Research that supports health equity
Reflections and learning
from EQUINET

R Loewenson, M Mamdani, T Loewenson, Y Dambisya, B Chitah, B Kaim, R Machemedze, L Gilson, A Zulu

EQUINET steering committee
In the Regional Network for Equity in Health in East and Southern Africa (EQUINET)

EQUINET DISCUSSION PAPER 120

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EXECUTIVE SUMMARY

This paper reflects on experience from over two decades of EQUINET research practice to promote health equity in east and southern Africa.

The paper was written by members of the EQUINET steering committee and the newsletter team. It draws examples and research features from EQUINET publications available online, a search of publications in the 221 issues of the EQUINET newsletter, and papers, reports, blogs, articles and editorials obtained from key word searches in Google.

Despite policy commitments and gains in selected aspects of health, conditions in the region are increasingly driven by a global economy and a regional response that is generating instability, environmental and social costs; intense extraction of natural resources; rising levels of precarious labour, social deficits and weakened public institutions, disrupting social cohesion, solidarity and collective agency. These conditions call for certain features and forms of research. The paper describes diverse research on the costs to health equity of social deficits, inequitable resource outflows and the commodification of public services, as well as research on alternatives and policies on food security, health services, environment and rights that confront these trends.

Many research design features and methods that have been used to address these issues are not unique to research for health equity. They also involve processes such as interacting with key stakeholders, ensuring rigour, quality, validity and ethical practice in research and sharing results in a range of media and interactions that are common to most research. These features are not simply dependent on technical capacities. They also depend on how relationships, trust and credibility are built between communities, researchers and policy actors.

However, specific features of research respond more directly to our understanding that power relations are central to inequities in health. These research processes explain and show alternatives to disempowering narratives of the inevitability of the status quo and generate knowledge in ways that intend to empower those affected. They pay attention to who defines the research questions, who designs, implements and uses the research. This implies designs and methods that involve people in affirming and validating their realities, generating reflection on causes and building analysis, self-confidence and organisation to act and to learn from action.

We describe many forms of research and examples from practice that seek to do this. These forms include various forms of implementation research, appreciative inquiry, participatory action research, as well as engaging methods such as narrative research, 'fiction', theatre, using photography, videos, cell phones, online media and Whatsapp. Technologies used in research can bring local evidence and analysis to regional and global levels, although their role in health equity depends on the wider processes they are embedded in. There are common features across these experiences. The research variably draws on diverse disciplines and paradigms, applies a system lens, builds interactions, relationships and organisation for change throughout the research and empowers change agents inside affected communities, including in health systems, civil society, health workers and parliamentarians.

The examples indicate many positive experiences and approaches. However, many researchers face the double task of investigating inequities, while also challenging inequity in a global research system that undervalues the cross disciplinary, reflexive approaches and interactions that are features of equity-related research. They face travel, visa, cost, gender, class and racial barriers that exclude those in the region from engaging in northern-based global processes.

Having a consortium network has enabled us individually and institutionally to address some of these challenges. The wide range of disciplines, lenses and constituencies in the network and the sharing of alliances, expertise and experience have brought support, resources, exchanges, publication platforms and associational power for more self-determined research, provoking and supporting us to be creative and demanding us to keep critiquing and reflecting whether and how our research practice is promoting the health equity goals we aspire to.

1. BACKGROUND: WHY AND FOR WHOM DID WE WRITE THIS PAPER?

In 1998, when the Regional Network for Equity in Health in East and Southern Africa (EQUINET) was formed in Kasane, Botswana, equity in health had been articulated in health policies in almost all East and Southern African (ESA) countries for several decades. EQUINET was first launched in the Southern African Development Community (SADC) region and expanded to include additional East African countries (Kenya and Uganda) in the early 2000s. Post-independence, ESA countries adopted public policies to support equity, with consequent gains in education, food security, labour markets and primary health care (PHC) services. However, after several years of structural adjustment programs reversing these gains and weakening the mechanisms for overcoming social inequality, the socio-political forces and choices had changed. It appeared that equity values needed to be revived in public policy, including by public demand. As raised by Amartya Sen, the social allocation of economic resources cannot be separated from the influence of participatory politics and informed public discussion (WHO 1999). EQUINET's concept of health equity thus not only included the distribution of resources for health in relation to need. It also included the extent to which different groups of people have the opportunity for participation and the *power* to direct resources towards their health needs (Loewenson, 1998).

