

Mapping Global Bioethics Organisations to Support a Policy-Focused Community of Practice

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Purpose

The purpose of this project was to identify bioethics organisations and networks that seek to influence policy, to characterise the connections between these organisations and networks, and to explore the value of establishing a global, policy-focused bioethics community of practice.

This project was commissioned by the Nuffield Council on Bioethics (NCOB), which sought to better understand the collaborative relationships between policy-oriented bioethics organisations and whether creating a policy-oriented bioethics network would be duplicative of existing networks or bring additional value to the broader practice.

From the inception of this work, we hypothesised that the field of policy-oriented bioethics organisations was comparatively narrow, and that only limited active networks of think tank organisations dedicated to this work existed.

Main Findings

Through our analysis, we characterised 76 organisations and 17 networks or partnerships in our [database](#). For our [visual network analysis](#), we included a total of 166 organisations, initiatives, and projects. We conducted interviews with 6 bioethics experts. A detailed description of our approach and its limitations is provided at the end of this report.

A network of loosely connected networks

We developed a [network map](#) in [Kumu.io](#) to identify connections between bioethics organisations, whether through collaborations or membership in bioethics networks with some policy focus.

This reveals several networks or collaborations between organisations and a minority of influential organisations involved in multiple networks or projects. For example, the National University of Singapore's Centre for Biomedical Ethics is a WHO Collaborating Centre for Bioethics, member of the Southeast Asia Bioethics Network, and has established a collaboration with the Hastings Center to develop bioethics scholarship in Asia.

Joint reports and publications serve as another main connecting point for organisations, though the abundance of academic organisations has in the main led to outputs in the form of peer-reviewed journal articles written by individuals, rather than as a collaboration of two or more organisations. In many cases, publications authored by organisations were done so independently or with authors from other organisations serving in a non-institutional capacity.

Some organisations in the network map, such as the Scottish Council on Human Bioethics and American College of Physicians Center for Ethics and Professionalism are free-floating, indicating an absence of collaborations or shared networks with other policy-oriented bioethics organisations. This map can be used as a starting point to identify organisations of interest, including well-connected organisations that can support the creation and/or expansion of a network and to highlight organisations that are comparatively disconnected/ or more connected from/to others.

Ethics-focused organisations often cluster around a central organisation

Many organisations, especially those at universities, were connected to other departments or programmes at a shared institution. For example, the University of Oxford is home to no fewer than three organisations that seek to influence policy through bioethics research: the Ethox Centre, Oxford Ethics and Humanities, and the Uehiro Oxford Institute. This could reflect deliberate efforts to incorporate bioethics inquiry across an institution, demonstrate the nature of individuals to have affiliations to several groups or organisations, or be guided by a shared funder.

Individuals, rather than organisations, are often sought out for collaborations

Although some organisations have participated in organisation-to-organisation collaborations, interview participants and an analysis of publications revealed a tendency for collaborations to develop between individuals acting in their own capacity and not as a representative of their primary organisation. As one participant noted, it is common for individuals to become known for their expertise in certain areas and through this to be repeatedly recruited to initiatives or projects in which that expertise was needed. While understandable from an expertise point of view, this bears a risk of repeated recruitment of the same experts, both restricting the expansion of networks to those not as well-established and risking homogeneity of thought.

The need for a policy-oriented bioethics network

Our analysis found that there are a small number of policy-oriented bioethics networks, but the most impactful ones tend to be at the national level and higher. Groups such as the UNESCO Intergovernmental Bioethics Committee (IGBC), comprised of representatives of 36 UNESCO member states, have clear policy-related mandates, including the discussion of key topics through an ethical framework and the distillation of findings and recommendations, to be disseminated to member states for reference.

Several of the bioethics networks that we uncovered are less policy-oriented, including regional networks that seek to share resources, develop the capacity of ethics centres, and to emphasise issues representative of shared, regional interests. Capacity development is of particular interest to – but not exclusive to – networks comprising members in low- and middle-income countries. For these organisations and networks, the ethics and policies of research partnerships between organisations in the Global South and Global North are also prominent topics of discussion and critical inquiry.

While we identified only a small number of organisation-to-organisation networks, some interview participants also noted the existence of informal networks of policy-oriented individuals who often collaborated with one another. At times, collaborations between such individuals are formalised through shared projects or initiatives, often focused on singular issues for ad hoc projects (e.g., genomics, special commissions, etc.). One participant raised the concern that members of working groups recruited to discuss ethical issues and develop consensus for publication in reports were often recruited due to similarity of thought. For those collaborations which did not hinge on the development of publications, which often signaled an end for the ad hoc working group, lack of sustained interest and investment risked dissolution or indefinite hiatuses. For example, the US National Human Genome Research Institute provided grants to establish 11 [Centers of Excellence in ELSI Research \(CEER\)](#) and 5 Exploratory Centers from 2004-2024, holding its [final network meeting](#) in May 2024.

