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Fair Resource Allocation to Health Research: Priority Topics for Bioethics Scholarship

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Box 1: Types of Health Research

These terms and definitions are used throughout the paper. Although no general agreement exists on ways to classify research, we have drawn on existing work to define a spectrum of research types to provide a sense of the range of possible funding targets.

Basic research is experimental or theoretical work undertaken primarily to acquire new knowledge about the underlying foundations (physiological and psychological) of disease, without any particular application or use in view.[1] It has traditionally been the preserve of laboratory-based researchers at universities or research institutions.[2]

Translational research aims to harness knowledge from basic research to produce new drugs, devices, and treatment options for patients. It is defined as "the transfer of new understandings of disease mechanisms gained in the laboratory into the development of new methods for diagnosis, therapy, and prevention and their first testing in humans."[3] Thus, it lies at the intersection of basic and clinical research. It does NOT focus on translating results from clinical research (e.g. new or modified vaccines, drugs, or diagnostics) into everyday clinical practice and health decision making, which is the aim of implementation science/research (a sub-field of health systems research).

Clinical research aims to develop novel interventions for the prevention, detection, diagnosis, and treatment of disease and to test and evaluate these interventions in humans in clinical/applied settings.[4] It also aims to adapt and optimise existing interventions. Clinical trials are often distinguished by particular phases. Phase I clinical trials are done to test a new intervention for the first time in a small group of people to evaluate safety (e.g. to determine a safe dosage range and identify side effects). Phase II clinical trials are done to study an intervention in a larger group of people (several hundred) to determine efficacy and to further evaluate its safety. Phase III studies are done to study the efficacy of an intervention in large groups of trial participants (from several hundred to several thousand) by comparing the intervention to other standard or experimental interventions. Phase IV studies are done after an intervention has been marketed. These studies are designed to monitor the effectiveness of the approved intervention in the general population and to collect information about any adverse effects associated with widespread use over longer periods of time.

Health systems research aims to generate knowledge to enhance the performance of health systems as a whole by focusing on their hardware and software components (e.g. financing, human resources, governance, and service delivery).[5] It can focus on these components at different levels of the health system: macro (architecture and oversight of health systems), meso (functioning of organisations within the health system), and micro (roles of individuals involved in health provision, utilization, and governance).[6] Health services research has been identified as a sub-field of health systems research.[7]

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[1] World Health Organization. 2013. *World Health Report 2013: Research for Universal Health Coverage*. Geneva: WHO.

[2] D. Cooksey. 2006. *A Review of UK Health Research Funding*. Norwich: The Stationary Office.

[3] S.H. Woolf. The Meaning of Translational Research and Why it Matters. *JAMA* 2008; **299**(2): 211-213.

[4] Cooksey op. cit. note 2; UK Medical Research Council. 2015. *UK Health Research Analysis 2014*. London: Medical Research Council.

[5] K. Sheikh, L. Gilson, I.A. Agyepong, et al. Building the Field of Health Policy and Systems Research: Framing the Questions. *PLoS Med* 2011; **8**(8): e1001073.

[6] Ibid.

Health services research examines healthcare at the organisational level (e.g. clinics and hospitals). It aims to improve the delivery of health services and has multiple sub-disciplines that include but are not limited to those listed below*[8]:

- Quality improvement aims to improve the quality and/or efficiency of health care and service delivery systems in health organisations. Quality improvement usually has a more internal (or bottom up) perspective addressing what kind of approaches actors within the organisation themselves can utilize to improve quality of care.[9]
- Operations research aims to solve operational issues that arise in health programmes and organisations.[10]
- Implementation science/research aims to develop strategies to improve access to specific health products (including vaccines and drugs) or services.[11]

Public health research focuses on the wider community or population, looking at issues such as how ill health varies within populations, disease prevention, and how to improve public health through interventions or programs.[12] The risks and causes of disease and health status that are examined can be biological, physical, chemical, social, or behavioural. Public health interventions or programs that are developed and tested can seek to reduce the risk of any of these determinants.[13] Thus, public health research encompasses research on the **social determinants of health**.

The overlap between public health research and health systems research includes research on the public health system and the delivery of public health interventions and programs.[14]

***Note:** In general, there is need for more work on clarifying the scope of different sub-fields of health services research to better understand where there is overlap, where there are gaps, and where they serve as terms describing the same areas of research.[15]

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[7] S. Hoffman, J.-A. Røttingen & S. Bennett et al. 2012. Background Paper on Conceptual Issues Related to Health Systems Research to Inform a WHO Global Strategy on Health Systems Research. Available at: http://www.who.int/alliance-hpsr/alliancehpsr_backgroundpaperhsrstrat1.pdf [Accessed 13 Jul 2014].

[8] Ibid; UK MRC op. cit. note 4.

[9] Hoffman et al., op. cit. note 7.

[10] J.H.F. Remme. Defining Research to Improve Health Systems. *PLoS Medicine* 2010; 7: e1001000.

[11] Ibid

[12] Cooksey op. cit. note 2.

[13] UK MRC op. cit. note 4; Cooksey op. cit. note 2; CSDH. 2008. *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health. Final Report of the Commission on Social Determinants of Health.* Geneva: WHO.

[14] Hoffman et al., op. cit. note 7.

[15] Ibid.

Fair resource allocation to health research: Priority topics for bioethics scholarship

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Abstract: This paper draws attention to the limited amount of scholarship on what constitutes fairness and equity in resource allocation to health research by individual funders. It identifies three key decisions of ethical significance about resource allocation that research funders make regularly and calls for prioritising scholarship on those topics—namely, how health resources should be fairly apportioned amongst public health and health care delivery versus health research, how health research resources should be fairly allocated between health problems experienced domestically versus other health problems typically experienced by disadvantaged populations outside the funder's country, and how domestic and non-domestic health research funding should be further apportioned to different areas, e.g. types of research, and recipients. These three topics should be priorities for bioethics research because their outcomes have a substantial bearing on the achievement of social justice. The proposed agenda aims to move discussion on the ethics of health research funding beyond its current focus on the mismatch between *worldwide* basic and clinical research investment and the global burden of disease. Individual funders' decision-making on whether and to what extent to allocate resources to non-domestic health research, health systems research, research on the social determinants of health, capacity development, and recipients in certain countries should *also* be the focus of ethical scrutiny.

