March 2025

Ethical, Legal and Social Contexts in Genomics workshop series

Report and forward look

Emma Keston, Peter Kilroy, Paul Meller, Urszula Pawlicka-Deger, Helena Wells

Discovery Research Programme team members, Wellcome Trust, UK.

Authors are listed alphabetically.

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Foreword

This report presents key findings from Wellcome's 'Ethical, Legal and Social Contexts in Genomics' workshop series, which took place between January and April 2024. The series aimed to explore the importance and potential of transdisciplinary collaboration for driving 'discovery research'* in this space, identify the key barriers to collaboration, and determine the actions needed to overcome them.

This report also presents Wellcome's immediate plans for action in response to workshop learnings.

We would like to thank the broad diversity of participants, speakers and facilitators who ensured that we had a productive and meaningful workshop series. The content of this report is a testament to their efforts.

We invite you to explore the following pages and consider the insights from our workshop series. It is our hope that this report can be a catalyst for funders, the research community, and wider stakeholders to help build the conditions for broader, grounded 'discovery research'* in genomics that has the potential to drive transformative health and social impacts in future.

Signed by the authors:

Emma Keston, Peter Kilroy, Paul Meller,
Urszula Pawlicka-Deger, Helena Wells.

Discovery Research Programme, Wellcome Trust, UK.

Contact: GenomicsELS@Wellcome.org

Scope and limitations

The content of this report is derived from the workshop participants, steering group members, and sources that were consulted during scoping activities.

The 'Background and Approach' section predominantly reflects the scoping and preparatory work carried out by the Wellcome Discovery Research Programme team prior to initiation of the workshop series.

The insights presented in the 'Summary of Workshop Findings' were derived exclusively from workshop discussions and should not be construed as incontrovertible facts or as reflections of Wellcome's opinions or stances. It is important to acknowledge that, while efforts have been made to accurately convey the content of the discussions, these accounts are not exhaustive and might not encompass all viewpoints or all available data.

The 'Forward Look' section summarises Wellcome's initial planned action in response to the insights obtained from the workshop series.

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Overview

1. Background

Genomics is a field with huge potential for discovery. It can also raise a wide range of ethical complexities, big and small, from how to conduct a particular study or responsibly share digital sequence information, to broader questions about how knowledge should be generated and what the implications of such knowledge might be.

The vital role of social, ethical and legal work in genomics for ensuring ethical, inclusive research and related practices is widely recognised. Less well recognised, however, is the huge potential of such work for driving research innovation; the intersection between genomics and its social, ethical and legal contexts holds significant promise for catalysing innovative 'discovery research'* but this potential appears to be underexplored and under-leveraged at present.

The 'Ethical, Legal and Social Contexts in Genomics' workshops aimed to explore the potential of transdisciplinary collaboration in this space for driving 'discovery research'*, identify the key barriers to collaboration, and determine the actions needed to overcome them.

2. Approach

Wellcome convened an international cohort of around 70 researchers, practitioners, and stakeholders from 27 countries to participate in the 'Ethical, Legal and Social Contexts in Genomics' workshop series. Expertise spanned ethics, biodiversity, human and pathogen genomics, humanities, law, policy, and the social sciences.

The 2024 workshop series consisted of three events:

- An online, collaborative co-development session in January to explore barriers to transdisciplinary collaboration between genomics researchers, researchers exploring its wider contexts, and broader stakeholders, and help shape the framing, content and format of subsequent workshops.
- A workshop in London, United Kingdom, in March, to identify and prioritise the key opportunities afforded by such transdisciplinary collaboration.
- A workshop in Cape Town, South Africa, in April, to examine the mechanisms that could enable the prioritised opportunities.

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3. Key findings*

A. Barriers to collaboration between genomics researchers, researchers exploring its wider contexts, and broader stakeholders include widespread logistical, political and epistemic challenges†

- **Logistical:** competing priorities and limited resources (time and money), incentives, and opportunities to meet.
- **Political:** complex power differences between stakeholders and exclusion of wider voices.
- **Epistemic:** differing knowledge systems, languages, methods, concepts, priorities and views on when and why to collaborate.

B. Opportunities afforded by collaboration differ by collaboration type

- **Earlier practical collaboration** to develop better research practices and procedures could enable equitable approaches to issues such as data diversity, consent, and data and benefit sharing.
- **Collaboration on underlying political dynamics** could unlock broader, critical perspectives on the wider social, ethical and legal contexts and implications of genomics.
- **Upstream, fully integrated collaboration throughout the research lifecycle** could unlock new concepts, research questions, approaches, ways of working, methods and technologies, building, opening and shaping fields.

The latter two collaboration types are underexplored areas of collaboration with huge potential for discovery research‡

C. Mechanisms for enabling underexplored areas of collaboration include:

- **Dedicated infrastructure**, including collaboration centres, institutes, platforms or hubs.
- Local, regional, national or international **alliances, networks or consortia**, paired with smaller-scale matchmaking of collaborative relationships.
- **Resources** to promote and support deep collaboration, including guidance documents, toolkits and frameworks. For example, participants identified and refined a list of 'critical questions' to support meaningful dialogue throughout the research lifecycle.
- **More / different funding** opportunities for collaborative research, including small-scale seed / targeted funding.
- **Education and training** to support the substantial culture shift required to incentivise greater transdisciplinary collaboration.

Participants recommended an initial focus on early-stage network-building, research development and seeding to catalyse deep collaboration and discovery.

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*These findings should be considered alongside the expertise and interests represented in the workshops and those that were absent.

†While some of these barriers were already known, they were reinforced and evidenced during the workshops, and remain a challenge.

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4. Key takeaways

Participants recognised the importance of existing efforts to address the wider social, ethical and legal contexts of genomics. They also confirmed the transformative potential of underexplored areas of collaboration between genomics researchers, researchers exploring its wider contexts, and broader stakeholders (including communities, civil societies, governments and industry) for opening fields and unlocking new 'discovery research'*.

This new kind of earlier, deeper collaboration will require a significant culture shift, necessitating new methods and concepts for working productively together. Existing power dynamics must be constructively worked through considering the different understandings, interests and needs of stakeholders. This will take time and dedicated capacity, incentivisation, guidance, an evolution of skillsets, and development of wider infrastructure for collaboration.

5. Forward look

Over the next few years, the Discovery Research team at Wellcome will work towards incentivising, creating space for and supporting earlier, deeper collaborations between genomics researchers, researchers exploring its wider social, ethical and legal contexts, and broader stakeholders. Initially, we will do this through:

- **Funding to support early-stage brokerage, networks and collaborative research.**
- **Developing the 'critical questions' toolkit to support collaborations and dialogue throughout the research lifecycle.**

Wellcome invites other funders, the wider research community, and broader stakeholders to consider the wide range of enabling mechanisms identified in this report and partner with us to help build the conditions for broader, grounded 'discovery research'* in genomics that has the potential to drive transformative health and social impacts in future.

