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## Engagement as ‘co-constructing knowledge’: A moral necessity in public health research

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countries. It spans topics such as priority-setting, community engagement, governance, capacity development, ancillary care, and post-study benefits.

**Abstract:** Undertaking engagement in public health research is ethically essential. There is a growing emphasis on practicing engagement as the ‘co-construction of knowledge’, which goes beyond other common forms of engagement in health research practice: consulting and informing. Taking such an approach means researchers jointly construct knowledge with research users and beneficiaries; all parties design and conduct research together and share decision-making power. This paper makes the normative argument that such engagement is necessary to achieve foundational moral aims of public health research—building relations of equality and addressing the health needs of the disadvantaged—which reflect the field’s underlying commitment to social justice. It next identifies and discusses three ways that co-constructing knowledge advances those moral aims: by facilitating self-determination, supporting individuals’ right to research, and maximising social knowledge to address cognitive and epistemic injustice. Objections to the arguments presented in the paper are then articulated and defended against.

**Key Words:** ethics, public health research, engagement, co-construction, knowledge, justice

## Introduction

The engagement movement is rapidly taking hold in research worldwide at the project and institutional levels.<sup>1</sup> Community-university engagement is one of the strongest trends currently found on university campuses, with funders identified as a major driver of this change.<sup>2</sup> It can entail disciplinary or single centre based

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<sup>1</sup> Woolf, S.H., Zimmerman, E., Haley, A., & Krist, A.H. (2016). Authentic Engagement of Patients and Communities can Transform Research, Practice, and Policy. *Health Affairs*. 35 (4), 590-594.

<sup>2</sup> Bivens, F., Haffenden, J., & Hall, B.L. (2015). Knowledge, Higher Education and the Institutionalization of Community-University Research Partnerships. In B.L. Hall, R. Tandon, & C.

arrangements such as a science shop in a Chemistry Department or all university structures such as the Community University Partnership Programme at Brighton University in England.<sup>3</sup> Increasingly, funders expect investigators to engage research users (e.g. policymakers, healthcare providers) and beneficiaries (e.g. patients, communities) in the design and conduct of health research projects.<sup>4</sup>

Several forms of engagement are used in research projects: co-constructing knowledge, consulting, and informing. Sharp and Foster describe a spectrum of power sharing in health research, from community dialogue through community consultation and approval to full partnership, where the latter implies the greatest community empowerment.<sup>5</sup> Tindana et al. distinguish between 'community consultation' and 'collaborative partnership', which means involving local stakeholders in assessing local health problems; planning, conducting and overseeing research; and integrating research into the health care system.<sup>6</sup> The latter is consistent with growing emphasis on practicing engagement in health research as the '*co-construction of knowledge*'.<sup>7</sup> Similarly, Arnstein's ladder of

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Tremblay (Eds.), *Strengthening Community University Research Partnerships: Global Perspectives* (pp. 5-30). Victoria: University of Victoria and PRIA.

<sup>3</sup> Ibid.

<sup>4</sup> Woolf *op. cit.*, note 1; van Bekkum, J.E., & Hilton, S. (2014). UK Research Funding Bodies' Views towards Public Participation in Health-Related Research Decisions: An Exploratory Study. *BMC Health Services Research*. 14, 318.

<sup>5</sup> Sharp, R.R., & Foster, M.W. (2000). Involving Study Populations in the Review of Genetic Research. *Journal of Law, Medicine, & Ethics*. 28(1), 41-51.

<sup>6</sup> Tindana, P.O., Singh, J.A., Tracy, C.S., Upshur, R.E.G., Daar, A.S., Singer, P.A., Frohlich, J., & Lavery, J.V. (2007). Grand Challenges in Global Health: Community Engagement in Research in Developing Countries. *PLoS Medicine*. 4(9), e273.

<sup>7</sup> Oswald, K., Gaventa, J., & Leach, M. (2016). Introduction: Interrogating Engaged Excellence in Research. *IDS Bulletin*. 47(6), 1-18; Hall, B., Tandon, R., & Tremblay, C. (2015). *Strengthening Community University Research Partnerships: Global Perspectives*. Victoria: University of Victoria and PRIA.

participation and a summary of public participation techniques by the New Economic Foundation in the United Kingdom describe a hierarchy of engagement ranging from 'tokenistic' methods of informing and consultation to power sharing strategies of partnership.<sup>8</sup>

This paper will present the normative argument that co-constructing knowledge is a moral necessity in public health research. Taking such an approach means researchers jointly construct knowledge with research users and beneficiaries; all parties design and conduct research together in ways that achieve the purposes of both sets of actors.<sup>9</sup> It entails shared decision-making in all phases of research projects.<sup>10</sup> Co-constructing knowledge is also a process of bringing together multiple kinds of knowledge and multiple perspectives to construct an understanding of research phenomena based on a plurality of situated knowledges.<sup>11</sup> This includes the knowledge and perspectives of those outside the research sector: of research users and beneficiaries, be they members of communities, businesses, governments, or activist organisations.

The co-construction of knowledge thus goes beyond other forms of engagement that are more common in health research practice: consulting and informing. A key point of difference is the balance of power between researchers and partners from outside the research sector. Unlike co-constructing of knowledge, consulting, and informing

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<sup>8</sup> Arnstein, S.R. (1969). A Ladder of Citizen Participation. *Journal of the American Institute of Planners*. 35(4), 216-224; New Economic Foundation. (1999). *Participation Works! 21 techniques for the 21st century*. London: New Economic Foundation.

<sup>9</sup> Hall, B. Tandon, R., Lepore, W., Singh, W., Easby, A., & Tremblay, C. (2016). Theoretical Pedagogical Framework for Community Based Research. In R. Tandon, B. Hall, W. Lepore, & W. Singh (Eds.), *Knowledge and Engagement: Building Capacity for the Next Generation of Community Based Researchers* (pp. 7-39). Canada: PRIA.

<sup>10</sup> Oswald, Gaventa, & Leach, *op. cit.* note 7.