Key Words: resource allocation; health research; ethics; social justice; fairness; equity

INTRODUCTION

Funding for health research has demonstrated steady growth in countries across the world since the 1980s.[1] Health research funders span a number of different categories: multilaterals, bilaterals, philanthropic foundations, private for-profit companies, and national research bodies.[2] Funders in these categories vary widely on a number of dimensions that include what types of health research they will fund (Box 1), who they will fund to perform health research, where they will fund the conduct of health research, and how their grant application processes are structured. These dimensions are highlighted because they affect how individual funders ultimately apportion their resources to health research. Here, it is important to recognise that many of the positions that funders, particularly those outside the

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[1] Global Forum for Health Research. 2008. *Monitoring Financial Flows for Health Research 2008*. Geneva: GFHR.

[2] M.A. Lansang, S. Tollman, J. Kasonde, et al. 2000. *Health Research for Development: The Continuing Challenge, A Discussion Paper Prepared for the International Conference on Health Research for Development*. Available at: http://www.cohred.org/publications/library-and-archive/health_research_for__1_183 [Accessed on 15 May 2014]; Multilaterals like the World Health Organization, bilaterals like the United Kingdom's Department of International Development (DFID), and philanthropic organisations like the Gates Foundation and Wellcome Trust spend part of their resources on health research. Multilaterals obtain their funding from multiple governments (and private sector sources). Bilaterals are public entities that primarily receive their funding from the government of their home country whereas philanthropic organisations are not-for-profit foundations that raise their funds through private investments. Multinational pharmaceutical, biotechnology, and medical instrument companies are the main health research funders in the private for-profit sector. National research bodies like the United States' National Institutes of Health are public entities that receive money from their governments, which is then allocated mainly to health research.

public sector, take on these dimensions are at their own discretion (and are not externally imposed upon them by law or other policies).

[INSERT BOX 1]

Existing data on resource allocation to health research suggests the current practices of many funders may be inconsistent with considerations of fairness and conceptions of social justice that call for reducing health disparities, domestically and globally. Achieving social justice globally requires greater investment in research that focuses on health problems typically (but not exclusively) experienced in poor countries. There is also increasing recognition that improvements in public health and equity in all countries are tied to the conduct of health systems research[3] and research on the social determinants of health.[4] The latter can focus on any area of life that has a direct impact on health, including non-health sector areas. Thus, in this paper, it is understood to strongly overlap with what has been called 'research for

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[3] Ministerial Summit on Health Research. 2004. *The Mexico Statement on Health Research*. Mexico City, Mexico; WHO Task Force on Health Systems Research. 2005. *The Millennium Development Goals Will Not be Attained Without New Research Addressing Health System Constraints to Delivering Effective Interventions.* Geneva: WHO.

[4] Global Forum for Health Research. *Strengthening Research for Health, Development and Equity*, 2009. Geneva: Global Forum for Health Research; WHO Task Force on Research Priorities for Equity in Health and the WHO Equity Team. Priorities for Research to Take Forward the Health Equity Policy Agenda. *Bull World Health Organ* 2005; **83**: 948-953; CSDH. 2008. *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health. Final Report of the Commission on Social Determinants of Health.* Geneva: WHO;

health'.[5] Yet health research on topics that are typically a problem in poor countries remains inadequately funded,[6] and investment in health systems research relative to basic and clinical research is very low in most countries.[7] Investment favours health research that can boost national economic competitiveness (i.e. science and technology research). R&D policies in knowledge-based economies create strong incentives for funding such research but not for investing in research needed to strengthen health systems or to address the social determinants of health.[8] As a result, spending on health systems research comprises only 1.5% of US health research funding, 1% of the US National Institutes of Health (NIH) budget,[9] and 4.8% of total funding for health research by the eleven largest government and charity funders in the UK.[10] The European Commission displayed a similar investment

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[5] Research for health aims to understand the health impact of policies, programs, processes, actions, and events originating in any sector, including economic, social, political, and other determinants of health. See: Global Forum for Health Research, 2008. *Monitoring Financial Flows for Health Research 2008*. Geneva: GFHR.

[6] Global Forum for Health Research. 2004. *Monitoring Financial Flows for Health Research 2004*. Geneva: GFHR; J-A. Røttingen, S. Regmi, M. Eide., et al. Mapping of Available Health Research and Development Data: What's There, What's Missing, and What Role is there for a Global Observatory? *Lancet* 2013; **382**(9900): 1286-1307.

[7] Alliance for Health Policy and Systems Research. 2004. *Strengthening Health Systems in Developing Countries: The Promise of Research on Policy and Systems.* Geneva: Alliance for Health Policy and Systems Research; D. Cooksey. 2006. *A Review of UK Health Research Funding.* Norwich: The Stationary Office; S. Bennett, T. Adam, C. Zarowsky, et al. From Mexico to Mali: Progress in Health Policy and Systems Research. *Lancet* 2008; **372**(9649): 1571-1578; S.H. Woolf. The Meaning of Translational Research and Why it Matters. *JAMA* 2008; **299**(2): 211-213; H. Moses III, E.R. Dorsey, D.H.M. Matheson, et al. Financial Anatomy of Biomedical Research. *JAMA* 2005; **294**: 1333–42; WHO Task Force on HSR, op. cit. note 3.

[8] ANONYMOUS.

[9] Woolf, op. cit. note 7.

[10] Cooksey, op. cit. note 7.

pattern from 2007-2012, with basic and clinical research allocated almost all its health research funding.[11]

Also of potential concern, health systems research carried out in poor countries focuses on service delivery and scale-up above other health system components such as human resources and governance.[12] Funders from high-income countries have a tendency to fund primarily high-income country organisations to perform health research.[13] As an illustration of this wider trend, from 1998-2007, 82% of Gates Foundation grants went to US-based recipients.[14] This example demonstrates that a major research funder has largely distributed its resources to recipients from its own country over a substantial period of time. Such practices mean funding for health research on conditions typically (but not exclusively) experienced in poor countries is often recycled within high-income country economies rather than reaching low and middle-income country (LMIC) economies.[15] Where health research resources are

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[11] Strengthening Engagement in Public Health Research. 2011. *Public Health Research – Europe's Future*. London: University College London.

[12] M.A. Gonzalez-Block. Health Policy and Systems Research Agendas in Developing Countries. *Health Research Policy and Systems* 2004; **2**: 6; T. Adam, S. Ahmad, M. Bigdeli, et al. Trends in Health Policy and Systems Research Over the Past Decade: Still too Little Capacity in Low-Income Countries. *PLoS One* 2011; **6**(11): e27263; S. Bennett, I.A Agyepong, K. Sheikh, et al. Building the Field of Health Policy and Systems Research: An Agenda for Action. *PLoS Med* 2011; **8**(8): e1001081.

[13] D. Sridhar. Seven Challenges in International Development Assistance for Health and Ways Forward. *J Law Med Ethics* 2010; **38**(3): 459-469.