As a consortium network of professionals in government, unions, civil society, parliament and academia from various institutions and countries, initially in Southern Africa and then broadening to ESA, EQUINET sought to generate and use research, information and knowledge to support the capacities, learning and dialogue necessary for such change. The networking of diverse constituencies and experience around a common concern for equity was in itself seen to be a catalyst, but EQUINET saw that research could inform and reinforce this. The network could make the extent and forms of avoidable and unfair inequality more visible, expose the determinants of these inequalities, assess policy and practice for its impact and propose effective measures for advancing equity in health and wellbeing. Research was thus not simply identified as a way of generating new knowledge, but also as a strategic process for intervening in the power relations that generate inequalities. As was stated in EQUINET's formation in 1998:

Equally for those involved in essential national health research, the development of new knowledge should lead us towards, as inexorably as we are moving away from, economic and social processes that integrate communities, rather than marginalising them, and that enhance informed and participatory decision making. New knowledge that reveals the health costs of marginalisation, insecurity and unsustainable development paths is an important warning signal of a need for change. New knowledge that identifies alternative ways of organising health systems gives direction to that change. New knowledge that builds empowerment and effective participation in economic and social processes yields a greater likelihood of that change being effected (Loewenson 1998:11).

This link between research and equity-oriented change has since informed EQUINET's two decades of work in ESA countries. We saw regional co-operation as necessary to engage with the often global forces that constrain our states from addressing equity, as well as to share evidence and analysis and learn from applying strategies for health equity.

In part, this lies in advancing an affirmative agenda for health equity. A decade later after the launch, in 2007, the EQUINET steering committee observed in its agenda of 'Reclaiming the Resources for Health': *We have the knowledge, ability and experience to overcome persistent inequalities in health in East and Southern Africa* (EQUINET SC, 2007:4). Evidence from the region showed how health equity improved when a fairer share of national resources was applied to improve the conditions for health of marginalised groups and ESA countries obtained a more just return from the global economy to increase resources for health and invest in redistributive health systems. Health systems were not simply identified as a constellation of inputs and service outputs, but as a sphere where leadership, relationships between people and social norms and values are shaped and promoted and where knowledge and capacities can be built to advance public interests (EQUINET SC, 2007).

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Five years later, in 2012, our regional analysis highlighted that aggregate gains had been made in health, education, employment and poverty reduction. Some ESA countries had passed new constitutional provisions on rights to health care, water, food security and health determinants and a commitment on universality in health care was stated globally (EQUINET, 2012). Yet these aggregate gains masked persistent or even widening social inequalities within and between countries in various dimensions of health and its causes.

Evidence suggested that measures for universal health coverage alone cannot be assumed to address equity – this needed to be explicitly addressed, monitored and advocated for, including by 'reclaiming the state' for public policies that would confront pressures for deeper privatisation of public services. The public and political support and leadership necessary for this called not just for evidence, but for the confidence to sustain strategies for public interests in the face of volatile, liberalised competitive conditions and multiple private, public and global interests (EQUINET, 2012). We were, thus, challenged to produce persuasive evidence to support equity, but also to build the alliances and confidence to engage political actors and the state on the policies and practices for health equity.

By 2019, over two decades after EQUINET was formed, the challenge we now face has deepened. Public goods – education, health, water, energy, air, plants, languages and culture - have been even more intensively commodified, privately owned and traded for profit, driven by speculative financial activities and concentrating global wealth and power in fewer hands. We have global Sustainable Development Goals (SDGs), but apply them in a global system that intrinsically generates instability, with environmental and social costs. In our region we respond to this through increasing extraction and export of natural resources through transnational mining companies, enabling speculation on land, industrialisation of farming and destruction of biodiversity. In 2015, resource outflows meant that forty-eight countries in sub-Saharan Africa were "collectively net creditors to the rest of the world", to the tune of US$41.3 billion (Bond, 2017:online), without the political power that being a creditor brings.

