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PUBLIC POLICY PROJECTS

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# Global Genomics Programme Phase 2 ‘Equity of Access and Return in Global Genomics’

A series of virtual roundtables to collect evidence and formulate policy considerations and recommendations through a Global Insights Report.

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## Project Summary: Global Genomics Phase One

The genomics revolution, the world has witnessed over the past three decades - serves as a welcome reminder of the capacity for human beings to innovate and create new solutions to health challenges previously considered insurmountable. There has been an explosion of genomics initiatives globally, and there is tremendous potential for greater international collaboration and development. The Covid-19 pandemic has served as a great indicator of the potential rewards which can be reaped from such global collaboration.

The first project in this *Global Genomics* series, 'Global Genomics: Bringing the benefits of genome sequencing to the world', brought together stakeholders and subject experts from multiple jurisdictions and from internationally leading organisations. The cohort of world-leading experts evaluated and discussed how collaboration across the genomics landscape can greatly aid in delivering the benefits of genomics can be achieved through international collaboration efforts. Through a series of 6 roundtables, 'Global Genomics: Bringing the benefits of genome sequencing to the world' examined and addressed the following key topics:

1. Realising the international potential of genomics and the need for an international approach
2. Lessons learned from past pandemics regarding global collaboration
3. Big data and genomics
4. The democratisation of genomic data
5. Increasing the diversity of genomic data
6. Financial benefits provided by engaging in genomics and genomic sciences

Phase One of the Global Genomics programme of work was greatly benefited from the support and contributions from the project's lead contributors which included:

**Amazon Web Services (AWS)**

**PHG Foundation**

**Dechert LLP**

**Wellcome Sanger Institute**

**Illumina**

**University Hospital of Leicester, NHS Trust**

**Genome Canada**

**Guy's and St Thomas', NHS Foundation Trust**

Our Global Insights Report will be published in late 2021 and will be freely available to all.

You can access the interim Phase 1 reports here:

[Global Genomics - Public Policy Projects](#)

We were also grateful for the perspectives of the following, which have contributed to this line of work:

Genomics Thailand

H3 Africa

Melbourne Genomics

ELIXIR

Genomics England

NIH

The Qatar Genome Programme

Hong Kong Genomics Institute

GA4GH

Royal Thai Embassy London

French Embassy, London

Canadian High Commission

## Project Abstract – Global Genomics Phase Two

Building upon the first phase of this *Global Genomics* series, the second phase will explore the repeatedly raised questions and issues surrounding the need for equity in genomics, both in terms of access and return.

As an important starting point, we need to explore what we really mean by equity of access and return. Is that purely building a more diverse and globally representative dataset? Is it about creating capacity within specific communities? Is it about changing the mindset of how the various elements of the genomics ecosystem interact with each other, whether they be from the research community, the clinical community, industry, or the public sector?

We must consider how the benefit of data sharing is returned to the communities and researchers that are making these contributions. That must be not only the short-term benefit of sharing the data, but also the translation of that data into long-term outcomes and benefits. It must, however be also understood *what* is meant and implied by the term ‘benefits’, both to countries which provide genetic resources and also to communities and populations. Increasingly ‘benefits’ need to be tangible or quantifiable, but thinking about more sophisticated ways of bringing benefits, especially non-financial ones, is needed. Establishing shared understandings of key terminology shall thus be essential.

We also need to examine how to change the basis of the dialogue so that we are clear from the outset that equity should mean equity for **all** not just for **some**. How will this be made possible? Should there be some sort of global framework to establish some key principles to which all elements of the genomics ecosystem can agree to adhere? Who would establish this and how would it be policed? Should we be seeking to explore whether a global value of genomics can be established? How would it be measured and calculated?

There is very timely opportunity to explore these issues in detail as we have seen through the global response to the pandemic that there was great international collaboration with respect to the sharing of sequencing data with respect to the virus. However, the benefits derived from the shared data were arguably not returned equally. There have been issues about protection of intellectual property, for example. Is this appropriate? Could – or should - a Global Framework or Global Partnership prevent this from happening again?