[14] D. McCoy, G. Kembhavi, J. Patel, et al. The Bill & Melinda Gates Foundation's Grant-making Programme for Global Health. *Lancet* 2009; **373**(9675): 1645-1653.

[15] M. Moran, J. Guzman, A.L. Ropars, et al. The Role of Product Development Partnerships in Research and Development for Neglected Diseases. *International Health* 2010; **2**: 114-122.

allocated to LMIC recipients, funders from the United Kingdom distribute them in a way that closely mirrors colonial ties (i.e. mainly to recipients in former colonial territories).[16]

The decision-making processes some funders rely on to allocate their resources to health research have been criticised for their lack of transparency and reliance on informal systems of personal networks and relationships.[17] Funders may also utilise selection criteria that favour certain types of research or recipients from certain countries. For example, funders often employ a selection criterion relating to the science behind proposed projects. This type of selection criterion, depending on how it is interpreted, may serve to bias the award of funding to types of research (e.g. basic and clinical research) utilising methods associated with a high degree of rigour such as randomised controlled trials over types of research (e.g. health systems research) that often utilise social science methods. Social science methods have been viewed as less rigorous by funders, which may result in projects that employ them scoring lower in terms of the quality of their science.[18]

Individual funders regularly make decisions not to fund a large amount of health systems research, public health research on the social determinants of health, research on health problems typically experienced in poor countries, and/or recipients from outside their

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[16] J.R. Fitchett, M.G Head, & R. Atun. Infectious Disease Research Investments Follow Colonial Ties: Questionable Ethics. *International Health* 2014; **6**(1): 74-76.

[17] McCoy et al., op. cit. note 14.

[18] Bennett et al. have noted that the 'perception that [health systems research] often does not yield high-quality research seems to be holding back greater investment, particularly by non-traditional funders' such as Wellcome Trust. See Bennett et al., op. cit. note 7, p. 1573; L. Gilson, K. Hanson, K. Sheikh, I.A. Agyepong, F. Ssengooba, & S. Bennett. Building the Field of Health Policy and Systems Research: Social Science Matters. *PLoS Med* 2011; **8**(8): e1001079.

country. Yet, within bioethics, there has been limited consideration of what comprises fair and equitable resource allocation to health research—namely, what the size and shape of a just health research portfolio looks like.[19] Accordingly, there is little specific guidance from either philosophy or bioethics on what a fair process of resource allocation to health research might entail, what outputs should emerge from it, and who is obligated to do what to ensure that the process and/or outputs are achieved. In its absence, bioethics lacks the tools to rigorously assess the fairness of individual health research funders' decision-making processes and the consistency of their resource allocation decisions with concepts of social justice.

This paper takes the position that more bioethics research on what constitutes fairness and equity in resource allocation to health research by funders is urgently needed. As a first step, it identifies three key decisions about resource allocation that *individual* research funders make regularly and calls for prioritising scholarship on these topics because they have a substantial impact on achieving social justice. Additionally, the paper highlights research questions related to these priority topics that are important to explore given how the global

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[19] Our extensive review of the bioethics literature revealed the following peer-reviewed publications: T.C. Bailey & J. Sugarman. Social Justice and HIV Vaccine Research in the Age of Pre-Exposure Prophylaxis and Treatment as Prevention. *Current HIV Research* 2013; **11**(6): 473-480; D. Resnik. The Distribution of Biomedical Research Resources and International Justice. *Dev World Bioeth* 2004; **4**(1): 42-57; J.H. Flory & P. Kitcher. Global Health and the Scientific Research Agenda. *Philos Public Aff* 2004; **32**(1): 36-65; T. Pogge. The Health Impact Fund: Enhancing Justice and Efficiency in Global Health. *J Human Dev Capabil* 2012; **13**(4): 537-559; C.A. Gericke, A. Riesberg, & R. Busse. Ethical Issues in Funding Orphan Drug Research and Development. *J Med Ethics* 2005; **31**: 164-168; T.M. Krahn & A. Fenton. Funding Priorities: Autism and the Need for a More Balanced Research Agenda in Canada. *Pub Health Ethics* 2014; **5**(3): 296-310; T. Pogge. 2008. *World Poverty and Human Rights: Cosmopolitan Responsibilities and Reforms*. Cambridge: Polity Press.

research system is organised (in terms of structures, policies, and actors). If an account of fair resource allocation to health research cannot provide guidance on these questions, it will offer an incomplete description of what is required for justice in today's world.

While previous (ethical) criticisms of expenditure on health research have primarily focused on overall investments *worldwide*,[20] those totals reflect separate decision-making by numerous research funders, each with their own resources. Thus, it is important to explore how individual funders should allocate their resources. In developing this agenda, the paper takes as a given that matters of resource allocation to health research can be meaningfully analysed from an ethics perspective and, more specifically, a justice perspective. This position is held in light of recent (albeit limited) ethics scholarship on resource allocation to health research.[21] Although that literature only begins to address the priority topics posed in this paper, it shows theories and principles of justice have direct applicability to ethical issues faced in health research resource allocation. Finally, the paper's focus on justice is not intended to suggest that the ethics of resource allocation to health research cannot be explored from other moral perspectives.

IDENTIFYING PRIORITY TOPICS

Three ethically significant decisions about resource allocation face individual research funders *and* should be the focus of bioethical inquiry. The first of these decisions is *what*

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[20] Pogge op. cit. note 19; Commission on Health Research for Development. 1990. *Health Research: Essential Link to Equity in Development.* Oxford: Commission on Health Research for Development.

[21] See: Bailey & Sugarman op. cit. note 19; Resnik op. cit. note 19; Flory & Kitcher op. cit. note 19; Gericke et al. op. cit. note 19; Krahn & Fenton op. cit. note 19; Pogge op. cit. note 19.

proportion of health resources ought to be allocated between public health and health care delivery versus health research.[22] Public health and health care delivery are understood to encompass the delivery of proven-effective health care interventions (vaccines, drugs, diagnostics) and services (treatment, rehabilitation) to patients and the delivery of proven-effective public health interventions and programs to populations and individuals respectively. Public health interventions can target proximate determinants (water, sanitation) and wider social determinants of health (gender norms, food security, labour policies). Health research refers to using scientific methods to generate new knowledge in order to improve understanding of health challenges and develop responses to address them.[23]

Determining the amount of resources to allocate to health and how they are to be apportioned between health research and implementing proven-effective health care and public health measures is the broadest level of decision-making that *directly* relates to health research. This decision is typically associated with governments but is also very relevant to any organisation that funds a combination of health care services, public health programs, and/or health research. For example, some bilateral aid agencies finance the conduct of all three activities in LMICs as do philanthropic foundations like the Gates Foundation.[24]

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[22] For the purposes of this paper, the overarching health budget is assumed to be fixed. The paper considers decisions made downstream of the decision regarding what amount of resources to allocate to health versus other sectors. However, we recognise that, in certain circumstances, arguments can be made to expand this higher-order budget allocation. For example, expanding the health budget is an option if the amount allocated to it would force a government or organisation to make tragic choices between two allocation options.

[23] World Health Organization. 2013. *World Health Report 2013: Research for Universal Health Coverage*. Geneva: WHO.

[24] McCoy et al., op. cit. note 14.

The second resource allocation decision is *what proportion of total funding for health research ought to be allocated to domestic health problems versus non-domestic health problems*. Here, the underlying moral question is how much research resources should be spent on the health problems of people within the funder's home country versus other health problems experienced by disadvantaged populations outside that country, who live primarily (but not exclusively) in LMICs? (Such populations often live in low-income countries and highly unequal middle-income countries. They may also live in high-income countries, particularly given the rise in refugee movements worldwide.) In this paper, non-domestic health research focuses on topics that are not a substantial problem in the funder's home country but are typically a problem for disadvantaged populations in other countries. Domestic health research focuses on topics that are typically a problem in a funder's home country. As an example, given that 97% of cases of Human African trypanosomiasis (HAT) occur in eight African countries[25], if funders from the Democratic Republic of Congo and India invested in a HAT research project, it would be considered domestic health research and non-domestic health research for them respectively. Thus, while the definitions of domestic and non-domestic research are fixed, what health problems fall into each category varies by country.

The need to make this decision reflects the increasing globalisation of the research enterprise. Health research that is funded by external organisations (largely from high-income countries) and conducted with populations in LMICs has grown significantly over the last twenty

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[25] Drugs for Neglected Diseases. 2016. *Human African Trypanosomiasis Fact-sheet*. Available at: http://www.dndi.org/wp-content/uploads/2009/03/DNDi_HAT_factsheet.pdf [accessed 30 Mar 2016]

years.[26] The decision is relevant to multilaterals, national research bodies, private for-profit companies, and philanthropic foundations.[27] Bilateral aid agencies do not face this choice because all their funding for health research is generally directed to non-domestic health research.

The third decision that research funders must make once health research resources are allocated to domestic and/or non-domestic health research is *how ought they to be further apportioned to different recipients and areas*. Recipients refer to the institutions or individuals who are eligible to apply and to the institutions and individuals who are ultimately awarded funding to complete research projects or programs. Areas of research include different types of research (Box 1), diseases, health system components, social determinants of health (e.g. income and wages, employment conditions, housing, transport, education, food security), capacity development targets (e.g. individuals, institutions, systems), and topics where research funding gaps exist. Health system components can include hardware components (financing, human resources, governance, information technology and service delivery) and software components (relationships, power, values and norms).[28]

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[26] M. Parker & S. Bull. Ethics in Collaborative Global Health Research Networks. *Clinical Ethics* 2009; **4**(4): 165-168.

[27] For entities without a clear nationality (e.g. multilaterals, multinational pharmaceutical companies), the decision would be reframed as determining what proportion of health research funding ought to be allocated to health problems typically experienced in high-income countries versus health problems typically experienced in low-income countries.

[28] K. Sheikh, L. Gilson, I.A. Agyepong, et al. Building the Field of Health Policy and Systems Research: Framing the Questions. *PLoS Med* 2011; **8**(8): e1001073.

This decision entails determining how much domestic health research funding should be allocated to health research projects and programs versus capacity development. Of the funding for domestic health research, how much should be allocated to basic, clinical, health systems, and public health research? How much should go to research on communicable versus non-communicable diseases? Of the funding for capacity development, how much should target individual research capacity strengthening versus institutional research capacity strengthening? The same decisions are pertinent for non-domestic health research funding as well.

These three decision points[29] in the resource allocation pathway *should* be priorities for bioethics research because their outcomes have substantial effects on the achievement of social justice. For the purposes of this paper, social justice is defined as attaining health equity between and within countries.[30] The first of these decisions determines the overall size of the portfolio and the latter two largely establish its content or shape. If decision-making on

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[29] Here, we make the assumption that at least two levels of resource allocation (i.e. two separate processes) take place in relation to health research. The first level of allocation occurs when a decision is made on what amount of resources should be directed to health research relative to other areas of health investment. The second level of allocation occurs once a health research budget is known. At this point, decisions are made about how health research resources should be distributed amongst non-domestic health research and domestic health research and amongst different areas of research.

[30] Health equity has been interpreted to mean achieving equal opportunity for health (normal functioning) or bringing individuals, especially the worst-off in health terms, up to a sufficient or optimal level of health (Powers and Faden, 2006; Daniels, 2008; Ruger, 2010). This paper does not weigh in on that debate but rather takes the position that health research is required to achieve both concepts of health equity. See: M. Powers & R. Faden. 2006. *Social Justice: The Moral Foundations of Public Health and Health Policy*. Oxford: Oxford University Press; N. Daniels. 2008. *Just Health: Meeting Health Needs Fairly*. Cambridge: Cambridge University Press; J.P. Ruger. 2010. *Health and Social Justice*. Oxford: Oxford University Press.

resource allocation is not conducted fairly, it can give rise to a research portfolio that helps perpetuate or exacerbate unequal opportunities for health and disparities in health outcomes between and within countries.

Unlike public health and health care delivery efforts, health research does not currently offer the prospect of an immediate impact on health. However, health research is essential for societies' health systems to provide equal access to high-quality public health and health care measures, which is required for individuals to achieve an equal opportunity for normal functioning[31] and a sufficient or optimal level of health.[32] A lack of evidence can perpetuate health disparities that arise due to gaps in knowledge on how to prevent or treat certain health conditions, particularly those experienced by disadvantaged populations, or on how to equitably and effectively deliver health services. Given that a scientifically-grounded evidence base is a necessary condition for achieving health justice, a fair amount of resources must be allocated to health research relative to public health and health care delivery.[33]

Where funders' research portfolios exclude research on health problems that are typically of high burden for disadvantaged populations in other countries, this serves to perpetuate or exacerbate unequal health opportunities and outcomes between countries.[34] Needed public health and health care measures are not created for diseases that typically affect

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[31] Upholding the fair equality of normal opportunity principle demands that just societies maintain their members' equal opportunity for normal functioning, where normal functioning is defined as an absence of pathology (Daniels, 2001).

[32] Daniels, op. cit. note 30; Ruger, op. cit. note 30; ANONYMOUS.

[33] ANONYMOUS, op. cit. note 32; Ruger, op. cit. note 30.