In a battle for ideas, ESA countries are framed as 'under-developed' and 'aid recipients', and the population seen to be in a development pathway. Yet, for the population of ESA countries these economic trends have brought increasingly precarious labour, resource depletion, social deficits and destruction of cultures. The region continues to produce what it doesn't consume and consume what it doesn't produce. A large share of people lack decent housing, safe water or sanitation and low wages, unemployment and weak social protection undermine public resources for health.

However, it is not just the material conditions that reflect inequity. It is also present in the values, ideas and consciousness that are being consolidated in these changes, and how they are reinforced or confronted, including in the rising levels of social and online connection in the region (Mbembe, 2016). It implies 'reclaiming collective agency', for people across communities and countries to explore and respond not just to the material experiences and trends, but to build explanations, analysis and organisation to overcome the destruction of solidarity and agency.

We have consistently understood that knowledge is not neutral. In our region, a battle of ideas and a struggle over power lies at the heart of these trends, influencing the questions asked and explanations generated, who controls this and what assumptions are brought to bear (Turner and Rovamaa, 2013). Yet African institutions contribute less than 1% of the global expenditure on research and development (Fonn et al., 2018), Africa is home to only 2.3% of the world's researchers, Increasingly driven by a culture of consultancies, African researchers often *provide raw material - in form of data - to foreign academics who process it and then re-export it back to Africa* (Kigotho, 2011:1; Nolte, 2019; Omanga and Mainye, 2019). Research has also become commodified, and with it the legitimate questioning from the region of a discourse that poses current systems as inevitable: *it is easier to imagine the end of the world, than the end of capitalism* (Slavoj Žižek in Fisher, 2010:2).

We wrote this paper to reflect on our experience on research practice over two decades as researchers for health equity in our region. We asked ourselves:

What kind of research practice promotes health equity? What have we learned from our interactions, from our own research for change and from the ideas, perspectives and experience we have heard and shared with others?

We intend the paper to inform our own future thinking, dialogue and practice as a network in how we use research, but also to provoke, encourage and inspire others. Although there are many other forms of engagement *beyond* research that are relevant, they are not the focus of this paper. We reflect on research methods, but do not intend this to be a toolkit nor a systematic review. The paper is rather our collective reflection from our own research practice and that of others on what forms of research and knowledge contribute to propelling equity-oriented practice and change.

2. METHODS: ORGANISING IDEAS, EVIDENCE AND REFLECTION

The paper was written by members of the EQUINET steering committee and the newsletter team. It was reviewed by the EQUINET steering committee and revised with inputs received from additional steering committee members. It was reviewed also by a past steering committee member. Not on the basis of a systematic review, the paper includes reflections from the authors and from public domain, open access documentation from the region. EQUINET publications, all available online on the EQUINET website, and a search of publications captured in the 221 issues of the EQUINET newsletter were a source for the evidence, work and publications cited in this paper.

To complement our own work and reflections, we drew evidence, debates and examples of research practice through selected searches using key words from the structure of the paper (context, methods, design; ethics, equity, power; change; health; policy; systems; disciplines; quality; innovation; reporting) combined with 'research'. We focused on papers from the ESA region and selected those that addressed equity in the context, systems and methods for research practice. We searched through Google and the 12000 publications on the EQUINET newsletter databases, including journal papers, reports, blogs, articles and editorials.

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3. PUTTING RESEARCH IN CONTEXT

Section 1 pointed to the changes in conditions that have affected equity in health and wellbeing. Economic policies have increasingly brought market interests and commercialised services into the health sector, raising tension between paradigms that position people as consumers of health commodities and services with (or without) purchasing power, with constitutional developments that position people as citizens with rights to services. Despite articulation of political commitments to equity, economic policies have led to a retreating state, underfunded social services, increased dependency on external funding and increased social burdens (EQUINET SC, 2007; EQUINET, 2012). Private transactions with the state are screened from public scrutiny, and public resources used in ways that enrich elites, while underfunding and sapping the vitality of the public sector as a sphere for public interests (Bhorat et al., 2017). Public distrust in state institutions has led to a rising demand for transparency in public finances and resistance to the privatisation of public institutions (Bhorat et al., 2017). Socio-political and constitutional changes have opened opportunities for engagement on these issues, but have also sometimes generated a hostile and violent response (CEHURD, 2019).

