THE GOVERNANCE OF GENOMICS SCIENCE AND TECHNOLOGY: PROSPECTS FOR DEVELOPMENT?

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Abstract

The completion of the Human Genome Project has opened up unprecedented possibilities in healthcare, but also ethical and social dilemmas. Some fear that the health concerns of developed countries will take precedence over those of developing countries, thereby creating a "genomics divide". This has led to calls for more effective governance of genomics science and technology. On a broader scale, international relations theorists have been arguing for reform of global governance frameworks in general. One possibility for bridging the genomics divide would be through implementation of three UNESCO instruments: the 1997 Universal Declaration on the Human Genome and Human Rights, the 2003 International Declaration on Human Genetic Data and the Draft Declaration on Universal Norms on Bioethics. All three contain articles on cooperation between developed and developing countries in knowledge sharing and capacity building. Other proposals include two different forms of global network.

Introduction

The completion of the Human Genome Project, the mapping of the entire human genome[1], has opened up unprecedented possibilities in healthcare, but also ethical and social dilemmas that need to be resolved. Some fear that the healthcare concerns of those in developed countries will take precedence over those in developing countries, thereby creating a "genomics divide".[2] This has led to calls for more effective governance of genomics science and technology at the global level. On a broader scale, a growing body of literature is arguing for reform of global governance structures more generally, to address the changing context of relations within and between different groups, often characterised by the all-encompassing term "globalisation". The analytical frameworks used fall under various guises within international relations theory: regime theory, global governance, civil society, networks and cosmopolitan democracy. Behind this movement is the notion that the nation-state no longer has sufficient capacity to regulate human interaction, given that state borders are increasingly less congruent with the barriers, or lack of them, between people.

Those addressing how the genomics divide might be bridged, either through existing mechanisms or suggested ones, have drawn on these ideas about the changing nature of world politics, to varying degrees. One means might be the implementation of three UNESCO[3] governance instruments: the 1997 Universal Declaration on the Human Genome and Human Rights (UDHGHR), the 2003 International Declaration on Human Genetic Data (IDHGD) and the Draft Declaration on Universal Norms on Bioethics (DDUNB). All three contain articles that call for cooperation between developed and developing countries in knowledge sharing and capacity building. Other proposals include two different forms of global network, one centralised and one made up of autonomous units.

This essay begins with a summary of the relevant international relations theories, before applying them to the case of genomics and health inequalities. It then examines the suggested networks and their potential relationship with the UNESCO instruments. The conclusion evaluates the prospects for effective global governance

[1] Sometimes referred to metaphorically as the "book of life". e.g., Steve Connor, "Rival Genome Teams Squabble as they Publish the Ultimate 'Book of Life'," *The Independent*, February 12 2001, 1.
[2] Peter A Singer and Abdallah S Daar, "Harnessing Genomics and Biotechnology to Improve Global Health Equity," *Science*, 294 (5 October 2001), 87.
[3] United Nations Educational, Scientific and Cultural Organization.

of genomics and the ensuing implications for development in terms of health and healthcare.

Regime theory

International regimes encompass varying levels of institutional development; they grow out of efforts to develop collaborative arrangements, formally or informally, within the international system.[4] Stephen Krasner defined regimes in the book he edited on the subject in 1982 as "sets of implicit or explicit principles, norms, rules and decision-making procedures around which actors' expectations converge in a given area of international relations."[5] Oran Young, in the same book, defined regimes somewhat more loosely as "social institutions governing the actions of those interested in specifiable activities (or accepted sets of activities)."[6] Krasner's definition has been described as woolly, vague and imprecise by various critics.[7]

Regime theory allows for cooperation between actors, even under the assumption that they are self-interested and egoistic.[8] A formal regime could emerge from collective legislative action on the part of international organisations and eventually include a governing council or an overarching bureaucratic body, whilst an informal regime might grow out of a consensus of interests and objectives among participants, leading to ad hoc agreements.[9] Although states are traditionally seen as the principal or official members of regimes, non-state actors such as non-governmental organisations (NGOs) are acknowledged as playing influential roles in their formation and operation.[10] Indeed, in 1997 Young suggested that there is "nothing out of the ordinary" about regimes of which states are not the key members.[11]

The power of regimes to enforce their norms or rules is limited.[12] Since stringent, unequivocal rules are usually more difficult to ratify than lenient or vague ones, negotiations tend to be biased towards the interests of the most reluctant states. An alternative to this lowest common denominator approach is to opt for guidelines, voluntary protocols or resolutions. Where legally binding measures are unavoidable they can be diluted with loopholes and opt-out clauses. Increased flexibility allows for fluctuating levels of compliance; should some parties fulfil obligations only half-heartedly the agreement does not have to be abandoned.[13] Regimes confer a degree

[4] James E Dougherty and Robert L Pfaltzgraff, Jr, *Contending Theories of International Relations: A Comprehensive Survey*, 4th edition (United States: Addison-Wesley Educational Publishers Inc, 1996), 436.
[5] Stephen D Krasner, "Structural Causes and Regime Consequences: Regimes as Intervening Variables," in *International Regimes*, ed Stephen D Krasner (Ithaca and London: Cornell University Press, 1982), 2.
[6] Oran R Young, "Regime Dynamics: The Rise and Fall of International Regimes," in ibid, 93.
[7] Dougherty and Pfaltzgraff, Jr, 439 and Baldev Raj Nayar, "Regimes, Power, and International Aviation," *International Organization*, 49 (1) (Winter 1995), 140. Nayar quotes from Susan Strange, "Cave! Hic Dragones: A Critique of Regime Analysis," in *International Regimes*; Friedrich Kratochwil, "The Force of Prescriptions," *International Organization*, 38 (Autumn 1984), 685-708, cited in Oran R Young, *International Cooperation: Building Regimes for Natural Resources and the Environment* (Ithaca, NY: Cornell University Press, 1989), 195; and Oran Young, *International Cooperation*, 195, respectively.
[8] MJ Peterson, "International Organizations and the Implementation of Environmental Regimes," in *Global Governance: Drawing Insights from the Environmental Experience*, ed Oran R Young (Cambridge, Massachusetts: MIT Press, 1997), 115.
[9] Dougherty and Pfaltzgraff, Jr, 436-437.
[10] Young, "Rights, Rules, and Resources in World Affairs," in *Global Governance: Drawing Insights from the Environmental Experience*, 6.
[11] Ibid.
[12] Nayar, 142. Quoting from Krasner, "Global Communications and National Power: Life on the Pareto Frontier," *World Politics*, 45 (April 1991), 337.
[13] Olav Schram Stokke, "Regimes as Governance Systems," in *Global Governance: Drawing Insights from the Environmental Experience*, 50.