[34] Resnik, op. cit. note 19.

disadvantaged populations in LMICs. Effective interventions to improve access and financial protection within health systems or to address structural determinants of these populations' poor health are not developed. This has a substantial effect on the well-being of the world's least advantaged.

Where funders' domestic or non-domestic health research portfolios primarily focus on certain types of research (e.g. basic, translational, clinical), they can perpetuate or exacerbate patterns of inequity by failing to invest in research that is essential to improving the health of the disadvantaged and marginalised.[35] Although it is necessary for new disease-specific interventions to be developed and existing disease-specific interventions to be adapted for resource-poor settings, making basic, clinical, and translational research the main types of health research that receive funding will have a limited impact upon disadvantaged populations' health. Other types of health research must be performed as well. Health systems research has been identified as essential to achieving health equity.[36] Significant knowledge deficits exist regarding what health system barriers are hindering the delivery and affordability of health care and services and what strategies are required for overcoming them, particularly for disadvantaged populations.[37] Health systems research can help address these knowledge deficits and improve health systems for such populations. Public health research is also needed on the global factors and processes that affect health equity and, at the national level, the societal and political structures and relationships that differentially affect people's chances to be healthy. Areas of concern include food security, labour market policies, gender norms, land-use planning's impact (e.g. on rural production and household

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[35] Krahn & Fenton, op. cit. note 19.

[36] WHO Task Force on Health Systems Research, op. cit. note 3.

[37] Ibid.

food security), education, housing, environmental protection, water and sanitation, transport, and security.[38] At present, these types of health research may even have a greater impact on the health of disadvantaged populations (in LMICs) compared to basic and clinical research. Most poverty-related health conditions are amenable to existing treatments.[39] While 22% of child deaths in low-income countries could be averted with better technologies (new drugs and vaccines), optimisation of health systems' delivery of existing technologies would result in a 66% reduction in child mortality.[40]

Where funders' domestic or non-domestic health research portfolios focus primarily on certain diseases, health system components, or social determinants of health, they may also be misaligned with the needs of the worst-off. For example, the diseases of focus may not be of high burden to disadvantaged populations within the funder's home country. Where funders' non-domestic health research portfolios disproportionately allocate resources to institutions in certain countries, the benefits of such research and capacity development projects are likely to be unevenly distributed and may serve to widen disparities in health and research capacity.

DEVELOPING AN ACCOUNT OF FAIR ALLOCATION TO HEALTH RESEARCH

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[38] WHO Equity Team op. cit. note 3.

[39] P. Stevens. 2004. Diseases of Poverty and the 10/90 Gap. In *Fighting the Diseases of Poverty*. P. Stevens, ed. London: International Policy Press: 126–140.

[40] J.L. Leroy, J.P. Habich, G. Pelto, & S.M. Bertozzi. Current Priorities in Health Research Funding and Lack of Impact on the Number of Child Deaths per Year. *Am J Public Health* 2007; **97**: 219–23.

In the remainder of the paper, we explore how to take bioethics research on the three priority topics forward, towards the aim of developing an account of fair resource allocation to health research. Attention is first drawn to cross-cutting considerations that apply across all priority topics and then to additional considerations that relate to certain priority topics. Where an account does not address these considerations, it will offer an incomplete description of what is necessary to achieve fairness and equity in today's world and, in effect, be of limited use to research funders and bioethicists. Cross-cutting considerations include decision-making processes, decision-making principles, power disparities amongst stakeholders in decision-making, research funders being from countries with varying levels of resources, and research funders representing different sectors (public, philanthropic, private for-profit). Additional considerations each comprise real-world conditions that may foment unfair decision-making by research funders. They include overarching global targets for health research spending, governments' national research and development policies, and funders' own operational structures. After these considerations are discussed, specific research questions relating to the priority topics are proposed in light of them.

Cross-cutting considerations

Ethical frameworks for making resource allocation decisions rely on identifying procedural conditions and substantive principles.[41] An account of fair resource allocation should, therefore, describe *processes* for making the three key decisions and/or *principles* for doing so. In terms of process, relevant theories of justice in political philosophy generally call for

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[41] L.M. Sabik & R.K. Lie. Principles Versus Procedures in Making Health Care Coverage Decisions: Addressing Inevitable Conflicts. *Theor Med Bioeth* 2008; **29**(2): 73-85.

relying on deliberative processes and norms to achieve fair priority-setting.[42] These norms include reasonableness, inclusion, accountability, and transparency.[43] An account of a fair process to allocate resources to health research ought to then provide guidance on who should be involved and how they should be involved (decision-making, consulting, informing). It should describe what deliberation, transparency, and accountability entail when allocating resources between public health and health care delivery versus health research, between non-domestic and domestic health research, and between different areas of research.

Such an account will further need to describe what constitutes a fair process in the context of power disparities between stakeholders. This reflects the fact that, where countries exhibit major social and economic inequalities within their populations, deliberative processes will likely serve to reinforce the status quo, giving an effective voice only to those stakeholders with considerable power and resources.[44] These conditions of inequality occur in almost all countries, at all levels of national income. Existing evidence confirms normative and structural barriers (patriarchy, poverty, low social status) frequently result in processes where certain groups aren't able have their voices heard in health decision-making.[45] Most recently, efforts to implement a prominent account of fair resource allocation that emphasises

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[42] I.M. Young. 2000. *Inclusion and Democracy*. Cambridge: Cambridge University Press; Daniels, op. cit. note 30; Ruger, op. cit. note 30.

[43] A. Gutmann & D. Thompson. 2004. *Why Deliberative Democracy?* Princeton University Press: Princeton; Young, op. cit. note 42.

[44] Young, op. cit. note 42.

[45] Ibid; K.B. Alderman, D. Hipgrave, & E. Jimenez-Soto. Public Engagement in Health Priority-setting in Low- and Middle-Income Countries: Current Trends and Considerations for Policy. *PLoS Med* 2013; **10**(8): e1001495.

democratic deliberation—Norman Daniels' 'accountability for reasonableness'[46]—have shown this effect. Research assessing the framework's implementation in Tanzania demonstrated that—even where district-level health decision-making processes included male and female individuals representing a diverse array of income-levels, education-levels, and ethnicities—being male, having a higher income or education level, and/or being from the main ethnic group in the district-under-study meant that a person was listened to more seriously and had greater influence on the outcome of the process.[47]

Such tendencies in health decision-making suggest that any account of a fair process for allocating resources to health research will be inadequate unless it offers guidance on what is necessary to achieve fairness in the context of power disparities. The accountability for reasonableness framework's inclusion requirement, for example, is insufficient because it demands simply involving a broad range of stakeholders, which does not ensure that less

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[46] Accountability for reasonableness proposes that a fair resource allocation process should meet four conditions: relevance, publicity, appeals and revision, and enforcement. The relevance condition requires resource allocation decisions to be made for reasons that pertain to meeting the varied health needs of a defined population 'fairly' under resource constraints; the reasons must also be accepted to be relevant in the context by 'fair-minded' stakeholders). The publicity condition calls for all decisions and their rationales to be made publically accessible). The appeals and revisions condition demands that there be mechanisms for challenge and dispute resolution regarding decisions. The regulative condition requires that there is public regulation of the process to ensure the former three requirements are met. See Daniels, op. cit. note 30.