These trends led EQUINET to do research with diverse communities, civil society and public sector actors who play a role in challenging inequitable resource outflows, such as health worker migration or the externalisation of health costs by transnational corporations in the mining sector to workers, ex mineworkers and communities. It has led to research on the privatisation and commodification of public assets, of health services and of other conditions affecting wellbeing. We have implemented research to provide a regional lens for negotiations on trade agreements on services and medicines access; for regional co-operation and south–south engagement in areas such as local production of medicines; or to inform social movements advocating public policies on food security, health services, environment and legal rights that confront the trends outlined in *Section 1.*

As raised in Mamdani and Mtenga (2012), beyond the specific problems explored, the question may be raised, *we already know the underlying reasons behind health inequities... can research make a difference?*

While our context has motivated particular areas of research, it has also affected who defines the research questions, who does the research and how we generate and use knowledge, discussed in later sections. Researchers are not passive within this. As successfully understood by corporate research in relation to public opinion on its products, research may influence political, professional and social opinion and raise policy demand (Loewenson, 2010). What gets asked, what draws political attention, what is financed and implemented relates in part to the quality and nature of the evidence, but equally to who drives the work and the interests and power relations involved (Crew and Young, 2002; Mamdani et al., 2015).

At a practical level, this implies being transparent about our understanding of context, to locate both the research and learning, and their relevance in other contexts (Daivadanam et al., 2019; Edwards and Barker, 2014; Mamdani et al., 2015). This understanding of context and framing of the questions emerges from relationships between researchers and different communities and institutions. For example, *Box 1* describes how the relationship that Ifakara Health Institute in Tanzania has built with state actors has embedded its work within state processes. CEHURD in Uganda, have built links as research activists within civil society processes, embedding this work in public interest litigation (CEHURD, 2019). As EQUINET, the diversity of institutions in our network have yielded an equal diversity of relations with state, civil society, academic, parliamentary and other institutions that bring different lenses to 'what will make a difference', where having shared equity values becomes a critical determinant of analysis and choice. Furthermore, given the dynamic nature of our context, the prediction, understanding, listening and relationships that define the questions for and designing of research means that it is both a strategic and an imprecise process, built from multiple interactions and sources (Daivadanam et al., 2019). A collective steering committee in EQUINET that periodically reflects on the changes in context from multiple countries and lenses and 'resets' agendas based on this has helped to share and ground the questions we ask.

Box 1: Ifakara Health Institute and its relationship to policy contexts

Ifakara Health Institute (IHI) has a firm understanding of the Tanzanian policy, socio-political and cultural contexts, applying its health systems research as to understand systems constraints, to identify, refine and test improvement strategies, embedding equity in the evidence and policy recommendations. IHI engages with health sector managers and local government authorities and is involved in various policy processes in technical working groups within the Ministry of Health and in health policy dialogues. This has helped the institution to respond to policy and system demands, but has also led to a perception of its role as a credible source of evidence in policy dialogue at national and regional levels.

This strategic position and the links with both the research and policy community have for example been used in testing and costing a model for recruitment, training and deployment of paid community health agents (CHAs) and in an emergency referral systems on maternal and child mortality, where ongoing collaboration with district and village authorities was important to ensure that the evidence generated was relevant to local conditions (Ramsey et al, 2013).

While such interactions are generally relevant, for research on health equity 'making a difference' implies understanding and engaging with power and its intersect with race, culture, wealth and other factors (Solar and Irwin, 2007; Braveman and Tarimo, 2002).

We often hear of power *over*, as a form of domination and control, but there are other forms of power. The consciousness and self-confidence to make decisions and act is a form of power *within*. The ability to act, to influence change, is referred to as the power to, while the power created through collective action is termed the power *with* (Loewenson, 2016). How we see ourselves in relation to others and our explanations of our experience affects the claims we think we can make (Mbembe, 2015).

The questions we ask, the issues we focus on, the processes through which we generate knowledge may empower- or disempower- the diverse communities that seek to 'make a difference' in multiple ways. The language we use affects the way we think about our conditions. For example, common reference to people and countries as 'under-developed' or 'developing', implies a certain image of and goal for development that drives us towards particular forms of knowledge and positions particular forms of social organisation as more advanced than others (Mbembe, 2015).

