Ethics of health research priority setting

Eden Palace au Lac, Montreux
28-29 November 2023

08:30	**Welcome and introduction to GFBR and the topic** Katherine Littler, World Health Organization, Switzerland
08:35	**Keynote presentation** Joseph Millum, University of St Andrews, UK
09:15	**Pecha Kucha session** Chair: Phaik Yeong Cheah, Mahidol Oxford Tropical Medicine Research Unit, Thailand Empowering communities in research - a model for shared decision-making and research priority setting in a rural population during a public health emergency *Margaret Kaseje – Tropical Institute of Community Health and Development, Kenya* Ethical issues in relation to engagement and involvement of marginalized and vulnerable groups in setting health research priorities 2013-2018, Tanzania *Emmanuel Makundi – National Institute for Medical Research, Tanzania* The ethics of the Philippine National Health Research System's (PNHRS) 2017-2022 National Unified Health Research Agenda (NUHRA) *Daphne Maza – Philippine Council for Health Research and Development, Philippines* Consideration of values when setting research priorities: a value-oriented guidance tool for priority-setting exercises *Wim Pinxten – Hasselt University, Belgium* Conducting high priority research in over-researched communities in Pakistan: the ethical burden *Sualeha Siddiq – Sindh Institute of Urology and Transplantation, Pakistan* Contribution of public universities to tackle leading causes of mortality in Ecuador: Evidence based on 100 years of scientific production *Ivan Sisa – Universidad San Francisco de Quito USFQ, Ecuador* Upholding autonomy and beneficence in research priority setting exercises in Ghana *Benedict Weobong – University of Ghana, Ghana*
10:00	*Tea/coffee break*
Theme 1 10:30	**Reflections from three national research priority setting exercises: stakeholder inclusion, transparency and evidence** Chair: Soumyadeep Bhaumik, The George Institute, India
	Introduction to the theme
	Re-imagining the ethics and the utility of existing frameworks for research priority setting: a case study of the family planning research and learning agenda in Uganda *Suzanne Kiwanuka – Makerere University, Uganda*
	An assessment of the priority setting exercise for health research in Peru

	Ramon Ponce Testino – Pontifical Catholic University of Perú, Peru
	Balancing ethics and stakeholder interests: insights from Malawi *Sibongile Kaphaizi – Ministry of Health Research Department, Malawi*
	Plenary discussion
11:45	**Breakout group discussion**
12:30	*Lunch*
Theme 2 13:45	**Amplifying marginalized voices in research prioritisation: The James Lind Alliance approach** Co-chairs: Toto Gronlund, James Lind Alliance Adviser *(*National Institutes for Health Research, UK) and Bridget Pratt, Australian Catholic University, Australia
	Introduction to the theme
	'Decentralized priorities for central schemes': experience of Department of Health Research's prioritization exercise for the Model Rural Health Research Units across India *Jaya Singh Kshatri – Indian Council of Medical Research, India*
	Women's pelvic floor disorders, Gondar, Ethiopia JLA Priority Setting Partnership *Zelalem Gashaw – University of Global Health Equity, Rwanda*
	Plenary discussion
14:45	**Breakout group discussion**
15:20	*Tea/coffee break*
16:00	**Funder panel** Chair: Ludovic Reveiz, Pan American Health Organization, USA - Michael Makanga, European & Developing Countries Clinical Trials Partnership, Belgium - Carleigh Krubiner, Wellcome, UK - Mongezi Mdhluli, South African Medical Research Council, South Africa - Barbara Sina, Fogarty International Centre-National Institutes of Health, USA - Do you see changes to the way your organization is considering research priority setting/agenda setting? - When does research priority setting take place in your institution? Who is involved in the process? - Are there limitations/pinch points in terms of funders obligations in terms of priority setting (i.e. public funder, limitations put upon by mandate or governments)? How do you build these into your decision-making processes? - What criteria are you currently using to set priorities?
35 min	Panel discussion based on questions above
20 min	**Plenary discussion**
16:55	**Breakout group discussion**
17:30	*Meeting day 1 close*

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08:30	**Summary – key themes from day 1** Francis Kombe, EthiXPERT, Kenya Ana Palmero, Consultant, World Health Organization, Argentina
09:00	**Pecha Kucha session** Chair: Mona Nasser, University of Plymouth, UK Mitigating disparity by harnessing fair process in heath research priority settings: what India might learn from It? *Abhishek Ghosh – Postgraduate Institute of Medical Education and Research, India* Ebola Virus Disease outbreak response in West Africa *Edward Kusewa – St Paul's University, Kenya* Need for awareness among funders, grant proposal reviewers, researchers and research ethics committees about ethical priority setting for research *Valerie Luyckx – University of Zurich, Switzerland* Lack of research of an endemic noncommunicable disease in Honduras: the case of Mesoamerican Nephropathy (MeN), a bioethical perspective *Guimel Peralta – Central American Technological University, Honduras* Ecology of engagement. A model for prioritizing research in mental health *Iliana Romero – Colectivo de Salud Mental TLP, Mexico* Prioritizing rare inherited diseases research in lower and middle income countries: the ethical dilemmas of cochrane evidence synthesis *Teguh Sasongko – International Medical University, Malaysia*
9:45	*Tea/coffee break*
Theme 3 10:30	**Governance of research priority setting: the role and responsibility of government** Chair: Sharon Kaur, University of Malaya, Malaysia
	Introduction to the theme
	Prioritizing health research in KwaZulu-Natal, South Africa: who sets the priorities, and how are they translated into research conducted? *Gugulethu Khumalo – KwaZulu-Natal Department of Health, South Africa*
	Health research priority setting experiences from Uganda, Tanzania and Zambia *Lydia Kapiriri – McMaster University, Canada*
	Ethical challenges and improvement pathways: a case study on health research priority setting in the Philippines *Joseph Oraño – Alliance for Improving Health Outcomes, Philippines*

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	Plenary discussion	
11:45	**Breakout group discussion**	
12.25	*Group photo and lunch*	
Theme 4 13:45	**Ethical and practical challenges to research priority setting** Chair: Annette Rid, Department of Bioethics, NIH Clinical Center & NIH Fogarty International Center, USA	
	Introduction to the theme	
	The US-Kenya Partnership: A model North-South 'unequal friendship' in health research where a balanced priority setting remains but a mirage *David Nderitu Wanjeri – Egerton University, Kenya*	
	Health research priorities in low resource settings – perspectives from rural North-east India *Starlin Mythri – Makunda Christian Leprosy and General Hospital, India*	
	'Deliverability of interventions' as a criterion in priority setting for health research: the case of H3Africa and gene-based interventions *John Barugahare – Makerere University, Uganda*	
	Plenary discussion	
15:00	**Breakout group discussion**	
15:35	**Concluding remarks, presentation of awards and announcement about next year's meeting** Anant Bhan, Yenepoya (deemed to be University), India Teck Chuan Voo, National University of Singapore, Singapore	
16:00	*Meeting close*	