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**RHR [Health Systems Research Consortia and Health Equity**

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**TITLE [HEALTH SYSTEMS RESEARCH CONSORTIA AND THE PROMOTION OF HEALTH EQUITY IN LOW AND MIDDLE-INCOME COUNTRIES**

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**ABSTRACT**

Health systems research is widely identified as an indispensable means to achieve the goal of health equity between and within countries. Numerous health systems research *consortia* comprised of institutions from high-income countries and low and middle-income countries (LMICs) are currently undertaking programs of research in LMICs. These partnerships differ from collaborations that carry out single projects in the multiplicity of their goals, scope of their activities, and nature of their management. Recent conceptual work has explored what features might be necessary for health systems research consortia and their research programs to promote health equity between and within countries. Identified features include selecting research priorities that focus on improving access to high-quality health services and/or financial protection for disadvantaged populations in LMICs and conducting research capacity strengthening that promotes the independent conduct of health systems research in LMICs. Yet, there has been no attempt to investigate whether existing consortia have such characteristics. This paper describes the results of a survey undertaken with health systems research consortia leaders worldwide to assess

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how consistent current practice is with the proposed ethical guidance. The findings suggest that consortia may be fairly well organised to promote health equity, but have scope for improvement, particularly in terms of achieving inclusive priority-setting.

## A HEAD [INTRODUCTION

Externally-funded health systems research is increasingly being performed in low and middle-income countries (LMICs).<sup>1</sup> Health systems research is characterised by the questions it asks, which typically focus on assessing health system performance, exploring the causes of poor performance, or developing and evaluating interventions to address particular health system shortcomings.<sup>2</sup>

Common interventions include new methods for delivering health services, creating demand for health services (for example, conditional cash transfer programs), improving health worker performance (for example, pay for performance programs), and strengthening financial protection for households against catastrophic spending on health services (for example, community-based health insurance schemes).<sup>3</sup> Research methods can encompass a wide range of quantitative and qualitative methods such as observational studies, cluster trials, economic evaluations, case studies, and participatory action research.<sup>4</sup>

Health systems research has been repeatedly identified as an indispensable means of reducing health disparities between and within countries.<sup>5</sup> New drugs and vaccines often do not reach those who need them most in LMICs because these countries' health systems are not capable of delivering them (or other forms of essential health services). Significant knowledge deficits exist about the barriers to the delivery and affordability of health services in LMICs and about effective strategies for overcoming them, particularly for disadvantaged populations.<sup>6</sup> Health systems research has the potential to address these knowledge deficits and to improve access to health services and financial protection for such populations in LMICs.

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<sup>1</sup> S. Bennett et al. From Mexico to Mali: Progress in health policy and systems research. *Lancet* 2008; 372: 1571-1578..

<sup>2</sup> S. Bennett et al. Building the Field of Health Policy and Systems Research: An Agenda for Action. *PLoS Med* 2011; 8: e1001081; L. Gilson. 2012. *Health Policy and Systems Research: A Methodology Reader*. Geneva: Alliance for Health Policy and Systems Research.

<sup>3</sup> A.A. Hyder et al. Ethical Review of Health Systems Research in Low and Middle Income Countries: A Conceptual Exploration. *Am J Bioeth* 2014; 14(2): 28-37.

<sup>4</sup> Gilson, *op. cit.* note 2.

<sup>5</sup> Ministerial Summit on Health Research. 2004. *The Mexico Statement on Health Research*, Mexico City; World Health Organization 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; WHO Task Force on Research Priorities for Equity in Health & the WHO Equity Team. Priorities for Research to Take Forward the Health Equity Policy Agenda. *Bull World Health Organ* 2005; 83: 948-953.

<sup>6</sup> World Health Organization Task Force on Health Systems Research, *op. cit.* note 5.

Yet simply conducting health systems research in LMICs will not necessarily generate the information needed to enhance health system performance for disadvantaged populations. Health systems research must be structured in a particular way to generate that type of information. *Here, it is posited that a focus of health systems research ethics must, therefore, be to investigate what features are necessary for health systems research to promote health equity and whether (and how) it is being organised to do so in practice.* This is consistent with calls to broaden the scope of research ethics to connect international research to justice in global health<sup>7</sup> and to gather evidence on how obligations of justice can be upheld in the research setting.<sup>8</sup> The latter is essential to ‘facilitate fulfilment of complicated and difficult, yet ethically essential processes’ in practice.<sup>9</sup>

Recent conceptual work has begun to take this agenda forward. Bearing in mind that investment in global health research is increasingly channelled to *consortia*<sup>10</sup>, scholars have explored what features are necessary for health systems research consortia to help reduce global health disparities.<sup>11</sup> Research consortia differ from project-level collaborations in the multiplicity of their goals, number of partners involved, and nature of their management. They constitute a partnership across multiple levels—researchers, research teams, and institutions—and carry out *programs* of research and/or research capacity strengthening in LMICs. Moreover, research consortia are often large enough to necessitate establishing official *governance* structures and setting formal priorities. Their governance structures can consist of, for example, a management team, a consortium steering committee, and/or a consortium advisory group.<sup>12</sup> Health systems research consortia include the Consortium for Health Policy and Systems Analysis in Africa (CHEPSAA), Future Health Systems, Resilient and Responsive Health Systems (RESYST), REBUILD, and REACHOUT.

