A Health Equity Research Agenda for India: Results of a Priority-Setting Exercise

Introduction

Equality in general and health equity, in particular, are key themes in the Sustainable Development Goals agenda for 2030.[1] India's National Health Policy 2017, also has equity as a guiding principle. Launching the new health policy is 2017, the Prime Minister of India stated that *"the National Health Policy marks a historic moment in our endeavor to create a healthy India where everyone has access to quality healthcare."* [2] Planning for and designing programs to achieve health equity calls for robust evidence on the extent and nature of inequities in health and the population groups most affected. Equally or more important would be evidence that unravels factors and mechanisms that create, sustain and reinforce inequities. Reviews of the current evidence base on health inequities in India show that it does not measure up to this task.

It is against this backdrop that the Achutha Menon Centre for Health Science Studies (AMCHSS), at the Sree Chitra Tirunal Institute of Medical Sciences and Technology (SCTIMST), Trivandrum, Kerala in south India, embarked in 2014 on the "Closing the Gap: Health Equity Research Initiative in India"#. The overall aim of the initiative was to *contribute to the advancement of a sound and actionable evidence-base on inequities in health in India to influencing government and civil society initiatives to prioritize the reduction of health inequities.*A critical task under the "Closing the gap" project was to develop a health equity research agenda for India, and a subset of priority areas where immediate engagement is necessary. The research agenda is aimed for use primarily by researchers from diverse disciplines and sectors, who are interested in or have been working on, health equity research. At the same time, we are sure that the agenda will also inform research-funding and research-policy making. In this paper, we present this research agenda along with a short list of immediate priorities. We also present a description of the exercise we undertook to develop this.

Methods

The methods we adopted for developing the research agenda were informed by the following guiding principles:

- The agenda would be for research that generates actionable evidence that could inform programming and policy-making to reduce health inequities, including, making visible health conditions and population groups about which/ whom little is known
- The agenda-setting process would be consultative and iterative

This was a four-year project (2014-18) supported by the International Development Research Centre (IDRC), Canada.

- Multiple stakeholders would be involved in developing the agenda: researchers as well as practitioners of diverse types – policymakers, programme managers, advocates and activists
- Every attempt would be made to represent the agendas of diverse marginalized groups
- The process would build on both the already existing evidence-base as well as the body of extensive experiential knowledge in the field.

The agenda- and priority-setting exercise was undertaken over a three-year period (2015-17). We adopted a five-step process to which more than 200 participants from diverse disciplinary backgrounds and sectors contributed (Figure 1):

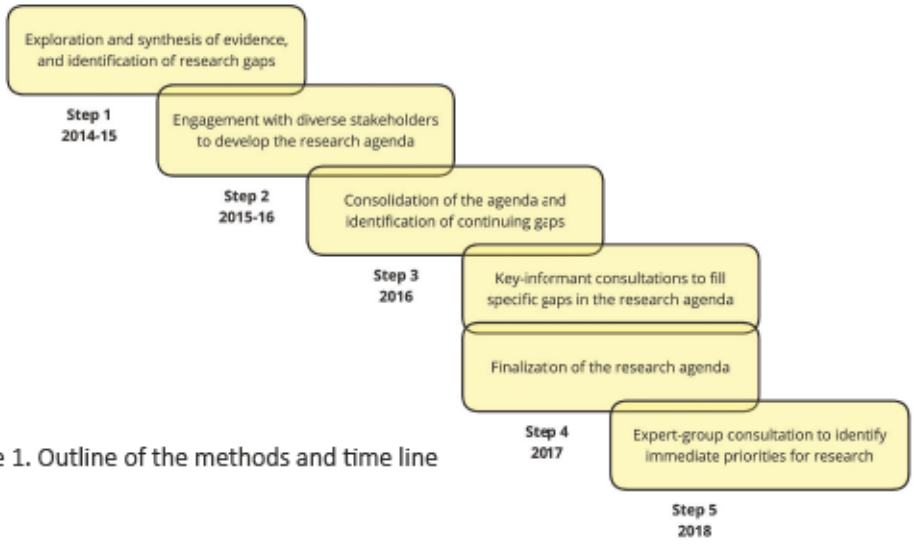

Figure 1. Outline of the methods and time line

Step 1: Exploration and synthesis of evidence, and identification of research gaps

Step 2: Engagement with diverse stakeholders to develop the research agenda

Step 3: Consolidation of the agenda and identification of continuing gaps

Step 4: Key-informant consultations to fill specific gaps in the research agenda; finalization of the research agenda

Step 5: Expert-group[$] consultation to identify immediate priorities for research in health equity

Research Agenda and Priorities Identified

We organized the medium-term research agenda and the priority questions that emerged from the three-year consultative process into the following four groups, based on the nature of the research question:

i. Descriptive research that answers the "what," "where" and "when" questions on the extent and nature and time trends of health inequities

ii. Explanatory research that answers the "why" and "how" questions, on the pathways through which health inequities are created, and the political/ policy environment that facilitates the process

iii. Explanatory research that answers "how" health systems create or facilitate inequities in accessibility, affordability, acceptability, and quality

iv. Intervention research which answers the "what works in addressing health inequities, in which context, and why?"

We present below the medium-term research agenda organized according to the above categories and within each category, also present areas identified as immediate priorities.

$ The following experts participated in developing the priority questions: Dr. Arima Mishra; Dr. Bhargavi Davar; Dr. Biraj Shome; Dr. Devadasan; Dr. Ganapathy Murugan; Ms. Jennifer Liang; Dr. Ketki Ranade; Dr. Lakshmi Lingam; Ms. Manjula Pradeep; Dr. Nakkeeran; Dr. Padma Deosthali; Dr. Padmini Swaminathan; Dr. Rama Baru; Dr. Ramila Bisht; Dr.Renu Addlakha; Ms. Renu Khanna; Dr. Sanghmitra Acharya; Dr. T. Sundararaman; Dr. Surekha Garimella;Dr. Vandana Prasad

I. Descriptive research that answers the "what," "where" and "when" questions on the extent and nature and time trends of health inequities

We have termed as "descriptive" studies those studies that describe the existence of health inequities, note the nature of the gaps across locations and over time. Descriptive studies are important to establish that specific population groups experience health inequities, and to motivate further studies into the reasons underlying the observed inequities. In the Indian context, there are several vulnerable population groups about whom such information is not available. The research agenda identified twelve groups who have been least represented in the evidence on health inequities, about whom it is crucial to initiate descriptive studies on health inequities. We need studies which describe the health situation of these groups, locating it in the context of population averages or comparing it with health outcomes of groups known to enjoy greater power and privileges. We also need studies on their health behaviors as well as health outcomes. In Table 1, we have presented the research agenda for descriptive studies on least studied population groups in two columns. The first column identifies the population groups to be studied, while the second column gives an illustrative list of health behaviors and outcomes of these population groups that need to be studied. The list of health behaviors and outcomes are relevant also for explanatory research studies (II & III below).

Table 1: A research agenda for descriptive studies on least studied population groups

Population groups to be studied	*Health Behaviors (Examples)*
Muslims and other religious minorities	Health literacy/ awareness of healthy behaviors and symptoms of health problems
Nomadic tribes	Care-seeking behavior (from whom, after how many days, for which conditions)
Urban homeless	Access and utilization, unmet need for health care/ treatment compliance/treatment completion and barriers to these
Migrants	Experience with healthcare providers/ in healthcare facilities
'Left behind' households of migrants	
Adolescents	*Health outcomes (Examples)*
Elderly	Overall health needs of specific populations
Single (never married/ widowed / separated)	Specific health conditions about which there is limited information (e.g., cervical cancer); Specific health conditions in specific population groups (e.g., TB in elderly or internal migrants;)
Persons living with physical /psychosocial disabilities	Ignored health needs of specific populations, e.g., beyond SRH for adolescents; beyond HIV for PLHA
LGBTQI communities	Nutritional status
Sex workers	Quality of life perceived psychological and physical wellbeing
People living with HIV/AIDS	

One example of a research question that would emerge using the above table would be,

What are the health needs of persons living with physical disabilities? How does this compare with the health needs of the general population?

The research agenda for descriptive studies on health inequities has a second part, which pertains to groups whose experience of health inequities has been well-established. Apart from many small-scale studies, there are a large number of studies analyzing data from National Family Health Surveys (NFHS), from Sample Registration Surveys (SRS) and National Sample Surveys (NSS). For such population groups, the need is to go beyond the analysis of the next round of NFHS and to look at more complex themes even within descriptive studies.

The research agenda for more complex descriptive studies include:

a. *Looking at within-group health inequities in vulnerable groups (e.g., within the group of Dalits or Adivasis, of women and men, of low-income groups)*

b. *Examining the consequences to health inequities of intersections of multiple vulnerabilities (e.g., elderly by class and gender, adolescents by rural-urban location and age, migrants by rural to urban or urban-to-urban migration)*

c. *Changes over time and differences across geographic locations of health inequities (e.g., changes over time in caste-based or gender-based health inequities)*

d. *Comparing relative position in the social gradient of different marginalized groups (e.g., Dalits versus Adivasis versus Muslims)*

The set of immediate priorities for descriptive research studies called for a focus on persons living with disabilities and on the North-East region of India, on within-group stratification among Dalit and Adivasi groups and health conditions beyond maternal and child health. We present a more detailed list in Box 1.

Box 1. Immediate Priorities for Descriptive Research

- Focus on persons living with physical or psychosocial disabilities; their health conditions beyond their disabilities, such as sexual and reproductive health; within-group variations by marital status, caste / tribal status/religion/ location/ combinations of these (e.g., the health of women living with disabilities in tribal communities)
- Focus on north-east India
- Focus on marginalized within Dalit and Adivasi populations: e.g., Valmikis, nomadic tribal groups.
- Focus on LGBTQI: desk review on policy and law, and overall health status across states of India
- Focus on morbidity; on health conditions beyond maternal and child health;
- An examination of how curriculum/pedagogy addresses sexuality and gender in medical and allied health professions
- Structural determinants of access to health care by workers in the informal sector (by gender, caste, age, geographic location)
- Mental health of people who have experienced violence (both interpersonal and social / communal / conflict-related) across gender and age

II. Explanatory research that answers the "why" and "how" questions, on the pathways through which health inequities are created, and the political/ policy environment that facilitates the process

For some population groups, research so far has focused on the nature and extent of the disadvantage they experience but has seldom gone deeper to understand the social processes that have led to the disadvantages. It is time now to shift gear and move towards explanatory studies on population groups such as Dalits, Adivasis, low-income groups, women in specific settings, and residents of rural areas, urban slums or poorly performing districts or states.

For each of these population groups, the research agenda for explanatory studies on social processes leading to health inequities calls for a focus on questions that explain how health inequities have come about and are sustained. The two broad strands of questions are:

- *What are the social processes that translate a specific social location into disadvantages in terms of access to resources and power, and through these, to good health? (e.g., social exclusion; discrimination; stigma which may be the pathway through which Adivasi households are deprived of access to health resources)*
- *What are the macro-level socio-economic and political determinants which are creating conditions that widen or narrow social stratification, contributing to health inequities? (e.g., cuts in public spending on the social sector; informalization of labor; corporate control over health care)*

The outcome variables to be examined would be similar to those listed for descriptive studies, namely health behaviors and health outcomes including morbidity, mortality, well-being; access to and utilization of health care and quality of care received.

As in the case of descriptive research studies, the research agenda for explanatory research studies also calls for exploring multiple axes of vulnerabilities. The first step towards this is to focus on building theoretical, conceptual and methodological tools, which will draw, among others, on experiences of struggles and interventions over the past decades to address inequities. The key research priorities identified are summarized in Box 2.

Box 2. Immediate Priorities for Explanatory Studies Related to Social Mechanisms and Processes

In the immediate future, the focus needs to be on building the theoretical, conceptual and methodological tools that will make possible such research

- A conceptualization of processes of inclusion, exclusion, discrimination, stigmatization, marginalization – how does (what are the processes through which) social position result in unequal access to social determinants
- What are the interfaces and interactions of macro-meso-micro-level factors in understanding health inequities?
- What are the processes through which specific groups of people are rendered invisible in data? Alternatively, what determines the collection or non-collection of data on specific groups and categories of people, on some conditions versus others
- How do we evolve methodologies to capture the dynamics of health inequities without assuming static, timeless categories for example by caste, gender or economic position?

III. Explanatory research that answers "how" health systems create/ reinforce or mitigate inequities in accessibility, affordability, acceptability, and quality of healthcare services and inequities in the social and economic consequences of ill health

The third category of research questions is about the role of the health system in increasing or mitigating health inequities. While health systems are expected to uphold values of equitable and universal access and respect the human rights of all its users, they have also been shown to reinforce and perpetuate health inequities and be blind to discrimination against vulnerable populations. For this reason, health systems are a crucial domain of inquiry when researching the mechanisms underlying health inequities.

There is a need for explanatory studies on the role of health systems in caste, gender and socio-economic status-based inequities in health, and in the poor low status of various vulnerable population groups, similar to those identified for research questions in category two ("why" and "how" questions in the politics / policy field) above.

The two broad strands of questions are:

a. *How does the structure of the health system (e.g., public/private mix, distribution of services across levels of care; the extent of decentralization; financing); the design of service delivery; the distribution of human and financial resources; and the processes of decision-making within the health system affect health inequities? (e.g., the requirement of residence permits may exclude migrant workers from accessing services; the lack of a woman doctor may discourage women from accessing gynecological services of a sensitive nature)*

b. *How do macro-level factors influence the structure and functioning of the health system (e.g., government policies on the privatization of health care; WTO intervention to alter the pharmaceutical scenario; employment opportunities abroad for nurses) leading to it contributing to the worsening or reducing of inequities.*

The outcome variables of interest are accessibility, acceptability, affordability, and quality of healthcare services and inequities in these across population groups. The social and economic consequences of the unequal access, acceptability/ affordability, and quality are also areas for further research. The key research priorities identified are summarized in Box 3.

Box 3. Immediate Priorities for Explanatory Research Related to The Health System

- What has been the impact of the growing presence of corporate private sector on access, availability, quality, and affordability of healthcare?
- What has been the impact of philanthro-capitalism on global and national health governance? With what consequences? Note here the impact also on the corporate private sector.
- How does one match bottoms-up planning, top-down financing, and choice of technology (strategy and design)? Does the tension between the three remain the same for groups across the social gradient?
- Districts with similar levels of social determinants perform differently at levels of health system performance. What features of governance make the difference? Can they be replicated?
- What is the perception of different levels of the health system on the scope of community involvement across the levels of the health system?
- What are the processes to follow to attract and retain workers to serve in marginalized areas?

IV. Intervention research which answers the question "what works in addressing health inequities, in which context, and why?"

Finally, as we move from asking what, why and how questions for various population groups, and the existing health inequities, it is crucial for research to also support for the development and evaluating of interventions that aim to address the health inequities identified.

In general, intervention studies could be classified into four based on what they are targetting:

- *Interventions aimed at improving health outcomes (for instance those aimed at reducing infant and maternal mortality)*
- *Interventions that target specific population groups (like children or elderly) or locations (like high priority districts)*
- *Interventions that attempt to improve awareness, or influence health-related behaviors*
- *Interventions that aim to improve access to social determinants of health thereby improving their health outcome (like access to better housing or nutritious food)*

In addition from the methodological point of view one could divide the emergent agenda into 'descriptive' and 'analytic' as described below.

Descriptive studies on interventions include those that describe in detail:

- *Health inequities addressed by the intervention;*
- *Actors involved;*
- *Strategies adopted;*
- *The theory of change of the intervention;*
- *Challenges of implementation; and*
- *The outcomes in terms of success or failure in reducing the health inequities targeted.*

The research agenda for analytical studies on health equity interventions included studies that would examine *among other thi*ngs the following factors at the local and macro-levels, which may have contributed to the success or failure of an intervention:

- *Context;*
- *Actors;*
- *Strategies;*
- *Implementation process; and*
- *Governance*

We have summarized the critical research priorities identified for intervention research in Box 4.

Box 4. Immediate Priorities For Intervention Research

- Documentation of successful pilots, projects, innovations that have broken the barriers to equity and worked with the marginalized populations to see how some of them can be upscaled and integrated into the health system
- What kind of interventions have worked or not worked for healthcare providers/ health system to become responsive to specific needs of vulnerable groups (e.g., LGBTQI, migrants, , persons with disability, sex workers)
- What interventions have worked to increase accountability to and participation by vulnerable groups?
- What has been the implementation and impact of Maternal Death Review for different population (e.g., increased maternal death reporting; increased action taken over deaths reported; has it led to better identification of 'high-risk' groups).
- What are the best practices of convergence models that have brought out better health and nutrition outcomes especially of vulnerable groups?
- What interventions have resulted in increasing the visibility and voice of marginalized groups?

Conclusion

The three-year-long exercise successfully evolved a medium-term research agenda for health equity research in India and also identified priorities for immediate research. The agenda includes a comprehensive set of research questions, ranging from the descriptive to the analytical and including intervention research. The process adopted was consultative and inclusive and drew on stakeholders from many disciplines, and from among researchers at all stages of their career and practitioners While much of the research agenda consists of empirical research questions, there is an emphasis on theory-building based on findings on the ground. A comprehensive programme of research based on this agenda would go a long way towards closing the information gap on health inequities and pave the way for mitigating the health inequities.

This article is a call to public health researchers to adopt and disseminate this research agenda so that sound evidence that lends itself to meaningful action against health inequities informs future research.

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