Critically, there seemed to be a general consensus amongst the experts we spoke with that there was a space for a dedicated policy-oriented bioethics network. One expert stated that policymakers lack bioethics-centred convening power and network familiarity that organisations like NCOB have. This can hinder the ability to assemble diverse perspectives and risk overreliance on individuals to recommend additional individuals rather than considering the request in a systematic way. Others indicated the special utility of a policy-oriented bioethics network amongst countries with similar governance structures/cultural contexts to ensure that knowledge shared was more generalisable to participants.

The field of bioethics is in a state of tension

In approaching the value of a policy-oriented bioethics network, two challenges became apparent through our discussions with experts: 1) the challenge of establishing policy recommendations at an organisational level and 2) shifting expectations from a progressively diminishing pool of funders.

The relative rarity of organisation-to-organisation collaborations can at least be partially explained by differing beliefs amongst bioethicists at an organisation, whether related to a specific ethical issue or disagreements in the extent to which bioethicists should attempt to effect policy change or public opinion at all. Policy-oriented bioethics organisations contribute to policy discourse in myriad ways, from public engagement to awareness raising, testimonies to lawmakers, and publication of reports and briefs ranging from circumspect analyses intended to guide policymakers to robust recommendations.

Many organisations and networks tend to measure their success in traditionally academic ways, through the publication and presentation of findings in peer-reviewed journals and at academic conferences. More partisan, policy-focused organisations such as the [National Catholic Bioethics Center](#) and [Scottish Council on Human Bioethics](#) have strongly established stances related to issues such as abortion and physician-assisted suicide. Such organisations can establish a quorum with considerably greater ease, whether within their organisation or in partnership with similarly oriented organisations.

Amid ongoing, substantial financial cuts across the United States' federal government—and termination of billions of dollars of grants for academic institutions—many researchers reliant on funding sources like the US National Institutes of Health are under immense pressure to identify and secure alternate funding. A rapidly narrowing finance pool threatens collaborative efforts as individuals and institutions vie for the same, limited funds and voluntary participation in workshops and commissions is deprioritised. Beyond this significant shockwave, increasing expectations that researchers link their work to real-world impact has demanded a greater focus on policy and led researchers—including those with less experience in policy—to issue more direct recommendations.

The Greenwall Foundation, through its [“Making a Difference in Real-World Bioethics Dilemmas”](#) grant program, has encouraged the application of bioethics research to pressing real-world bioethics issues. Noting that “successful teams commonly involve a bioethics scholar and persons with on-the-ground experience with the bioethics dilemma,” this foundation indirectly encourages interdisciplinary partnerships relying on and building upon counterparts' specific expertise. Other funders have had a clear impact in the development of bioethics networks. Under the National Institutes of Health, the Fogarty International Center has stimulated connectivity through its efforts to develop bioethics research capacity through its [African Bioethics Post-Doctoral Fellowship Program](#), creating direct connections between African bioethicists and bioethicists at Johns Hopkins University and the Ethox Centre. The Wellcome Trust has been a critical participant or funder in several networks and collaborative projects, including the Southeast Asia Bioethics Network, the Global Infectious Disease Ethics Collaborative (GLIDE), the Nuffield Council on Bioethics, and the Global Forum on Bioethics and Research.

What experts say is needed or would be beneficial

Relevant to the success of a policy-oriented bioethics community of practice is a commonality to tie organisations together, such as a shared legacy, legal approach, language, or region of practice. Several regional networks have developed with this in mind, especially in areas of the Global South where networks like the Southeast Asia Bioethics Network seek to develop capacity of member organisations and to “raise Southeast Asian perspectives and provide a platform for unheard and underrepresented voices in bioethics.” One expert described a common phenomenon by which networks may be funded as part of a broader funding package, with a comparatively small amount allocated for ethical thinking that encourages collaboration around a more focused cause. Although this can create small networks, this narrow focus could impinge the ability or desire for such networks to be brought into a broader one, where interests may not always align. Finally, outside of cultural or legal similarities driving engagement, One interviewee noted that the value of international engagement (or not) can also be driven by practicalities of project staging: “does it add value to my work to engage more broadly *now*?...”

As noted throughout this report, differences in culture, capacity, governance, project management, mechanisms to influence policy, and progress toward elevating bioethics issues to the policy level can mean that what is successful or useful in one context may not be in

another. For this reason, networking may or may not make individuals' or organisations' work more efficient. The experts we spoke with predominantly came from the Global North but conducted research with partners in the Global South. Although our analysis found that organisations and networks in the Global South tended to have a greater focus on capacity development and equitable research partnerships than their counterparts in the Global North, many work on similar ethical issues such as artificial intelligence, pandemic preparedness and health equity, and genomics research.