of stability by allowing reciprocal expectations and mutual information networks to develop. States will enter into multilateral agreements on the understanding that although no one signatory will reap the benefits continually, each can expect to benefit at some point.[14] Moreover, these benefits will only accrue to those staying in the relationship. Thus whilst realists are wont to reduce regimes to a reflection of the balance of power, such that regimes will collapse when bargaining abilities or national interests change, in practice the longer parties stay in a relationship, the more interconnected they become and the harder it is to withdraw. "[E]ven though it might formally seem as if treaty regimes have no real power over member states," writes Robert Goodin, "the informal reality is that they typically provide an awful lot of leverage."[15]

Global governance

In the era of globalisation, several theorists have written about the concept of global governance. Pierre de Senarclens has commented that governance has taken its place within international relations theory "in the aftermath of the debate about 'regimes'."[16] The congruence between the two is evident in James Rosenau's 1992 definition:

Governance…is a more encompassing phenomenon than government. It embraces governmental institutions, but it also subsumes informal, non-governmental mechanisms whereby those persons and organizations within its purview move ahead, satisfy their needs, and fulfill their wants.[17]

Like regimes, governance comprises rules, principles and procedures, but on a broader level. Where regimes revolve around fairly well-defined issues, governance is not confined to a single sphere.[18] The machinery of traditional governance is inter-state, but private institutions are becoming significant in global rule making, to the extent that "some areas of global public policy would barely exist were it not for non-state actors."[19] Governance at the global level has arisen as both states and non-state actors have become increasingly interdependent.[20] It is defined by Robert Keohane as rule-making and the exercise of power on a global scale, but by entities not necessarily authorised to act by general consensus, with ensuing implications for legitimacy.[21] Rosenau uses the same premise, but comes at it from a different angle: because governance systems lack the traditional legitimacy conferred by, for example, democratic elections, they can only be effective if the great majority of those they cover agree to them. Thus governance has an inherent normative purpose; it is derived from shared goals rather than formal authority.[22] Some question

14 Marie-Claude Smouts, "Some Thoughts on International Organizations and Theories of Regulation," International Social Science Journal, 45 (November 1993), 445 and 447.
15 Robert E Goodin, "Globalizing Justice," in Taming Globalization: Frontiers of Governance, eds David Held and Mathias Koenig-Archibugi, (Cambridge: Polity, 2003), 82.
16 Pierre de Senarclens, "Governance and the Crisis in the International Mechanisms of Regulation," International Social Science Journal, 50 (155) (March 1998), 92.
17 James N Rosenau, "Governance, Order, and Change in World Politics," in Governance Without Government: Order and Change in World Politics, eds James N Rosenau and Ernst-Otto Czempiel (Great Britain: Cambridge University Press, 1992), 4.
18 Marie-Claude Smouts, "The Proper Use of Governance in International Relations," International Social Science Journal, 50 (155) (March 1998), 82.
19 John Gerard Ruggie, "Taking Embedded Liberalism Global: The Corporate Connection," in Taming Globalization, 117.
20 Robert O Keohane, "Global Governance and Democratic Accountability," in Taming Globalization, 131.
21 Ibid, 132.
22 Rosenau, 4.

whether governance can (yet) be equated with government in terms of efficacy.[23] Furthermore, according to David Held, trends towards more fluid governing mechanisms are neither inevitable nor irreversible, but contingent upon several factors.[24] Nor is globalisation mirrored by a growing sense of global citizenship; people's loyalties and identities are still rooted at local, subregional or national levels.[25]

Civil society

Global or transnational civil society[26] is "the domain that exists above the individual and below the state but also across state boundaries, where people voluntarily organize themselves to pursue various aims."[27] It is integral to any endeavour to understand global governance, because its growth parallels the decline in the legitimacy of state politics.[28] The efforts of NGOs to induce governments to adopt their recommendations can lead to the establishment of the institutions, norms and principles (again, the phraseology of regime theory is very prominent) necessary for global governance.[29] Civil society engages in norm-shaping both directly, with policy-makers and businesses, and indirectly, through public opinion. Its part in engendering and fulfilling transnational norms is becoming increasingly significant, particularly with regard to issues such as the environment and human rights.[30] Concentration on single issues[31] allows actors to "avoid the messy trade-offs among issues that constitute the heart of governmental politics."[32]

Networks

Margaret Keck and Kathryn Sikkink concentrate on "transnational advocacy networks"[33], which are broader than civil society per se, because they can include governments and profit-seeking entities.[34] Nevertheless, they have as their central motivation principled ideas or values, rather than material concerns or professional norms.[35] Contrary to the sovereignty principle, networks regard concern for the circumstances of residents of another state as both legitimate and necessary.[36] Critics have characterised them as vehicles for imposing the preoccupations of northern states and non-state actors on social movements in developing countries[37],

23 Helen Yanacopulos, "Patterns of Governance: The Rise of Transnational Coalitions of NGOs," Open University, UK.
24 David Held, "Democratic Accountability and Political Effectiveness from a Cosmopolitan Perspective," Government and Opposition, 39 (2) (April 2004), 366.
25 Held, "From Executive to Cosmopolitan Multilateralism," in Taming Globalization, 166.
26 Ann Florini and PJ Simmons prefer the term "transnational civil society" to "global civil society", on the grounds that the societies referred to rarely are global, although they encompass linkages across borders. Ann M Florini and PJ Simmons, "What the World Needs Now?", in The Third Force: The Rise of Transnational Civil Society, ed Ann M Florini (Japan Center for International Exchange, Tokyo, and the Carnegie Endowment for International Peace, Washington, DC, 2000), 7.
27 Paul Wapner, "Governance in Global Civil Society," in Global Governance: Drawing Insights from the Environmental Experience, 66.
28 James H Mittelman, "Globalisation and Environmental Resistance Politics," Third World Quarterly, 19 (5) (December 1998), 855.
29 Wapner, 83.
30 Ruggie, 105.
31 Ramesh Thakur and Hans van Ginkel, "A Safer World and a Better Life for All," UN Chronicle 37 (2) (2000), 17.
32 Florini, "Lessons Learned," in The Third Force, 232.
33 Margaret E Keck and Kathryn Sikkink, Activists Beyond Borders: Advocacy Networks in International Politics (New York: Cornell University Press, 1998), 1.
34 Florini and Simmons, "What the World Needs Now?", 7.
35 Keck and Sikkink, 1.
36 Ibid, 34-37.
37 Ibid, 197.

although as new forms of collective action emerge from grassroots organisations in the South such concerns are becoming anachronistic.38 Differential participation within transnational networks can be a problem, however.39 Whilst networks operate through exchanges of information and services that are both voluntary and reciprocal,40 power within them often reflects an unequal distribution of resources, usually in favour of northern members.41