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Background and approach to workshops

The content presented in this section predominantly reflects the scoping and preparatory work carried out by the Wellcome Discovery Research Programme team prior to initiation of the workshop series. The hypothetical examples referred to herein were derived from scoping work, the workshops series, and discussions with members of the Steering Group.

Background

Fast-paced field

The genomics field continues to evolve at pace.[1] While developments such as artificial intelligence (AI) and genomics-based precision medicine are seen by some as poised to revolutionise healthcare,[2] they also have the potential to increase research and health inequity.[3,4] Careful consideration of the wider social, ethical and legal contexts of genomics and equitable social partnerships is required to collectively shape the direction of these developments and to ensure any associated benefits are shared fairly.

The status quo

Efforts to tend to ethics and inclusivity in genomics have largely focused on specific questions surrounding a particular area of research, in part due to our current research processes and oversight mechanisms. Common topics include optimal approaches to consent, thoughtful communication of sensitive findings, and data protections and confidentiality.[3]

This work is vital. But consideration of the social, ethical and legal contexts of genomics also presents opportunities for sparking new ideas and shaping new research directions. This considerable value tends to be under-recognised and underexplored, in part because genomic researchers, researchers working on the social, ethical and legal contexts of genomics, and broader stakeholders have tended to make progress within their own 'areas', with limited intersection.

A new approach

What if there were structured ways to increase intersection? To allow genomics researchers, researchers working on the wider social, ethical and legal contexts of genomics, and broader stakeholders (including those from communities, civil societies, governments and industry) to work together throughout the research lifecycle to set the agenda and to develop and implement research?

In addition to fuelling real-time adoption of best practice in ethics, could this kind of deep, transdisciplinary collaboration also unlock new and innovative opportunities for discovery research*, leading to social and health benefits?

Early scoping work carried out by the Wellcome Team suggested that it could. Hypothetical examples emerging from conversations around the workshop series included:

- Collaborations between genomic pathogen surveillance researchers and social psychologists and/or human geographers, to gain a deeper understanding of how behavioural factors and the movement and interaction of people interplay with the spread and evolution of disease, unlocking new research avenues.
- Collaborations between genomics researchers and community stakeholders, drawing more deeply on concepts and methods from Indigenous-led genomics to centre communities as core drivers and owners of research agendas and inform the community engagement critical to diversifying genomic data sampling.
- Collaborations between researchers and broader stakeholders working in Critical Disability Studies and genetics-based precision medicine, which could help challenge issues of discrimination, stigmatisation or marginalisation as the latter develops, reshaping research as it happens.

In other words, deep, early collaboration could enable a new frontier of ethical, grounded 'discovery research'* that could have wider health and social impacts in the future.

Workshop aims

The 'Ethical, Legal and Social Contexts in Genomics' workshop series was designed to gather insights into the challenges and opportunities around deeper transdisciplinary collaboration in this space, and to explore enabling strategies. It also served as a networking platform for researchers, practitioners and other stakeholders interested in the wider social, ethical and legal contexts of genomics to connect.

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1. Zhao *et al*. Intell Med, 2021;1(3):128–133.
2. Johnson *et al*. Clin Transl Sci, 2020;14(1):86–93.
3. Horton and Lucassen. New Bioeth, 2022;29(1):37–51.
4. de Vries *et al*. BMC Med Ethics, 2011;12:5.

Approach

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Workshop participants

Through an open expression of interest call and direct invites to key experts, Wellcome convened an international cohort of researchers and practitioners to participate in the ‘Ethical, Legal and Social Contexts in Genomics’ workshop series.

- On average, each of the workshops was attended by **70 diverse researchers**, **practitioners** and **other stakeholders**
- Participants were representative of **27 countries** worldwide
- Participant expertise spanned **ethics**, **biodiversity**, **human and pathogen genomics**, **humanities**, **law**, **policy**, and the **social sciences**

Workshop series

The workshop series was made up of three sequential events:

22 January 2024

Co-development session:
Online

Focus: barriers and opportunities

Aims:

- Explore barriers and opportunities to transdisciplinary collaboration between genomics researchers, researchers exploring its wider contexts, and broader stakeholders
- Help shape the framing, content and format of subsequent workshops

Key agenda topics:

- Collaboration opportunities and gaps
- Collaboration challenges world café

25–26 March 2024

Workshop 1:
London, UK

Focus: opportunities

Aim:

- Identify and prioritise the key opportunities afforded by deep transdisciplinary collaboration and dialogue

Key agenda topics:

- Collaborative opportunities:
  - to develop broader critical perspectives
  - for field opening
  - on practical issues
- Review and development of ‘critical questions’

24–25 April 2024

Workshop 2:
Cape Town, South Africa

Focus: mechanisms

Aim:

- Examine the mechanisms that could enable the opportunities prioritised in Workshop 1

Key agenda topics:

- Infrastructure for collaboration
- Resources (such as guidance, toolkits, frameworks)
- Alliances, networks and consortia
- Funding calls and funding models

In each workshop, agenda topics were contextualised through a number of case studies, followed by reflection and small group discussions.

The series’ sequential design not only provided participants with time to network and build trust but also allowed the Steering Committee* and Wellcome staff to carry learnings from one event forward when co-developing the next.

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*For details of the Steering Committee group, please see the acknowledgements section.

Summary of workshop findings

The content presented in this section represents the discussions and insights provided by participants during the workshop series and should not be construed as incontrovertible facts or as reflections of Wellcome’s opinions or stances. It is important to acknowledge that, while efforts have been made to accurately convey the content of the discussions, these accounts are not exhaustive and might not encompass all viewpoints or all available data. This section serves as a summary of discussions rather than an expression of Wellcome’s official position or a factual assertion.

Barriers

Barriers to collaboration between genomics researchers, researchers exploring its wider contexts, and broader stakeholders included logistical, political and epistemic challenges.

During the workshops, participants identified multiple barriers to collaboration between genomics researchers, researchers working on its wider social, ethical and legal contexts, and broader stakeholders. While many of these barriers were already known, the workshop highlighted their extensiveness across a wide range of contexts. Many of the barriers cited herein also manifested during the workshop series itself.