Within the region, when nationalism and 'development' became a homogenising discourse, it was argued to have overshadowed other lenses on inequality and to have generated a totalising hold on what intellectual work was relevant: *We are more attuned to foreign experts and many intellectuals accepted the injunction: 'silence: we are developing'* (Mkandawire, 2005:2). A high level of external health funding has brought with it a strong, sometimes dominant influence of international agencies over the questions asked and knowledge used in policy and practice. Our research cannot be separated from these contexts.

Simply put, research is not value free. In relation to health equity, it affects what is asked, who asks the questions and how evidence is generated and used to build consciousness (the power within) and collective agency (the power with) for equity-oriented change.

Given this, the context in our region has implied both collaboration and challenge. In the global context, the political and institutional realities of ESA countries have made it important to show evidence of how to achieve local or national goals to motivate self-determined improvements that support health equity. This involves work with public sector personnel for regional engagement in global negotiations through to local level frontline workers and civil society for engagement in national processes, taking advantage of windows of opportunity to advance particular changes.

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For example, Tanzania's Essential Health Interventions Project (TEHIP) used local evidence to support decentralised health planning at district level, taking advantage of a political and health leadership receptiveness for this, showing change as a process, with adjustments made over time based on locally owned and analysed evidence (de Savigny et al., 2004; ODI, undated).

Our realities also call for challenge to the status quo and existing explanations, whether within countries or in relation to global policies. For example, this has been evident in responding to demand from communities to advance and use constitutional rights and ratification of international norms to challenge inequalities in access to services, such as CEHURD's work in Uganda (CEHURD, 2019); or in work with unions and ex-mineworkers to challenge the inadequate public sector regulation of transnational mining companies around internationally accepted liabilities for health (Loewenson, 2018). Challenges have been raised on financing options that fragment or weaken health equity (Doherty, 2019); on how performance-based financing affects health systems and national strategic priorities, such as for comprehensive PHC (Mamdani et al., 2015; Loewenson et al., 2019) and on capital flows in health that drive privatisation (Ruiters and Scott, 2009).

Stepping outside the comfort of mainstream ideas and paradigms, exposing sometimes deliberately hidden realities and challenging 'established' wisdoms can be frustrating and demanding for communities and researchers, potentially risking career paths, resources or even personal security (Sukarieh and Tannock, 2019). The risks and potential gains for 'activist' researchers and the constituencies involved need to be explored from the onset, as the decision is as strategic as it is technical.

These relationships and decisions are made in a global research environment that reflects the same contexts and power relations. Communities are not regarded as 'researchers' in their own rights and African researchers in the region and in the diaspora see themselves as positioned in internationally funded work as 'informants', junior researchers and secondary authors, even though they contribute knowledge, facilitate access and navigate complex social and political contexts (Green 2019).

Research institutions in high income countries are better resourced, have easier ability to travel and greater publishing capacities to position as *producers* of research (Jayawardane, 2019). Researchers from the region face visa denials amongst other challenges in engaging in international platforms, especially those from low income communities and organisations. Peer review systems exercise an academic gate-keeping to exclude certain forms of research as 'non-scientific' if they divert from existing paradigms (Macharia, 2019; Grant, 2019; Bailey, 2019).
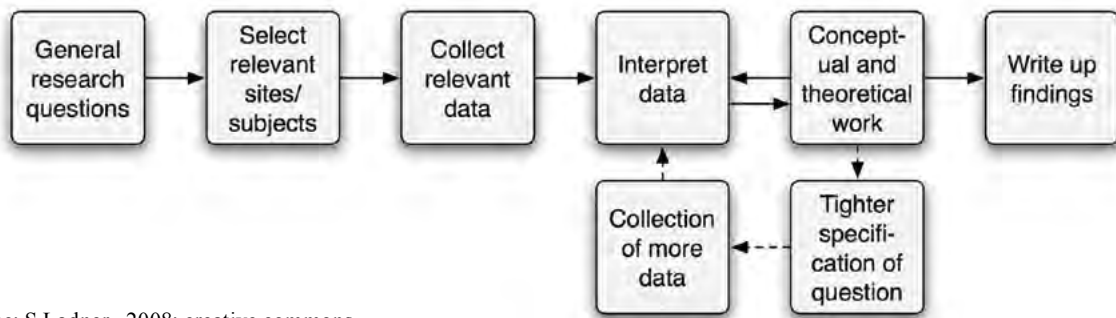
These inequities in power and resources in the research environment pose contextual challenges for the diversity of people researching on health equity in the region, especially for young, emergent researchers and those from minority and marginalised groups. Where the context demands a more bottom-up, self-determined path and more embedded, innovative methods for this, researchers in the region may find themselves taking on inequities not only in the issues explored, but in the research community itself!

