2018 - a year of big thinking at PHG Foundation

- Technologies for better healthcare
- My healthy future
- The rise of artificial intelligence
- Citizen generated data
- Innovative science
- Personalised prevention in breast cancer
- Clinical implementation
2018 has been a year of significant progress for the PHG Foundation. It has been a privilege to lead such a talented multidisciplinary team - which has expanded this year - and work with our many expert stakeholders in analysing scientific innovations and policy challenges, sharing information and shaping solutions that will help make healthcare better, faster.

Our core work on medical applications of genomics has been supported by complementary programmes examining the role of emergent science in the long-term future of healthcare; legal and regulatory issues posed by medical applications AI and algorithms; and the imminent applications of technologies for personalised healthcare within the NHS.

We are delighted to have formally become part of the University of Cambridge as a linked exempt charity under the auspices of the globally renowned School of Clinical Medicine, and are looking forward to working more closely with different parts of the University. Gaining three new Trustees – Prof Patrick Maxwell, Prof Liba Taub and Prof Nita Forouhi – to our Board further strengthens our strategic direction and puts us in prime position to deliver increasing impact over the years ahead.

Although we do not yet know what the effects of political change may be for science or healthcare, it is more important than ever before that science should be put to the best possible use for health – and the PHG Foundation has never been better placed to help this happen.

Director
Dr Mark Kroese
Technological innovations offer unprecedented opportunities for better and more personalised healthcare, as recognised by NHS England’s *Five Year Forward View* and 2015 report *Improving Outcomes through Personalised Medicine*. But how do we know which technologies are ready for clinical implementation?

As experts in the field, PHG Foundation were commissioned by NHS England to produce an independent evidence synthesis of the recent developments in science and technology that would have the greatest impact on the personalisation of medicine.

Our landmark report, *The personalised medicine technology landscape* was the result, a comprehensive overview of those technologies likely to make a big difference to healthcare within the next three years.
“This evidence synthesis by the respected policy analysts at the PHG Foundation provides important insights as to how to take this vision forward and the issues we will face in implementation.”

Professor Dame Sue Hill
Chief Scientific Officer and SRO for Genomics, NHS England

The personalised medicine technology landscape report was launched by NHS England at the 2018 NHS Health and Care Innovation Expo

The National Director of Medicine, Professor Stephen Pavis highlighted the session as one of the ‘top picks’ of the event

@NHSgms
@PHGFoundation Director Dr Mark Kroese sets out 7 key technologies for and highlights cross-cutting considerations from the #personalisedmedicine Technology Landscape report
My healthy future

This major programme of research, workshops and roundtables to identify the hopes, fears and challenges of delivering personalised healthcare has kept us busy in 2018.

Throughout the year we published a number of blogs focused on the future of health, and were pleased to welcome workshop participants’ own guest blogs.

Clear themes emerging from four dedicated life stages workshops (looking at reproduction and birth, young people, the healthy adult and healthy ageing) included person centred healthcare, overdiagnosis, autonomy and privacy and health inequalities. These areas were explored further in expert roundtables and discussion papers.

@NIHR_MindTech

Our own @beffdizzle is @PHGFoundation #myhealthyfuture workshop today - looking forward to the discussions!
@JamesCSanderson
Great discussion this afternoon #myhealthyfuture @PHGFoundation on Person Centred Care and the relationship between Precision Medicine, Technology & #PersonalisedCare
The rise of artificial intelligence

Our project on regulating algorithms in healthcare included an international workshop examining intellectual property & liability.
2018 was a big year for AI, both for healthcare and for the PHG Foundation. Our project *Regulating algorithms in healthcare* has made great strides in assessing the complexities of this important field.

The project included an international workshop organised in collaboration with the Centre for Law, Medicine and Life Sciences, University of Cambridge and the Centre for Advanced Studies in Biomedical Innovation Law, Faculty of Law, University of Copenhagen (CeBIL).

We have published three policy briefings explaining the implications of European legislation for the regulation of algorithms and examining who is liable when machine learning causes harm.

Senior Policy Analyst Johan Ordish spoke at the RSA citizen jury on AI for health and worked with the RSA to produce a related video.

The House of Lords report on AI, published in April, recognised recommendations from the PHG Foundation presented at an earlier parliamentary evidence session in November 2017.

Head of Humanities Alison Hall was invited to be an expert peer reviewer on AI, genomics and human enhancement at an international workshop led by the Sienna Project.