[47] E.H. Shayo, O.F. Norheim, L. Mboera, et al. Challenges to Fair Decision-making Processes in the Context of Health Care Services: A Qualitative Assessment from Tanzania. *Int J Equity Health* 2012; **11**: 30; S.O. Maluka. Strengthening Fairness, Transparency and Accountability in Health Care Priority-setting at District Level in Tanzania. *Global Health Action* 2011; 4: 7829.

powerful stakeholders have an equal opportunity to have their voices heard or to influence decision-making.

Aside from procedural conditions, consideration of *principles* to guide resource allocation is relevant across the priority topics. A set or sets of ethical principles should be developed to direct resource allocation between public health and health care delivery versus health research, between non-domestic and domestic health research, and between different areas of research. Such principles can be applied to help determine if individual funders’ resource allocation decisions reflect fair outcomes.

Whether these principles and procedural conditions should vary based on the income level of a funders’ home country or the sector a funder represents should be explored as well. The former consideration reflects the fact that some funders are located in countries with limited resources for even domestic health research. This may have a bearing on what constitutes fairness and equity in their resource allocation to health research. The latter consideration reflects the fact that funders’ remits largely vary based on whether they are in the public, philanthropic, or private for-profit sectors, though there is also likely to be diversity within sectors.

In the public sector, national research bodies are typically charged with generating knowledge to enhance the health of (primarily) their country’s population. As an example, the US National Institutes of Health aims ‘to develop, maintain, and renew scientific human and physical resources that will ensure the Nation's capability to prevent disease and to expand the knowledge base in medical and associated sciences in order to enhance the

Nation's economic well-being.'[48] Bilateral aid agencies focus on public health programs, health care delivery, and health research to benefit LMIC populations, often in countries or regions of strategic importance to the donor country. For example, Australia's Department of Foreign Affairs and Trade mainly focuses on countries in the Indo-Pacific such as Indonesia and Papua New Guinea.[49] In the private sector, multinational pharmaceutical companies largely aim to fund health research that will generate commercialiseable products with the best return for investment. In contrast, there is more flexibility for philanthropic foundations to set the scope of their own remits because they are not part of government and do not have shareholders to whom they are accountable. Their remits can differ substantially and may entail a primary focus on domestic health research (Wellcome Trust) or on health research and health care delivery in LMICs (Gates Foundation).[50] It is unclear whether these differences mean that the processes and principles used to make fair decisions about resource allocation to health research should vary. A comprehensive account would speak to this matter.

Additional real world considerations

Real world conditions have the potential to generate resource allocation decisions that are inconsistent with social justice. We highlight three such conditions here that can affect

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[48] National Institutes of Health (NIH). 2015. *Mission*. Available at: http://www.nih.gov/about/mission.htm [Accessed 15 Feb 2015].

[49] Australian Government Department of Foreign Affairs and Trade. 2016. *Where We Give Aid*. Available at: http://dfat.gov.au/aid/where-we-give-aid/Pages/where-we-give-aid.aspx [Accessed 30 Mar 2016].

[50] A. Jha. 2010. Science Funding Cuts: We Won't Fill the Gaps, Say Firms and Charities. *The Guardian*. Available at: http://www.guardian.co.uk/science/2010/oct/07/science-funding-cuts-firms-charities [Accessed 12 Mar 2012]; McCoy et al., op. cit. note 14.

individual funders' resource allocation between public health and health care delivery versus health research, between non-domestic and domestic health research, and/or between different areas of research but acknowledge that there may be others.

Global targets for health research spending (as a percentage of health budgets) are relevant to governments and bilateral aid agencies' decision-making on how to apportion health resources between public health and health care delivery versus health research. In 1990, the Commission on Health Research for Development proposed that governments should spend 2% of their national health budgets on research and aid agencies should spend 5% of their official development assistance for health on research.[51] These targets were later endorsed at subsequent ministerial summits on health research.[52] As such, they constitute global norms and can influence the decision-making of numerous funders in these two categories. If the targets set by these policies are not fair in themselves, they can promote unfair outcomes (e.g. too little investment in health research). A *useful* account of resource allocation to health research would provide guidance in support or dispute of currently endorsed global targets.

National governments' research and development (R&D) policies can have a huge impact on whether or not individual research funders invest in non-domestic health research and in types of research without commercialiseable outputs, many of which are strongly linked to the promotion of health equity (e.g. health systems research, public health research on the social determinants of health). Evidence indicates that the model of R&D legislation (technology transfer legislation) currently adopted in knowledge-based economies does not

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[51] CHRD, op. cit. note 19.

[52] Global Ministerial Forum on Research for Health. 2008. *Bamako Call to Action on Research for Health*. Bamako, Mali.

provide strong incentives for funding such research, resulting in very low levels of investment.[53] This type of legislation is typical in many high-income countries and is increasingly being adopted in LMICs.[54] An account of resource allocation to health research should address the role of national R&D policies in funders' decision-making.

Another important consideration to bear in mind is how funders' operations are structured. Often, their allocation of health research funding occurs at two levels: first to funding schemes and then to particular research or research capacity development projects and programs. Funding schemes are grantmaking programs that individuals or institutions can apply to in order to support the costs of research or research capacity development projects and programs. Research funders decide upon particular schemes and determine how much of their financial resources will be allocated to each of them. Once resources are allocated to particular schemes, funders rely on specific application processes and selection criteria to choose proposed projects and programs to award money.

The way funding schemes are set up may engender potentially unfair resource allocation outcomes by largely *excluding* certain types of research, e.g. the NIH has traditionally focused on basic, translational, and clinical research; *excluding* health systems research or social determinants research on certain components/determinants, e.g. UK Department for International Development's 2009 research program consortia funding call focused on service delivery, human resources, and governance of health systems; or *excluding* certain recipients, e.g. the European Commission requires lead applicants to be from European countries, even where research is performed in LMICs. These examples illustrate current practices of major

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[53] ANONYMOUS, op. cit. note 8.

[54] ANONYMOUS

health research funders that may be inconsistent with social justice but are not necessarily representative of other funders.