Having a network like EQUINET of researchers at all levels, that levers resources and funds locally defined research, that facilitates constructive, mentoring forms of peer review and builds networks of exchange and publication that reach beyond academia into diverse communities has helped to facilitate more self-determined research collaboration. It provides support, but not yet the organisation and continuity of alliances to redress the deeper structural challenges in the research environment.

4. DESIGNING AND IMPLEMENTING RESEARCH FOR HEALTH EQUITY

The research process is commonly represented as an iterative set of activities, starting with setting the question and formulating objectives, designing the protocol and methods, implementing data gathering, analysing, interpreting and reporting results. The steps imply a single, rational pathway to a conclusion, sometimes ending with new questions, as shown in *Figure 1a.*
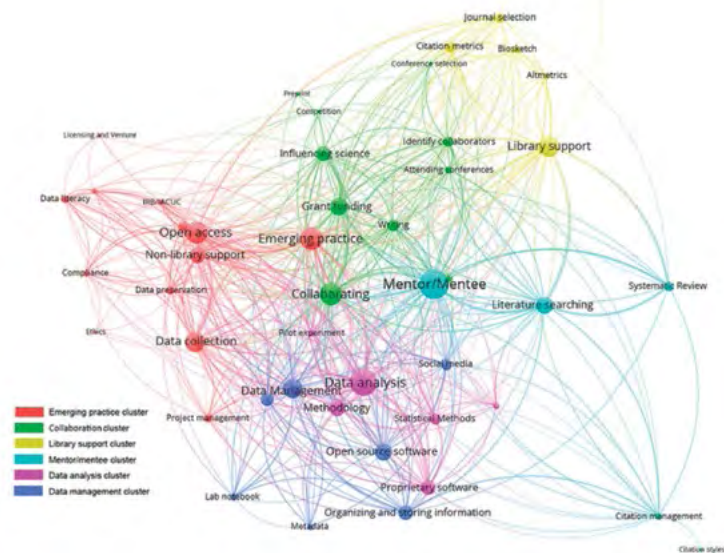
Figure 1a: The iterative research process

Source: S Ladner , 2008; creative commons

Figure 1b: Interactive research processes

Yet research processes involve multiple interactions, feedback loops, sometimes with side pathways to explore specific issues or learning from action, in pathways that are less linear and more interactive, as suggested by one mapping of interactions and connections shown in *Figure 1b.*

Source: Ragon, 2019, creative commons.

Our experience is that health equity related research is not usually the elegant linear pathway of *Figure 1a*. It may involve many iterative interactions to set the questions and objectives, blending stages of analysis and reporting to 'test' and learn from reality in participatory and implementation research, with many intervening processes between producing and engaging or acting on findings, awaiting windows of opportunity.

Research designs generally draw from a range of exploratory, descriptive or explanatory types of studies, informed by various disciplinary perspectives:

a. **Cross sectional studies** observe the program, policy or problem of interest at a particular moment in time using quantitative and/ or qualitative methods. This is a generic category as some of the other methods identified below are also cross sectional

b. **Case studies** provide detailed descriptions of particular events, programs, processes, situations or policies, to understand 'how and why' questions. Analysis across case studies can explain variations. Case studies can be performed at the micro- (individual/household), meso- (facility/district) or macro- (national and international/ global) levels.

c.   **Ethnographic studies** use methods drawn from sociology and anthropology to provide an in-depth description of life and practice, from the micro level (such as interactions between health workers and communities) to the macro level (such as in health policy debates).

d.   **Impact evaluation**, including **experimental and quasi-experimental methods**, seek to determine the magnitude and strength of relationships between the intervention and an outcome, often applying epidemiology and health economics and exploring what would have happened in the absence of the intervention. