

PHG FOUNDATION ANNUAL REVIEW 2024







FROM PETE MILLS

Peter Mills Director, PHG Foundation



A lot has happened in the wider world this year, which has seen significant change in both domestic and international politics, tragic environmental and climatic events, and more unsettling social turmoil and insecurity.

For PHG, the open and close of 2024 were marked by our contribution to the Sinker review of the NHS innovation ecosystem in January, with the review finally published in November.

We have held some really successful events throughout the year: the WYNG-Hatton lecture and conference on AI, data and digital health in April, and the meeting on AI and Liability at the end of November were notably well appreciated. This is not all, of course: there have been academic papers, blogs, collaborations, speaking engagements and placements. We are particularly excited by the steady growth in

commissions from new and established clients. Some of this work is less visible than our flagship reports and briefings but all take considerable thought and application.

We finalised and published our strategic direction for 2025 to 2030, setting out our priority areas of interest that will guide our thinking over the next five years.

I would like to thank the PHG team and our supporters - including interviewees, reviewers and collaborators - for continuing the impressively high standard and distinctive value characteristic of PHG's work.



EXPLAINING EMERGING TECHNOLOGIES

Our horizon scanning activities revealed multiple innovative technologies and approaches emerging from research. Across briefings and podcasts, we offer bite-size evaluations of the state of the science and the challenges of implementation.



Summary

 DNA is being actively researched and developed in the public, academic and private sectors as a storage device for digital (binary) information
DNA is stable over long time periods and can store information at high density

ONA, and information retrieval
More specific exploration of the use of DNA for health data storage is needed

 While DNA is not yet used routinely for data storage, it has potential to address challeness of aerbiden aver increasion volumes of right light.

DNA as a storage device – elso commonly referred to as 'DNA Digital Data Storage' or 'DN storage' – is an approach for storing digital information in DNA malecules. It is analogous to storing data on a computer hard alfwe, bui instead of using magnetic or electronic technolow. Atta new toped using chemical technologia in the form of DNA malecules.

In appriments a sequence of the four DMA nucleotides – A, T, G, C – code for a set of instructions to moving a protein. These four nucleotidise, or fetters con close functions as a coding system analogues to the binary digital code usue By comparison to represent future nucleotidia or effective sets (SMA has been used to represent binary code hast. The fast grout-6-ic concept summitive varies (DMA and Bue due to the code of the code

The data challenge

Glebial data production is expected to score exceed the copooly of currently available storoge methods and DNA eligible data storoge is server to possible solution to meet these demonds. Although this is a technology based on molecular science, it has potential application in more field where data storage and serving are meded. Current work in this area is not yet looking specifically into healthcare applications, but on developing the storage behavioration.

WYNG

The views set out in this briefing note do not necessarily represent those of the WYNG Foundation

Supported by the WYNG Foundation

We were generously supported by the WYNG Foundation to produce a series of policy briefings on hot topics in biomedical technologies.

DNA as data storage

DNA as a high-density, long-term storage medium for digital data promises stability and capacity advantages. But there are challenges including cost, writing speed, and data retrieval.

• Infection and autoimmune disease

There is an established but complex relationship between infection and increased risk of autoimmune disease. How could further research improve patient care?

• Pathomics, genomics and AI in cancer care

What is pathomics and how might artificial intelligence help scientists understand the complex interplay between pathomic and genomicgenerated data? In this briefing we address these questions in the context of improving cancer care.

UNIVERSITY OF CAMBRIDGE

Host genomics: lessons for infectious diseases



Host genomics: lessons for infectious diseases

Published just as 2024 was coming to end, we will be using its insights and recommendations to engage key stakeholders throughout 2025.

We explore the potential for host genomics to support the complex field of infectious diseases. Using four pathogens as case studies, we found that host genomics can provide crucial clues to better understand key mechanisms within the immune system. However despite this potential, the research field is fragmented and few host genomics insights have been translated into diagnostic tests or treatments.