<sup>11</sup> Oswald, K. (2016). *Interrogating an Engaged Excellence Approach to Research*. Brighton: Institute of Development Studies.

don't entail research user and beneficiaries' participation in decision-making.<sup>12</sup> Consulting is a particularly common form of engagement in health research.<sup>13</sup> It is characterised by research users and beneficiaries being invited to give their input (feedback, suggestions, critiques) on aspects of research projects but having no assurance that it will be used by those who decide.<sup>14</sup> There is wide consensus that they can potentially be consulted about a broad range of health research activities, from protocol development to research conduct, reviewing access to data and samples, and dissemination or publication of research findings.<sup>15</sup> Often, their consultation occurs through specifically established advisory groups.<sup>16</sup> Informing means raising awareness and understanding of what research is and/or of already defined research projects within host communities or populations. Research users and beneficiaries are told of the outputs of decision-making in research projects but do not inform the process or decisions in any way.<sup>17</sup> Informing can be achieved through public meetings or by having research institution staff go out into a host community to conduct science cafes, school visits, or theatre performances.<sup>18</sup> For

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<sup>12</sup> Marsh, V.M., Kamuya, D., Rowa, Y., Gikonyo, C., & Molyneux, S. (2008). Beginning Community Engagement at a Busy Biomedical Research Programme: Experiences from the KEMRI CGMRC-Wellcome Trust Research Programme, Kilifi, Kenya. *Social Science & Medicine*. 67(5), 721-733.

<sup>13</sup> Dickert, N. and Sugarman, J. (2005). Ethical goals of community consultation in research. *American Journal of Public Health*. 95(7), 1123–1127; Participants in the Community Engagement and Consent Workshop, Kilifi, Kenya. (2011). Consent and Community Engagement in Diverse Research Contexts: Reviewing and Developing Research and Practice. *Journal of Empirical Research on Human Research Ethics*. 8(4): 1–18.

<sup>14</sup> Arnstein, *op. cit.* note 8.

<sup>15</sup> Marsh et al., *op. cit.* note 12.

<sup>16</sup> Participants in the Community Engagement and Consent Workshop *op. cit.* note 13.

<sup>17</sup> Arnstein, *op. cit.* note 8.

<sup>18</sup> Participants in the Community Engagement and Consent Workshop *op. cit.* note 13.

example, science-themed theatre performances have been employed to raise awareness of the importance of research on antimicrobial resistance in Thailand.<sup>19</sup>

Within the field of bioethics, arguments have been made that it is ethically essential to undertake some form of engagement in health research. Ethical reasons for doing so include its being central to showing respect for communities and the traditions and norms that they share, being likely to improve health outcomes, facilitating the stewardship of resources, enhancing prospects for justice, and building public trust.<sup>20</sup> These arguments do not typically draw on theoretical foundations from philosophy to provide a rationale for engagement (of any form). A philosophical rationale for why researchers should perform engagement in health research as the co-construction of knowledge has thus far not been provided by ethics scholars, though some normative work has been done in other disciplines like development studies and community-based participatory research (CBPR) in support of undertaking it.<sup>21</sup> For

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<sup>19</sup> Cheah, P.Y., Jatupornpimol, N., Suarez-Idueta, L., Hawryszkiewicz, A., Charoenboon, N., Khirikoekong, N., Wismol, P., Khu, N.H., & Richardson, E. (2018). Understanding a Science-themed Puppet Theatre Performance for Public Engagement in Thailand. *Wellcome Open Research*.3, 7.

<sup>20</sup> Tindana et al., *op. cit.* note 6; King, K.F., Kolopack, P., Merritt, M.W., & Lavery, J.V. (2014). Community Engagement and the Human Infrastructure of Global Health Research. *BMC Medical Ethics*. 15, 84; MacQueen, K.M., Bhan, A., Frohlich, J., Holzer, J., Sugarman, J., & the Ethics Working Group of the HIV Prevention Trials Network. (2015). Evaluating Community Engagement in Global Health Research: The Need for Metrics. *BMC Medical Ethics*. 16, 44; Solomon, M.Z., Gusmano, M.K., and Maschke, K.J. (2016). The Ethical Imperative and Moral Challenges of Engaging Patients and the Public with Evidence. *Health Affairs*. 35(4), 583–589; Council for International Organizations of Medical Sciences. (2017). *International Ethical Guidelines for Health-related Research Involving Humans*. Geneva: World Health Organization.

<sup>21</sup> Oswald, *op. cit.* note 11; Cargo, M. & Mercer, S.L. (2008). 'The Value and Challenges of Participatory Research: Strengthening its Practice'. *Annual Review of Public Health*, 29: 325-350; Wallerstein, N. & Duran, B. (2010). The Theoretical, Historical, and Practical Roots of CBPR. In N. Wallerstein & M. Minkler (Eds.), *Community-based Participatory Research for Health: From Process to Outcomes* (pp. 25-46). San Francisco, CA: John Wiley & Sons.

example, CBPR, which entails co-constructing knowledge, is identified as advancing values like social justice. It is linked to critical social theory and post-structuralism, which inform its aims and approach.<sup>22</sup>

This omission in the ethics literature is important for several reasons. First, it is unclear whether the co-construction of knowledge, in particular, is morally necessary for health research or whether any form of engagement is sufficient. Second, a theoretical foundation would help to clarify what the ethical goals of such engagement might be and to develop a coherent approach to its practice and evaluation, providing guidance on, for example, who should be engaged and how.<sup>23</sup> A lack of consensus exists regarding the ethical goals and approaches for engagement in health research.<sup>24</sup> Different ethical goals for engagement in health research suggest that different types of people should be engaged in different ways in different aspects of the research activity.<sup>25</sup>

To begin exploring the moral necessity of co-constructing knowledge, this paper considers the normative question *why should we adopt this form of engagement in public health research?* It will argue that co-constructing knowledge is necessary to achieve the moral aims of public health research. (Whether co-constructing knowledge advances the moral aims of other types of health research is beyond the scope of the paper.<sup>26</sup>) First, two moral aims of public health research are identified

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<sup>22</sup> Wallerstein & Duran, *op. cit.* note 21; Cargo & Mercer, *op. cit.* note 21.

<sup>23</sup> ANONYMOUS 1

<sup>24</sup> MacQueen et al., *op. cit.* note 20.