The notion that capacity development is unidirectional belies how much institutions and networks in the Global North can learn from those in the Global South, particularly with regards to establishing new networks. One expert commented that organisations in high-income countries may lag in applying the needed mechanisms and mobility to easily bring organisations together to discuss bioethics issues: actions that networks in the Global South are often well-organised to facilitate.

Amongst experts, opinions varied on what a successful network might look like. Suggestions included:

- A network or registry of experts that could be leveraged to discuss pertinent bioethics issues, similar to the model of the [National Academies of Science](#), which explicitly states “All committee members serve as individual experts, not as representatives of organizations or interest groups.”
- A network of organisations and/or individuals who meet semi-regularly to discuss bioethics issues and conduct horizon-scanning exercises to identify and anticipate emerging bioethics issues. This is [similar to work that the NCOB currently conducts](#).
- A community of practice in which organisations could share current approaches and best practices to support and develop the capacity of participating individuals and institutions to translate ethics research into policy impact. Such work should be strongly caveated with the understanding that perspectives, cultural relevance, ascribed importance, and progress in approaching bioethics issues will vary substantially between organisations and regions.

Conclusions

- The field of bioethics has made strides toward achieving real-world impact and influencing policy, but formalised policy-focused networks and cross-organisation collaborations remain relatively rare.
- Many policy-oriented collaborations tend to convene experts serving in their individual, rather than institutional, capacities and draw from small and informal networks that could favor the same, well-connected experts.
- The global landscape of policy-oriented bioethics organisations generally consists of concentric networks with connections between a minority of member institutions involved in bioethics collaborations rather than direct collaborations at the network level.

- Funding tensions should be borne carefully in mind. A rapidly narrowing pool threatens collaborative efforts as individuals and institutions vie for the same, limited funds. The value-add and non-duplicativeness of a network for all participating organisations should be clear, with the argument for a ‘rising tide which lifts all ships’ made carefully.
- There is likely to be value in creating a policy-oriented bioethics community of practice, but the capacity, comfort, and experience to contribute may differ significantly between members, depending on their individual priorities, pressures, and cultural contexts. Focusing the network on mutually beneficial areas—such as horizon scanning or the sharing of best practices in translating ethics outputs into policy impact—may be the most beneficial.

Approach

We conducted desk research and informal, unstructured interviews with key opinion leaders to identify notable bioethics groups and existing partnerships and networks. This research employed an iterative process, with early research informing our understanding of how organisations were connected and the different forms in which policy impact might manifest. We began our search by examining influential organisations like the Nuffield Council on Bioethics, Hastings Center for Bioethics, the Ethox Centre (University of Oxford), the Johns Hopkins Berman Institute of Bioethics, and the UNESCO International Bioethics Committee to identify additional organisations and collaborations through publications and member affiliations.

We extracted information on the mission; stated goals, objectives, or aims, especially as they related to policy impact; location; bioethics focus areas; activities through which organisations sought to exert policy impact; and funding streams. In establishing the mission and activities of each organisation and partnership, we often extracted information verbatim from organisational websites, noting that an organisation’s perception of its influence on policy might vary from our own. This approach was not intended to be exhaustive but rather to provide a general overview of the different ways in which influential organisations and networks were connected and identify notable gaps that a new network might fill. We excluded organisations from the database for which there was not a clear reference to policy-oriented activities and those whose policy focus was limited to research ethics.

We used kumu.io to create a network map visualising how different organisations and networks were or were not connected. We displayed key publications, collaborative projects, and networks that connected organisations. To facilitate a better understanding of the network in a limited period of time, we adjusted our approach to include additional relevant organisations without extracting the data described previously.

Limitations

There are a vast number of bioethics organisations and networks throughout the world that, combined with a limited project scope, precluded the development of a more complete bioethics

network map. Our ability to identify organisations and networks was further influenced by the scope of our own networks and the tendency of individuals to refer and work with those with similar perspectives as themselves. The need to conduct interviews with bioethics experts in the Global South to develop a more global understanding of how bioethics and policy converge is critical for future work. Some organisations, such as the [Observatorio de la Red Iberoamericana de Bioética \(ORIBI\)](#) in Mexico have conducted more exhaustive, regional mapping exercises of bioethics organisations, though these have not been limited to policy-oriented organisations.

There were interpretative limitations to whether or not organisations should be included in our analysis. While several organisations (e.g., the Monash Bioethics Centre, European Group on Ethics in Science and New Technologies, and Global Initiative on AI for Health) describe clear policy-oriented initiatives and activities such as testifying to governmental bodies and establishing normative policy guidance, others described goals of interacting with policymakers with limited examples provided. The organisations that were excluded from the analysis for not having a clear policy linkage may conduct policy-related work despite the absence of such work from their websites. Additionally, our research may not have captured all relevant collaborations, especially those which have ended. Our analysis comprises bioethics organisations with a broad spectrum of policy influence, but we did not endeavour to establish a scale by which we could rank their impact.