Logistical barriers result in narrow-view research

- Research is often performed in silos, with limited **opportunities** to meet potential collaborators outside of the 'home field' (including other researchers and community, civil society, government or industry partners) or be exposed to others' work.
- Researchers have limited **time**, **resources** and **funding** to engage with each other's work.
- **Priorities** sometimes imposed on researchers by funders and academic institutions (including pressures to produce research outputs, fast) can force researchers to concentrate their limited time and resources on generating data, rather than fully considering the broader social, ethical and legal contexts of their work.
- There are currently a lack of **incentives** (professional or monetary) to collaborate.

Political barriers hamper dialogue and mutual benefit

- Historical and ongoing **discriminatory practice** and the **misuse of research** have eroded trustworthiness and created complex power differences between genomics researchers, those researching its wider social, ethical and legal contexts, and broader stakeholders.
- Research and funding ecosystems for genomics and its contexts are predominantly **shaped** by those with **strong institutional backing** and **resources**, which can further marginalise marginalised voices; this might occur between geographies (for example, the 'Global North' vs the 'Global South') or within them (for example, in settler-colonial contexts).

Epistemic barriers prevent transdisciplinary understanding

- Different stakeholders have different **knowledge bases**, **concepts**, **ideas about when and why to collaborate**, **languages** and **lexicons**; this can make it difficult for potential transdisciplinary collaborators to arrive at a point of shared understanding from which they can embark on frictionless work.
- Institutional 'politics of knowledge' (deep-held beliefs about what counts as knowledge, how it is valued and by whom) can devalue wider perspectives on the contexts of genomics, such as those centring community sovereignty or those from the humanities and social sciences.

Current tendencies can limit collaboration

- Emphasis is often placed on diagnosing problems in practices or research conduct.
- Only a limited number of stakeholders are typically engaged; for example, humanities and social science researchers and broader stakeholders are often excluded, marginalising voices and limiting debate. Work is needed to bring together genomics researchers; the full spectrum of researchers focused on the wider social, ethical and legal contexts of genomics; and community, civil society, government or industry partners.

These barriers hinder dialogue and collaboration, which in turn inhibits creative and critical discovery research*, as well as the health or social impacts it could enable.

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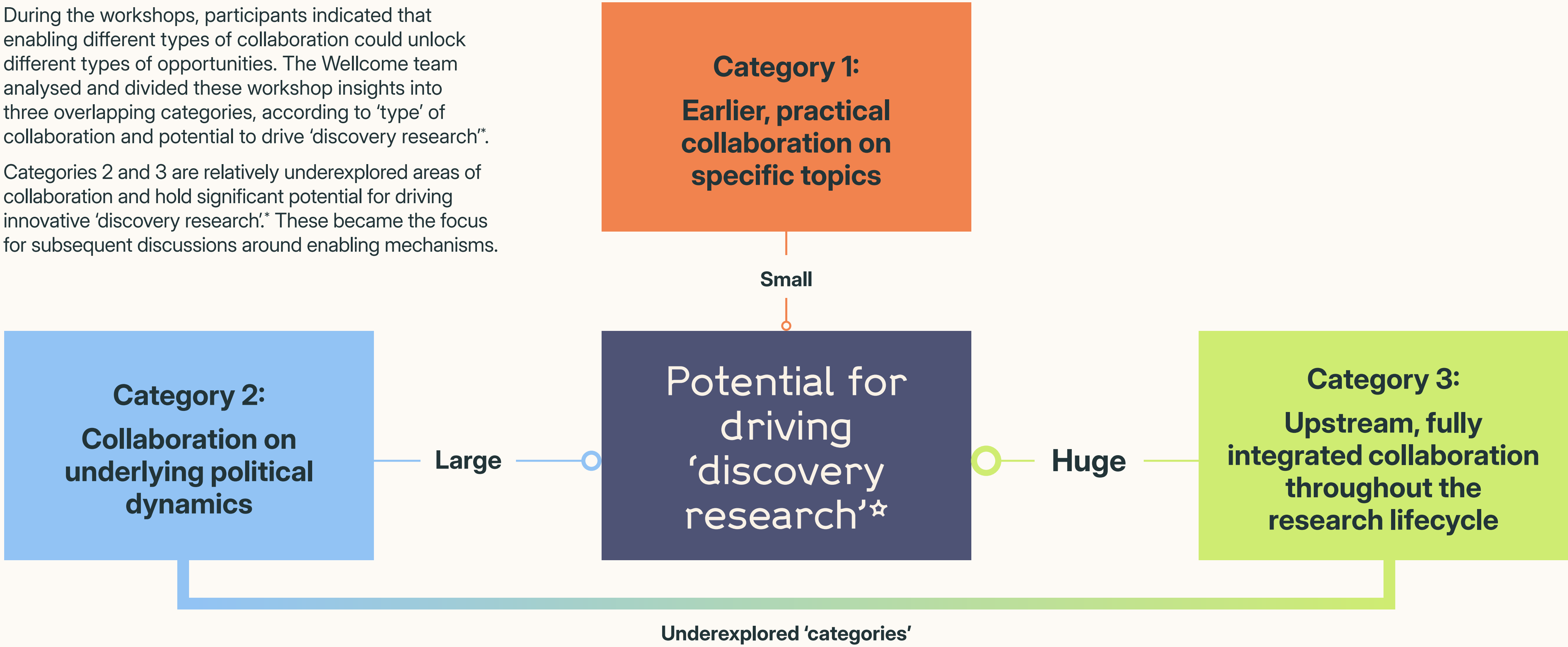
Opportunities

Opportunities afforded differ by type of collaboration.

During the workshops, participants indicated that enabling different types of collaboration could unlock different types of opportunities. The Wellcome team analysed and divided these workshop insights into three overlapping categories, according to ‘type’ of collaboration and potential to drive ‘discovery research’*.

Categories 2 and 3 are relatively underexplored areas of collaboration and hold significant potential for driving innovative ‘discovery research’.* These became the focus for subsequent discussions around enabling mechanisms.



Category 1:

Earlier, practical collaboration on specific topics

Small

Potential for driving ‘discovery research’*

Category 2:

Collaboration on underlying political dynamics

Large

Huge

Category 3:

Upstream, fully integrated collaboration throughout the research lifecycle

Underexplored ‘categories’

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Category 1: Earlier, practical collaboration on specific topics

- Workshop participants saw research ethics (such as processes for gaining informed consent and ensuring benefits are shared fairly) as crucial to the development of a genomics field that considers its wider contexts and partners.
- Collaboration around **data**, including diversity, collection, privacy, ownership, analysis, sharing, storage and use could yield more representative and accountable data and research.
- Equitable partnerships to discuss who should **benefit**, what constitutes a benefit and when that benefit can be considered 'achieved' would help build trustworthiness, leading to fruitful relationships and better-quality research.