Jean-François Rischard has attempted to lay out a framework for "networked governance" that is designed to circumvent the cumbersome processes of international institutions to address matters of global urgency. Single-issue networks, known as GINs (Global Issue Networks), will create new international public space.[42] Made up of representatives of governments, NGOs and businesses with knowledge of the matter in hand, these innovative tripartite bodies will produce norms and standards and then act as "rating agencies" to assess compliance among both state and non-state actors.[43] Crucially, the timetable for action will be a lot faster than for a more traditional multilateral institution, with the constitutional (that is, setting up) phase lasting about one year, the norm-producing phase two to three years.[44] Norm formation could begin once a "rough consensus" has been reached, comprising sufficient agreement rather than full consensus, which would take too long. This would be done partly through a "potentially vast electronic town meeting", involving citizens responding to polls via the internet.[45] The GINs would have no power to pass legislation, only to encourage nation-states to do so. Even so, Rischard describes them as "anything but soft", as their "moral authority" would enable them to engender strong reputational effects towards both state and non-state actors.[46] This would, of course, depend on renegade actors being susceptible to a burden of shame. In the context of transnational network activity, Keck and Sikkink have pointed out that if governments face the threat of being labelled a pariah with perfect indifference, as did Haiti when criticised for its human rights record, a campaign will be ineffectual.[47]

Cosmopolitan Democracy

In 2003 Keohane wrote, "[I]t is no longer even a reasonable simplification to think of world politics simply as politics among states."[48] As transnational political action has grown, through regimes, governance initiatives and civil society organisations, "overlapping networks of power" have been created that do not fit neatly within state borders.[49] The fates of distant communities are interwoven, thus local level economic, social or environmental issues and events can have global ramifications and vice versa.[50] Decisions taken by democratically elected governments

[38] Florini and Simmons, "What the World Needs Now?", 5-6.
[39] Ibid.
[40] Keck and Sikkink, 200.
[41] Ibid, 207.
[42] Jean-François Rischard, "Global Issue Networks: Desperate Times Deserve Innovative Measures," *The Washington Quarterly*, 26 (1) (Winter 2002-03), 24-25.
[43] Rischard, "A Novel Approach to Problem-solving," *Global Agenda*, 1 (January 2003), available as an HTML full text through Academic Search Premier; Rischard, "Global Issue Networks," 25.
[44] Rischard, "Global Issue Networks," 25-26. Note that Rischard was writing about GINs as early as 2001. Rischard, "High Noon: We Need New Approaches to Global Problem-solving, Fast," *Journal of International Economic Law*, 4 (3) (September 2001), 507-525.
[45] Rischard, "Global Issue Networks," *The Washington Quarterly*, 26 (1) (Winter 2002-03), 27.
[46] Ibid, 28.
[47] Keck and Sikkink, 118.
[48] Keohane, 130.
[49] Held, "From Executive to Cosmopolitan Multilateralism," 161 and 167.
[50] Ibid, 162.

increasingly have repercussions for people in other countries who had no say in their appointment[51], creating a democratic gap or vacuum.[52]
Intergovernmental organisations (IGOs) are also important decision-making bodies. Such organisations can be somewhat ad hoc, with overlapping or contradictory functions, mandates, aims and objectives.[53] Within negotiations there is often an accountability deficit, due to power imbalances between states. Some countries can afford to make available large delegations of experts to back up the official representative, whilst others may only be able to send one person, who may not be a specialist in the field.[54] Despite these problems, Keohane defends IGOs as perhaps the most accountable bodies on the world political stage, along with weak states. By contrast, multi-national corporations (MNCs), transgovernmental networks, religious movements, terrorist networks and powerful states are relatively unaccountable.[55]

All these factors have led some to question the assumption that democracy must be contained within domestic borders; why, indeed, should it not be "cosmopolitan"? Despite much scepticism[56], the idea of cosmopolitan democracy, to simultaneously globalise democracy and democratise globalisation,[57] has grown rapidly within international relations theory since its relatively recent inception.[58] It is described by Daniele Archibugi as a "political project", a term that denotes both its normative tendencies and its instigators' belief that it could bear tangible fruit. The project involves regulating the dynamics of globalisation at a transnational level, particularly in those areas where this would be difficult, if not impossible, through democratic means at the state level. The state model of democracy will not be directly replicated at the global level, however; a global government per se is not envisaged.[59] Rather, the project "attempts to specify the principles and the institutional arrangements for making accountable those sites and forms of power which presently operate beyond the scope of democratic control".[60] The notion of sovereignty and the concurrent principle of non-interference would no longer offer renegade states impunity.[61] That a body should be immune from the need to justify its actions simply because it sits within certain borders is deemed incompatible with democracy[62]: "States…should not be thought of as ontologically privileged."[63] Governance at the global level will not always be the most appropriate means to achieve the project's aims. Held articulates this as follows:

> Today, if people are to be free and equal in the determination of the conditions which shape their lives, there must be an array of fora, from the city to global associations, in which they can hold decision-makers to account. If many

[51] Held, "Democracy and Globalization", in *Re-imagining Political Community: Studies in Cosmopolitan Democracy*, eds Daniele Archibugi, David Held and Martin Köhler (Blackwell, Oxford: Polity Press, 1998), 22.
[52] Daniele Archibugi, "Demos and Cosmopolis," *New Left Review*, 13 (Jan-Feb 2002), 26, 27 and 32.
[53] Held, "Democratic Accountability and Political Effectiveness from a Cosmopolitan Perspective," 368.
[54] Ibid, 369-370.
[55] Keohane, 133. Presumably in the case of terrorist networks one could say they are *absolutely* unaccountable.
[56] Archibugi, "Demos and Cosmopolis," 29-30, 33-34 and 36.
[57] Archibugi, "Cosmopolitan Democracy and its Critics: A Review," *European Journal of International Relations*, 10 (3) (2004), 438 and 464.
[58] William E Scheuerman, "Cosmopolitan Democracy and the Rule of Law," *Ratio Juris*, 15 (4) (December 2002), 439.
[59] Archibugi, "Demos and Cosmopolis," 28-29.
[60] Marc Lynch, "Globalization and International Democracy," *International Studies Review*, 2 (3) (Fall 2000), 95, quoting from *Global Transformations: Politics, Economics and Culture*, by David Held, Anthony McGrew, David Goldblatt and Jonathan Perraton (Stanford, California: Stanford University Press, 1999), 449.
[61] Archibugi, "Demos and Cosmopolis," 33-34.
[62] Archibugi, "Cosmopolitan Democracy and its Critics," 452.
[63] Held, "From Executive to Cosmopolitan Multilateralism," 168.

