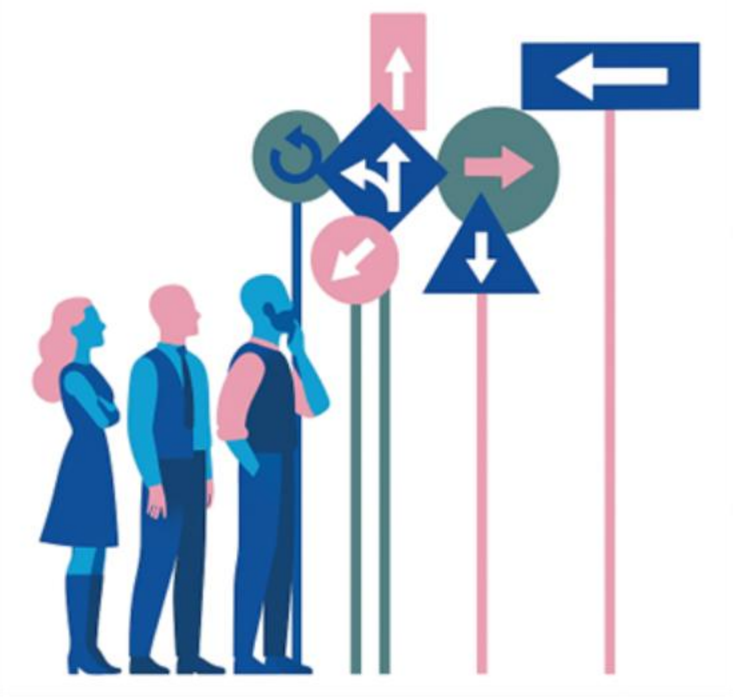
Environmental Ethics and Genomic Data Governance LINEAGE Targeted Research Project Workshop (August 2025)



WORKSHOP REPORT

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1. Introduction: Professor Ainsley Newson

Professor Ainsley Newson introduced the LINEAGE Study to attendees and explained how the Targeted Project on Environmental Ethics and Genomic Data Governance fits into the overall research program.

The LINEAGE study's main aim is to explore how genomic datasets can be governed effectively and responsibly while accounting for the various settings where genomic data is generated and used. To achieve this, the legal, sociological and ethical dimensions of genomic data governance need to be considered. LINEAGE's main output will be a framework for the ethical governance of genomic data in Australia.

Whether and how environmental considerations should be accounted for throughout the genomic data life cycle remain unanswered questions. Currently there is an assumption that genomic data is a public good, and the more we have of it, the better for society. Existing regulatory and governance instruments are mostly silent on the environmental consequences of genomics. This is problematic as human genomics generates, stores and uses large amounts of data that necessarily impacts the environment.

The **aims of this targeted research project** within LINEAGE are to: consider the strongest objections to incorporating environmental ethics in genomic data governance, develop normative bioethics scholarship to draw attention to this issue, and generate recommendations in collaboration with workshop participants.

2. Keynote presentation - Embedding Environmental Ethics in the Genomic Age: Challenges and Imperatives

Dr Gabrielle Samuel from King's College London provided a powerful overview of the environmental impact of both healthcare and digital technologies throughout their respective lifecycles.

Data ultimately requires material infrastructure to be stored, processed and transported. The environmental impact therefore doesn't only arise from intensive energy consumption but starts from:

- The mining and extraction of resources,
- Manufacturing of hardware, and
- Disposal of waste once the lifespan of the hardware has expired.

Dr Samuel also noted that human genomics involves both wet labs (e.g., biobanking and sample processing) and dry labs (e.g., data repositories) and is a subset of both healthcare and digital technology with significant environmental impact that is growing rapidly.

At all junctures of the genomics data lifecycle, there are humans involved who are impacted in different ways, from those who mine the materials used in hardware, to those who analyse the data, through to people in low-income countries processing toxic e-waste.

In exploring whether ethics demands we should do something about the environmental harms associated with human genomics, Dr Samuel noted that regardless of whether one believes the environment has intrinsic moral value, or whether it only has instrumental value in relation to humans, both views converge on the need to care for the environment. It is contradictory to aim to improve health through genomics while simultaneously contributing to environmental harms that undermine health.

To understand how ethics can guide responses to environmental harms in genomics, we can draw on several traditions. A summary of different scholarly traditions that address environmental ethics was highlighted, including care ethics, Indigenous approaches, one health, planetary health, and eco-feminism among others. Regardless of the approach taken, key overarching tensions that need to be considered include the relative moral value of the environment and humans; the relative moral claims of future versus present generations; and the magnitude versus certainty of harms and benefits.

Distributive justice was highlighted as a critical consideration, as it is important to be clear about whose interests are being pursued. There are the beneficiaries of human genomics, who are mainly living in high-income settings, and then there are people in low income settings who are working in unsafe environments to support human genomics infrastructures. How do we value and balance the impact that our actions have, both

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directly and indirectly, on all the different groups that bear the benefits and harms of the entire human genomics data lifecycle? This, and other critical questions, need to be addressed and how we answer them ultimately depends on what theoretical framework we decide to use.

Once we have decided that the environmental harms of genomic data need to be tackled, the next issue to consider is who will be responsible for taking the necessary steps. This requires us to consider both collective and individual responsibilities, as well as the capacity for different individuals and groups to respond effectively. So, for instance, while hospitals may contribute to environmental harms, some have argued it is not necessarily their responsibility to mitigate the harms, as they don't have the expertise, resources, or tools to make the required changes. This has given rise to a significant grass roots advocacy movement that is driving the development of tools and resources for researchers, clinicians and other groups to enable them to understand the environmental impacts of their decisions and to raise awareness and thereby encourage them to take the responsibility they have.[1]

If we accept that responsibility requires one's capacity to respond, then we must recognise that it is difficult to demand responsibility in contexts where the decisions of individuals are severely constrained by context. This includes the conceptual context that promotes the socio-technical imaginary where collecting ever more data will improve health and wellbeing; the socio-political context that promotes a neoliberal and competitive version of research where you have to move fast and be first to get recognition, undermining potential opportunities for collaboration; and the institutional context which has its own primary goals and interests to pursue. We must also seriously consider the possibility that neoliberal ideals are so deeply embedded in our current cultural milieu, or that institutions are so single-minded in pursuit of their interests, that the space to minimise environmental harms is highly limited.

There are a wide array of institutions and individuals involved in human genomics, and when thinking of responsibilities, we must consider them all. This includes individual researchers, healthcare professionals, laboratory technicians, hospitals and other healthcare institutions, biobanks, funding bodies, governments, among others. We could argue that all actors have some capacity to take action but must recognise that this ability is highly contingent. For instance, individuals employed and contractually bound to institutions have limited power to make changes if those changes are not supported by institutions. It is therefore unlikely that significant change will happen without monitoring and accountability, especially at the national and international levels. The challenge is

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[1] There are also accreditation systems that have been developed for institutions such as UNSW's Laboratory Efficiency Assessment Framework (LEAF) which has become one of the most significant green lab accreditation programs globally, and now in France the government requires any AI-related funding applications to include an environmental footprint assessment.

national priorities do not always align with environmental goals, and international agreements are not binding.

It is important to recognise that our work is not just about reducing environmental impacts directly, but more fundamentally and pragmatically, it is about advocacy targeted at building awareness which will drive the type of change that is needed. The evolution of animal research ethics is an instructive case in point. It has been shown that the main driver for the development of animal research ethics was socio-political changes in response to advocacy. The animal rights community made a reasonable moral compromise, starting with the three R's: replace (i.e. don't use animals unless necessary), reduce (i.e. if still necessary, utilise the least amount of animals needed), and refine (i.e. enhance animal wellbeing). This made it possible to institutionalise animal research ethics. We can learn from this example and likewise seek a moral compromise for managing environmental harms in human genomics as well.

