued our ties with Cambridge Institute of Public Health, Genomics England, Hong Kong University, University of Cambridge’s Faculty of Law and Association for Clinical Genetic Science

APPG on Personalised Medicine

As secretariat for the APPG on Personalised Medicine we have organised events this year on our own and in collaboration with cross-parliamentary groups.

The year began with parliamentarians and experts from the medical, academic, corporate and public sectors coming together to explore patient needs and scientific opportunities for more personalised and effective cancer care for people with lung cancer.

We’ve also collaborated with the APPG on Health to hold an event on genomic medicine and had an initial evidence session for an inquiry on personalised medicine for cardiovascular disease. At the APPG’s AGM, Helen Whately MP, took over as Chair from Jo Churchill MP, who had to step down due to her promotion to Personal Parliamentary Secretary to Secretary of State for Health Jeremy Hunt MP.

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Our consultancy services

Using 20 years’ experience to help you

In 2017 our commissioned work included

- Weekly regulatory and policy briefings for industry
- A horizon scanning report on innovative products and techniques
- Analysis for the global insurance sector on innovative technologies
- Economic evaluations on Whole Genome Sequencing at Addenbrooke’s Hospital and for King’s Health Partners Biomedical Diagnostic NGS hub
- Producing and designing reports, including a report on setting up an expanded NHS genetic testing service to women with epithelial ovarian cancer and a workshop report on variant classification and interpretation for the Association of Clinical Genetic Scientists

We work with companies from start-ups to multi nationals, providing the concrete evidence for technology decision-making through systematic research and direct engagement with scientists, clinicians, patients, buyers and policy makers. An independent charity we can help with technology strategy, and policy and regulatory factors. Visit phgfoundation.org/consultancy
Celebrating 20 years

Ensuring biomedical innovation delivers better health to all

Looking to the future

Close to one hundred and fifty friends and supporters of the PHG Foundation attended our gala dinner at Trinity College, where we celebrated 20 years as pioneers for the use of genomics to improve health in the UK.

This celebration of our past was filled with excitement for the future as the Vice Chancellor of University of Cambridge, Prof Sir Leszek Borysiewicz announced our imminent affiliation with the University. With this strong union we are looking forward to the next twenty years, helping to ensure innovations in healthcare and personal health bring improvements in health to all.

“As we move on to the next phase, we shall be working even more closely with the University. We shall help to bridge the gap between the sciences and the humanities. In future years, as science develops, the humanities and social sciences will without a doubt be as important to this endeavor as the sciences themselves.”

Dr Ron Zimmern, PHG Foundation Chair and founder
Speaking at the 20th anniversary dinner
Want to stay up-to-date with our latest opinions, work and events? Sign up on our monthly newsletter on our website.