> contemporary forms of power are to become accountable and if many of the complex issues that affect us all – locally, nationally, regionally and globally – are to be democratically regulated, people will have to have access to, and membership in, diverse political communities.[64]

The most appropriate governance level for any given issue will not be obvious or natural, but Held sees disputes over which is the most suitable as preferable to leaving problems to be resolved through geopolitics or market mechanisms.[65]

Cosmopolitanism depends on three principles: individuals are "the ultimate units of moral concern", everyone has equal worth and rules and practices must be universally and impartially shared.[66] Advocates of cosmopolitan democracy vary in their prescriptions for how it should be achieved, but tend to agree that individuals should be considered cosmopolitan citizens and as such should be empowered to take part in policy formation at the international level.[67] David Chandler and Marc Lynch have criticised the project for its lack of practical application[68] or supportive evidence beyond "normative enthusiasm".[69] Archibugi acknowledges that cosmopolitan democracy is likely to evolve through several campaigns that pursue realistic and limited objectives rather than a one-off, momentous shift[70], while Held has made concrete suggestions as to how it can be achieved. As a first step, the United Nations (UN) should live up to its Charter. Beyond this, Held proposes concrete innovations, such as regional parliaments, general referenda (perhaps similar to Rischard's online polls), new, socially-oriented IGOs to offset the market-oriented ones and greater transparency among IGOs and NGOs.[71]

Some authors have assessed the cosmopolitan democracy project from a developing country perspective. Hassan Hanafi sees it as only a weak antidote to global capitalism, particularly if it is dominated by northern culture and interests.[72] Simeon Ilesanmi defends the normative vision of socio-economic and development rights as a way to mitigate the deleterious effects of unguarded globalisation.[73] He is more hopeful than Hanafi, believing this vision can be achieved if the global institutional order is reformed principally by reference to its impact on rights fulfilment.[74]

Genomics and development

Fears of a genomics divide have been spawned by the precedents set by the perceived digital divide[75] and previous medical advancements: "Unfortunately, the undesired but foreseeable result of medical progress tends to increase inequalities, because it is oriented by vested interests and directed towards the rich instead of general goals."[76] Disparities in health, wealth and human rights are widening at both

[64] Held, "Democratic Accountability and Political Effectiveness from a Cosmopolitan Perspective," 387.
[65] Ibid.
[66] Held, "From Executive to Cosmopolitan Multilateralism," 170.
[67] Lynch, 96.
[68] David Chandler, "New Rights for Old? Cosmopolitan Citizenship and the Critique of State Sovereignty," *Political Studies*, 51 (2003), 339.
[69] Lynch, 96.
[70] Archibugi, "Cosmopolitan Democracy and its Critics," 465-6.
[71] Held, "From Executive to Cosmopolitan Multilateralism," 176-179 and "Democratic Accountability and Political Effectiveness from a Cosmopolitan Perspective," 383-385.
[72] Lynch, 98. Lynch cites the chapter in Hassan Hanafi's book *What is Globalization?* entitled "Globalization between Reality and Delusion." The original is in Arabic (Beirut: Dar al-Fikr, 1999).
[73] Simeon O Ilesanmi, "Leave No Poor Behind: Globalization and the Imperative of Socio-economic and Development Rights from an African Perspective," *Journal of Religious Ethics*, 32 (1) (2004), 71.
[74] Ibid, 89.
[75] Singer and Daar, "Harnessing Genomics and Biotechnology to Improve Global Health Equity," 87.
[76] Giovanni Berlinguer, "Bioethics, Health, and Inequality," *Lancet*, 364 (18 September 2004), 1088.

national and international levels; those in health and healthcare are deemed the "single gravest problem of medical ethics" by Solomon Benatar.[77] Peter Singer and Benatar write of the need to redress "one of the greatest ethical challenges in the world – the unconscionable inequities in global health."[78] Poverty is a direct factor in nearly one third of the global disease load.[79] With this the case, it might be expected that access to biotechnological solutions to ill-health would be of second-order importance, after more immediate remedies such as clean water, adequate nutrition and sanitation[80], but this is not so. Genomics is crucial to the future of healthcare, as it is likely to affect disease diagnosis, treatment and prevention.[81] In 2001, for example, clinical trials of a DNA-based vaccine, based on observations that some prostitutes in Nairobi seemed to have developed immunity to HIV, were conducted in Kenya and Britain.[82]

Giovanni Berlinguer distinguishes between "frontier bioethics", which deal primarily with future, almost inconceivable dilemmas, such as the morals of human cloning, and "everyday bioethics", which address "the daily persistent conditions of most of the world's population, often difficult and sometimes tragic."[83] The former enjoys a higher profile than the latter, but they are actually closely related; for example, if biotechnological sex selection is deemed acceptable in developed countries, this could thwart endeavours to stop sex selection through infanticide or preferential feeding. By considering both types, says Berlinguer, it should be possible to reach consensus on universal bioethical norms and values, perhaps endorsed by legal international regulations. This is necessary to address the fact that science reaches beyond national borders (Berlinguer cites transfers of stem cells, DNA samples and genetic data as examples) and because "positive actions for health are essential on a world and local scale." This combination of the universal and specific mirrors the existence of both collective interests and value pluralism within the global community.[84]

The existence of global collective needs would indicate that the interests of rich and poor are interdependent. Though cosmopolitanism may be a weak antidote to global capitalism, as Hanafi suggests, self-interest may yet lead to health inequalities being addressed. Benatar frames global health in terms of a new concept of security that concentrates on improving life chances for everyone, thus negating the need for military might (freeing up some of the huge expenditures on military research and hardware[85]). "[I]t is neither beneficence nor altruism that are required to address national and global problems, but rather rational self-interest and a longer-range view than we currently seem willing to take."[86] This illustrates how states will join together to address issues if each perceives it to be within the national interest to do so, as observed by regime theory. Elizabeth Dowdeswell, Abdallah Daar and Singer draw a similar conclusion to Benatar: "An interconnected and interdependent world in which

[77] Solomon R Benatar, "Global Disparities in Health and Human Rights: A Critical Commentary," *American Journal of Public Health*, 88 (2) (February 1998), 295 and 299.
[78] Singer and Benatar, "Beyond Helsinki: A Vision for Global Health Ethics," *British Medical Journal*, 322 (31 March 2001), 748.
[79] Benatar, "Reflections and Recommendations on Research Ethics in Developing Countries," *Social Science & Medicine*, 54 (2002), 1132.
[80] Ibid.
[81] Richard D Smith, Halla Thorsteinsdóttir, Abdallar S Daar, E Richard Gold and Peter A Singer, "Genomics Knowledge and Equity: A Global Public Goods Perspective of the Patent System," *Bulletin of the World Health Organization*, 82 (5) (April 2004), 385.
[82] Singer and Daar, "Harnessing Genomics and Biotechnology to Improve Global Health Equity," 88.
[83] Berlinguer, 1086.
[84] Ibid, 1087.
[85] About one fifth of research scientists and engineers work exclusively on military research and development. Benatar, "Global Disparities in Health and Human Rights," 296.
[86] Benatar, "Reflections and Recommendations on Research Ethics in Developing Countries," 1140.

the greatest majority have limited access to health care while the quality of life of the minority expands is a recipe for social confrontation."[87]

Any separation of public and personal health is a false one; the overall health of the community is dependent on individuals choosing to take vaccines or treatments, for example. Thus, "Bioethics for the individual cannot be severed from bioethics for the collective."[88] According to Onora O'Neill, the preoccupations of medical ethicists and political philosophers with, respectively, individual autonomy and justice within states have meant that public health concerns, which must often be addressed uniformly, compulsorily and across borders, have been neglected.[89] She writes,

> Health economists and health policy analysts typically focus on (just) health-care provision within boundaries, and bracket ill health beyond boundaries. The huge health problems of poorer parts of the world, for which public health interventions are often of decisive importance, are then seen as matters for development programs and development studies, rather than as part and parcel either of mainstream theories of justice or of mainstream medical ethics. The common neglect of ill health beyond borders reflects well-entrenched features of contemporary political philosophy, which has typically confined questions of distributive justice within societies, and viewed transborder justice (at best) as a secondary matter.[90]

O'Neill highlights some difficulties in bringing cosmopolitanism to bear on health inequalities. Progress will be limited as long as the state is the key feature of the world order. She criticises those who point to international institutions such as the UN and the World Health Organization (WHO) to illustrate that states themselves have a global vision, as they usually support such bodies out of self-interest and justice at the domestic level remains paramount. While boundaries do not have to be justified but are presupposed, there can be no "full account of global or cosmopolitan justice." If, however, borders are considered arbitrary and obligations of justice fall on everyone, richer societies should have to support public health in poorer ones, however distant.[91]

This is in fact exactly the type of shift that is taking place within bioethical thinking. Just as political philosophers are currently questioning the ontological privilege of the nation-state, so are bioethicists beginning to look beyond state borders. Some have drawn a connection between economic globalisation and health.[92] Medical research is largely market driven, to the detriment of those suffering from diseases such as tuberculosis and malaria, which are so widespread because "those who suffer from these conditions are out of sight, their lives are not valued and there is an insufficient profit motive driving treatment regimes," not because they are untreatable.[93] Furthermore, whilst those in developing countries may see little benefit from medical research, they may well have found themselves participating in it: open access to

[87] Elizabeth Dowdeswell, Abdallah Daar and Peter Singer, "Bridging the Genomics Divide," *Global Governance*, 9 (2003), 6.
[88] Melissa Lane, "Bioethics, Health, and Inequality," *The Lancet*, 364 (18 September 2004), 1017.
[89] Onora O'Neill, "Public Health or Clinical Ethics: Thinking beyond Borders," *Ethics and International Affairs*, 16 (2) (2002), 35.
[90] Ibid, 39.
[91] Ibid, 40.
[92] e.g., Benatar, "Commentary: Justice and Medical Research: A Global Perspective," *Bioethics*, 15 (4) (2001), 333; Benatar and Singer, "A New Look at International Research Ethics," 826; Berlinguer, 1088, 1090 and 1091.
[93] Benatar, "Reflections and Recommendations on Research Ethics in Developing Countries," 1139.

patients, lower costs and fewer regulations have produced a "research sweat shop".[94]

As both a global public good (GPG), in that it is represented by knowledge in the public domain and across national boundaries, and a private good, in that its applications translate into marketable products, genomics needs a mechanism that will ensure that where the market fails, people will still have access to its benefits[95], thus recognising that returns on investment can be both social and economic.[96] At present, despite the pervasive principle of universal dissemination and use that is an outcome of the Human Genome Project, the potential of genomics is not being fulfilled in the South due to practical difficulties, namely lack of investment, infrastructure and expertise, fuelling the genomics divide.[97]

One statistic that is quoted by several commentators and seems to have become a kind of shorthand to describe disparities in health equality is that ninety per cent of the $56 billion spent annually on medical research is devoted to mitigating only ten per cent of the global disease burden: the "10/90 gap".[98] Benatar questions whether the rubric of human rights is sufficient to counter this gap.[99] In his opinion, human rights declarations (of which the UDHGHR is one), have not had the capacity, thus far, to guarantee access to "even the most basic requirements for a decent human existence."[100] Moreover, declarations cannot prescribe ethics; rather, they need to be morally interpreted.[101] Like O'Neill, Benatar highlights the importance of duties in upholding rights. The problem is not that the concept of rights is in itself inadequate, but that there has been a lack of real commitment to it by powerful states. A greater emphasis on social justice is needed.[102] Singer and his colleagues hold up the "major challenge" of health inequalities not only to the adversely affected nations, but to the "entire world community".[103] This assumes an interdependence and civic responsibility on a cosmopolitan scale. In a similar vein to Berlinguer, Benatar posits that both "imaginative, global thinking" and "visionary actions specific for particular societies" are needed to address disparities in access to human rights[104], reflecting Held's emphasis on the regional and global alongside rather than in place of the local

[94] Benatar, "Commentary: Justice and Medical Research," 337.
95 Tara Acharya, Abdallah S Daar, Elizabeth Dowdeswell and Peter A Singer, "Better Global Governance to Promote Genomics for Development," (undated), available at http://www.utoronto.ca/jcb/genomics/documents/CGI-paper.pdf**,** downloaded on 26.4.05.
96 Dowdeswell, Daar and Singer, 3.
97 Richard Smith et al, 386.
98 Benatar, "Commentary: Justice and Medical Research," 335 and Singer and Daar, "Harnessing Genomics and Biotechnology to Improve Global Health Equity," 89; see also Benatar, "Reflections and Recommendations on Research Ethics in Developing Countries," 1132 and 1138; Benatar, "Human Rights in the Biotechnology Era I"; Benatar and Singer, "A New Look at International Research Ethics," 824; Singer and Benatar, "Beyond Helsinki," 748; Berlinguer, "Bioethics, Health, and Inequality," 1088; Dowdeswell, Daar and Singer, 3.
99 Benatar, "Reflections and Recommendations on Research Ethics in Developing Countries," 1132.
100 Benatar, "Human Rights in the Biotechnology Era I," BMC International Health and Human Rights, 2 (3) (2002) (page numbers not given for citation purposes).
101 Benatar and Singer, "A New Look at International Research Ethics," British Medical Journal, 321 (30 September 2000), 824 and Benatar, "Reflections and Recommendations on Research Ethics in Developing Countries," 1137. Benatar and Singer distinguish between moral reasoning that takes into account context and moral relativism: "Failure to distinguish moral relativism from the morally relevant considerations of context that are necessary for the specification of universal principles shows a lack of knowledge of the ethical decision making process," 825.
102 Benatar, "Human Rights in the Biotechnology Era I."
103 Alyna C Smith, John Mugabe, Peter A Singer and Abdallah S Daar, "'Harnessing Genomics to Improve Health in Africa' – an exclusive course to support genomics policy," Health Research Policy and Systems, 3 (2) (2005) (page numbers not given for citation purposes).
104 Benatar, "Global Disparities in Health and Human Rights," 295.

and national. Likewise, he and Singer recommend that international codes be enforced in national codes and related to local situations.[105]