Category 2: Collaboration on underlying political dynamics

- Bringing diverse stakeholders together to acknowledge and 'work through' deep-seated power differences could not only improve equity but could also encourage broader, critical perspectives on research and enable important (potentially new) questions to surface, diverse ideas to flourish and new avenues for transformative research to open.
- Topics that workshop participants indicated stakeholders should think critically about together included:
    - How **colonial histories, legacies and racism** have produced patterns of inequality and exclusion that continue to resonate in genomics today, not only in terms of who can participate in research, but also in how that research is interpreted and used.
    - **Disciplinary and geographical power differences**, including imbalances in resourcing and setting agenda priorities.
    - What counts as knowledge, how it is valued, and by whom (the '**politics of knowledge**'); who has the power to determine what knowledge or research questions are valuable and what data are collected or excluded? Why, how and to what end?

Category 3: Upstream, fully integrated collaboration throughout the research lifecycle

- From agenda setting through to project completion, integrated collaboration between genomics researchers; those investigating the wider contexts of genomics; and community, civil society, government and industry partners could unlock new concepts, theories, research questions, approaches, ways of working, methods and technologies. This would enable greater 'discovery research'* opportunities and the opening, building and shaping of fields.
- Example areas that workshop participants indicated were ripe for this type of collaboration included:
    - **Indigenous-led genomics**, which already integrate genomics, wider contexts and community engagement as a matter of course but could be amplified and expanded.
    - **Precision or personalised medicine and pharmacogenomics**, which have significant potential to revolutionise healthcare but also to increase research and health inequities.
    - **Emerging technologies and AI**, which will likely revolutionise how genomics research is carried out, posing ethical concerns as well as opportunities for collaborative 'discovery research'*.
    - **Bioethics** in relation to genomics, which could include greater emphasis on ideas of environmental ethics, solidarity and ethics of care, and better handle newly emerging ethical issues around data-intensive genomics.

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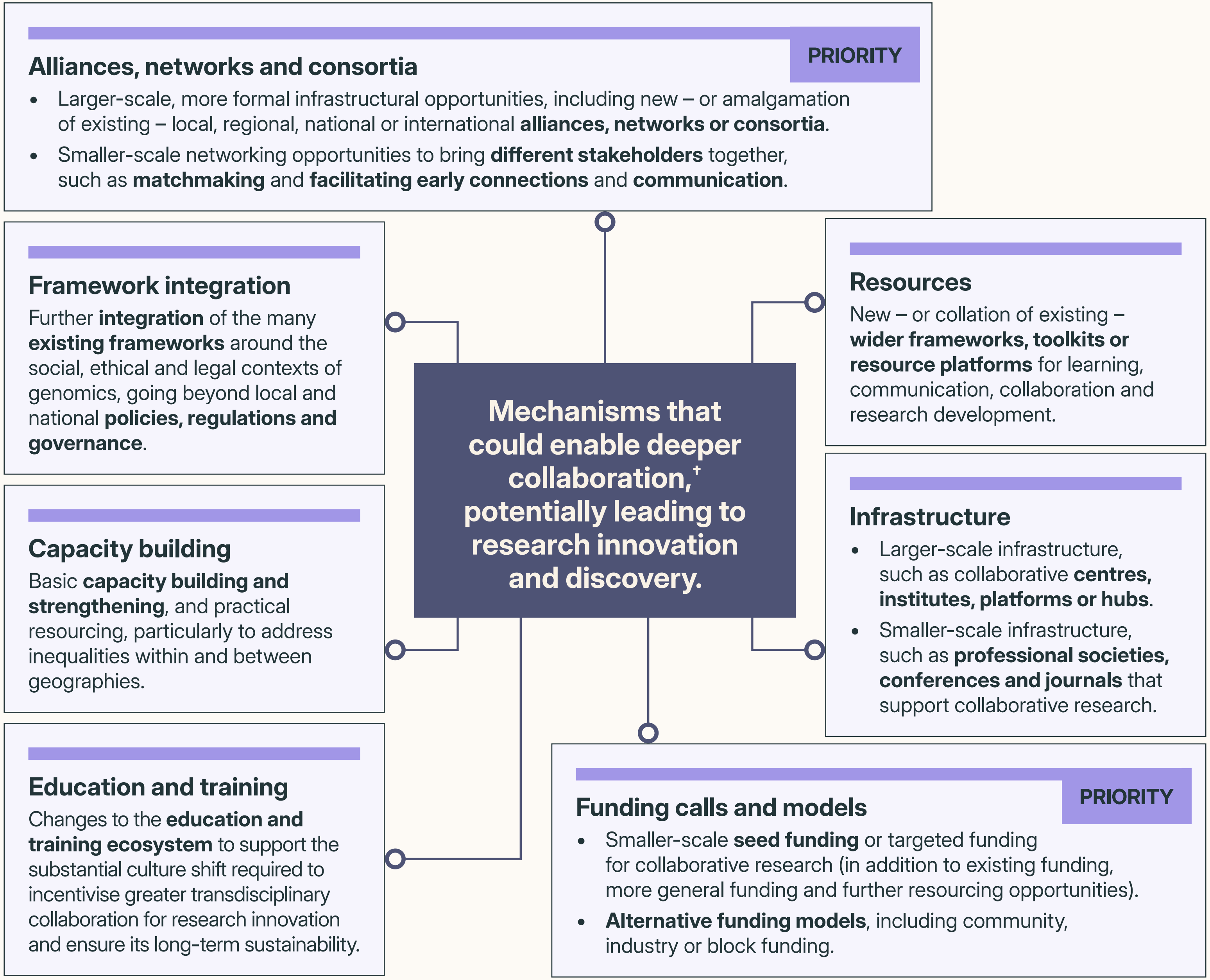
Mechanisms

Mechanisms for enabling underexplored areas of collaboration include infrastructure, networks, resources and funding

Throughout the workshop series, participants surfaced various mechanisms that could enable deeper collaboration, research innovation and discovery. In the final workshop, participants reviewed, discussed and prioritised these mechanisms, which are summarised opposite.*

All of these mechanisms are important to consider as activity in this area is taken forward.

For Wellcome, participants recommended an initial focus on brokerage, early-stage network building, research development and seed funding to catalyse deep collaboration and discovery.*



Mechanisms that could enable deeper collaboration,† potentially leading to research innovation and discovery.

Alliances, networks and consortia

PRIORITY

- Larger-scale, more formal infrastructural opportunities, including new – or amalgamation of existing – local, regional, national or international **alliances, networks or consortia**.
- Smaller-scale networking opportunities to bring **different stakeholders** together, such as **matchmaking** and **facilitating early connections** and **communication**.

Framework integration

Further **integration** of the many **existing frameworks** around the social, ethical and legal contexts of genomics, going beyond local and national **policies, regulations and governance**.

Capacity building

Basic **capacity building and strengthening**, and practical resourcing, particularly to address inequalities within and between geographies.

Education and training

Changes to the **education and training ecosystem** to support the substantial culture shift required to incentivise greater transdisciplinary collaboration for research innovation and ensure its long-term sustainability.

Resources

New – or collation of existing – **wider frameworks, toolkits or resource platforms** for learning, communication, collaboration and research development.

Infrastructure

- Larger-scale infrastructure, such as collaborative **centres, institutes, platforms or hubs**.
- Smaller-scale infrastructure, such as **professional societies, conferences and journals** that support collaborative research.

Funding calls and models

PRIORITY

- Smaller-scale **seed funding** or targeted funding for collaborative research (in addition to existing funding, more general funding and further resourcing opportunities).
- **Alternative funding models**, including community, industry or block funding.

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*Prioritisation should be calibrated against the different participants in the workshops and those who were not represented.

†Between genomics researchers, researchers working on the wider social, ethical and legal contexts of genomics, and broader stakeholders (including those from communities, civil societies, governments and industry).

Examples

Examples of existing collaborative initiatives

During the workshops, multiple examples of innovative initiatives already bringing together genomics researchers, researchers exploring its wider contexts, and broader stakeholders were presented. These cut across different collaboration categories and enabling mechanisms.

The following six examples are a selection intended to represent the breadth of cases discussed and the ways in which they have catalysed 'discovery research'* through different forms of collaboration. Such cases are, however, only the beginning. Future transdisciplinary endeavours that include an even greater breadth of perspectives and depth of integration, span across the whole research lifecycle, and address new advances in genomics and its contexts could hold even greater potential for identifying and driving novel programmes of 'discovery research'* and a wider culture of collaboration.

Human Heredity and Health in Africa (H3Africa)

Key enabling mechanism: Consortium

Erisa Mwaka (Makerere University, Uganda) reported on his experience at H3Africa: a consortium of African genomic scientists and ethicists that empowers and nurtures collaborative partnerships across Africa.

Erisa explained that H3Africa was governed by a transdisciplinary committee comprised of all Principal Investigators from H3Africa-funded projects: a mixture of genomic scientists and ethicists. The committee operated on mutual respect and equal peer status, working collaboratively to guide H3Africa's activities. For example, in response to a perceived gap, the committee organised a webinar with ethicists, policymakers and genomics researchers from across the African continent to collaboratively develop and publish a joint paper on data governance.

All H3Africa-funded projects were also represented within each of H3Africa's 12 working groups, one of which focused on Ethics and Community Engagement. This structure brought the ethics and genomics communities closely together over years, nurturing understanding and engagement and shaping research in real time.

Zika Platform

Key enabling mechanism: Resources

Bethânia Almeida (Centre for Data and Knowledge Integration for Health – CIDACS/ FIOCRUZ Bahia, Brazil) introduced the Zika Platform: a long-term surveillance platform for Zika and microcephaly in Brazil. The platform is being used to research the consequences of congenital Zika syndrome in newborns through time, supported by linked secondary data.

Bethânia explained that the project had necessitated the construction of a data platform capable of receiving, processing, integrating and providing access to a vast volume of linked data, with strong data security, privacy and ethics provisions. A team including epidemiologists, data scientists, statisticians, lawyers and social scientists (among other disciplines) worked alongside data providers, regulators, data managers and international collaborators to build the Zika Platform. A major output of the collaboration was a data governance framework to address questions around data access and data ethics. Bethânia emphasised the value of continuously incorporating broader perspectives into research, yielding cumulative gains, helping to overcome challenges, and shaping research.

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H3Africa, Human Heredity and Health in Africa.

Genome Canada

Key enabling mechanism: Funding

Sapna Mahajan (Genome Canada) introduced Genome Canada: a national, federally funded non-profit organization saving lives, strengthening communities and fuelling economic growth through research and innovation in genomics and associated biosciences. This aims to drive real-world impact in health, climate action and food security.

Sapna explained how Genome Canada has leveraged funding mechanisms to encourage transdisciplinary collaboration in genomics. For example, projects funded under their Climate-Smart Agriculture and Food Systems initiative were required to have an environmental, economic, social, ethical and legal component, an Indigenous-engagement component, and have partnerships and funding from wider social partners (including industry). The funded projects work closely with two hubs specialising in data sharing and driving knowledge mobilisation and implementation, shaping the research and its impact.

Genome Canada has also partnered with the Social Sciences and Humanities Research Council to fund Knowledge Synthesis Grants: small pots of money to intentionally bring new voices, including social science and humanities experts, to the genomics field – for example, that of Yao Zheng, a lifespan researcher with a developmental psychopathology perspective that he had not previously applied to genomics.

Center for ELSI Resources and Analysis (CERA)

Key enabling mechanisms: Infrastructure and funding

Sandra Soo-Jin Lee (Columbia University, USA) introduced CERA: an organisation supporting community building and resource sharing among scholars, clinicians, educators, trainees and the wider community focused on the ethical, legal and social implications (ELSI) of genetics and genomics.

Besides provision of ELSIhub (an online hub supporting ELSI research), CERA recently provided nimble, fluid funding of up to $20,000 over two years to four transdisciplinary working groups collaborating to develop innovative approaches to emerging, high priority or understudied ELSI issues. CERA supported the assembly of these groups through the ELSIhub scholar directory, connecting collaborators based on expertise gaps.

For example, a working group assembled to develop educational resources for people facing DNA testing at the US border included experts in ethics; genetics; genomics; policy; forensic DNA; anthropology; computational science; law; human, Indigenous and migrant rights; communication; and ethnography. After two years, the group had generated a range of educational resources and gone on to apply for further grants to continue the collaboration. This initiative brought together people who otherwise would not have met, leading to new research directions.

Australian Alliance for Indigenous Genomics (ALIGN)

Key enabling mechanisms: Alliances and capacity building

Alex Brown (National Centre for Indigenous Genomics, Australian National University, Australia) introduced ALIGN: an alliance established as part of efforts to deliver equity and benefit to Indigenous Australians through genomics. The alliance is formed of community, health, research, government and industry partners across Australia. It works to enhance Indigenous understanding of genomics, identify the concerns and priorities of this population, nurture capability development, and build and extend Indigenous leadership and involvement in genomic science, research, precision healthcare, data sciences, ethics, and Indigenous knowledge systems. ALIGN is evidence that community empowerment can be a powerful research method.

ALIGN, Australian Alliance for Indigenous Genomics; CERA, Centre for ELSI Resources and Analysis; DNA, deoxyribonucleic acid; ELSI, ethical, legal and social implications.