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<sup>7</sup> S.R. Benatar and P.A. Singer. Responsibilities in International Research: A New Look Revisited. *J Med Ethics* 2010; 36: 194-197; S.R. Benatar and P.A. Singer. A New Look at International Research Ethics. *BMJ* 2000; 321: 824-826: 826; A.J. London. Justice and the Human Development Approach to International Research. *Hastings Cent Rep* 2005; 35(1): 24-37; C.B. Ijsselmuiden et al. Evolving Values in Ethics and Global Health Research. *Global Public Health* 2010; 5: 154-163.

<sup>8</sup> B. Pratt et al. Closing the Translation Gap for Justice Requirements in International Research. *J Med Ethics* 2012; 38(9): 552-8.

<sup>9</sup> Ibid.

<sup>10</sup> H.M. Dockrell. Presidential Address: The Role of Research Networks in Tackling Major Challenges in International Health. *International Health* 2010; 2: 181-185.

<sup>11</sup> B. Pratt and A.A. Hyder. Governance of Transnational Global Health Research Consortia and Health Equity. *Am J Bioeth* (in press)

<sup>12</sup> Future Health Systems. 2014. *Management*. Available at: <http://www.futurehealthsystems.org/>

management [Accessed 19 May 2015]; RESYST. 2014. *Consortium Management*. Available at: <http://resyst.lshtm.ac.uk/about-us/consortium-management> [Accessed 19 May 2015].

This paper will, first, briefly describe initial ethical guidance linking health systems research consortia to global health justice.<sup>13</sup> That guidance informed the design of a survey carried out to assess whether the practices of health systems research consortia are consistent with its recommendations. Aside from this survey, to our knowledge, no work to-date has examined whether or not existing health systems research consortia are structured to contribute to the reduction of health disparities between and within countries. The survey was undertaken with consortia leaders worldwide who perform externally-funded health systems research in LMICs. The remainder of the paper then describes the survey methods and findings. In doing so, it aims to contribute to health systems research ethics' task of investigating whether such research is being organised to advance global health justice in practice.

#### A HEAD [BACKGROUND: CONCEPTUAL WORK

The principles and concepts of a theory of justice called the health capability paradigm have been used to derive initial guidance on the equity-oriented operation of global health research consortia (comprised of high-income country and LMIC institutions). The health capability paradigm has roots in capability theory and specifically addresses justice in health. Previous work has demonstrated that this theory is highly capable of serving as the basis of a framework linking international research—and health systems research, in particular—to the reduction of health inequities.<sup>14</sup> It provides sufficiently detailed guidance on what health justice demands of health systems and how global health justice should be promoted by global actors (direct assistance, capacity-building, shared health governance) to facilitate the analysis of health systems research practice at the consortia level.<sup>15</sup> For this conceptual work, the health capability paradigm was also supplemented by Iris Marion Young, Henry Richardson, and David Crocker's scholarship in order to generate more specific instruction on what may be required for *inclusive* consortia priority-setting in contexts of power disparities between stakeholders.<sup>16</sup>

According to the guidance derived from these sources, global health research consortia should function to help reduce worst-off LMIC individuals' gap in health status from the optimal level achieved worldwide in terms of morbidity and mortality indicators. Three elements of consortia's research enterprise are then key—priority-setting, capacity-building, and research uptake and translation—because these elements can link their activities to the ends of justice.<sup>17</sup> Global health research

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<sup>13</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>14</sup> B. Pratt and A.A. Hyder. Global Justice and Health Systems Research in Low and Middle-Income Countries. *J Law Med Ethics* 2015; 43(1): 143-161; B. Pratt, D. Zion, and B. Loff. Evaluating the Capacity of Theories of Justice to Serve as a Justice Framework for International Clinical Research. *Am J Bioeth* 2012; 12(11): 30-41.

<sup>15</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>16</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>17</sup> Pratt and Hyder, *op. cit.* note 11; Pratt and Hyder, *op. cit.* note 14.

consortia must ensure such elements are present *and* structured to promote the health of those with the poorest health globally (Figure 1).<sup>18</sup>

[Insert Figure 1]

Figure 1: Ethical guidance on how health systems research consortia can promote global health justice

First, consortia must set research priorities that promote health equity. Where a consortium conducts health systems research, its research priorities should relate to achieving equal access to high-quality health services and/or progressively-financed universal health insurance within LMICs.<sup>19</sup> These priorities should also convey a commitment to research focused on individuals within LMICs that are worst-off in terms of their health.<sup>20</sup> As health systems research is typically performed with groups, communities, or districts within host countries, this might consist of concentrating on those groups or sub-populations that have a sizeable gap in their health status relative to those groups or sub-populations that have the best health within a country. Alternatively, it could mean focusing on those groups or sub-populations afforded substantially worse access or financial protection by the health system relative to those groups or sub-populations that have the best access and financial protection within a country.<sup>21</sup>