At the regional level, the first Roundtable on Africa, Science, and Technology in the Age of Globalization took place in Nairobi in 2001. This "early consensus-building effort" was greeted with enthusiasm by Singer and Daar.[106] More recently, the Africa Centre for Technology Studies and the University of Toronto Joint Centre for Bioethics coordinated a Genomics and Public Health Policy course, the first of a series taking place across the South. There were thirty participants from ten countries, including representatives from government, the media, law, NGOs and academia, but not the private sector (later courses in other developing countries did attract industry personnel, however). One of the course objectives was to "to help [participants] understand, anticipate and possibly influence the legal and regulatory frameworks which will operate, both nationally and internationally." Recommendations included a regional approach as the key to reaping the potential benefits of genome-related biotechnology for health and development in Africa. The course begat much enthusiasm among attendees, one of the outcomes of which was the creation of a virtual network, the African Genome Policy Forum (AGPF). Unfortunately, although the network continues in e-mail form (a web-based discussion board proved unsustainable), contributions are infrequent, due to time and technology constraints.[107]

Such regional networks could in the future form a platform for inter-regional dialogue.[108] At the global end of the scale there have been several propositions for effective governance of genomics. Dowdeswell, Daar and Singer, like Benatar, have called for creative institutionalism. Initially they suggested a consensus-building commission as a means to avoid one of the pitfalls of regimes, agreements at the lowest common denominator.[109] Their 2003 proposal in Global Governance reads as follows:

> An appropriate response by the world community – governments, citizens, and experts from industry and academia – would be to foster global dialogue and provide a forum for shaping the necessary governance framework through a commission on genomics and global health.[110]

Of course, this presupposes that these various categories of persons do in fact form a world community. Realistically, there would have to be safeguards in place to ensure that the dialogue did not become dominated by only certain parts of that community. In an earlier paper, Singer and Daar highlighted the need for southern voices to be heard directly: "Those protesting in Genoa are not the ones who are sick in Africa."[111] In other words, like Keck and Sikkink, they have raised the issue of the legitimacy of northern-based civil society organisations. The important viewpoints, they say, are those of opinion leaders in developing countries.[112] This assumes that these leaders have a more rightful mandate, although in countries with fledgling democracies or poor human rights records this may not be the case.

105 Singer and Benatar, "Beyond Helsinki," 747.
106 Singer and Daar, "Harnessing Genomics and Biotechnology to Improve Global Health Equity," 89. A search for further information on the strategies proved unsuccessful. There do not appear to be plans afoot for a second round table.
107 Alyna Smith et al.
108 Ibid.
109 Dowdeswell, Daar and Singer, 4-5.
110 Ibid, 1.
111 Singer and Daar, "Harnessing Genomics and Biotechnology to Improve Global Health Equity," 89.
112 Ibid.

Dowdeswell, Daar and Singer, with Tara Acharya, have since moved beyond their commission model.[113] In a report entitled "Better Global Governance to Promote Genomics for Development", available through the Toronto Joint Centre for Bioethics website, they have proposed a new global governance network as a means to balance the risks and benefits of genomics and guarantee that those benefits are available to developing countries, in pursuit of "the all-important promotion of genomics for global health equity." They use words that would be equally at home in a paper on cosmopolitan democracy to outline why such an initiative is necessary: "[T]he governance structure with which we are most familiar – the nation state – is ill-equipped to effectively tackle global issues."[114]

The network would follow the GIN model. Borrowing directly from Rischard[115], Acharya et al deem treaties insufficient to deal with pressing global predicaments on the grounds that (as noted by regime theory) negotiations are a slow business and adherence is weak, whilst global commissions are seen as too unwieldy. Groupings of countries like the G-8 or G-20 are also inappropriate, because of their exclusivity towards both states and non-state actors. Thus a new framework is needed. The GIN model is apposite, so it is argued, because they are quick to set up, inclusive rather than "club-like", responsive, flexible and equitable.[116] "A major appeal of the global network model," write Acharya, Daar and Singer, "is that it…allows initiation and leadership from the South."[117] This seems a somewhat idealised view, given Keck and Sikkink's observations on power relations within networks.

The main objective of the proposed network, the Global Genomics Initiative (GGI)[118], would be to promote knowledge exchange, leading to informed decision-making "that will help close the imminent genomic divide." It would do this through putting safeguards in place that would allow genomics knowledge to be openly available, thus preserving its GPG status, but also minimise the risk of misuse.[119] MNCs would be encouraged to share intellectual property[120], for example (something Merck did in 1998 through putting its "Merck Gene Index Project" in the public domain[121]). The network would also request financial support from northern governments.[122] Its added value would be in its role as coordinator of the various relevant bodies already in existence and, spanning the local to global spectrum, as bridge between public-private partnerships and bilateral alliances and higher level international organisations.[123] Acharya et al predict that these partnerships and alliances in particular would benefit from membership of a global network, through expansion and

113 Note, however, that many of their stipulations, such as the need for urgency, creative thinking, new financial models and champions from government, industry and civil society remain the same. Dowdeswell, Daar and Singer, 5-6 and Acharya et al, "Better Global Governance to Promote Genomics for Development."

114 Acharya *et al*, "Better Global Governance to Promote Genomics for Development."

115 The arguments expressed by Acharya *et al* can be found in all three of Rischard's papers cited in this essay.

116 Acharya *et al*, "Better Global Governance to Promote Genomics for Development."

117 Acharya, Daar and Singer, "Biotechnology and the UN's Millennium Development Goals," *Nature Biotechnology* 21 (12) (December 2003), 1436.

118 Confusingly, the term "global genomics initiative" appears in a commentary in *The Lancet* by Thorsteinsdóttir, Daar, Smith and Singer from March 2003, the same year Daar and Singer were writing about a possible global commission with Dowdeswell. Perhaps the explanation is a faster submission/publication turnaround in *The Lancet* than in *Global Governance*. In any event, the linear progression in their thinking seems to have been from a commission to the GGI.

119 Acharya *et al*, "Better Global Governance to Promote Genomics for Development."

120 Thorsteinsdóttir, Daar, Richard Smith and Singer, "Genomics – A Global Public Good?" *The Lancet*, 361 (15 March 2003), 891.

121 Eike-Henner W Kluge, "Patenting Human Genes: When Economic Interests Trump Logic and Ethics," *Health Care Analysis*, 11 (2) (June 2003), 127.