Funding schemes' organisation may also engender unfair processes of resource allocation by forcing decisions to be made in a particular order. To demonstrate how this can occur, two hypothetical examples of how a funder might organise its funding schemes are provided. Option One is to organise funding schemes on the basis of disease, thereby setting up funding calls on particular diseases or sets of diseases (e.g. HIV/AIDS, tuberculosis, and malaria). Once a set amount is apportioned to schemes for different diseases, separate budget allocations might be set within these schemes for different types of research. This would result in, for example, a certain amount of funding being available for basic science, translational, clinical, health systems, and public health research on malaria.

Option Two is to organise funding schemes around the different types of research and then allocate resources between them. Within the different funding schemes for disease-driven research, e.g. basic and clinical research, budget allocations might be set for different diseases. Health systems research funding schemes might have budget allocations for research on each of the goals (equity, financial protection, responsiveness) or components of health systems (governance, finance, human resources, service delivery).[55] Funding schemes for public health research on the social determinants of health might have budget allocations for research on known social determinants (e.g. poverty, gender, education).

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[55] J. Kutzin. Health Financing for Universal Coverage and Health System Performance: Concepts and Implications for Policy. *Bull World Health Organ* 2013; **91**: 602-611; Sheikh et al., op. cit. note 28.

Option One forces resources to be allocated by disease *prior* to their allocation to different types of research. This may not be the best choice from a social justice perspective because it results in the fragmentation of non-disease specific forms of research that are needed to achieve public health and equity across countries. Michael K. Ranson and Sara Bennett affirm that 'linking health systems research questions to specific diseases, rather than seeing them in total…contributes to the fragmentation of health systems research.'[56] Ultimately, the organisation of funding schemes, the amount of funding allocated to different schemes, and the processes and selection criteria used to determine which projects receive funding have a huge influence on what research areas and recipients get supported. An account of fair resource allocation to health research should offer guidance in relation to all three matters.

Research questions

Research questions relating to the priority topics are proposed in light of the considerations identified in the previous two sections. The first two research questions relate to resource allocation to non-domestic health research:

1. Do public *and* private health research funders have an obligation of justice to allocate resources to non-domestic health research?
2. Does this obligation and its content vary depending on whether a funder is located in a high-income, middle-income, or low-income country?

So far, there has been some consideration of the second of these questions, demonstrating that certain cosmopolitan theories of justice do, in fact, establish such an obligation for research

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[56] M.K. Ranson & S. Bennett. Priority Setting and Health Policy and Systems Research. *Health Res Policy Syst* 2009; **7**: 27.

funders in *high-income countries*.[57] However, justice may demand different obligations for funders from LMICs. It may not be fair to expect the same amount or, perhaps, any investment in non-domestic health research from funders in less affluent countries. Jennifer Prah Ruger and Nora Y. Ng argue that, while emerging economies Brazil, China, India, Russia, and South Africa do have a role in improving the health of populations in other LMICs, their potential contribution to the global health enterprise differs from that of high-income countries.[58] Theories of justice that assign obligations on the basis of actors' functions (e.g. the health capability paradigm) might then ground an obligation for funders from Brazil, China, India, Russia, and South Africa to invest in non-domestic health research, but they may deem its content (e.g. the amount owed) to be different to that of high-income country funders. There is little, if any, scholarship on the role of lower middle-income and low-income countries in global health or their obligations to support health achievements in other countries. It is possible that ethical arguments could be made for these countries having no or limited obligations to support non-domestic health research.

Beyond establishing if investment in non-domestic health research is ethically required, additional research questions to investigate are:

3. What constitutes a fair process in the context of power inequalities when allocating resources between: a) public health and health care delivery versus health research, b) non-domestic and domestic health research, and c) areas of research?
4. What ethical principles should guide these resource allocation decisions?

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[57] ANONYMOUS, op. cit. note 32.

[58] J. Ruger & N.Y. Ng. Emerging and Transitioning Countries' Role in Global Health. *Saint Louis University Journal of Health Law & Policy* 2010; **3**: 253-290.

5. Do the answers to questions 3 and 4 vary by funding sector?[59]

Questions 3b, 3c, and 4 entail exploring what procedural conditions and principles should guide resource allocation at two levels: funding scheme and project, i.e. when allocating resources between non-domestic health research funding schemes and domestic health research funding schemes, between funding schemes targeting different areas of research, and amongst proposed projects and programs. Who should be involved and how in these decision-making processes should be clarified. Answering these questions will (amongst other things) permit evaluation of the fairness of individual funders' application processes and selection criteria for choosing projects to fund, which were previously noted could be non-transparent and/or biased against certain types of research.

Given the impact funding schemes' organisation can have on resource allocation, it is vital to investigate:

6. How should *funding schemes* for domestic health research and funding schemes for non-domestic health research be structured by target research areas and eligible recipients to promote fairness and equity?

Answering question 6 will facilitate assessing whether the practices of the NIH, DFID, and European Commission described in the previous section are consistent with social justice. When exploring question 6, whether its answer might vary by funding sector or income-level of the funding country should be considered. Perhaps there should be a division of labour across sectors such that public, private for-profit, and philanthropic funders are responsible for only investing in certain areas of research.

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[59] If funders in certain sectors do not have an obligation of justice to invest in non-domestic health research, then there is no need to consider what fair processes and principles for allocating resources between non-domestic and domestic health research might be for them.

In light of global targets for health research spending, research questions should also include:

7. Do the principles identified in question 4 support existing resource allocation targets for public funders of health research?
8. Are there certain conditions that might make a higher (or lower) allocation ethically permissible for particular countries?

The former question investigates whether current global targets—2% of governments' national health budgets and 5% of aid agencies' official development assistance—are fair. LMICs often do not meet the 2% target.[60] It is unclear whether resource constraints ethically justify LMICs spending nearly all their health resources on public health and health care delivery. Perhaps a 2% target is unfair for low-income countries. The latter question is relevant because there is a substantial degree of variation amongst high-income countries like Norway and Italy that spend just above 2% of their national health budget on health research compared to countries like Sweden and Switzerland that spend roughly 9%.[61] Provided a 2% target is fair, it is unclear whether high-income countries should invest substantially more in research than global targets demand, as there may be significant opportunity costs associated with this decision. For instance, fewer resources are allocated to delivering proven-effective public health and health care to their populations.

Towards generating guidance on fairness and equity in resource allocation *outcomes*, the following research questions could usefully be investigated, bearing in mind the principles identified in question 4:

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[60] Ibid.

[61] GFHR, op. cit. note 1.