Biodiversity, Responsibility, Innovation, Development, Growth and Education (BRIDGE) Colombia

Key enabling mechanisms: Networks and capacity building

Federica Di Palma (Genome BC and Department of Medical Genetics, University of British Columbia, Canada) described BRIDGE Colombia: a multidisciplinary network of researchers and organisations working to understand, promote and preserve Colombia's biodiversity, with the ultimate goal of stimulating economic and social growth through science and policy.

The project brought together a network of academics (including genomic scientists), with stakeholders from government, industry and local, Indigenous and marginalised communities to build trust and co-create goals. Federica discussed the complexity and time-consuming nature of uniting such diverse stakeholders, describing a year of working together before the group were able to converse using shared semantics and agree on an approach.

This effort led to a project shaped by a wide range of stakeholders, each with their own defined benefits and therefore investment, building towards project longevity and sustainability. The latter also included building a pipeline of skills and capabilities, such as retraining local land custodians to collect genetic samples and enabling sample storage and processing within Colombia.

Throughout the workshop, participants stressed the importance of building sustainability into collaborative efforts, both in terms of funding and of capacity building, and the need to deprioritise traditional scientific success measures (such as rapid publication) in lieu of setting up healthy, collaborative networks that can go on to shape research and push boundaries as a unit.

BRIDGE, Biodiversity, Responsibility, Innovation, Development, Growth and Education

Critical questions

A 'critical questions' toolkit could help enable greater collaboration and discovery research

During the workshops, participants identified, reviewed and refined the types of 'critical questions' that researchers and partners should consider throughout the research lifecycle to enable greater transdisciplinary collaboration and 'discovery research'*.

Aims of the 'critical questions' toolkit (suggested by Wellcome)

- Serve as an initial structured framework to open the door to transdisciplinary knowledge exchange.
- Foster a culture of transdisciplinary teamwork by supporting continuous and meaningful exchanges at all stages of research, from design and implementation to dissemination and translation.
- Prompt deep reflection on the various social, ethical and legal issues in the context of genomics and their nuances in different cultural and geographical settings.
- Signpost emerging literature and innovative approaches around the social, ethical and legal contexts of genomics to foster a forward-thinking research environment.
- Galvanise a culture shift towards greater collaboration and integration by helping stakeholders appreciate how it can benefit research and unlock transformative 'discovery research'*.

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Contents

Critical questions identified by participants

1. Building the research team and engaging stakeholders

- Have impacted communities been engaged and is research aligned with their needs?
- Have a broad range of specialists from genomics and its wider ethical, legal and social contexts been included?
- Have respectful team dynamics and a shared conceptual ground been built, with plans for maintaining them?
- Is everyone equipped with the knowledge and language necessary to meaningfully participate?
- Do all partners agree on the reason for the research and the benefits for all involved?

2. Designing the research

- What is the research trying to achieve?
- What is the socioeconomic context?
- Are time and resources available to engage and change the design based on feedback?
- How can everyone's input be appropriately credited?
- Who might be affected by research outputs?
- How could social and research norms evolve during the project and is there space to adapt?

3. Research development and data management

- What specific types of data are being collected?
- What guidelines exist?
- What is the data management plan and who is responsible for it?
- Do participants or data owners fully understand how their data will be handled, managed, analysed and used?
- Are systems (such as counselling) in place to address the data's ethical implications?
- How will benefits be shared?
- Is there regular, ongoing engagement with communities?
- Do all personnel have the appropriate training?
- How can we track and measure progress?
- How could sustainability be ensured beyond the funding process?

4. Research dissemination

- How have social and research norms and techniques evolved since research initiation and what does this mean for the data?
- Who is impacted by the dissemination of findings?
- Could the findings increase stigma or be weaponised and, if so, how can this be prevented?
- How can findings be turned into benefits?
- Are cultural protocols around dissemination well understood?
- What types of outputs and language should be used?
- Is there a living dissemination risk assessment plan?

5. Post-project reflection

- Was the right team assembled?
- What went wrong / was learnt along the way? Where can these be documented so they can be leveraged by other researchers?
- How can researchers and communities be empowered to apply the results?
- How can the voices that emerge from the data be amplified?

These questions will be developed into a resource for supporting dialogue and a new way of conducting research.

Key takeaways

Findings from the Wellcome ‘Ethical, Legal and Social Contexts in Genomics’ workshop series provided other important learnings

1. Need for a broader spectrum of collaborators

Expanding the spectrum of voices collaborating around genomics and its social, ethical and legal contexts could stimulate transformative ‘discovery research’* with future health and social impacts.

While ‘ELSI research’ tends to be interpreted as ‘research ethics’, participants emphasised the need to also consider the broader diversity of fields and practices relating to the wider social, ethical and legal contexts of genomics, which could lend additional, crucial perspectives for research innovation.

Participants also emphasised the importance of diversifying genomics research beyond humans, and of including insights from wider stakeholders, such as communities, civil societies, governments and industry.

Stakeholders to include in collaborations around genomics and its contexts:

- Communities
- Broad range of researchers interested in the wider contexts of genomics
- Broad range of genomics researchers
- Broader stakeholders, including from governments, industry and civil societies

2. Transformative potential of earlier, deeper collaboration

Participants recognised the importance of procedural ethics in genomics and existing types of collaboration between different researchers in the space. They also confirmed that exploring beyond this with broader, earlier, deeper collaborations between genomics researchers, researchers interested in its wider social, ethical and legal contexts, and broader stakeholders could spark new ideas and unlock new forms of ‘discovery research’*.

Upstream, fully integrated collaboration throughout the research lifecycle is an underexplored approach with huge potential for challenging assumptions; developing skills, methods, theories and concepts; and ultimately opening new fields. It could be employed to drive progress in areas such as community-led genomics; tensions between data sovereignty and data sharing; personalised and precision medicine; the application of new technologies; and synthetic genomics. However, this type of collaboration is in its early stages.

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*Defined as research across fields and disciplines that generates new knowledge with the potential to transform life, health and wellbeing.

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3. Ingredients for catalysing a culture shift

Enabling upstream, fully integrated transdisciplinary collaboration throughout the research lifecycle that fully harmonises and leverages the skills and perspectives of diverse contributors will require a significant shift in culture, research questions and epistemic orientations.

Significant logistic, political and epistemic barriers will need to be addressed by:

- Affording dedicated time, capacity and resources for collaboration, particularly in lower-resource settings.
- Incentivising collaboration, including through funding and career-based reward.
- Finding ways to constructively work through existing power differences (without dismissing them) that consider different stakeholder's understandings, interests, language and needs.
- Developing new methods and resources for working productively together.
- Evolving collaborative skillsets.
- Setting up wider infrastructure for collaboration.

Guidance, thought leadership and examples of success will help to support and catalyse this change.

Ingredients list

Thought leadership

Time and resources

Incentives

Working through power differences

New collaboration methods

Skills development

Dedicated infrastructure

Examples of success

Significant shifts in approaches to genomics, its contexts and partners

Implications for Wellcome

The content presented in this section is derived from analysis and consideration of workshop findings by the Discovery Research Programme Team at Wellcome and reflects Wellcome's commitment to action in this space.

Forward look

Based on the learnings from the Wellcome ‘Ethical, Legal and Social Contexts in Genomics’ workshop series, the Discovery Research team at Wellcome plan to work towards incentivising, creating space for and supporting earlier, deeper collaborations between genomics researchers, researchers exploring its wider social, ethical and legal contexts, and broader stakeholders. This work aims to drive broader, grounded ‘discovery research’[*] with the potential for wider health and social impacts in future. Initially, the team plans to take two actions that support enabling mechanisms prioritised by workshop participants. These are outlined below.

Action 1:
Support early-stage brokerage, networks and collaborative research through a three-step convening and funding process

1. Generate **pre-call transdisciplinary engagement opportunities** for a wide range of stakeholders,[†] fostering potential collaborations
2. Provide ‘**seed funding**’ to enable the newly formed collaborative teams to develop creative and critical discovery research[*] ideas
3. Convene funded teams to **share learnings, evaluate success** and consider routes to scale up and sustain collaborations

Wellcome’s support of this process is a recognition of the value earlier transdisciplinary collaboration at research inception can provide. It aims to create the space and freedom stakeholders need to think creatively and trial new ways of working together. Ideally, developing partnerships could be sustained in the longer-term, leading to shifts in current fields of research or the opening of new fields.

Action 2:
Further develop the ‘critical questions’ toolkit

Many guidelines exist around the social, ethical and legal contexts of genomics but these tend to focus on specific problems and are often limited to ‘home’ networks. Development of the ‘critical questions’ toolkit aims to provide a resource that can support smooth collaboration between different disciplines and geographies, helping people working on genomic research projects to fully consider how, why and when to collaborate and providing resources and case studies to support them to do so. More integrated collaboration throughout the research lifecycle could catalyse wider culture shifts and the emergence of more grounded, diverse ‘discovery research’[*]. Wellcome will explore partnerships best placed to aid the development, testing, refinement and dissemination of this toolkit.

What more can be done?

Wellcome invites other funders, the wider research community, and broader stakeholders to consider the wide range of enabling mechanisms identified in this report and partner with us to help build the conditions for broader, grounded ‘discovery research’[*] in genomics. Together, we can enable a shift in how transdisciplinary research in genomics and its wider social, ethical and legal contexts are imagined and drive transformative health and social impacts in future.

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[*] Defined as research across fields and disciplines that generates new knowledge with the potential to transform life, health and wellbeing.

[†] Including genomics researchers, researchers working on the wider social, ethical and legal contexts of genomics, and broader stakeholders (including those from communities, civil societies, governments and industry).

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Appendix

Acknowledgments

Steering Group

An international, interdisciplinary Steering Group was appointed to support development of the workshops, as well as inputting as speakers and participants. This group met before and between the events of the workshop series to advise on the format and thematic focus, review content and identify key contacts and invitees. They also provided reflections following the workshop series on the process, findings and potential next steps. The following individuals gave their consent to be acknowledged in this report for their work in shaping the series as members of the Steering Group.

Steering Group members:

Natalie Banner – Director of Ethics, Genomics England (Chair)

Alta Charo – Professor of Law & Bioethics, University of Wisconsin

Claire Chewapreecha – Senior Fellow, Genetics of Tropical Disease, MORU

Jantina de Vries – Director of the Ethics Lab and Professor of Medicine at the University of Cape Town

ThankGod Ebenezer – Bioinformatician, University of Cambridge

Zimitri Ellmore Erasmus – Associate Professor of Anthropology, Wits University

Segun Fatumo – Associate Professor of Epidemiology & Bioinformatics, Queen Mary University of London

Jessica Kolopenuk – Associate Professor and the Alberta Health Services Chair in Indigenous Health in the Faculty of Medicine and Dentistry, University of Alberta

Erisa Mwaka – Clinician & Bioethicist, Makerere University

Ting Wang – Professor of Medicine, Washington University School of Medicine

Workshop facilitation

Workshops were supported by a facilitation team from The Collective (https://www.thecollectivefacilitation.co.uk/about-us).

Writing assistance

This report was drafted with writing assistance from Helen Sims (Science Writer, Wellcome Trust, UK).

Author information

All authors were employees of Wellcome Trust, UK, at the time the work described herein was carried out. Emma Keston is now affiliated to University College London.

Contents

Co-development session participants*

Alaa Abouelfetouh, Alexandria University and Alamein International University

Abdulrazak Adebayo, Lagos State University

Julian Mawuli Adinkrah, Noguchi Memorial Institute for Medical Research

Mercy Alawode, University of Ibadan

Pamela Andanda, University of the Witwatersrand

Katja Andric, GlaxoSmithKline

Bouchra Benmrid, Mohammed VI Polytechnic University

Felicity Boardman, University of Warwick

Sarion Bowers, Wellcome Sanger Institute

Alex Brown, Australian National University

Gemma Brown, Global Alliance for Genomics and Health

Daima Bukini, Muhimbili University of Health and Allied Sciences

Alta Charo, University of Wisconsin

Patience Chatukuta, Max Planck Institute for Biology, Tübingen

Samuel Chawner, Cardiff University

Claire Chewapreecha, Mahidol-Oxford Tropical Medicine Research Unit

Bethânia de Araújo Almeida, Oswaldo Cruz Foundation

Jantina de Vries, University of Cape Town

Federica Di Palma, Genome British Columbia

ThankGod Echezona Ebenezer, University of Cambridge

Zimitri Erasmus, University of the Witwatersrand

Cornelius Ewuoso, University of the Witwatersrand

Segun Fatumo, The London School of Hygiene and Tropical Medicine

Cristina Fonseca, Genetics Society

Richard Gorman, Brighton and Sussex Medical School

Sasha Henriques, Wellcome Connecting Science

Maui Hudson, University of Waikato

Kazuto Kato, Osaka University

Robyn Kerr, University of the Witwatersrand

Thandeka Khoza, Africa Health Research Institute

Candice King, Genomics England

Diana Gladys Kolieghu Tcheumeni, University of Buea

Jessica Kolopenuk, University of Alberta

Melodie Labuschaigne, University of South Africa

Sandra Soo-Jin Lee, Columbia University

Valeriano López Segura, Universidad de los Andes

Mavis Machirori, Ada Lovelace Institute

Maxine Mackintosh, One Health Tech and Data Science for Health Equity

Ali Mahmoud Youssouf, Bio-reach

Don Mangowa, University of Johannesburg

Sapna Mahajan, Genome Canada

Aisling McMahon, Maynooth University

Lebogang Montewa, University of South Africa

Tiwonge Mtande, Kamuzu University of Health Sciences

Irene Muchada, University of the Western Cape

Catherine Mutinda, Pumwani Maternity Hospital

Erisa Mwaka, Makere University

Monde Mwamba, Zambart

Harriet Nankya, Makerere University

Barbara Nerima, Makerere University

Lydia Okoibhole, Wellcome Connecting Science

Taiwo Crossby Omotoriogun, Elizade University

Chika Onwuamah, Nigerian Institute of Medical Research, Centre for Human Virology and Genomics