How we frame environmental concerns is critical. If we want to have a real impact, we need to frame them in terms of co-benefits for all actors. For instance, if we can make human genomics more environmentally sustainable, we could emphasise that this will also have a co-benefit of reducing cost. In the process, we de-politicise the topic and make the focus about doing science well and efficiently. If we can make environmental considerations an integral component of scientific quality, rather than merely an add-on concern, then we can start to achieve real change.

In summary, embedding environmental ethics into genomic data governance requires recognising the full lifecycle of data, the diverse actors involved, and the ethical tensions that arise. Advocacy, awareness, and institutional support are key to driving meaningful change.

3. Targeted Project - Limiting Human Genomic Data Generation and Retention for Environmental Reasons[2]

Building on the overview presented by Dr Samuel, project Research Assistant Dr Wendy Xin presented a robust philosophical defence for limiting genomic data generation and retention on environmental grounds. Dr Xin ***formulated the claim of those who may object to limiting data generation and retention*** *as follows:*

> "We should not limit the generation and retention of human genomic when it might become valuable in future for human health. We should resort to other means (e.g., improve data storage facilities) to reduce the environmental harms associated with human genomic data."

In analysing this claim, Dr Xin noted that there are two types of costs that must be compared. The first is the potential loss of health benefits from genomics if data generation and retention is limited, and the potential environmental harms if it is not. Dr Xin argued that accepting the proposed claim makes certain assumptions regarding the magnitude and certainty of the costs. At the very least, it assumes the potential loss of health benefits from less genomic data is always more valuable and should always outweigh environmental harms. However, this does not hold up to scrutiny as it is entirely possible that the potential environmental harms could be of proportionally greater magnitude and certainty than the potential loss in health benefits.

The original claim also ignores how benefits and harms are distributed. It is well established that people living in low resource settings are disproportionately impacted by climate change, yet at least some types of genomic data research (e.g. those leading to the development of high-cost drugs for rare diseases) are most likely to be of benefit to relatively wealthy individuals, or individuals living in relatively wealthy countries. Pursuing genomic data research without consideration of such disparities will exacerbate social injustices.

If we accept that human genomics generates a net benefit for some, and a net harm for others, it is important to know how to modify our decisions to mitigate or minimise the potential injustice. This requires us to have a concept of a "sufficiently good" or "good enough" life. While defining such a concept in detail is not the intention here, and any definition will be highly contested, for our purposes we will assume such a concept exists in principle. This would suggest that our decisions regarding genomic data generation and retention should be modified in a way to prioritize shifting people from a life that is not good enough, to a good enough life, and avoid shifting people from a good enough to a not good enough life. In this case, there is a strong reason to argue that in cases where the benefits of human genomics seek primarily to move people from a "good enough" life

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[2] The paper related to this project has now been accepted for publication. Xin W, Ghinea N, Newson A. Limiting human genomic data generation and retention for environmental reasons. *Bioethics* (In Press).

to a better life, we should prioritize reducing environmental harms that may at the same time move people from “good enough” to a worse state.

Another more controversial reason to prioritise reducing environmental harms when it comes to deciding whether to generate and retain genomic data is to make a distinction, as some philosophers do, between committing a harm, and allowing a harm to happen. If we accept that allowing a harm to happen is not as morally blameworthy as committing a harm, then we could argue that the harms that arise from not collecting genomic data that may improve treatment downstream is less blameworthy than actively causing environmental harm by collecting, storing and analysing the data.

In summary, Dr Xin concluded that the **original claim (as stated at the start of this summary) cannot be sustained all the time**, due to modifiers such as the magnitude of harm, certainty of the harms, and whether we accept harms arising from commission are more morally problematic than those arising from omission.