We must recognise that this is not an area without challenges, but that should not mean that we do not seek to explore these issues collectively, bringing the perspectives of the public, private and philanthropic/research sectors together. As discussed in the first stage of the Global Genomics Programme no one part of the genomics ecosystem can solve these issues in isolation.

For example, genomic research leads to clinical application and plays a fundamental part in drug discovery and the development of clinical trials that result in medicine delivery. So, reciprocal agreements at the point of genomic data collection, that directly link to medicine delivery, are on people’s minds. We want to understand how pharma sees the relationship and what fairness and justice (from a data donor perspective) looks like to them.

These issues can only truly be even articulated when we have all elements of the ecosystem represented. There has to be an ability for different voices to be heard and respected. To enable this

to happen we need a “trusted broker” bringing these different perspectives to bear and through the first phase of our Global Genomics Programme PPP has demonstrated its ability to fulfil this role.

There are particular challenges for Low-to-Middle-Income Countries (LMICs) in this debate and we need to use this network to explore these challenges so that any global framework is fully cognisant of these perspectives. Genomics should not become the preserve of only those who can afford to make significant public sector investment. Without question there is an important role for the private sector in these areas – but we need to find a way for all participants to feel as though they are contributing on an equal footing, not that one party is trying to trip the other up. A global framework could really help set some parameters here.

Building upon this, the second phase of the Global Genomics programme will aim to explore and discuss the following questions:

1. What is meant and understood by the terms “equity”, “access” and “return” in the context of genomics?
2. How should we articulate the need for equity for all not just for some? Should there be some sort of global framework? Could it help establish how data is co-created in partnership and indeed how we co-share and co-benefit from everything that genomics can give the world?
3. Should we be seeking to explore whether a global value of genomics can be established? How would it be measured and calculated?
4. How can we bring the perspectives of all elements of genomics ecosystem (public, private, research, philanthropic) equally to these issues? How can we help address issues of mistrust?
5. Are the challenges facing low-to-middle income countries the same or different from high-income countries? Why? And what should be done to address this?

## Project Breakdown

Through a series of 6 virtual roundtable sessions, taking place every 6 weeks, PPP will convene key subject experts, industry leaders and stakeholders to explore the key issues outlined, encourage discussion, and debate in order to gather evidence, which will contribute to the final Global Insights Report. As with Phase 1 reports will be produced following each session and this phase of the Programme will conclude with a final published report, openly available, containing key insights derived from the discussions and case-studies providing further evidence. The report will be launched through our networks.

To socialise the publication of the Phase 2 Global Insights Report, as will occur with the Phase 1 report, PPP will host a virtual launch event, at which key project contributors will be invited to speak and share reflections upon the project. In conjunction with this, the report shall be advertised through PPP's social media platforms, stakeholder networks, and in collaboration with the marketing teams of key project contributors.

It will also be possible for participants to contribute thought leadership pieces, to be published in PPP's online publications. These will provide running commentary upon the topics addressed, or which are deemed relevant, to the overall project.

The project will be Chaired by PPP's Kate Orviss, Senior Adviser – Global Genomics.

## Public Policy Projects

Public Policy Projects (PPP) is a global, subscription-based public policy institute. Chaired by The Rt Hon Stephen Dorell, the institute is independent and cross-party, bringing together public and private sector leaders, investors, policy makers and commentators with a common interest in turning public policy into actionable insights. With the belief that good public policy is the essential foundation of an open and liberal society, the work and insights produced by PPP focus upon three primary fields: Health and Life Science, Infrastructure and, Environment and Climate.

PPP understands and recognises the impact genomics and life sciences will have upon both the health care systems and population health. Previous projects and reports, examining both the global and UK genomics landscapes, can be accessed [HERE](#).