122 Thorsteinsdóttir *et al*, "Genomics – A Global Public Good?", 891.

123 Acharya *et al*, "Better Global Governance to Promote Genomics for Development."

enhanced access to knowledge and scientific capacity. Learning is vital for the establishment of national systems of innovation.[124] Developing countries would be able to strengthen their research and development (R&D) sector in genomics[125], thus changing the frame to one of genomics "by" rather than "for" developing countries.[126] UN Secretary-General Kofi Annan has emphasised the importance of science and technology for development, stating that no country can afford to be without its own capacity in these areas.[127] Similarly, NEPAD has declared science and technology as fundamental to Africa's renewal.[128]

The skeleton of the network is already being put in place: "We are now in the process of bringing together some of the best creative minds from these fields [industry, academia, civil society, government] to begin the dialogue and to learn from their experiences so that any decision-making will come from the bottom up."[129] Specific activities will include foresight exercises, design of alternative financing and intellectual property mechanisms and drafting of regulation in the form of (using the language of regimes) norms and principles, "for the global harmonization of ethical standards applied to genomic technology research, with benefit-sharing and risk minimization."[130] At the same time, developing countries will need to secure their own, complementary expertise in the ethical, legal and social implications of genomics.[131]

One hurdle that the GGI may have to overcome (as with Rischard's GINs more generally) may be in establishing legitimacy. It could well fall within Keohane's category of entities lacking general authority and there are question marks over whether it has a justifiable claim to act as overall coordinator and how it will persuade existing organisations to join. Under cosmopolitan democracy, empowering citizens to take part in policy formation confers legitimacy. If Acharya et al intend to use the internet-based polls proposed by the GIN model to do this, there may be practical difficulties. The fact that participation in the AGPF online forum quickly faded, even among professionals, does not bode well for such a scheme. In this sense, the purported digital divide may well feed the growth of the genomics divide. Nevertheless, the emphasis on garnering developing world representation and leadership[132] within the GGI may mean that a common weakness among networks, whereby actors in the North map their concerns on to those in the South[133], can be avoided.

Acharya et al acknowledge that the GGI may face legitimacy problems, but believe these can be solved through strong leadership and broad membership, as long as "champions" can be found among governments, industry and civil society. This may be a problem in Africa, given the difficulties encountered in trying to attract industry representatives to the Genomics and Public Health Policy course. Success will be measured in terms of whether dialogue is inclusive and stimulates a sense of urgency among policy-makers to take effective action. Flexibility will be necessary in order to achieve a balance between equal participation on a global basis and

[124] Acharya, Daar, Thorsteinsdóttir, Dowdeswell and Singer, "Strengthening the Role of Genomics in Global Health," *PloS Medicine*, 1 (3) (e40) (December 2004), 196.
[125] Acharya *et al*, "Better Global Governance to Promote Genomics for Development."
126 Singer and Daar, "Harnessing Genomics and Biotechnology to Improve Global Health Equity," 88.
127 Kofi Annan, "Science for All Nations," Science, 303 (13 February 2004), 925.
128 Alyna Smith et al.
129 Acharya et al, "Better Global Governance to Promote Genomics for Development."
130 Ibid.
131 Singer and Daar, "Harnessing Genomics and Biotechnology to Improve Global Health Equity," 88.
132 Acharya et al, "Better Global Governance to Promote Genomics for Development."
133 Keck and Sikkink, 197.

countries having the autonomy to prioritise their own health agendas.[134] Thus, in line with Held, Berlinguer and Benatar, Acharya et al recognise that though inequalities may be global in scale, the right solutions may be localised.

The Toronto group are not the only ones thinking about how best to harness the benefits of science and technology. In a Science "viewpoint" article, David Weatherall, lead writer of the 2002 WHO report Genomics and World Health[135], discusses a "virtual global network" that has been suggested in response to frustration at inefficiency and bureaucracy among IGOs. He judges that, "given the unwieldiness, political complexity, and other uncertainties of major international organizations, this bottom-up approach to international health research has many attractions."[136] Interestingly, however, although these words reflect almost perfectly the concerns of Acharya et al, it is not to their proposal that Weatherall is referring, but to one by Gerald Keusch and Carol Medlin that leading national research agencies (such as the US National Institutes of Health and the UK Medical Research Council) form a health research network that will be collaborative and coordinated but with each member remaining independent. They advocate "small science" (autonomous, investigator-initiated, apolitical), arguing that "there is no theoretical justification for preferring a highly orchestrated, centrally controlled effort to a decentralized one". Turning the "10/90 gap" statistic on its head, they use it to demonstrate the wealth of experience and expertise among the research councils of the North. To prevent the network becoming a "politically correct, all-inclusive, but dysfunctional, tool for development," only those research bodies with established national funding and scientific records will be able to join, but parallel support for capacity building in resource-poor countries will be available.[137] It seems, then, that calls for a mechanism outside the usual instruments are coming from more than one source, but with different approaches. Although both networks would claim to be bottom-up, Keusch and Medlin's would be far less centralised than the GGI.

The usual instruments, or at least the two UNESCO declarations on human genetics and the draft declaration on bioethics, seem to have been largely ignored in the bioethics literature, despite their commitment to capacity building and knowledge sharing. Article 18 of the UDHGHR reads,

> States should make every effort…to continue fostering the international dissemination of scientific knowledge concerning the human genome, human diversity and genetic research and, in that regard, to foster scientific and cultural co-operation, particularly between industrialized and developing countries.[138]

Given this shared focus, it seems strange that Acharya *et al* fail to mention such provisions at all in their papers. Perhaps such lack of recognition is inevitable, considering their low opinion of international treaties and conventions. Any norms and principles devised by the GGI are bound to duplicate the declarations to some degree, however, particularly the DDUNB, which covers the bioethics field in general.

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134 Acharya et al, "Better Global Governance to Promote Genomics for Development."
[135] David Weatherall, Dan Brock and Heng-Leng Chee, *Genomics and World Health: Report of the Advisory Committee on Health Research*, (Geneva: World Health Organization, 2002).
[136] David J Weatherall, "Genomics and Global Health: Time for a Reappraisal," *Science*, 302 (24 October 2003), 598.
[137] Gerald T Keusch and Carol A Medlin, "Tapping the Power of Small Institutions," *Nature*, 422 (10 April 2003), 561-562.
[138] Article 18 of the 1997 Universal Declaration on the Human Genome and Human Rights, UNESCO. Article 18 of the 2003 International Declaration on Human Genetic Data, UNESCO, is very similar. The only difference is that where the 1997 declaration reads "human genome, human diversity and genetic research," the 2003 declaration reads "human genetic data and human proteomic data."

Singer and Benatar deem ethics capacity building absolutely crucial if documents outlining research norms are to have any effect.[139] They hold that it is simplistic to assume that international instruments in themselves can promote ethical behaviour.140 Benatar writes,

> While the Universal Declaration on the Human Genome, the first universal instrument in the field of biology, sets out to safeguard human rights, fundamental freedoms and the freedom of research, it is clear that there are many obstacles to achieving the high ideals expressed in this document.[141]

Perhaps going some way towards answering this challenge, the declarations are proving useful as standard-setting documents in Kenya. Their proponents are able to lobby for their being incorporated into national law on the grounds that other countries will be striving to do the same.[142] They are not so visible in other contexts, however. By contrast, the leaders of the 2002 African course on Genomics and Public Health Policy, in the session on international regulation, failed to mention the 1997 declaration or the upcoming 2003 one, or at least these were not highlighted in the detailed paper describing the proceedings.[143]