<sup>25</sup> H3Africa Working Group on Ethics and Regulatory Issues for the Human Hereditary and Health. (2014). H3Africa Guidelines for Community Engagement. Retrieved December 7, 2017, from [http://www.health.uct.ac.za/sites/default/files/image\\_tool/images/116/documents/research/H3Africa%20CE%20Guidelines\\_Final.pdf](http://www.health.uct.ac.za/sites/default/files/image_tool/images/116/documents/research/H3Africa%20CE%20Guidelines_Final.pdf); Entwistle, V., Calnan, M., & Dieppe, P. (2008). Consumer Involvement in Setting the Health Services Research Agenda: Persistent Questions of Value. *Journal of Health Services Research & Policy*. 13(Suppl 3), 76-81.

<sup>26</sup> It is also beyond the paper's scope to consider what economic and political aims can be furthered by co-constructing knowledge in health research.

as building relations of equality and addressing the health needs of the disadvantaged. They reflect an underlying commitment to social justice, which is a foundational moral value for public health research, practice, and policy.<sup>27</sup> The paper next identifies and discusses three ways that co-constructing knowledge advances the two moral aims: by facilitating self-determination, supporting individuals' right to research, and maximising social knowledge to address cognitive and epistemic injustice. These concepts are primarily drawn from the work of Iris Marion Young, Arjun Appadurai, and Boaventura de Sousa Santos. Their scholarship focuses on social justice and spans the disciplines of philosophy and sociology. Its application in this paper begins to identify some initial guidance on *how* a requirement for co-constructing knowledge should be realised. That initial guidance is briefly compared to existing CBPR literature, which describes how the goal of advancing social justice informs CBPR's approach to co-constructing knowledge. However, the paper's main focus is to establish a general moral justification for performing engagement as co-construction in public health research. Finally, objections to the arguments presented in the paper are articulated and defended against.

### **Moral aims of public health research**

Two core moral aims of public health research are: a) addressing the health needs of the disadvantaged and b) building relations of equality by supporting self-determination and self-development. These aims are identified by both theories of

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<sup>27</sup> Baylis, F., Kenny, N.P., & Sherwin, S. (2008). A Relational Account of Public Health Ethics. *Public Health Ethics*. 1(3), 196-209; Beauchamp, D.E. (1999). Public Health as Social Justice. In D.E. Beauchamp & B. Steinbock, (Eds.), *New Ethics for the Public's Health* (pp. 101–109). New York: Oxford University Press; Gostin, L.O., & Powers, M. (2006). What does Social Justice Require for the Public's Health? *Public Health Ethics and Policy Imperatives*. *Health Affairs*. 25, 1053–1060; Powers, M., & Faden, R. (2006). *Social Justice: The Moral Foundations of Public Health and Health Policy*. Oxford University Press: New York; Rogers, W. (2006). Feminism and Public Health Ethics. *Journal of Medical Ethics*. 32, 351–354.



social justice and feminist ethics.<sup>28</sup> Social justice and self-determination have also been identified as “values” or “drivers” of participatory research approaches in public health.<sup>29</sup> That averting and alleviating disadvantage is a priority and duty is a key point of convergence amongst theories of social justice.<sup>30</sup> Powers and Faden’s theory of social justice, for example, purports that the moral aims that animate public health are to improve health and related dimensions of well-being and to do so by focusing on the needs of the most disadvantaged.<sup>31</sup> It assigns special moral urgency to addressing the needs of individuals affected by *systematic disadvantage*—those experiencing sizeable deficits on multiple dimensions of well-being—both globally and within countries. Dimensions of well-being include health, respect, personal security, reasoning, and attachment. Similarly, accounts of public health ethics that draw on feminist theory identify equity as being central and call for paying particular attention to ‘identifying and unravelling complex webs of privilege and disadvantage’ that generate health disparities.<sup>32</sup> This entails focusing on economic and material disadvantage as well less tangible elements of inequity that impede health and well-being such as a lack of power, a lack of opportunities, and discrimination.<sup>33</sup>

Building relations of equality is a second core moral aim of public health research. Wendy Rogers grounds this argument using Young’s account of social justice, which calls for furthering two key values: participating in determining one’s or society’s actions (self-determination) and developing and exercising one’s capacities (self-

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<sup>28</sup> Powers & Faden, *op. cit.* note 27; Rogers, *op. cit.* note 27; Baylis, Kenny, and Sherwin, *op. cit.* note 27.

<sup>29</sup> Cargo & Mercer, *op. cit.* note 21.

<sup>30</sup> Bailey, T.C., Merritt, M.W., & Tedioso, F. (2015). Investing in Justice: Ethics, Evidence, and the Eradication Investment Cases for Lymphatic Filariasis and Onchocerciasis. *American Journal of Public Health*. 105(4), 629-636; Wolff, J., & de-Shalit, A. (2007). *Disadvantage*. Oxford: Oxford University Press.

<sup>31</sup> Powers and Faden, *op. cit.* note 27.

<sup>32</sup> Rogers, *op. cit.* note 27; Baylis, Kenny, and Sherwin, *op. cit.* note 27, p. 203.

<sup>33</sup> Rogers, *op. cit.* note 27.

development).<sup>34</sup> Denial of the former constitutes domination, while denial of the latter constitutes oppression.<sup>35</sup> Societies in which individuals stand in relations of equality are characterised by collective self-determination of institutional rules and policies by means of open discussion.<sup>36</sup> They are also characterised by individuals being able to develop and exercise the capabilities necessary to function as human beings, participants in a system of economic cooperation, and citizens of a democratic state.<sup>37</sup> Some but not all democracies in today's world have these features and to varying degrees. In hierarchical societies, relations of inequality exist where some individuals are not able to (amongst other things) exercise their right to political participation, access the goods and relationships of civil society, access education, and/or access the conditions necessary for health and human agency.<sup>38</sup>

Co-constructing knowledge in public health research can advance these two moral aims through three mechanisms. As the paper will subsequently show, it can help build relations of equality by facilitating self-determination and by supporting the right to research. It can help address the health needs of the disadvantaged by maximising the social knowledge used to solve complex problems that impede their health and well-being. Other forms of engagement do not facilitate self-determination, support the right to research, or maximise social knowledge as well as the co-construction of knowledge and, therefore, do not advance the moral aims of public health research as effectively.

## **Ways that co-constructing knowledge advances the moral aims of public health research**

### *Facilitating self-determination*

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<sup>34</sup> Ibid.