@Paul Wyatt
As part of my documentary work for @theRSAorg's Forum for Ethical AI I visited Cambridge recently to meet @JohanOrdish and team @PHGFoundation an independent & non-profit think tank with the mission to make science work for health. Fascinating stuff.
An emerging concept in the health context, citizen generated data encompasses all the data produced by individuals - whether deliberately, perhaps using a prescribed health monitor or a commercial fitness tracker, or indirectly, for example as a result of internet searches or shopping choices.

We started gathering our own data on citizen generated data early in the year, an initial analysis of which we published in a policy briefing *What is Citizen Generated Data*.

At our workshop in September, strategists and experts on health technologies and data explored the opportunities and challenges to the use of this expanding resource to prevent disease and improve health.

A report will be available in 2019.

@cflashman

At @PHGFoundation event in Cambridge on citizen generated data. Some great people in the room - looking forward to a stimulating afternoon representing @OrchaUK.
Health Minister Lord O’Shaughnessy addresses the APPG on Personalised Medicine
We are knowledge brokers - though our multidisciplinary team has rich experience and expertise, to develop and support robust policy we also draw on the deep knowledge of a diverse range of professionals in different fields. A big thank you to all who have helped us make science work for health throughout the year. In 2018 we:


- Partnered with University of Cambridge groups including the Centre for Law, Medicine and Life Sciences, and the Centre for Research on Arts, Social Sciences and Humanities

- Convened 15 stakeholder workshops where experts discussed topics relevant to genomics and personalised healthcare

- Organised two parliamentary meetings as the secretariat to the APPG on Personalised medicine

- Prepared information, for the Global Alliance for Genomics and Health, on how health-related, genetic and biometric data are to be treated under GDPR

“Personalised medicine is such an exciting and fast paced area of healthcare. It was fantastic to see so many clinicians and parliamentarians come together to hear from Health Minister Lord O’Shaughnessy and those in the field.” Helen Whately, MP (then Chair of the APPG on Personalised Medicine)
Science moves fast and our horizon-scanning function keeps us up to date on the latest technologies with healthcare applications.

Identifying the new technologies that we think have the greatest potential to revolutionise healthcare, is only the first step. Through exhaustive research and cross-disciplinary collaboration, we identify and explain the potential benefits and scientific and regulatory challenges of emerging science for policy makers.

Our policy briefings cut through the hype to present realistic and practical recommendations for realising the potential of new technologies.
Vaccination is one of the major success stories of modern medicine, greatly reducing the incidence of infectious diseases such as measles, and eradicating others, such as smallpox. Conventional vaccine approaches have not been as effective against rapidly evolving pathogens like influenza or emerging disease threats such as the Ebola or Zika viruses. RNA based vaccines could have an impact in these areas due to their shorter manufacturing times and greater effectiveness. Beyond infectious diseases RNA vaccines have potential as novel therapeutic options for major diseases such as cancer.

Summary

- Unlike a normal vaccine, RNA vaccines work by introducing an mRNA sequence (the molecule which tells cells what to build) which is coded for a disease specific antigen, once produced within the body, the antigen is recognised by the immune system, preparing it to fight the real thing.
- RNA vaccines are faster and cheaper to produce than traditional vaccines, and RNA based vaccine is also safer for the patient, as they are not produced using infectious elements.
- Production of RNA vaccines is laboratory based, and the process could be standardized and scaled, allowing quick responses to large outbreaks and epidemics.
- Most current research creates RNA vaccines for infectious diseases and cancer, for which there are several early-stage clinical trials; there is also some early work into the potential of RNA vaccines for allergies.
- There is still a lot of research to be done before RNA vaccines can become standard treatments in the meantime, we need a better understanding of their potential side effects, and more evidence of their long-term efficacy.

New policy briefings providing succinct ‘need to know’ explanations of the science and potential of long read DNA sequencing and RNA vaccines

A briefing on the potential impact of European regulations for In-vitro diagnostic medical devices

A range of blogs covering everything from heritable genome editing to wearable technology and AI, from regulatory developments to ethical issues

Co-authored 13 published papers during the year, covering a range of topics: from congenital disorders to AI and data protection

Journal of Community Genetics publishes special issue on congenital disorders. PHG Foundations's Dr Sowmiya Moorthie is a guest editor and a lead author on several of the papers included.
Personalised prevention in breast cancer

- Very stimulating discussions!
- Lots of new ideas generated
- Finally a meeting where the main question is now on the table: When is risk prediction good enough to start using it in practice?
Science is presenting exciting opportunities for personalised disease prevention including common cancers. Our first report for the EU-funded B-CAST project, released in late 2017, examined the policy landscape for personalised prevention in breast cancer.