Consortia priorities should be determined through *inclusive* and *deliberative* processes. Inclusion encompasses not only who is invited to be present for priority-setting but also how they are involved. Consortia priority-setting processes should, therefore, involve a range of stakeholders that represent not only the different consortia partners but also the range of positions (senior and junior faculty members, post-doctoral researchers, student researchers, and research implementers) and demographics within them. Certain roles such as senior researchers and demographics such as men should not be disproportionately represented relative to one another in order to ensure that particular groups do not dominate priority-setting by force of numbers.<sup>22</sup> Inclusion further means that it is highly desirable for consortia priority-setting processes to be informed by the views of health research users and beneficiaries within partner countries such as health policymakers, administrators, providers, and patients served by the health system. This is especially the case for patients from disadvantaged groups that experience poor health and the providers who service them.<sup>23</sup>

High-income country researchers are only expected to play a 'supportive and facilitative' role in priority-setting. Their role should *at most* consist of helping LMIC researchers identify equity-oriented

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<sup>18</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>19</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>20</sup> Use of the term 'worst-off' in the paper should be understood to mean worst-off in terms of health status.

<sup>21</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>22</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>23</sup> Pratt and Hyder, *op. cit.* note 11.

research priorities that are relevant to their countries, facilitating a process through which such priorities are identified and decided upon by LMIC consortia members.<sup>24</sup> Accordingly, it is highly desirable that a greater mass of representatives from LMIC partner institutions be included relative to representatives from high-income country partner institutions. Consortia priority-setting processes should also be structured to ensure that LMIC consortia members have a greater opportunity to influence the selection of research priorities compared to high-income country members.<sup>25</sup>

Beyond priority-setting, health systems research consortia should have research capacity strengthening objectives and strategies. Both must explicitly articulate and advance the aim of building LMIC partner institutions' and researchers' *independent* health systems research capacity.<sup>26</sup> In terms of selecting consortia partners, high-income country institutions should specifically partner with an equal or greater number of LMIC institutions with whom they have (or intend to have) a long-term partnership. This is because short-term partnerships rarely succeed in building institutions' capacity to perform research independently.<sup>27</sup>

Finally, health systems research consortia should promote their research findings to benefit worst-off individuals. Consortia should have research translation objectives and a strategy to advance them. Both should reflect the underlying ambition for study findings to inform policy and practice in host countries in ways that *benefit the health of the worst-off* within them.<sup>28</sup> For health systems research consortia that test interventions, this could entail having a research translation objective (amongst others) to promote interventions proven successful being implemented in the research setting post-study. To achieve that objective, research translation activities might then include purposefully identifying and engaging those stakeholders with the power to ensure the continued delivery and financing of interventions post-study.<sup>29</sup>

## A HEAD [SURVEY METHODS

### B HEAD [Survey design

The survey was designed to elicit responses based on health systems research consortia leaders' experience conducting externally-funded health systems research in LMICs. Respondents, who self-identified as being consortium leaders, were asked to answer all survey questions in relation to the consortium they lead. The survey was written in English and consisted of five modules: 1) researcher information, 2) consortia information, 3) consortia priority-setting 4), consortia research capacity-building, and 5) consortia research translation. Module 1 asked questions about the respondent such

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<sup>24</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>25</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>26</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>27</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>28</sup> Pratt and Hyder, *op. cit.* note 11.

<sup>29</sup> Pratt and Hyder, *op. cit.* note 11.

as age, gender, and number of years conducting health systems research in LMICs. Module 2 collected information on the consortia related to its objectives as well as its processes and structures for basic-decision-making. Modules 3-5 assessed whether consortia were structured to promote health equity. Questions in these modules were specifically designed in light of the ethical guidance derived from the health capability paradigm.

The survey was first pilot tested with ten health systems researchers and bioethicists from both the United States and LMICs. These included individuals for whom English was not their first language. The survey was revised based on received feedback and then deployed.

#### B HEAD [Sampling frame]

As no database of researchers who perform health systems research in LMICs exists, our sampling frame was constructed de novo by conducting internet searches of 244 organisations listed as members of the Alliance for Health Policy and Systems Research (AHPSR) based at the World Health Organization (WHO). This list was supplemented by our own knowledge of institutions (including those that are members of health systems research consortia) with health systems researchers not listed on the AHPSR website.<sup>30</sup> Of the 244 institutions listed on the AHPSR's website, 75 institutions (from all regions worldwide) did not have an associated website, did not list their staff's names, and/or did not list their staff's emails. Consequently, researchers at these institutions were not included in our sampling frame. The final sampling frame consisted of 642 researchers. In addition, Health Systems Global, a professional society of health systems researchers, distributed the survey to its members on our behalf. At the time of the survey, Health Systems Global officials estimated membership to be around 1500 from all regions worldwide.

#### B HEAD [Survey distribution]

The survey was designed using the Qualtrics platform and electronically distributed via two main mechanisms in May 2014: 1) direct email to health systems researchers in our database and 2) the Health Systems Global electronic newsletter. Given that 72 of the direct emails bounced, the final sampling frame consisted of 572 researchers. Of these, 172 (30.1%) are from institutions in the Americas (90 from United States and Canadian institutions, 61 from Mexican and Central American institutions, and 20 from South American institutions), 146 (25.5%) from European institutions, 116 (20.3%) from Southeast Asian institutions, 99 (17.3%) from African institutions, 19 (3.3%) from Western Pacific institutions, and eight (1.4%) from Eastern Mediterranean institutions. The remaining researchers are primarily employed by multilateral or regional organisations such as WHO, World Bank, and the Pan American Health Organization.