Dowdeswell, Daar and Singer argue that the capacity of developing countries to participate effectively in international negotiations also needs to be enhanced.[144] What was striking at the January 2005 negotiations of the draft declaration on bioethics, held at UNESCO headquarters in Paris, was the fairness of the procedures in allowing every delegate equal voice, of which some developing and middle-income country representatives took full advantage.[145] On the surface, then, it would seem that this capacity is already in place, but on closer inspection it appears that Held's observations about quality and quantity of representation at international organisations were borne out. Whilst the United States IGBC member had several aides and submitted a number of suggestions in writing, a significant proportion of which were later agreed upon, those from some sub-Saharan African countries were alone and were not present for a sizeable part of the sessions.[146]

Another noticeable feature of the January 2005 DDUNB negotiations was that consensus was only possible over non-controversial issues.[147] Some of these were precisely the "everyday" issues that Berlinguer says have not been given proper attention by the bioethics field; namely, poverty, illiteracy, living conditions,

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[139] Singer and Benatar, "Beyond Helsinki," 747.
[140] Benatar and Singer, "A New Look at International Research Ethics," 825. Note that all three UNESCO declarations include articles calling on states to promote education and training in ethics or bioethics.
[141] Benatar, "Human Rights in the Biotechnology Era I."
[142] Conversation with a delegate at the January 2005 IGBC and International Bioethics Committee (IBC) meetings, held at UNESCO headquarters in Paris.
[143] Alyna Smith *et al*. The documents mentioned were the WHO's draft Guiding Principles on Medical Genetics and Biotechnology, the Human Genome Organization's principles and statement on benefit sharing, the conventions and protocols that came out of the United Nations Conference on Environment and Development, the Conventions on Biological Diversity, the Cartagena protocol and the International Treaty on Plant Genetic Resources for Food and Agriculture.
[144] Dowdeswell, Daar and Singer, 3.
[145] Notable examples were Brazil, Chile, Egypt, India and Mexico.
[146] Personal observations of the IBC and IGBC meetings held at UNESCO headquarters, Paris, 24-28 January 2005. Note also that one sub-Saharan African delegate never arrived, despite having been nominated for the position of rapporteur. The partial absence of the other sub-Saharan African delegates might have been because they may also have been attending a concurrent conference on biodiversity, which took place in the same venue.
[147] Personal observations of the IBC and IGBC meetings held at UNESCO headquarters, Paris, 24-28 January 2005.

marginalisation and exclusion, nutrition, water, quality healthcare (including reproductive and children's health) and essential medicines.[148] Moreover, the issues that the declaration will purposely avoid covering are "frontier" issues such as cloning, beginning and end of life, stem cells and euthanasia.[149] This may indicate that the hopes of Berlinguer and the Joint Centre for the success of future consensus-building endeavours are futile. Alternatively, it may illustrate perfectly the claims of Acharya *et al* that a different framework to that of the IGO is necessary. Perhaps if Rischard's "rough consensus" technique had been adopted in Paris, more controversial issues could have been addressed in the draft declaration. This seems unlikely, however; given the diversity of opinions, even rough consensus would have been hard to achieve.

[148] Article 13 of the Preliminary Draft Declaration on Universal Norms on Bioethics, UNESCO, 9 February 2005. It seems likely that the promotion of social responsibility clauses was in part influenced by the current debate about inequalities in health and bioethics: e.g., a delegate from Mexico said that the declaration should aim to close the "10/90 gap".

149 Personal observations of the IBC and IGBC meetings held at UNESCO headquarters, Paris, 24-28 January 2005.

Conclusion

What are the prospects for avoiding the potential harms of biotechnology and harnessing its benefits for the improvement of human health worldwide? And what can be learnt from examining the international relations literature in this context? Is Benatar's call for an "ethics of international relations"[150] feasible? It is clear that any initiative aimed at bridging the genomics divide must feature the local as much as it does the global. Benatar, Berlinguer, the Toronto group and Keusch and Medlin all suggest that overarching global entities need to be supported by initiatives at regional and local levels, although they may differ as to the degree of emphasis that should be placed at either end of the spectrum. This reflects Held's prediction that finding the appropriate level for effective governance for any given issue will not be obvious or uncontentious.

The UNESCO instruments on human genetics have thus far received little attention within the literature on genomics and bioethics. If this is related to their efficacy, there are two possible interpretations relevant to the GGI's prospects. Firstly, this may demonstrate that there is indeed a need for a new kind of network for the management of genomics. Conversely, the precedent set by the existing regulatory framework may not augur well for any future governance system. Which of these alternatives turns out to be the case will rest with both the reasons behind any problems facing the declarations and the degree to which the new network is truly innovative. If the declarations prove inconsequential because of some of the classic reasons that international relations theory would predict, such as the lack of coercive power behind non-binding resolutions, whether or not the GGI will suffer the same fate will depend on whether it is sufficiently different to overcome such difficulties.

If the GGI is successful as an instrument of governance, this could have implications more broadly, for the project of cosmopolitan democracy. It would demonstrate that deliberative democracy is possible beyond borders and that its outcomes can be upheld without the need for coercive power. Archibugi predicts that the project will come to fruition over a series of steps. The current plans for the reform of the UN[151] could be one of these steps, the GGI could be another. Whether this is likely depends on whether the goals of cosmopolitan democracy as a whole can be met. In order to be a part of the GGI, nations will have to engage with human rights fully, recognising that they have a duty to address inequalities in health, and in order to do so will probably have to give up some of their power and sovereignty. Thus the GGI could prove to be a test case for cosmopolitan democracy.

"The problems of Africa are so enormous that the debate on genetic engineering has had a minimal profile on the continent," writes Benatar.[152] This stark reality draws us back to the crux of the problem, global inequality. The fundamental question must be: how will global genomics governance affect health development? The facts of the matter – the 10/90 gap that bioethicists are so fond of quoting – should move us beyond mere theorising towards finding solutions to the very real problems of poverty and ill-health in developing countries. Those affected can not afford to wait and see whether something like the GGI or the virtual network will fulfil its aims. It is easy to be critical and point out various reasons why such initiatives may not work, such as lack of industry interest or the need for massive investment in information technology, but it is far harder to suggest superior alternatives. At least things are being done, both practically and to generate new ways of thinking. Acharya *et al* write:

[150] Benatar, "Reflections and Recommendations on Research Ethics in Developing Countries," 1132.
[151] See the report of the UN Secretary-General's High-level Panel on Threats, Challenges and Change, "A More Secure World: Our Shared Responsibility." (A/59/565) Available at http://www.un.org/reform/highlevelpanel.html.
[152] Benatar, "Human Rights in the Biotechnology Era I."

> International participation in global governance networks like the GGI can help prevent a bleak future of even greater disparities between industrialized and developing countries. Appropriate action *now* by the world community – governments, citizens and experts from industry and academia – can shape a more equitable global future."[153] (italics added)

This is not just a philosophical debate; the fact is that the GGI, the UNESCO declarations, the virtual network or a combination of all three, in the absence of any better solutions, *have* to be successful in addressing gross inequalities in health, for the benefit of those suffering from 90 per cent of the global disease burden.

[153] Acharya *et al*, "Better Global Governance to Promote Genomics for Development."