9. What constitutes a fair allocation of individual public, private for-profit, and philanthropic foundations' total health research resources to non-domestic health research?[62]
10. What constitutes a fair allocation of these funders' resources to domestic health research and non-domestic health research by research areas and recipients?
11. Should the answers to questions 9 and 10 vary based on whether a funder is from a high, middle, or low-income country?

Questions 9 and 10 entail exploring what may constitute fair allocations at the funding scheme (program) level and across the spectrum of funded research projects. Question 10 draws attention to the fact that the outcomes of funders' allocation of non-domestic health research funding and domestic health research funding should be subject to ethical scrutiny. This includes *but should not be limited* to assessing whether there is alignment between basic and clinical research funding and disease burden (e.g. non-domestic basic and clinical research and the typical burden of disease in low-income countries and middle-income countries, and domestic basic and clinical research and the burden of disease in a given country). This is the main type of analysis that has been done previously.[63] (It is possible that the fair allocation of basic and clinical research funding should reflect additional considerations (other than disease burden), though it is beyond the scope of this paper to consider what they are.) An account of fair allocation outcomes should *also* provide guidance on how much money should be distributed to areas of research beyond diseases and to

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[62] This research question assumes that funders in all three sectors have an obligation of justice to invest in non-domestic health research, which may or may not be supported by exploring research question 1.

[63] L.A. Gillum, C. Gouveia, E.R. Dorsey, et al. NIH Disease Funding Levels and Burden of Disease. *PLoS One* 2011; **6**(2): e16837; Røttingen et al., op. cit. note 6.

recipients in different countries. Such guidance will enable assessment of whether or not individual funders that invest little in health systems research, research on the social determinants of health, capacity development, and/or LMIC recipients are making decisions consistent with social justice.

Finally, given the impact R&D policies can have on resource allocation to health research, questions that bear consideration are:

12. What are the broader obligations of governments and other influential actors to create an environment in which research funders allocate a fair amount of their funds to non-domestic health research and to types of research without commercialisable outputs?
13. How should global and national R&D policies be designed to uphold these obligations?

Thomas Pogge has argued that high-income country governments have an obligation to reform the existing patent system to create greater incentives for non-domestic (basic and clinical) health research.[64] The overarching R&D policy environment in which research funders operate can have a substantial effect on how they allocate their resources to health research. How this environment should be structured to promote fairness and equity is a vital question to examine. More bioethics scholarship is needed to investigate what obligations high-income country governments and other parties may have to reform R&D legislation such that funders achieve fairer levels of investment in, for example, non-domestic health research, health systems research, and research on the social determinants of health.

To examine these research questions, conceptual work should be supplemented by empirical work that gathers data on the decision-making processes actually used by research funders, as

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[64] Pogge op. cit. note 19.

little information is publically available. Such research will likely capture that, in practice, research funders' resource allocation decision-making incorporates political and economic considerations. It should, therefore, identify how such factors influence allocation processes and consider how better alignment with fairness and social justice can be achieved given such constraints.

CONCLUSIONS

This paper has advocated for increasing the amount of bioethics scholarship on resource allocation to health research by research funders because collectively their individual decisions can have a substantial impact on the achievement of social justice. It has proposed that three such decisions constitute priority topics for bioethics research. Towards the development of an account of fair resource allocation to health research, specific research questions relating to those topics have been identified.

To take the proposed agenda forward, one approach might be to start conceptual work on any of the aforementioned research questions by applying theories of justice or ethical principles. Norman Daniels and Florencia Luna have recommended relying on theories from political philosophy to take forward a broader bioethics agenda.[65] When utilising this approach, the theories of justice must be appropriate for the topic under investigation. Justice is a complex concept expressed through many ethical principles (such as treat like cases alike and different cases differently) and numerous theories from political philosophy (such as social-contract,

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[65] F. Luna. Poverty and Inequality: Challenges for the IAB: IAB Presidential Address. *Bioethics* 2005; **19**: 451-459; N. Daniels. Equity and Population Health: Toward a Broader Bioethics Agenda. *Hastings Cent Rep* 2006; **36**(4): 22-35.

rights-based, utilitarian, and capability theories). For example, when investigating research questions of fair process, drawing on deliberative democratic accounts such as those of Amy Gutmann, Henry S. Richardson, and Iris Marion Young may be useful. Young's work may be especially relevant, as it considers how deliberative processes should be structured where unequal power relations exist between the stakeholders involved.[66] When considering fair allocation to domestic versus non-domestic health research (research questions #1, #2, #4, #9), theories that consider the scope of justice beyond the nation-state, e.g. John Rawls' Law of Peoples, Pogge's human rights cosmopolitanism, and Ruger's health capability paradigm, are relevant. Exploration of whether and what obligations extend to private sector research funders might be informed by theories of justice that discuss the private sector such as Pogge and Rugers' theories. In taking this approach, it is also important to recognise that theories of justice often offer competing accounts. Priority topics should, therefore, be investigated using competing relevant theories and areas of overlap and divergence should be identified once these theories' guidance has been applied.

To further support this scholarship, we echo recent calls for improving data collection and reporting on the financial flows for health research through the establishment of a global observatory on health R&D.[67] However, we would emphasise that this observatory must collect data that is disaggregated by disease, type of research, non-domestic versus domestic health research, capacity development targets, health system components, social determinants of health, recipients' country, and funding organisation. Only then will major gaps in our knowledge of the amount of non-domestic health research and areas of research being done

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[66] I.M. Young. 1990. *Justice and the Politics of Difference*. Princeton, NJ: Princeton University Press; Young, op. cit. note 42.

[67] Røttingen et al., op. cit. note 6.

be addressed. The G-FINDER survey, which reports global investment in neglected disease R&D (138 product areas across 34 neglected diseases), does not measure non-product R&D (i.e. *health services and access research*).[68] Individual funders (public, private-for-profit, philanthropic) also need to improve their reporting of their budget allocations to health research, clearly disaggregating data by the aforementioned factors in their annual reports.

Ultimately, this paper starts to formulate a bioethics research agenda on fair resource allocation to health research. It is hoped this agenda will be taken forward and the resultant body of scholarship will lead to the eventual development of guidance for funders. Even so, developing guidance is not the end of the process. Upholding it in practice is required for individual funders' decision-making to become more consistent with social justice. Consideration of how ethical guidance on fair resource allocation to health research might be translated into practice, e.g. though international guidelines or individual funders' ethics statements, also bears exploration. Prior to that, however, substantial bioethics scholarship is needed and the authors hope this paper serves as a call to action.

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[68] M. Moran, J. Guzman, K. Henderson, et al. 2011. *Neglected Disease Research and Development: Is the Global Financial Crisis Changing R&D?* Sydney: Policy Cures.

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