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4. Targeted Project - Environmental Considerations in Human Genomic Data Governance: Overcoming Normative Challenges[3]

*Project Research Fellow Dr Narcyz Ghinea presented his work which identified and sought to respond to **five main challenges** to the idea that genomic data governance should take account of environmental considerations.*

The five challenges were identified based on a deep reading of available literature. The focus of this work was on conceptual challenges to environmental action, rather than structural challenges which have been documented and discussed elsewhere.

It is critical to recognise that human genomics is already a form of big data, and the amount of genomic data we are collecting, storing and analyzing is exponentially increasing, because there is a:

1. significant push to conduct routine whole genome sequencing rather than targeted sequencing; and
2. concerted effort to implement genomic medicine routinely in clinical care.

This is therefore the right time to consider the environmental implications of these activities and consider what we can do about it. The below table summarises the five challenges and responses to them, as outlined in the presentation.

Challenge	Explanation	Responses
Genomic Data Optimism	Assumption that more data is better for society as it will improve health and well-being.	- Generating more data than we need - Generating more data than we can use/understand. - Old data made redundant by new sequencing technology - Need to manage "dark data" i.e. lost and forgotten
Outcome Measurement	Challenging to measure environmental harms so cannot account for it meaningfully.	- Certainty of harm: environmental impact of genomics exists - Uncertainty of benefits of genomics: difficult to measure actual impact - Ethics allows for weighing incommensurable and unquantifiable values/benefits
Responsibility challenge	Difficult to assign responsibility for environmental harms to individuals.	- All can choose the least worst option available to them: weak duty - All have a responsibility not to be complicit within epistemic and control constraints - Institutional responsibility to facilitate individual duties - Can limit strong duty to specific targeted initiatives
Worse Offender	Other industries are less valorous yet more polluting so focus on those first.	- Environmental harm is the result of cumulative actions, so a collective response is also need. - What determines a valorous industry is ambiguous, as benefits often accrue to the few, but environmental harms burden everyone

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[3] The paper related to this project has now been published. Ghinea N, Xin W, Samuel G, Lucassen A, Newson AJ. Environmental considerations in human genomic data governance: overcoming normative challenges. *BMC Med Ethics*. 2026;27(1):64. doi:10.1186/s12910-026-01417-3

Technological idealism	Technology will solve the problem.	- Rebound effect: greater efficiency leads to more intensive use mitigating benefits from technology - Need to behavioural interventions based on values to ensure efficiency gains are utilised appropriately

Dr Ghinea concluded by noting that humanity has had a poor history managing long-term consequences of their actions, even when they are entirely foreseeable, and especially with regard to the environment. He contended that the environmental impact of human genomics, is largely certain, even if the exact magnitude is not. If we want to avoid an exacerbation of the environmental harms we are confronting today, now is the best time to take action.

5. Discussion and Conclusion

Participants agreed on numerous points that should be considered when it comes to incorporating environmental ethics in genomic data governance.

- **Maintaining competitiveness:** Nations compete in a global economic context. If accounting for environmental considerations disadvantages Australia's competitive position in the human genomics sector, it is less likely to be adopted. There is potentially scope for creating a market for "greener" human genomics solutions.
- **Indigenous ethics:** The challenge of Indigenous land-related ethics is that it has been developed within the context of relatively localised spaces and small communities. It is not necessarily suited for large, complex, global communities. We therefore need to take the ideas from Indigenous modes of thinking about the environment and incorporate them to make it workable on a global scale.
- **Focus on advocacy**: Focusing on reducing environmental impact at this stage is premature. We should focus on advocacy, awareness raising, creating legacies, and then the change will come. Rather than try to make massive resource-intensive system changes, we can focus on making small incremental changes that gradually raise awareness through bottom-up advocacy. What is critical is signalling - we don't necessarily believe our suggestions will solve the environmental challenges, but at least we are thinking about the problem and thereby demonstrating its importance.
- **Clarity around a "good enough" life:** Regarding a baseline for a "good enough" life, we need to consider how we build in variability in experience. We can't just group everyone under a single standard as this could lead to injustices. The standard will likely differ depending on the community and the stage in the life course of a disease. There is a temporal element, and multiple intersections with the health system throughout. Need to consider how this flexibility gets conveyed in the governance framework. What is "good enough" for an informal e-waste worker in India is very different to what may be "good enough" to a patient with a rare disease in Australia. At the same time, we must be wary of adaptive preferences, that is, people may settle for lower standards because of oppressive environments but that doesn't make it a legitimate standard.
- **Need to start empirical work and broader conversations:** It is time to have conversations about the issues raised with a much broader audience, especially those with genetic conditions. We could start with the LINEAGE Consumer Advisory Group and go from there. This work could also help identify which co-benefit framing of the issue would gain most traction. It was noted that it is critical to carefully consider "how" such conversations with the wider community should be approached.
- **Harms arising from commission and omission:** When considering the moral difference between omission and commission of an act that leads to harm, it was

suggested that it is important to consider the degree of potential harm and ease of intervening. For instance, there is a large difference between not saving someone who is drowning when it is well within one's power to do so, and not taking action to help improve someone's eczema when you are able to so. Context seems to dictate the moral evaluation of commissions and omissions.

- **Innovation idealism:** One overlooked question is whether innovation is, in fact, necessary. There is an assumption that innovation will always lead to some improvement, when in fact it can lead to harm. For instance, we may overuse new innovations or use interventions that have no clear benefit and may produce harms. If you add the environmental harm aspect to this, then it changes the calculus. Companies involved in these areas do have a responsibility. The challenge is that politicians are very supportive of technological innovation because they are looking at economic productivity, and economic value. What necessitates innovation?
- **Mapping:** It would help to better understand this issue if we could put together a stakeholder map that looks at what issues need to be addressed, and by whom, at different points in the human genomic data lifecycle. To do this we need greater clarity regarding who produces the data, who collects it, who owns it, who shares it, who benefits or is disadvantaged from its use.
- **Be wary of overreach:** Solving environmental challenges is ultimately a socio-political challenge that demands international collaboration. We need to be very cautious of over-reaching and be aware that LINEAGE isn't going to solve the environmental challenges associated with human genomics as it is embedded in a far larger digital technology and innovation economy. We need to consider what is it that LINEAGE can achieve. It may simply be to raise awareness, promote a weak duty to act where possible, or for case building. Part of raising awareness could be to help people realise more data is not always better, and if we share data more effectively, we probably don't need to generate so much new data.
- **Gap analysis:** There is no literature and no data about the environmental impacts of human genomics. This means any work in this space is going to be highly conceptual. We could start by identifying what the empirical gaps are as part of raising awareness and putting in place the pieces needed to tackle the challenge and inform the narrative.
- **Translatability of other work:** It was noted that we should not try to reinvent the wheel when it comes to tackling environmental harms. We need to consider what makes human genomics different to other industries and see if there is any work easily translatable from those contexts to our project.
- **Balancing interests:** There is still work to be done in understanding the circumstances under which environmental concerns should trump human interests, and how to balance long-term impacts versus short term gains.

Overall, embedding environmental ethics into genomic data governance demands a nuanced, context-sensitive approach. While global competitiveness may limit uptake of sustainability measures, opportunities exist to embed greener genomic solutions.

At this stage, advocacy and awareness-raising of environmental costs of genomic data are more feasible than sweeping reforms, and small, strategic actions can signal the importance of environmental concerns. We must also engage with communities, especially those with genetic conditions, to shape meaningful responses.

Ethical distinctions between commission and omission, and the risks of innovation idealism, further complicate the landscape. Mapping stakeholders and identifying empirical gaps will help us understand who holds responsibility and where interventions are most needed. Ultimately, this LINEAGE Targeted Project can play a vital role in building the case for change, even if it cannot solve the challenge alone.

Workshop Thanks

Workshop Convenors:

Professor Ainsley Newson, Dr Narcyz Ghinea, Dr Wendy Xin

International Keynote Speaker:

Dr Gabrielle (Gabby) Samuel

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