In <u>our report</u> we make recommendations to research funders to develop a host genomics research strategy, to improve collaboration and incentivise translation into treatments.

Continuing our work in synthetic biology

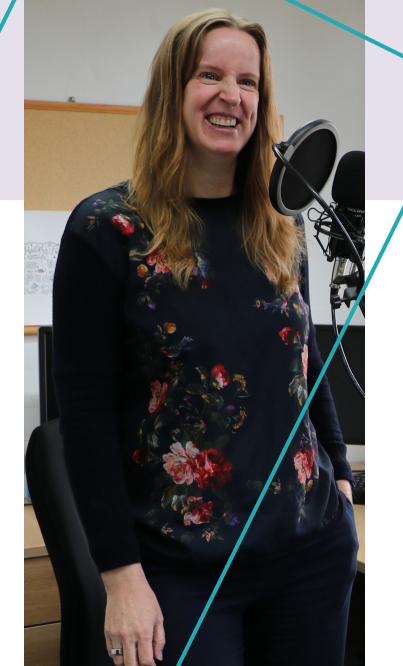
A new technology that piqued the interest of Policy Analyst, Dr Chaitanya Erady was electrogenetics - an emerging field within synthetic biology research. One ambition is to develop ways to use electrogenetics to correct certain gene disorders, including type 1 diabetes.

Electrogenetics: a new avenue in precision medicine



In the PHG podcast, Making science work for health, PHG policy analysts weigh up the potential of technologies as future game-changers. In an episode released in December, Bhavya Krishnan and Elizabeth Redrup Hill discussed the use of digital twins across a range of conditions, including digital twin technology's role in improving post-surgery outcomes.

Digital twins for health care and research



Phages stage a comeback

Interest in phages has waxed and waned since their discovery over a hundred years ago. Now it seems they are making a comeback.

Senior Policy Analyst, Chantal Babb de Villiers has been keenly tracking the advances of phage research. In the PHG podcast she discussed how phages could become a vital weapon against antimicrobial resistant infections.

She highlights that these antimicrobial resistant infections are a critical global health threat, and each year over a million people are dying from them. There is an urgent need to find alternatives to antibiotics.

Phages: a virus on our side?

INNOVATION REGULATION AND GOVERNANCE

In 2024 we continued to assess and evaluate the implications of emerging technologies and approaches to data sharing to ensure there will be responsible implementation within health systems.

Policy briefing

The federation of trusted research environments for genomics and health PHG FOUNDATION making science

The problem of data sharing at scale

Deta sharing can be alkalonica and humanaratic process for hetilt researchers and is frought with therhical, legal and practical challenges. The <u>Goldstern</u> Berleye in 2022 perioded a critical individual of the way that data sharing the reasonality the tute of "humber enserch environments" which readers the dots humber groucess away from direct transfers of data baseling controller timed access. Herevere, a significant direveloxia it this models is the added complexity that reason-there for Here years a significant direveloxia it this models is the added complexity that reason-there fore Herevere a significant direveloxia it this models is the added complexity that reason-there fore they read access the bage-scale and multimoded data which its access multiple different for the product access the significant data which are access.

Terminolo

Several terms are used kinet-hospitably in the literature to encopaukter privacy enhanced data advantage papers and in a "usation research enhancement". "data advantage is a transfer execution of the several several several several encourses of the isa transfer execution environments are predominantly used in research only spaces, they are by and foregraphy environes. If the term "transfer has been heavily debated in the Restrute wideh hose does contributed to the readient of the states.

The challenges of having multiple entities with their own data sharing environments include • Complex negatives: Researchers may need to negative access to multiple environments and complete several efficis approved processes while undertaking analysis according to the set technical functionality that each enables. These can take months to complete.

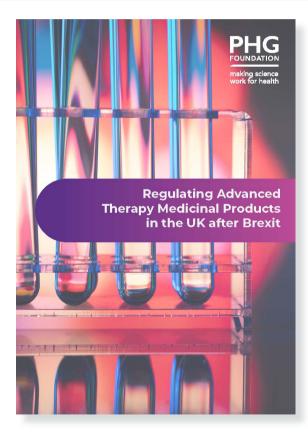


Sharing data to improve research outcomes

We published a new briefing explaining the implications of federated trusted research environments for genomics and health.