Mike Parker, University of Oxford

Thato Regonamanye, Botswana-Baylor Children's Clinical Centre of Excellence

Daniela Robles-Espinoza, Universidad Nacional Autónoma de México

Daniel Sekwo, University of Leicester

Yemisrach Seralegne, Armauer Hansen Research Institute

Mercury Shitindo, St Paul's University, Africa Bioethics Network

Musonda Simwinga, Zambart

Patricia Swart, Stellenbosch University

Abraham Tekola Gebremedhn, Armauer Hansen Research Institute

Limbani Thengo, Partners In Health

Lealem Wagaw, Addis Ababa University

Ting Wang, Washington University, School of Medicine

Abdulmojeed Yakubu, Nasarawa State University

Betselot Yirsaw, Global Fund-Country Coordinating Mechanism of Ethiopia

Khoo Yoong Khean, Duke-National University of Singapore, Centre for Outbreak Preparedness

---

*Excluding Wellcome staff and facilitators.

Contents

London workshop participants*

Alaa Abouelfetouh, Alexandria University and Alamein International University

Abdulrazak Adebayo, Lagos State University

Julian Mawuli Adinkrah, Noguchi Memorial Institute for Medical Research

Mercy Alawode, University of Ibadan

Pamela Andanda, University of the Witwatersrand

Katja Andric, GlaxoSmithKline

Natalie Banner, Genomics England

Bouchra Benmrid, Mohammed VI Polytechnic University

Benjamin Berkman, National Institutes of Health

Felicity Boardman, University of Warwick

Sarion Bowers, Wellcome Sanger Institute

Alex Brown, Australian National University

Gemma Brown, Global Alliance for Genomics and Health

Daima Bukini, Muhimbili University of Health and Allied Sciences

Alta Charo, University of Wisconsin

Patience Chatukuta, Max Planck Institute for Biology, Tübingen

Claire Chewapreecha, Mahidol-Oxford Tropical Medicine Research Unit

Chinenyenwa Fortune ChinChukwuneme, Vaal University of Technology

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Jantina de Vries, University of Cape Town

Federica Di Palma, Genome British Columbia

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Segun Fatumo, The London School of Hygiene and Tropical Medicine

Cristina Fonseca, Genetics Society

Richard Gorman, Brighton and Sussex Medical School

Sasha Henriques, Wellcome Connecting Science

Sarah Hersey, World Health Organisation

Maui Hudson, University of Waikato

Kazuto Kato, Osaka University

Robyn Kerr, University of the Witwatersrand

Thandeka Khoza, Africa Health Research Institute

Candice King, Genomics England

Diana Gladys Kolieghu Tcheumeni, University of Buea

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Melodie Labuschaigne, University of South Africa

Sandra Soo-Jin Lee, Columbia University

Valeriano López Segura, Universidad de los Andes

Mavis Machirori, Ada Lovelace Institute

Ali Mahmoud Youssouf, Bio-reach

Don Mangowa, University of Johannesburg

Gerald Mboowa, Makerere University

Johanna McEntyre, EMBL-EBI Services

Aisling McMahon, Maynooth University

Lebogang Montewa, University of South Africa

Tiwonge Mtande, Kamuzu University of Health Sciences

Irene Muchada, University of the Western Cape

Catherine Mutinda, Pumwani Maternity Hospital

Erisa Mwaka, Makere University

Monde Mwamba, Zambart

Harriet Nankya, Makerere University

Barbara Nerima, Makerere University

Wesley Oakes, Genome Canada

Lydia Okoibhole, Wellcome Connecting Science

Taiwo Crossby Omotoriogun, Elizade University

Chika Onwuamah, Nigerian Institute of Medical Research, Centre for Human Virology and Genomics

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Ting Wang, Washington University, School of Medicine

Susie Weller, Clinical Ethics, Law, and Society (CELS) research group, University of Oxford

Abdulmojeed Yakubu, Nasarawa State University

Betselot Yirsaw, Global Fund-Country Coordinating Mechanism of Ethiopia

Khoo Yoong Khean, Duke-National University of Singapore, Centre for Outbreak Preparedness

Cape Town workshop participants*

Alaa Abouelfetouh, Alexandria University and Alamein International University

Abdulrazak Adebayo, Lagos State University

Julian Mawuli Adinkrah, Noguchi Memorial Institute for Medical Research

Mercy Alawode, University of Ibadan

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Agenda

Co-development session
22 Jan 2024

Time (GMT)	Activity
12:30	Welcome
13:00	Opportunities and gaps discussion
14:00	Challenges world café
16:00	Next steps

ELS: Ethical, legal and social
GMT: Greenwich Mean Time
SAST: South African Standard Time

London workshop
Day 1 – 25 March 2024

Time (GMT)	Activity
09:30	Day one introduction
10:00	Beyond ELS: opportunities to develop broader critical perspectives
14:30	Rethinking and reshaping genomics and ELS: opportunities for field opening
17:00	Reflections on day one

Day 2 – 26 March 2024

Time (GMT)	Activity
09:00	Day two introduction
09:30	Integrating Genomics and ELS: opportunities for practical collaboration
12:00	Research lifecycle and critical questions: critical questions development
15:30	Emerging issues and priorities

Cape Town workshop
Day 1 – 24 April 2024

Time (SAST)	Activity
10:00	Day one introduction
11:30	Infrastructure for collaboration
14:00	Resources (including guidance, toolkits and frameworks)
17:00	Reflections on day one

Day 2 – 25 April 2024

Time (SAST)	Activity
09:00	Day two introduction
09:30	Alliances, networks and consortia
11:30	Funding calls and funding models
15:00	Reflections on day two and emerging priorities

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Wellcome Trust, 215 Euston Road, London NW1 2BE, United Kingdom
T +44 (0)20 7611 8888, E contact@wellcome.org, wellcome.org

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