<sup>35</sup> Young, I.M. (1990). *Justice and the Politics of Difference*. Princeton: Princeton University Press.

<sup>36</sup> Anderson, E. (1999). What is the Point of Equality? *Ethics*. 109(2), 287-337.

<sup>37</sup> Ibid.

<sup>38</sup> Ibid.

Self-determination has been identified as necessary to build relations of equality.<sup>39</sup>

Self-determination means that all those who are significantly affected by a problem and its solution are included in discussions and decision-making about it.<sup>40</sup>

‘Significantly affected’ refers to those whose options for action would be substantially conditioned by the decision—namely, those whose basic interests would be affected by the decision.<sup>41</sup> Relying on this definition, in health research, decision-making should then include all parties whose options are substantially conditioned by the selection of health research topics and questions and the translation of the evidence generated by their investigation.

The co-construction of knowledge in public health research expresses self-determination because it entails shared decision-making by researchers and significantly affected parties.<sup>42</sup> Members of society, including the vulnerable and

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<sup>39</sup> Young, *op. cit.* note 35; Alkire, S. (2002). *Valuing Freedoms: Sen’s Capability Approach and Poverty Reduction*. Oxford: Oxford University Press; Crocker, D.A. (2008). *Ethics of Global Development: Agency, Capability, and Deliberative Democracy*. Cambridge: Cambridge University Press; Ruger, J.P. (2011). Shared Health Governance. *American Journal of Bioethics*. 11(7), 32-45; Young, I.M. (2000). *Inclusion and Democracy*. Oxford: Oxford University Press.

<sup>40</sup> Young, *op. cit.* note 39.

<sup>41</sup> *Ibid.*

<sup>42</sup> Additionally, co-constructing knowledge in public health research expresses the related concept of shared sovereignty. Shared sovereignty is a principle of shared health governance that specifies who should take part in decision-making about health matters and how the process of decision-making should be undertaken. Shared health governance is an account of the type of social cooperation required to advance health justice. Health justice is defined as reducing health disparities by bringing individuals up to an optimal level of health, with priority going to those whose health is substantially below that level (Ruger *op. cit.* note 39). Shared health governance identifies five components of social cooperation as essential— *shared sovereignty*, shared resources, furthering the ideals of health justice, mutual collective accountability, and shared responsibility based on the specific functions and roles individuals and groups take on in a joint enterprise (Ruger *op. cit.* note 39). Shared sovereignty calls for inclusive and deliberative decision-making on health policy: health care, public health and

disadvantaged, are significantly affected by the conduct of public health research. Whether they receive preventative care and treatment for their illnesses in part depends on what public health interventions and medicines have been developed and whether health systems can deliver them efficiently and affordably. This, in turn, depends on what research has been prioritised and performed. Where public health research does not focus on particular health conditions (e.g. rare diseases, diseases that predominantly affect marginalised groups), effective preventative interventions will not be developed for them. Where public health research does not generate new knowledge on strategies for those interventions' provision and financing, health systems will not be optimised to promote population health and to reduce health disparities. As a result, some individuals, especially the disadvantaged and marginalised, will be more likely to get communicable and non-communicable illnesses than others. This is evidenced by the effects of the 10/90 gap: less than 10% of global funding for research is spent on diseases that afflict more than 90% of the world's population.<sup>43</sup>

Whether and how members of society (research beneficiaries) can meet their health needs is impacted by what preventative interventions are available and affordable to them. Co-constructing knowledge in public health research thus enables members of society to participate in decisions that affect their basic interests. They can assert control over the research projects that affect them.<sup>44</sup> Within a society, those significantly affected by public health research would include people living in the research setting or people who are part of the groups and populations of focus in projects. The CBPR literature also affirms that community members should be

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*health-related research* (Ruger *op. cit.* note 39). It requires the participation of all those whose options for action would be substantially conditioned by the decision under discussion. In the health research context, this may (again) be understood to refer to all parties whose basic interests are substantially affected by the selection of research priorities, the conduct of research, and/or the translation of the evidence it generates (ANONYMOUS-2).

<sup>43</sup> Vidyasagar, D. (2005). Global Notes: The 10/90 Gap Disparities in Global Health Research. *Journal of Perinatology*, 26: 55–56.

<sup>44</sup> Cargo & Mercer, *op. cit.* note 21.

involved as decision-makers in research, with the greatest inclusion achieved when they are part of decision-making in all stages of projects.<sup>45</sup>

In terms of *how* co-constructing knowledge should be undertaken in public health research, Young's account would further call for the special representation of the disadvantaged and marginalised (amongst the significantly affected). She argues that, in societies where sizeable social and economic inequalities exist, the views and experiences of the privileged dominate, and this must be counteracted to ensure procedural fairness and self-determination by providing mechanisms for the representation of oppressed and disadvantaged groups in decision-making processes (Young, 1990). The engagement of those with pertinent knowledge of the health needs of the disadvantaged within the research population—the disadvantaged themselves and their healthcare providers—is then required because it can help make their needs visible in the research priorities and questions set by projects.<sup>46</sup> This is consistent with the Southern emancipatory tradition in CBPR, where partnerships are formed with disadvantaged and marginalised groups. Research seeks to identify and transform the root causes or material circumstances that produce and reproduce social disparities and hierarchies.<sup>47</sup>

In contrast, other forms of engagement—consulting and informing—do not typically entail participation in decision-making for research projects. In effect, they do not

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<sup>45</sup> Wallerstein & Duran, *op. cit.* note 21

<sup>46</sup> Similarly, it has been proposed that sharing sovereignty in health research decision-making means specifically including (amongst the significantly affected) those who have the knowledge and power to improve the health of the disadvantaged (ANONYMOUS 1). That who takes part in health research decision-making is linked to the goal of advancing health justice seems consistent with the account of shared health governance. The engagement of members of disadvantaged groups is then required because it can help make their needs visible in health research topics and questions. Engagement of those with the power to impact the health of disadvantaged groups—healthcare providers, policymakers, managers—can promote their use of research findings, supporting changes that improve disadvantaged groups' health and well-being (ANONYMOUS 1).

<sup>47</sup> Cargo & Mercer, *op. cit.* note 21.

express self-determination, which restricts their capacity to build relations of equality between researchers and other members of society. Unlike informing, however, consultation does have the potential to at least give those consulted a voice in what research is done and how it is conducted. For example, in the VOICES project, members of the public were included in discussions that informed research priorities for the 'Climate action, environment, resource efficiency and raw materials' dimension of the European Commission's Horizon 2020 Work Programme. They were able to give input, though they did not make *decisions* about what priorities were chosen.<sup>48</sup> Specifically consulting those considered disadvantaged and marginalised would also be essential to advance social justice.

### Supporting the right to research

Taking part in democratic society and standing in relations of equality with others requires one to be informed and to develop certain capacities.<sup>49</sup> Arjun Appadurai contends that being able to undertake research is one such capacity. He argues that research should be recognised as a right of a special kind owed to all members of society—namely, the triple capacity to inquire, to analyse, and to communicate<sup>50</sup>. It is the capacity to make disciplined, systematic inquiries into those things we need to know about our own lives and worlds in order to gain strategic knowledge. He states that

*research, in this sense, is an essential capacity for democratic citizenship... in a modern world, of rapid change, where markets, media, and migration have destabilised secure knowledge niches and have rapidly made it less possible for ordinary citizens to rely on knowledge drawn from traditional, customary or local sources... the capacity to distinguish knowledge from rumour, fact from*

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<sup>48</sup> Final Report Summary - VOICES (VOICES). (2015). Retrieved October 5, 2018, from [https://cordis.europa.eu/result/rcn/158173\\_en.html](https://cordis.europa.eu/result/rcn/158173_en.html).

<sup>49</sup> Anderson, *op. cit.* note 36.

<sup>50</sup> Appadurai, A. (2006). The Right to Research. *Globalisation, Societies and Education*. 4(2), 167-177.

*fiction, propaganda from news, and anecdote from trend, is vital for the exercise of informed citizenship.*<sup>51</sup>

Developing the capacity to inquire, to analyse, and to communicate results has ‘a powerful effect on [individuals’] capacity to speak up as active citizens on matters that are shaping their city and their world.’<sup>52</sup>

The co-construction of public health knowledge supports research users and beneficiaries’ realisation of their right to research and thereby promotes their self-development. It seems a clear path for members of society to develop the capacity to inquire, to analyse, and to communicate. Being involved in decision-making over each stage of the public health research process would build their ability to formulate research questions, collect and analyse data, and disseminate research findings. Co-constructing knowledge thus could help create relations of equality between public health researchers, research users, and research beneficiaries in societies.

Other forms of engagement—consulting and informing—could each support the right to research but to a lesser extent because they entail more limited involvement in the research process than co-constructing knowledge. For example, informing builds individuals’ understanding of what research is but not their understanding of how they can perform research themselves. Unlike co-constructing knowledge, neither consulting nor informing comprises learning-by-doing, which is a key capacity development mechanism for health research.<sup>53</sup>

### Maximising social knowledge

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<sup>51</sup> Ibid, p. 167-168, 176.

<sup>52</sup> Ibid, p. 175.

<sup>53</sup> Lansang, M.A. & Dennis, R. (2004). Building Capacity in Health Research in the Developing World. Bulletin of the World Health Organization. 82, 764-70; Nchinda, T.C. (2002). Research Capacity Strengthening in the South. Social Science & Medicine. 54, 1699–1711.

Drawing out the 'epistemologies of the South'<sup>54</sup> promotes cognitive and epistemic justice and maximises the social knowledge generated to identify and solve complex problems that impede health and well-being, especially for the disadvantaged. Epistemologies of the South is defined as 'ways of knowing from the perspectives of those who have systematically suffered the injustices... caused by capitalism, colonialism, and patriarchy.'<sup>55</sup> Here, the global South is not a geographical concept, even though the great majority of its populations live in the Southern hemisphere. Instead, the global South encompasses all those who experience systemic and unjust human suffering. It exists in places like Europe and North America in the form of undocumented immigrants, the unemployed, ethnic or religious minorities, and victims of sexism, homophobia, racism and islamophobia.<sup>56</sup> Cognitive justice refers to the right of different forms of knowledge to co-exist.<sup>57</sup> Epistemic justice means giving proper respect to individuals as knowers and sources of information.<sup>58</sup>

According to Santos, modern knowledge is characterised by '*abyssal thinking*', which divides social reality into two realms: this side of the line and the other side of the line.<sup>59</sup> Whatever lies on the other side of the line remains invisible, is radically excluded, and becomes non-existent. On this side of the line falls modern science, philosophy and religion, with modern science granted the monopoly of distinguishing between what is truth and what is false over reason and faith. The most entrenched premise of abyssal thinking is that modern science is the only exact and valid form of knowledge.<sup>60</sup> On the other side of the line falls popular, lay, and indigenous

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<sup>54</sup> Santos, B. (2014). *Epistemologies of the South: Justice Against Epistemicide*. Boulder, CO: Paradigm Publishers.

<sup>55</sup> Santos, B. (2016). *Epistemologies of the South and the Future*. *From the European South*. 1, 17-29.

<sup>56</sup> *Ibid.*

<sup>57</sup> Santos, *op. cit.* note 59.

<sup>58</sup> Fricker, M. (2007). *Epistemic Injustice: Power and the Ethics of Knowing*. Oxford: Oxford University Press.

<sup>59</sup> Santos, *op. cit.* note 60.

<sup>60</sup> Santos, *op. cit.* note 59.



knowledges and the knowledges of oppressed peoples of the world at large. These forms of knowledge vanish as irrelevant and not real knowledge because they don't meet scientific standards of truth; they are only opinions, intuitions, and subjective understandings.<sup>61</sup> Similarly, Miranda Fricker describes a comparable form of silencing of marginalised social groups that results from testimonial injustice. Such groups are susceptible to unjust credibility deficits, which prevents their views from being solicited. They are not asked to provide their knowledge, opinions, thoughts, or judgements.<sup>62</sup>

Abyssal thinking and silencing due to prejudicial credibility deficits make subaltern forms of knowledge invisible and violate cognitive and epistemic justice.<sup>63</sup> Such injustices result in gaps in the collective hermeneutical resources and the lost capacity to learn from experiences of the world.<sup>64</sup> Significant areas of marginalised groups' social experiences are obscured from understanding. This leaves them unable to make sense of these experiences, which, in turn, prevents identifying and implementing measures to address them.<sup>65</sup> Society can't solve problems that it doesn't see or understand. Communicating the experiences and knowledge derived from different social positions helps to correct the dominance of partial perspectives over the definition of problems and their possible solutions.<sup>66</sup> Deliberative decision-making must, therefore, be informed by disadvantaged and oppressed groups.<sup>67</sup>

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<sup>61</sup> Ibid.

<sup>62</sup> Fricker, *op. cit.* note 63.

<sup>63</sup> Santos, *op. cit.* note 59; Fricker, *op. cit.* note 63.

<sup>64</sup> Santos, *op. cit.* note 60; Fricker, *op. cit.* note 63; Hutchison, K., Rogers, W., & Entwistle, V.A. (2016). Addressing Deficits and Injustices: The Potential Epistemic Contributions of Patients to Research. *Health Care Analysis Advance Access* published June 8, 2016, DOI: 10.1007/s10728-016-0323-5.

<sup>65</sup> Fricker, *op. cit.* note 63.

<sup>66</sup> Young, *op. cit.* note 39.

<sup>67</sup> Young, *op. cit.* note 35.

Even where problems of global social injustice are recognised, existing approaches formulated and developed by Western modernity are not solving them.<sup>68</sup> Modes, models, means, and ends of social transformation are potentially much vaster than those identified by modern science. Ways of knowing beyond Western modernity can identify other forms of knowledge that point to additional ways of intervening.<sup>69</sup> Maximising the social knowledge base used to develop interventions by pooling the knowledge of all social positions will construct a more comprehensive account of how social processes work and the likely consequences of proposed interventions. Here, the situated knowledge of the disadvantaged is identified as an especially vital resource.<sup>70</sup> It is thus imperative to capture the immense variety of knowledges and practices to maximise our transformative potential. Without cognitive and epistemic justice, larger struggles for social justice will not be realised.<sup>71</sup>

Co-constructing knowledge comprises a way of drawing out epistemologies of the South and maximising the social knowledge base. It can help address global social injustice by making sense of aspects of marginalised social groups' social experiences that are obscured from understanding and identifying new ways of intervening to address complex problems based on multiple ways of knowing. As such, this form of engagement is well-suited to the field of public health research. Identifying ways to alleviate disadvantage 'needs a local focus, involving those who

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<sup>68</sup> Santos equates global social injustice with the emergence of societal fascism: a 'set of social processes by which large bodies of the population are kept outside or thrown out of the social contract.' For example, individuals are expelled through the elimination of their social and economic rights; by blocking access to citizenship to social groups that previously had a reasonable expectation of being granted citizenship. Social regimes of very unequal power relations grant stronger parties veto power over the life and livelihood of weaker parties. Santos identifies five forms of social fascism that lead to 'particularly severe forms of exclusion... both within national societies and in the relations among countries': fascism of social apartheid, contractual fascism, territorial fascism, fascism of insecurity, and financial fascism (Santos, *op. cit.* note 59, p. 50, 131).

<sup>69</sup> Santos, *op. cit.* note 59.

<sup>70</sup> Young, *op. cit.* note 39.

<sup>71</sup> Santos, *op. cit.* note 59; Fricker, *op. cit.* note 63.

are affected and the circumstances of their disadvantage... it is only by valuing the perspective of the disadvantaged that we can come to understand the problems as they face them, and the kinds of solutions that are possible.<sup>72</sup> Co-constructing knowledge also seems particularly useful for addressing one of public health research's morally urgent and complex challenges: to intervene in multiple overlapping social determinants with pervasive effects on clusters of well-being dimensions including health.<sup>73</sup>

Epistemologies of the South further call for co-constructing knowledge to rest on two main foundations: ecologies of knowledge and intercultural translation. *Ecologies of knowledge* recognise the existence of a plurality of systems of knowledge. They affirm that it is necessary to explore alternatives to scientific knowledge because it has intrinsic limits to the types of real-world interventions it makes possible.<sup>74</sup> The global South, in particular, is an especially rich resource of alternative systems of knowledge. They have been forced to respond to colonialism and the immediate needs of survival, which has generated 'innovative and rebellious ways of knowing.'<sup>75</sup> *Intercultural translation* is defined as dialogue and translation among different knowledges and practices to develop new constellations of knowledge.<sup>76</sup> The aim is to create a new type of knowledge using both scientific knowledge and other types of knowledge, especially from the other side of the abyssal line.

Per Santos, where co-constructing knowledge is based on ecologies of knowledge and intercultural translation, it can bridge the divide between academic knowledge and popular knowledges.<sup>77</sup> This will inform the development of interventions that are better equipped to address the complex causes of social injustice. A key feature is that the embedded knowledge of people living lives of poverty, exclusion,

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<sup>72</sup> Rogers, *op. cit.* note 27, p. 353.

<sup>73</sup> Powers & Faden, *op. cit.* note 27.

<sup>74</sup> Santos, *op. cit.* note 60.

<sup>75</sup> Santos, *op. cit.* note 59, p. 200.

<sup>76</sup> *Ibid.*

<sup>77</sup> Santos, *op. cit.* note 60.

oppression, and disadvantage is respected, engaged, and made visible.<sup>78</sup> In terms of *how* co-constructing knowledge should be undertaken, it is thus imperative to involve those experiencing oppression and disadvantage. Tandon et al. and the 2016 World Social Report further affirm that a *transformational* knowledge agenda is also co-constructed by those able to influence changes in policies and practice.<sup>79</sup>

In contrast, informing does not comprise a way to draw out the epistemologies of the South or the situated knowledge of the disadvantaged. Consultation may be able to serve this function to some extent if done with such a goal in mind. That would mean performing consultations in a targeted way in terms of who input is sought from and what information is sought from them. Consultations have been shown to enrich the knowledge researchers use to identify the problems facing communities.<sup>80</sup> However, unlike co-constructing knowledge, the capacity of consultations to support intercultural translation is questionable. The development of new constellations of public health knowledge will rest solely with researchers using information derived from those considered disadvantaged. Any new knowledge will be constructed by researchers rather than be a joint product of dialogue and translation. This may limit such knowledge's transformative potential. It also means only researchers' understanding of the problem will be broadened rather than both parties' understanding being enriched.

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<sup>78</sup> Oswald, Gaventa, and Leach, *op. cit.* note 7; Rowell L.L., & Hong, E. (2017). Knowledge Democracy and Action Research: Pathways for the Twenty-First Century. In L.L. Rowell, C.D. Bruce, J.M. Shosh, & M.M. Riel (Eds.), *The Palgrave International Handbook of Action Research* (pp. 63-83). New York: Palgrave MacMillan.

<sup>79</sup> Tandon, R., Singh, W., Clover, G., & Hall, B. (2016). Knowledge Democracy and Excellence in Engagement. *IDS Bulletin*. 47(6), 19-36; ISSC, IDS, & UNESCO. (2016). *World Social Science Report 2016, Challenging Inequalities: Pathways to a Just World*. Paris: UNESCO Publishing.

<sup>80</sup> Mosavel, M., Simon, C., van Stade, D., & Buchbinder, M. (2005). Community-based participatory research (CBPR) in South Africa: Engaging multiple constituents to shape the research question. *Social Science & Medicine*. 61, 2577-2587.

## Possible Objections

Several objections can be anticipated to the normative arguments presented in favour of performing engagement in public health research as the co-construction of knowledge. First, different public health ethics frameworks might emphasise values other than social justice as foundational moral values for public health research, practice, and policy. If social justice is not a foundational (or at least an important) value for public health research, then adopting a form of engagement that furthers such a value is not essential to the field. In response, it is important to note that social justice has been identified as a foundational value in numerous public health ethics frameworks.<sup>81</sup> There seems to be strong convergence amongst ethics scholars and public health practitioners that advancing social justice is a core goal of the field of public health. However, even were this not the case, the co-construction of knowledge can advance other ethical values underlying public health: procedural justice, population level utility, solidarity, and community trust. Each of these values has been identified as foundational by existing public health ethics frameworks.<sup>82</sup> For instance, by facilitating democratic participation, co-constructing knowledge can promote procedural justice. By maximising the social knowledge base, co-constructing knowledge can support the development of interventions capable of addressing complex problems and maximising population health benefits.

Second, it might be argued that other forms of engagement can advance other moral values of public health research equally or more effectively than the co-construction of knowledge. This is potentially true and requires further exploration that is beyond the scope of this paper. The paper is not disputing the value of other forms of

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<sup>81</sup> Lee, L.M. (2012). Public Health Ethics Theory: Review and Path to Convergence. *Journal of Law, Medicine, & Ethics*. 40(1), 85-98.

<sup>82</sup> Baylis, Kenny, & Sherwin, *op. cit.* note 25; Baum, N. M., Gollust, S. E., Goold, S. D., & Jacobson, P. D. (2007). Looking Ahead: Addressing Ethical Challenges in Public Health Practice. *Journal of Law, Medicine & Ethics*. 35(4), 657-667; Childress, J. R., Faden, R. R., Gaare, R. D., Gostin, L. O., Kahn, J., Bonnie, R. J., Kass, N. E., Mastroianni, A. C., Moreno, J. D., & Nieburg, P. (2002). Public Health Ethics: Mapping the Terrain. *Journal of Law, Medicine & Ethics*. 30(2), 170-178.

engagement or saying that co-constructing knowledge is the only form of engagement that should be performed in public health research. Instead, it is hoped that the arguments presented show readers why such a form of engagement is necessary in the field of public health research to advance its moral aims relating to social justice.

Another objection is that undertaking engagement as the co-construction of knowledge creates significant burdens on research users and beneficiaries that are disproportionate to the benefits they will accrue. Co-constructing knowledge is a huge time commitment. If the aim is to work with the oppressed and disadvantaged, doing so will take away time that they would otherwise use to address their survival needs. The benefits of co-constructing knowledge largely consist of helping individuals realise their right to research rather than generating any improvements to their health. It, therefore, may not be ethical to expect individuals, particularly those from oppressed and disadvantaged groups, to assume such a role in public health research because the benefits of their participation will not balance the threat posed to their basic needs.

In response, it is affirmed to be essential to co-construct knowledge in ways that either balance the benefits and burdens to individuals or that ensure benefits exceed burdens. Yet there *are* ways to involve the disadvantaged in public health research that ensure threats to their basic needs are minimised and a balance is achieved. One way is to employ them as co-researchers and to pay them a salary. At a minimum, they can be given a job title and remunerated in a way that adequately reflects their time and work. Additionally, discussions between researchers and partners at the outset of studies can further identify burdens for partners and develop strategies to minimise them. Desired benefits and strategies for delivering them can be identified too. Where a balance of burdens and benefits cannot be achieved for particular individuals, then it may not be ethical to involve them as partners in a study. Selecting other partners will be a more ethical choice.

Finally, any substantial increase in public health research being performed as the co-construction of knowledge will require significant changes to the research environment. The short-term project-based funding cycle that is common to most

research funders is ill-suited to support this form of public health research.<sup>83</sup> For example, supporting the co-construction of research priorities may entail offering funding for planning phases to engage with research users and beneficiaries in priority-setting prior to full grant applications' submission, which is not currently common funding practice.<sup>84</sup> Effectively co-constructing knowledge will also demand building researchers' capacity in community based research and social responsibility, which many existing education programs in public health may not do or do well. Without strong attention to the training of new generations of researchers, we cannot expect to realize the full benefits of co-constructing public health knowledge.<sup>85</sup> The inclusion of oppressed and marginalised groups will likely further require building trust, relationships, and capacity, which would mean performing studies over longer timelines and perhaps with more resources. This raises the question: does furthering the moral aims of public health research justify restructuring research funding and education?

While appreciating that making structural changes to the funding and education sectors will be a challenging and politically-fraught process, effecting such shifts seems necessary to get closer to solving the complex problems with which public health grapples. '[K]nowledge from one location or one point of view can no longer sufficiently deal with problems which manifest themselves in thousands of ways across diverse global contexts. Knowledge must be multi-sited and pluralistic in its assumptions and worldviews.'<sup>86</sup> The co-construction of knowledge has been shown to challenge dominant narratives and contextualise knowledge in the practical

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<sup>83</sup> Dolan, C., & Shahrokh, T. (2016). Engaged Excellence or Excellent Engagement? Collaborating Critically to Amplify the Voices of Male Survivors of Conflict-Related Sexual Violence. *IDS Bulletin*. 47(6), 37-54.

<sup>84</sup> ANONYMOUS 3

<sup>85</sup> ISSC, IDS, & UNESCO, *op. cit.* note 85.

<sup>86</sup> Gaventa, J., & Bivens, F. (2014) Co-constructing Democratic Knowledge for Social Justice: Lessons from an International Research Collaboration. In J. Shefner, H.F. Dahms, R.E. Jones, & A. Jalata (Eds.), *Social Justice and the University: Globalisation, Human Rights and the Future of Democracy*. New York: Palgrave, p. 155.

realities of those interested in or affected by change, thus making it more useful and relevant and increasing the likelihood of its achieving policy impact.<sup>87</sup> In effect, the social value of the resultant public health research may well be higher than where knowledge is not co-constructed. The short-term costs may then be well outweighed by long-term social benefits.

## Conclusions

The arguments developed in this paper support the position that co-constructing knowledge is necessary to link public health research to its foundational value of social justice. The paper has identified three ways that such engagement advances social justice: by facilitating self-determination, supporting individuals' right to research, and maximising social knowledge. In doing so, the aim was to show readers why that form of engagement is morally necessary in the field of public health research (not just CBPR) and why performing engagement as consulting or informing is insufficient. The paper primarily relied on the work of Young, Santos, and Appadurai but suggested other theorists' work is complementary (e.g. Fricker and Ruger). More work is needed to explore the connections between these theories and how they collectively support a moral justification for co-constructing knowledge in public health research. Future work can also empirically test the ideas presented in this paper against the moral intuitions of public health researchers: do they identify co-constructing knowledge as furthering self-determination and maximising social knowledge and/or identify other ways it advances social justice?

A normative foundation helps to clarify what the ethical goals of co-constructing knowledge should be and to develop a coherent approach to how its practice and evaluation should be undertaken to advance social justice. The paper has not deeply delved into teasing out the implications of linking such engagement to social justice

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<sup>87</sup> Apgar, J.M., Mustonen, T., Lovera, S., & Lovera, M. (2016). Moving Beyond Co-Construction of Knowledge to Enable Self-Determination. *IDS Bulletin*. 47(6), 55-72; Pittore, K., te Lintelo, D.J.H., Georgalakis, J., & Mikindo, T. (2016). Choosing between Research Rigour or Support for Advocacy Movements, a False Dichotomy? *IDS Bulletin*. 47(6), 101-118.



for its conduct. How a requirement for co-construction should be upheld requires further investigation. The CBPR literature will provide a rich resource for informing approaches to co-construction that advance social justice. Other literatures may also be helpful to draw upon such as work on Mode 2 as a form of knowledge production and the triple-helix model of university-government-industry relations.<sup>88</sup> They can inform approaches to co-construction, offer insights into how to incentivise such approaches, and suggest who is responsible for creating those incentives.

There does appear to be some convergence amongst the work applied in this paper, which identifies the disadvantaged and those with the power to change policy and practice as key parties with whom to co-construct knowledge. This may offer a starting point for developing an approach to co-construction to use in public health research practice. Yet there are likely to be inherent challenges and risks in engaging these two sets of actors, which will need to be explored further. Substantial power disparities exist between them and co-constructing knowledge is not a neutral process. Unequal power dynamics can lead to presence without voice and voice without influence. Dilemmas of inauthentic representation may also arise such as where individuals have conflicts of interest or lack shared experience or identity with those they are representing. Members of disadvantaged groups will have very different worldviews and ways of knowing relative to policymakers. Dilemmas will, therefore, arise around how to value and use these different actors' knowledge in health research projects.

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<sup>88</sup> Gibbons, M., Limoges, C., Nowotny, H., Schwartzman, S., Scott, P., & Trow, M. (1994). *The New Production of Knowledge: The Dynamics of Science and Research in Contemporary Societies*. London: SAGE Publications; Nowotny, H., Scott, P., & Gibbons, M. (2001). *Re-Thinking Science: Knowledge and the Public in an Age of Uncertainty*. Cambridge: Polity Press; Nowotny, H., Scott, P., & Gibbons, M. (2003). INTRODUCTION: 'Mode 2' Revisited: The New Production of Knowledge. *Minerva*. 41(3), 179-194; Etzkowitz, H. & Leydesdorff, L. (2000). The dynamics of innovation: from National Systems and "Mode 2" to a Triple Helix of university–industry–government relations. *Research Policy*. 29(2), 109-123.

By investigating how co-construction should be performed, the paper identifies additional key questions to explore about its value. They are: do identified approaches advance self-determination, support the right to research, and maximise social knowledge and do they do so better than forms of consultation? These questions can be empirically tested to demonstrate whether and how models for co-constructing knowledge in public health research promote social justice in practice. At present, there is some evidence that co-constructing knowledge advances self-determination when it starts with local needs and leadership<sup>89</sup> but more evidence is needed. Data is also needed to show whether co-constructing knowledge can support the right to research and develop interventions that are strongly equipped to address disparities in health and well-being. There is currently limited data on the effectiveness of different research capacity development strategies. As a result, there isn't an evidence base showing that learning-by-doing can successfully generate the capacity to inquire, analyse, and communicate.<sup>90</sup> Ultimately, it is hoped that this paper will stimulate more discussion and investigation of these matters.

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<sup>89</sup> Apgar et al., *op. cit.* 93.

<sup>90</sup> Bennett, S., Paina, L., Kim, C., Agyepong, I., Chunharas, S., McIntyre, D., & Nachuk, S. (2010). What Must be Done to Enhance Capacity for Health Systems Research? Retrieved November 1, 2018, from [http://healthsystemsresearch.org/hsr2010/images/stories/4enhance\\_capacity.pdf](http://healthsystemsresearch.org/hsr2010/images/stories/4enhance_capacity.pdf); Cooke, J., Gardois, P., & Booth, A. (2018). Uncovering the Mechanisms of Research Capacity Development in Health and Social Care: A Realist Synthesis. *Health Research Policy and Systems*. 16, 93.



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