While these secure environments protect data, they also limit certain types of analysis, creating challenges for large-scale, crossenvironment research.

The federation of trusted research environments for genomics and health



The challenges of regulating ATMPs

Advanced therapy medicinal products (ATMPs) could offer considerable benefits to patients where either there are no existing interventions or where existing interventions have not been effective.

This briefing provides an introduction to ATMPs and their applications, outlines the EU and UK regulatory and governance landscape, and explores the key changes in recent years, following the UK's departure from the EU.

Regulating Advanced Therapy Medicinal Products in the UK after Brexit



Familial genomic information:

Scope, context and implications for practice

A Joint Workshop Report from the British Society for Genetic Medicine, the PHG Foundation, and the Centre for Personalised Medicine, University of Oxford.



Helping clinicians navigate familial genomics

Familial genomic information: Scope, context and implications for practice was a joint report produced with the Centre for Personalised Medicine (University of Oxford) and the BSGM.

Available from the Centre for Personalised Medicine website, the report is an analysis of discussions at the 2023 jointly held workshop involving more than 50 representatives from patient organisations, academics, lawyers, and healthcare professionals.

THE WYNG-HATTON LECTURE 2024



Around 80 delegates joined us for the WYNG-Hatton lecture, which we hosted in April at St Catharine's College, Cambridge.

Dr. Eric M. Meslin, former President and CEO of the Council of Canadian Academies and PHG Senior Fellow, delivered a talk exploring the causes of gaps and inconsistencies in current guidelines and governance tools, while offering insights on ensuring AI benefits healthcare ethically and effectively.

As well as some challenging questions from the audience, Prof Jeffrey M. Skopek, Deputy Director of the Centre for Law, Medicine and Life Sciences, and Dr Kristin-Anne Rutter, Executive Director at Cambridge University Health Partners, gave their individual responses to this thought-provoking talk.

Artificial Intelligence Policy as a Contact Sport: Why Bioethics and Governance Need to up Their Game in the Health Sector

AI AND LIABILITY ROUNDTABLE



With the Centre for Law, Medicine and Life Sciences, we convened an outstanding group of experts in law, policy, clinical practice, and AI to discuss the liability for the use of medical AI in November. The roundtable is part of the International Collaborative Biomedical and Innovation Law (Inter-CeBIL) programme involving the law faculties at the universities of Copenhagen, Cambridge (who PHG is supporting in this programme), Harvard and other partners.

EXTERNAL ENGAGEMENT

Whether to present or to take part on an expert panel, several of the PHG team were invited to speak at events, locally, nationally and globally. Highlights include:

- <u>The Genomic Medicine Horizon</u> (Pete Mills) The Council of Europe Bioethics Committee, Paris
- <u>Multidisciplinary models for engaging stakeholders in</u> precision health (Susan Mitchell, moderator) EXACT Conference, Brussels



- Al as expert team member: some epistemological and moral considerations (Tanya Brigden, Pete Mills and Colin Mitchell)
 Centre for Medical Ethics and Law, Hong Kong University, Hong Kong
- The reference genome and variant databases and what the lack of diversity in these has meant for clinical care (Chantal Babb de Villiers)
 Diversity in Clinical Genomics: Minding the gap, Cambridge
- <u>The role of ethics in guiding the development of</u> <u>emerging technologies</u> (Pete Mills)
 Dauphine-OECD Conference, Paris
- Artificial intelligence for genomic medicine: policy and ethics (Pete Mills) Academy of Medical Sciences-Royal Irish Academy meeting, Dublin
- <u>The Lifetime Genome</u> (Colin Mitchell, panelist) Genomics England Research Summit, London
- <u>Genomics, Bioethics and Policy</u> (Pete Mills) Bioethics in Action, Cambridge

GROWING AND SHARING EXPERTISE

From our earliest work, we have harnessed the technical expertise of our science team, coupled with the critical input of our humanities team, to define the way forward for the evaluation of technologies from genetic tests to AI devices. As the pace and volume of innovation increases we have expanded our capabilities in the humanities and social sciences, to address the human factors that are essential to making science work in practice.



Dr Susan Mitchell - Director of External Affairs

Susan brings over 20 years of experience and knowledge within policy influencing and health service delivery, underpinned by strong academic, communication and project delivery skills.



Jamie Hearing - Policy Analyst (Humanities)

Jamie has joined the Humanities team. Prior to joining the PHG Foundation, Jamie carried out qualitative research and engagement to inform health, science and technology policy.



Valena Reich - Policy Analyst (Humanities)

Valena also joins the Humanities team. Her expertise in AI has contributed to projects around public AI literacy, aiming to empower people as they navigate AI's growing influence.

COMMISSIONS

PHYSIOLOGY PASSPORT: PUTTING PERSONALISED

BT OF RESILIENT HEALTH SYSTEMS

We continued to develop our already established track record of nurturing new and existing partnerships. We were delighted to work again with the global non-profit FINDdx on our fourth project which will be published in 2025.

> A shared interest in climate change health led to us connecting with the UK Physiological Society.

> We were thrilled when they commissioned us to work on a joint report showcasing the crucial role of physiology in advancing precision medicine.

The resulting report, The Physiology Passport: Putting personalised prevention at the heart of resilient health systems, was launched at a Westminster event in early 2025.

Throughout 2024 we enjoyed working with a varied range of organisations. Whilst we were active in several multicentre collaborations, our client base also continued to grow. All have allowed us opportunities to explore, suggest and challenge new ideas in healthcare and data innovation.







Department for Business & Trade









OUR STRATEGIC DIRECTION 2025-2030

The three principal priority areas of our strategic direction reflect our intention to address the challenges and opportunities that arise in a life sciences and health ecosystem which has increasing volumes and complexity of knowledge.

Priority area 1

Support the implementation of emerging health technologies for public benefit

Priority area 2

Optimise the use of data to deliver better population health

Priority area 3

Shape the future of personalised and preventative health services

PHG FOUNDATION STRATEGIC DIRECTION 2025-2030

Read more about our strategic direction and priority areas

phgfoundation.org/what-we-do



OUR VISION, MISSION AND VALUES

Our vision

A world in which the responsible application of science and technology leads to better health for people and populations.

Our mission

We want science to work for health. We support the responsible development and adoption of technologies based on knowledge of the human genome, other biomarkers and health information.

We promote the conditions that enable such technologies to deliver genuine public benefit, while guarding against unethical or undesirable consequences for individuals or populations.

Our values

We value science and its profound impact on human health and wellbeing. We believe that the responsible pursuit and translation of scientific knowledge should be promoted.

We value all people in their individuality and diversity. We recognise that people are not all the same and that their health needs can be met better with a more personalised approach.

We value population health and appreciate that the health of each of us is entwined with the health of others. We recognise the important role that family and community play in health. We are committed to fairness in the expectations placed on people as patients, and as members of families and of the wider population, in respect of their own health and the health of others.

We value practical approaches that help address the challenges of health innovation in complex systems. We are committed to genuine engagement across disciplines and sectors, including the sciences, humanities and health services, to achieve workable, sustainable solutions.

FINANCIALS

The PHG Foundation is funded by donations and grants, primarily from the Hatton Trust and the WYNG Foundation. We are not funded by the University of Cambridge. Other income is from commissions, collaborations, and commercial and public sector consultancy. We also have a modest investment portfolio. Most of our spending is on charitable activities, which includes our work programme and staff costs.





The PHG Foundation is a health policy think-tank and linked exempt charity of the University of Cambridge. We work to achieve better health through the responsible and evidence-based application of biomedical science.

We are a registered company, no. 5823194.