In the second phase of this work we examined the technologies that could drive progress in this neglected area. A three-day international stakeholder workshop examined the potential impact of biosensors, biomarkers, wearables and novel data analytical tools on the patient care journey, and considered how to ensure the most benefit for patients and clinicians.

We will be presenting policy recommendations from this work to the EU in 2019.

@paulpharoah
Excellent workshop today discussing if/how to implement risk stratifies prevention/screening for breast cancer. Clinical translation is a slow process.
Clinical implementation

We have always emphasised the importance of developing policy that is grounded in both sound science and practical reality. Ensuring only the most robust technologies make it into clinical use is an essential part of making science work for health.

In 2018, we leveraged our years of experience across a range of projects focussed on clinical implementation, building on our well established expertise in the applications of clinical genomics, to bring insights into the implications of GDPR on health data, and the implementation of the promising technologies underpinning liquid biopsies for genomic cancer testing and pathogen genomics in infectious disease control.

Public Health England asked us to produce a report on the implementation of their central whole genome sequencing service and its impact on how they investigate and manage infectious diseases.
PHG Foundation was awarded Preferred Supplier Status on the NHS Shared Business Services framework in 2018. We are recognised as a category expert on Healthcare Innovation & Research.

We published *Genomics in mainstream clinical pathways*, in which we set out the findings from a stakeholder summit on implementing genomics into the NHS, convened by the PHG Foundation.

Working with Cellular Molecular Pathology Initiative (CM-Path), and Cancer Research UK, we released a consensus statement on the role of pathologists in the implementation of innovative technologies, such as liquid biopsies, into the health system. The collaboration is a result of our previous work on liquid biopsies and the industry roundtable we convened earlier in 2018.

At our liquid biopsy/ctDNA roundtable representatives from the research, clinical, biotech/diagnostics, investment and insurance sectors discuss where next for this promising technology.

@NCRI_partners
(...)

read #CMPath consensus statement about the role of pathologists in the implementation of liquid biopsy technologies’ written in collab with @PHGFoundation @GenomicsEngland @CR_UK http://ow.ly/ZMbR30muSn
Speaking

- NHS Health and Innovation Expo (September) - Dr Mark Kroese on key findings at the launch of the *Personalised Medicine Technology Landscape* report
- European Public Health Association conference (November) - Dr Mark Kroese expert panellist on personalised healthcare session
- PHE regional meeting ‘Genomics Today and Tomorrow’ (March) - Dr Mark Kroese on genomics and its implications for public health
- Westminster Health Forum (November) - Dr Sobia Raza on genomics and personalised medicine
- Risk Matters (October)/ReGenerate (November) - Dr Philippa Brice on the impact of genetics on the insurance industry
- King Baudouin Foundation/Belgian Scientific Institute of Public Health (February) - Dr Philippa Brice on public dialogue in relation to genomes
- Hong Kong University (November) - Alison Hall on genomic data, AI and GDPR
- Deep Learning in Healthcare Summit (September) - Alison Hall on panel to speak on AI regulation and policy
- Cancer Research UK (September) - Dr Laura Blackburn on health policy and clinical implementation of research and technology
We aim for excellence in everything we do - and sometimes it’s good to check we are getting it right and where we can do better. In 2018 we commissioned an independent external evaluation involving a survey and interviews with a wide selection of our main stakeholders from the clinical, policy and research communities. We’ll use these findings to help improve our work in the future.

99% of responders thought that we deliver our mission of making science work for health, citing our expertise, authority, multidisciplinarity and stakeholder engagement as the main drivers of our impact.

**Listening**

- PHG have the power to convene key stakeholders...
- They were really ahead of the curve on identifying the opportunities and challenges of whole genome sequencing
- No-one gives as close to a 360 degree view as they do
- Ethical organisation... Staff are friendly and approachable so are a pleasure to collaborate with

Effective engagement with diverse stakeholders underpins our achievements
In April 2018, PHG Foundation became a linked exempt charity of the University of Cambridge; this has not changed how PHG Foundation functions, or our funding situation.

PHG Foundation is funded through a number of different income streams, chief among which are the generous donations made by The Hatton Trust and The Wyng Foundation.

We are currently the recipients of a number of grants, have a modest investment portfolio, and generate some revenue through our charitable work, through consulting and collaborations.

The deficit for the year 2017-2018 has been covered by extra money from our financial reserves.

*For year 2017 - 2018*
The great majority of our funding is channelled into our charitable activities, which includes our own work programmes and staffing costs. We employ the brightest and the best from a wide range of disciplines to help us make science work for health.

*For year 2017 - 2018*
PHG Foundation is a health policy think tank with a special focus on how genomics and other emerging health technologies can provide more effective, personalised healthcare

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