#### B HEAD [Survey analysis]

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<sup>30</sup> In addition, the sampling frame included researchers from the AHPSR database on health systems research projects, which could be found on its website at the time of our study in May 2014 (it can no longer be found on the AHPSR website).

The data from surveys completed by researchers were exported from the Qualtrics platform and stored in Microsoft Excel.<sup>31</sup> Surveys in which 90% of questions were answered were considered 'complete' and used for data analysis. Data editing and analysis were done using Stata version 13.0<sup>32</sup> to determine frequency of responses by each variable. To measure the strength of association between variables, tests of significance such as chi-squared tests and Fisher's tests were calculated.<sup>33</sup>

B HEAD [Ethics approval

This study was approved by the [removed for review purposes] Institutional Review Board (IRB No: 0005490).

A HEAD [SURVEY RESULTS

B HEAD [Respondent characteristics

In total, we received 154 responses, 129 of which were from respondents in our database of 572 researchers (response rate: 22.6%) and 25 of which were from Health Systems Global members. Of those 154 respondents, 50 respondents self-identified as consortia leaders and completed the survey in relation to their consortia.

Most self-identified consortia leaders ( $N=50$ ) were 41 years or older (86%) and had been conducting health systems research in LMICs for more than six years (82%) (Table 1). Two-thirds of respondents were men and the majority of respondents (64%) worked for a university. Nearly equivalent numbers of respondents (40% and 42%) came from middle-income countries and high-income countries respectively. (These classifications were based on World Bank data.) Region of citizenship spanned all WHO regions except the Eastern Mediterranean region. A substantial proportion (30%) were citizens of African countries and fewer (6%) were citizens of South American countries (Table 1). It is unclear whether these demographics were representative of the total population of health systems research consortia leaders, as information on that population does not exist. Respondents

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<sup>31</sup> Qualtrics. 2013. *Version 2013 of the Qualtrics Research Suite*. Qualtrics. Provo, UT, USA.

<sup>32</sup> StataCorp. 2013. *Stata Statistical Software*, Version 13.0. College Station, TX: StataCorp.

<sup>33</sup> N. Kass & A.A. Hyder. 2001. Attitudes and Experiences of U.S. and Developing Country Investigators Regarding U.S. Human Subjects Regulations. In *Ethical and Policy Issues in International Research: Clinical Trials in Developing Countries, volume II*. Bethesda, MD: National Bioethics Advisory Commission; K.J. Rothman, T.L. Lash & S. Greenland. 2012. *Modern Epidemiology*. LWW.

represented at least 36 different past or current consortia that conduct health systems research.<sup>34</sup> Ten respondents reported they were part of two or more consortia.

INSERT [Table 1

#### B HEAD [Priority-setting

Nearly all (98%) leaders reported that their consortium had set research priorities. They largely reported that those priorities focused on improving equal access to high-quality health services and/or financial protection in LMICs (Table 2). The vast majority of these priorities (85%) were consistent with global health priorities such as the Millennium Development Goals<sup>35</sup> (44%) and Universal Health Coverage<sup>36</sup> (25%). Where host countries of consortia research had set national research priorities, 90% of leaders reported that their consortium's priorities were consistent with them. Just over half (52%) of these national priorities were consistent with the Millennium Development Goals and/or Universal Health Coverage.

The parties primarily responsible for selecting consortia research priorities were most frequently identified as the consortium's highest decision-making body (44%), funders (29%), and/or the entire consortium membership (25%) (Table 2). Nearly a third (29%) of respondents said that their consortium's highest decision-making body was the party responsible for selecting research priorities. These highest decision-making bodies *and* funder(s) were identified as being the responsible parties by 10% of respondents. Funders alone were said to select consortia research priorities by 10% of respondents. Nearly one-fifth of respondents (19%) reported that the entire consortia membership was primarily responsible for priority-setting.

INSERT [Table 2

Consortia decision-making bodies then had a key role in priority-setting. Nearly three-quarters (73%) of respondents said that their consortium's decision-making body had equal representation of all partner institutions. Almost half (45%) of leaders said their consortium had a majority of decision-making body members from LMICs (Table 3).

INSERT [Table 3

#### B HEAD [Research capacity strengthening

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<sup>34</sup> Not all respondents identified which consortia they were part of, e.g. they left the question blank, listed the consortium funder, or simply said they were part of multiple health systems research consortia. As such, they may have represented additional consortia.

<sup>35</sup> World Health Organization. 2016. Millennium Development Goals. Available at:

[http://www.who.int/topics/millennium\\_development\\_goals/en/](http://www.who.int/topics/millennium_development_goals/en/) [Accessed 20 January 2016].

<sup>36</sup> World Health Organization. 2016. Leadership Priorities. Available at: <http://www.who.int/about/agenda/en/> [Accessed 20 January 2016].

The vast majority (92%) of consortia leaders affirmed that research capacity strengthening was a main objective of their consortium. Accordingly, 90% reported that their consortium had a research capacity strengthening strategy. However, less than half (46%) reported that their consortium had a research capacity strengthening manager (Table 4).

INSERT [Table 4]

Most consortia leaders indicated that their consortium supported capacity strengthening at the individual (80%) and institutional (86%) levels. The most common forms of individual capacity-building were short courses in health systems research (79%), training to improve researchers' skills at communicating with policymakers (77%), and mentorship (62%) (Table 4). In terms of building capacity to conduct *equity-oriented* health systems research, 46% of consortia leaders reported that capacity-building included training on what health equity is and how health systems research can promote it. The most common forms of institutional capacity-building were increased links with other research institutions performing health systems research (83%), increased numbers of researchers trained in health systems research (68%), increased links with policymakers (68%), and grants administration and management (63%). Less common forms were building fundraising capacity (37%) and degree programs in health systems research (32%) (Table 4).

Less than half (43%) of consortia leaders reported their consortium supported systems level research capacity development. Of these leaders, just over a third (37%) reported having built capacity to undertake national research priority-setting and to develop laws and regulations to govern health systems research (Table 4).

B HEAD [Ensuring research translation]

Nearly all (94%) consortia leaders indicated that their consortium had a research uptake strategy, though only just over half (57%) employed a research uptake manager (Table 4). Nevertheless, the majority of consortia leaders reported their consortium undertook multiple research uptake activities. The most common were dissemination workshops for LMIC policymakers (92%), dissemination of policy briefs to host country policymakers (88%), and collaborating with host country policymakers during health systems research projects (84%). Additionally, where respondents were part of consortia that developed successful interventions, two-thirds reported that those interventions were made available in the research setting and/or host country post-study.

B HEAD [Associations]

Chi-squared and Fisher's exact tests showed few associations between select variables. No significant differences in terms of self-reported index study features were observed by gender, age (<40 or >40), years of experience with health systems research (<5 or >5), citizenship (HIC or LMIC), or location of employer (HIC or LMIC).

## A HEAD [DISCUSSION

Initial guidance on how transnational health systems research consortia might reduce global health disparities was used to develop a survey instrument, which was then employed to gather data on the practices of such consortia. Survey findings indicate that consortia research priorities largely promote health equity. However, it is slightly less clear whether these priorities reflect the *country-specific* needs of consortia partners from LMICs. Although many consortia priorities aligned with host countries' national research priorities, over half (52%) of these national priorities were consistent with the Millennium Development Goals and/or Universal Health Coverage. Most consortia leaders also reported their priorities aligning with global targets. Health systems research is a context-driven field due to the complex and varied nature of health systems, so it is important that national and sub-national health authorities set research priorities to reflect their populations' needs. Concern has been raised that global priorities and targets influence and possibly determine national priorities for health systems research in LMICs.<sup>37</sup> The findings of our survey suggest that the Millennium Development Goals and Universal Health Coverage may play such a role. It should also be noted that the survey did not capture whether or not consortia priorities focused on worst-off individuals.

Health systems research consortia's priority-setting *processes* may be less inclusive than they ideally could be. Only 19% of survey respondents reported that their consortia's entire membership was primarily responsible for selecting its research priorities. This may mean that a range of roles and demographics were not strongly included in 81% of consortia's priority-setting processes. The survey did not capture whether high-income country consortia members acted as facilitators while LMIC consortia members acted as decision-makers or whether processes were structured to ensure that LMIC consortia members had a greater opportunity to voice their ideas. As such, we cannot judge whether consortia, whose priorities were set by their entire membership, were consistent with that proposed guidance.

Nearly half of respondents reported that their consortia's highest decision-making body and/or funder were primarily responsible for selecting research priorities. In such instances, priority-setting processes are unlikely to have achieved a breadth of participants. Consortia decision-making bodies often mainly consist of senior consortia members. When survey respondents were asked how the members of their consortia's decision-making body were chosen, the most common answer (20%) was that the individuals were principal investigators of partner institutions.<sup>38</sup> As such, it is possible that more junior members of consortia (post-docs, PhD students, research assistants, research implementers) and/or research users may not be included. Additionally, only 45% of consortia

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<sup>37</sup> B. Pratt and A.A. Hyder. Applying a Global Justice Lens to Health Systems Research Ethics: An Initial Exploration. *Kennedy Inst Ethics J* 2015; 25(1): 35-66; Bennett et al., *op. cit.* note 2.

<sup>38</sup> Other answers to this question did not reveal whether the selected members of decision-making bodies were senior or not. For example, other responses to the question were simply the decision-making body members were: appointed, elected by the consortia members, appointed by the CEO, or chosen based on expertise or their role.

decision-making bodies had a greater or equal number of LMIC representatives relative to high-income country representatives.

The fact that funders were identified as playing a primary part in priority-setting by a third of respondents is highly inconsistent with the features of health systems research consortia that advance health equity. It indicates that external actors played a decision-making rather than facilitative role in the process. Funders were reported to be the main party responsible for determining consortia priorities by 10% of respondents. In such cases, the priority-setting processes would, in effect, fall short of including a range of consortia members, having the appropriate mass of LMIC consortia members involved, *and* giving LMIC consortia members a greater voice.

Most respondents reported that their consortia consider research capacity strengthening to be a main objective and carry it out at both the individual and institutional levels, which is highly consistent with equity-oriented practice. These consortia's role in capacity development could potentially be further strengthened if more were to employ research capacity strengthening managers to coordinate their efforts. It is not clear if lack of planning, need, or funds were reasons for consortia not having such a manager. The most common form of capacity-building activity reported at the individual-level was short course training, a finding consistent with previous studies.<sup>39</sup> Such forms of capacity development alone are unlikely to effectively generate independent individual research capacity. However, nearly half of consortia leaders reported that capacity-building efforts encompassed post-graduate education for LMIC researchers. Institutional capacity-building demonstrated an emphasis on training researchers and building networks. Its focus on developing institutions' education programs in health systems research and fundraising capacity could be augmented. Both are necessary for LMIC institutions to do health systems research independently. Predictable and sustainable core funding is critical to the success of health systems research organizations and yet very few possess it.<sup>40</sup>

Survey findings indicate that health systems research consortia strongly emphasise research translation, which is consistent with promoting the reduction of health disparities. It is less clear whether these efforts are guided by the objective of benefiting worst-off individuals within host countries, as this was not captured by the survey. Further exploration, perhaps using qualitative methods, should assess whether and how research translation strategies are designed to promote such a goal and whether consortia interventions are made available post-study in ways that benefit disadvantaged individuals within LMICs.

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<sup>39</sup> Bennett et al. 2010. What must be done to enhance capacity for health systems research? Available at: [http://healthsystemsresearch.org/hsr2010/images/stories/4enhance\\_capacity.pdf](http://healthsystemsresearch.org/hsr2010/images/stories/4enhance_capacity.pdf) [Accessed 17 February 2016].

<sup>40</sup> Ibid.

There were a number of limitations to our survey methods, primarily resulting from our sampling strategy. Nevertheless, it should be noted that, as there is no global list of health systems researchers, the sampling strategy used reflects a first attempt to generate such information. First, consortia leaders in non-English speaking countries may be under-represented because it was difficult to identify researchers at organisations whose main website was not in English. The authors relied on colleagues from Mexico and China to assist us in identifying researchers from such countries. The survey was written in English, which also likely contributed to the lower number of responses we received from consortia leaders in Eastern Mediterranean and South American countries.

Second, the sampling frame largely consisted of health systems researchers working for universities because government ministries, multilateral agencies, and non-governmental organisations less frequently list their staff or contact information on their websites. To try and address this shortcoming, Health Systems Global, whose membership is much broader than academia, sent out the survey on our behalf, but this did not generate many responses. As a result, the survey findings can be seen to mainly reflect the views of health systems research consortia leaders from the academic sector.

Third, the survey was directed solely at health systems research consortia *leaders*. As a result, our findings largely reflect the perspectives of *senior* consortia members. It is possible that the results might differ were more junior members of consortia to be surveyed, especially as this group might include a greater proportion of women. Future surveys should also capture the perspectives of other relevant parties, including research implementers and LMIC research users and beneficiaries, particularly those involved in consortia priority-setting and/or from the host populations of consortia research.

Finally, this study does not indicate whether all features of equity-oriented health systems research consortia were met; only those measured by the survey. Instances of this limitation—namely, where certain features were not measured by the survey—have been noted throughout this discussion.

Despite these limitations, this paper, nonetheless, describes the first effort to document the degree to which transnational health systems research consortia are organised to help reduce global health disparities. Health systems research ethics has (at least) two fundamental tasks in relation to global justice: 1) to investigate how health systems research should be structured to promote health equity and 2) to assess whether (and how) it does so in practice. Scholarship in both areas is in early stages but is essential to the development of health systems research ethics. Although this study takes that agenda forward, further research is needed in both aforementioned areas at the consortia level. With respect to the former task, future conceptual research could explore what guidance might be offered by other relevant theories of justice (beyond the health capability paradigm) such as those of Daniels or Powers and Faden. With respect to the latter task, aside from follow-up surveys, empirical work could include case studies looking at how specific health systems research consortia uphold the

ethical guidance summarised in Figure 1. These case studies should capture the perspectives of researchers, research users, and research beneficiaries. Future research could also investigate why the shortfalls in current practice identified by this survey have eventuated and consider whose obligation it might be to address them.

The data reported in this paper offers an *initial* picture of where consortia practices advance equity objectives and where they might be better organised to promote their research programs contributing to improved health systems for the worst-off. Based on the survey findings, it is recommended that health systems research consortia maintain their current practices of setting research priorities focusing on equal access and financial protection, performing research capacity development, and promoting research translation. These three elements are essential to linking consortia to the ends of global health justice. However, more attention should be given to LMIC ownership and inclusion in consortia priority-setting and to performing research capacity strengthening that will enhance LMIC institutions' independent health systems research capacity. Documentation of decision-making on priorities, capacity development, and research uptake within consortia will also allow for greater global learning on operationalizing justice in health research.

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**Table 1: Characteristics of health systems research consortia leaders**

| <b>Respondent characteristic (N=50)</b>        | <b>% (n)</b> |
|------------------------------------------------|--------------|
| Gender                                         |              |
| <i>Male</i>                                    | 66 (33)      |
| <i>Female</i>                                  | 34 (17)      |
| Age                                            |              |
| <i>21-30 years</i>                             | 0 (0)        |
| <i>31-40 years</i>                             | 14 (7)       |
| <i>41-50 years</i>                             | 30 (15)      |
| <i>&gt; 50 years</i>                           | 56 (28)      |
| Region of citizenship                          |              |
| <i>Africa</i>                                  | 30(15)       |
| <i>Americas</i>                                |              |
| <i>Latin America, Mexico, and Caribbean.</i>   | 14(7)        |
| <i>South America</i>                           | 6(3)         |
| <i>US and Canada</i>                           | 8(4)         |
| <i>Eastern Mediterranean.</i>                  | 0(0)         |
| <i>Europe</i>                                  | 12(24)       |
| <i>South-East Asia</i>                         | 10(5)        |
| <i>Western Pacific</i>                         | 8(4)         |
| Country of citizenship                         |              |
| <i>Low-income country</i>                      | 18(9)        |
| <i>Middle-income country</i>                   | 40(20)       |
| <i>High-income country</i>                     | 42(21)       |
| Employer                                       |              |
| <i>University</i>                              | 64 (32)      |
| <i>Government</i>                              | 14 (7)       |
| <i>NGO</i>                                     | 4 (2)        |
| <i>Other</i>                                   | 18 (9)       |
| Total years conducting health systems research |              |
| <i>&lt; 2 years</i>                            | 2 (1)        |
| <i>2-5 years</i>                               | 16 (8)       |
| <i>6-10 years</i>                              | 26 (13)      |
| <i>&gt; 10 years</i>                           | 56 (28)      |

**Table 2: Health systems research consortia priority-setting**

| <b>Research priorities</b>                                                                                                                                                            | <b>% (n)</b> |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------|
| A main purpose of the consortium is to promote health equity between and within countries (N=50)                                                                                      |              |
| Yes                                                                                                                                                                                   | 74 (37)      |
| No                                                                                                                                                                                    | 24 (12)      |
| Don't know                                                                                                                                                                            | 2 (1)        |
| The main research themes or priorities of the consortium focus on improving equal access to high-quality health services and/or financial protection in LMIC partner countries (n=48) |              |
| Yes                                                                                                                                                                                   | 90 (43)      |
| No                                                                                                                                                                                    | 10 (5)       |
| Don't know                                                                                                                                                                            | 0 (0)        |
| <b>Party primarily responsible for selecting research priorities* (n=48)</b>                                                                                                          |              |
| Consortium's highest decision making body                                                                                                                                             | 44 (21)      |
| Members of the consortium's highest decision making body from HICs                                                                                                                    | 10 (5)       |
| Members of the consortium's highest decision making body/committee from LMICs                                                                                                         | 10 (5)       |
| Consortium membership (all its researchers and staff)                                                                                                                                 | 25 (12)      |
| Consortium members (researchers and staff) from HICs                                                                                                                                  | 6 (3)        |
| Funder                                                                                                                                                                                | 29 (14)      |
| Other                                                                                                                                                                                 | 2 (1)        |
| <b>Alignment with national research priorities (n=29)</b><br>(where host countries have set them)                                                                                     |              |
| Yes                                                                                                                                                                                   | 90 (26)      |
| No                                                                                                                                                                                    | 7 (2)        |
| Don't know                                                                                                                                                                            | 3 (1)        |

HSR = health systems research; HIC = high-income country

\* Respondents were instructed to select *all* options that applied for this question. As a result, the percentages do not add up to 100.

**Table 3: Decision-making in health systems research consortia**

| Feature of consortia decision-making (N=50)*                                                    | % (n)   |
|-------------------------------------------------------------------------------------------------|---------|
| Presence of decision-making body or committee                                                   |         |
| Yes                                                                                             | 96 (48) |
| No                                                                                              | 2 (1)   |
| Don't know                                                                                      | 2 (1)   |
| Equal representation of all consortium partners on decision-making body                         |         |
| Yes                                                                                             | 73 (35) |
| No                                                                                              | 25 (12) |
| Don't know                                                                                      | 2 (1)   |
| Proportion of decision-making body members from LMICs (n=44)                                    |         |
| Less than 25%                                                                                   | 10(4)   |
| 25-50%                                                                                          | 45(20)  |
| 51-75%                                                                                          | 43(19)  |
| Greater than 75%                                                                                | 2(1)    |
| Party primarily responsible for making basic decisions about the consortium                     |         |
| All consortium members                                                                          | 32 (16) |
| Senior consortium members                                                                       | 52 (26) |
| Senior consortium members from high-income countries                                            | 10 (5)  |
| Other                                                                                           | 6 (3)   |
| Representatives of disadvantaged groups involved in making basic decisions about the consortium |         |
| Yes                                                                                             | 30 (15) |
| No                                                                                              | 70 (35) |
| Don't know                                                                                      | 0 (0)   |

\* N=50 unless otherwise stated

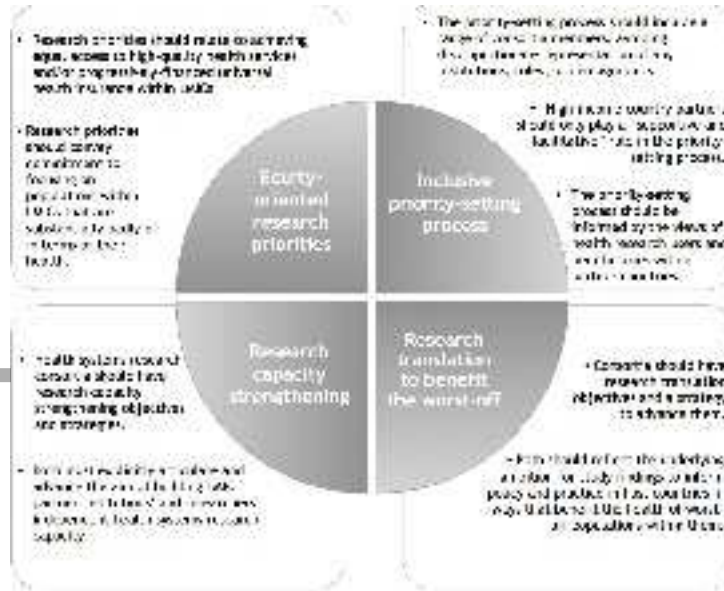
**Table 4: Health systems research consortia research capacity strengthening and research translation**

| <b>Research Capacity Strengthening</b>                                               | <b>% (n)</b> |
|--------------------------------------------------------------------------------------|--------------|
| Research capacity strengthening was a main objective of the consortium (N=50)        |              |
| Yes                                                                                  | 92 (46)      |
| No                                                                                   | 8 (4)        |
| Don't know                                                                           | 0 (0)        |
| Consortium had research capacity strengthening strategy (N=50)                       |              |
| Yes                                                                                  | 90 (45)      |
| No                                                                                   | 8 (4)        |
| Don't know                                                                           | 2 (1)        |
| Consortium had research capacity strengthening manager (N=50)                        |              |
| Yes                                                                                  | 46 (23)      |
| No                                                                                   | 50 (25)      |
| Don't know                                                                           | 4 (2)        |
| Consortium supported research capacity strengthening at:                             |              |
| Individual level (n=49)                                                              | 80 (39)      |
| Institutional level (n=49)                                                           | 86 (42)      |
| Systems level (n=47)                                                                 | 43 (20)      |
| Types of individual research capacity building performed* (n=39)                     |              |
| Short-course training in HSR                                                         | 79 (31)      |
| Training to improve skills at communicating with policymakers about HSR              | 77 (30)      |
| Mentorship programs                                                                  | 62 (24)      |
| Post-graduate degree programs in HSR                                                 | 49 (19)      |
| Training to build understanding of health equity and how HSR can promote it          | 46 (18)      |
| Training to improve leadership skills                                                | 36 (14)      |
| Training to improve ability to establish partnerships and collaborations             | 31 (12)      |
| Other                                                                                | 8 (3)        |
| Types of institutional research capacity building performed* (n=41)                  |              |
| Increased links with other research institutions involved in HSR                     | 83 (34)      |
| Increased numbers of senior or junior researchers trained in health systems research | 68 (28)      |
| Increased links with policymakers                                                    | 68 (28)      |
| Grants administration and management                                                 | 63 (25)      |
| Ability to get HSR into policy and practice (e.g. establish research uptake unit)    | 59 (24)      |
| Development of clear institutional goals for HSR                                     | 44 (18)      |
| Fundraising                                                                          | 37 (15)      |
| Development of education programs in HSR (Bachelors, Masters, PhD)                   | 32 (13)      |
| Infrastructure for HSR                                                               | 30 (12)      |
| Types of systems level research capacity building performed* (n=19)                  |              |

|                                                                                                  |              |
|--------------------------------------------------------------------------------------------------|--------------|
| Establishment of national priority setting mechanisms for HSR                                    | 37 (7)       |
| Establishment of HSR financing mechanisms                                                        | 11 (2)       |
| Development of laws and regulations to govern HSR                                                | 37 (7)       |
| Other                                                                                            | 11 (2)       |
| <b>Ensuring research translation</b>                                                             | <b>% (n)</b> |
| Consortium had research translation strategy (N=50)                                              |              |
| Yes                                                                                              | 94 (47)      |
| No                                                                                               | 4 (2)        |
| Don't know                                                                                       | 2 (1)        |
| Consortium had research translation manager (N=50)                                               |              |
| Yes                                                                                              | 57 (28)      |
| No                                                                                               | 39 (19)      |
| Don't know                                                                                       | 4 (2)        |
| Types of research translation activities performed by consortia* (n=49)                          |              |
| Dissemination workshops for policymakers in LMIC partner countries                               | 92 (45)      |
| Dissemination of policy briefs to policymakers in host countries of HSR projects                 | 88 (43)      |
| Collaborating with policymakers from host countries during HSR projects                          | 84 (41)      |
| Participation in relevant national policy committees in LMIC partner countries                   | 76 (37)      |
| Collaborating with policymakers from host countries to select research questions                 | 67 (33)      |
| Capacity building for policymakers and/or researchers on communicating with one another          | 59 (29)      |
| Other                                                                                            | 5(63)        |
| Implement successful interventions post-study in the research setting and/or host country (n=27) |              |
| Yes                                                                                              | 67 (18)      |
| No                                                                                               | 7 (2)        |
| Don't know                                                                                       | 26 (7)       |

HSR = health systems research; HIC = high-income country

\* Respondents were instructed to select *all* options that applied for this question. As a result, the percentages do not add up to 100.



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