

# Building the field: ethics in health systems research

Members of the Future Health Systems (FHS) consortium have spearheaded important and previously unexplored work on the ethics of health systems research (HSR). FHS has contributed empirical knowledge on understanding how researchers are dealing with the ethics of HSR on the ground, as well as conceptual thinking, including exploring issues of justice, health capabilities, and responsiveness. The work has engaged new actors, built a movement of parties interested in the issues, and influenced the agendas of global institutions such as the World Health Organization.

## Background

During FHS Phase One, Dr Adnan Hyder of Johns Hopkins University (JHU) brought together work on health systems and ethics through research documenting research-to-policy processes. In the inception period of FHS Phase Two, Dr Hyder wrote a concept note on the ethics of HSR, inviting others to collaborate. With support from colleagues, he started conceptual thinking on ethics of health systems and ethics of HSR, and published two conceptual and philosophical papers in the *American Journal of Bioethics* (Hyder et al, 2014) and *Health Systems* (Krubiner and Hyder, 2014).

This led to work on HSR with four key facilitators:

- 1 **Dr Bridget Pratt** working as a post-doc researcher to pursue this stream of work.
- 2 Dr Hyder held a meeting in June 2013 on the ethics of HSR with **African Fogarty fellows** working on ethics.
- 3 Dr Hyder and Dr Pratt established a Health Systems Global (HSG) Thematic Working Groups (TWG) on the ethics of HSR, with **Dr Charles Michelo** from Zambia as co-chair.
- 4 **The Alliance for Health Policy and Systems Research (AHPSR) at the World Health Organisation (WHO)** requested research on the implications of ethics for HSR, partly to address issues with Institutional Review Board (IRB) reviews. This led to Dr Hyder giving a seminar in June 2013, which became the foundation for a 2014 *American Journal of Bioethics* paper examining how IRB review for HSR may be different than other areas when it comes to ethics.

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In Feb 2014, JHU hosted a second meeting on ethics in HSR with additional funding from the Wellcome Trust, bringing together colleagues working on ethics from Africa, FHS and the Wellcome Trust. This meeting resulted in the publication of a call to action on the ethics of HSR in low- and middle-income countries (LMICs). A follow-on meeting was held in Geneva in September 2014 with additional support from the Brocher Foundation, which included AHPSR, pharmaceutical companies, and colleagues from the UK, Europe and Asia, broadening reach and creating movement in the field.

Others started engaging with JHU (e.g. University of Oxford, KEMRI), broadening the boundaries beyond traditional ethics professionals. This increasing visibility allowed Dr Hyder and JHU to push WHO to recognise the need for guidance on ethics in HSR for LMICs, and AHPSR

commissioned his team (with Dr Pratt and Joe Ali) to undertake a scoping review of the health policy and systems research (HPSR) ethics literature. This review was presented at the July 2015 WHO ethics meeting in Zurich and was published in *Health Policy and Planning*.

In September 2015, the Ethox Centre, University of Oxford hosted the Global Health and Bioethics International Conference, attended by ethicists, donors, researchers, and collaborators from LMICs. As part of this conference, Dr Hyder and Dr Pratt hosted a side workshop on the role of ethics priority-setting for HPSR, which was well attended by speakers and participants from five continents and twelve countries. At the November 2016 Global Symposium on Health Systems Research, Dr Hyder and Dr Pratt co-organised a HSG TWG

panel session on the ethics of HSR priority-setting, investigating the relationship between different levels – global, national, local – of priority-setting for HSR and what might be ethically required for priority-setting at those levels.

Empirical work from FHS has been published in peer-reviewed scientific journals and [a supplement in \*Developing World Bioethics\* was published in 2016](#), including papers emanating from earlier workshops, a critique of Dr Hyder's 2014 paper, and several new contributions highlighting the relevance of the topic to others beyond the original audience.

## What changes took place?

Ethics of HSR, particularly in its application to LMICs, has emerged as a new field as a result of this work. Changes are taking place among global actors and institutions, including the WHO AHPSP, other researchers, and professionals in LMICs.

## How FHS contribute to the changes?

FHS has contributed to empirical findings as well as conceptual work on ethics of HSR. Conceptually, the thinking that has emerged from various meetings, in which FHS played a key role, has led to several key publications, and different elements of ethics in HSR have been explored more deeply, including issues of justice, health capabilities, and responsiveness. A main focus of this work, led by Dr Pratt, was developing

ethical guidance for HSR from a global justice perspective, including guidance on how equity-oriented HSR projects should be structured, and how consortia governance should be organised to advance health equity.

Empirically, Dr Pratt has led studies during her tenure with FHS to understand how researchers deal with ethics of HSR on the ground and to test proposed ethical guidance linking HSR to global justice against practice. This has included case studies of the FHS MANIFEST project in Uganda and FHS Phase Two governance processes, and a broad-based survey of health systems researchers and HSR consortia leaders to assess what ethics challenges they face when doing HSR, how they resolve them, and – tangentially – whether they consider their work to be HSR.

## What next?

Conceptual work will continue to address in-depth issues, such as inclusiveness and the operationalisation of a capability framework. Dr Pratt was awarded a three year fellowship on a topic emerging from FHS work on citizen/community engagement in research priority-setting for HSR projects and consortia. This highly competitive "Discovery Early Career Researcher Award" by Australian Research Council will allow Dr Pratt to work on urgently-needed ethical guidance for engaging research users and beneficiaries when setting priorities for HSR, particularly around issues of power and diversity.

## CREDITS

This Story of Change was prepared by Daniela Rodriguez and Adnan Hyder.

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## Key references

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Read more about FHS work on ethics at <http://www.futurehealthsystems.org/ethics/>



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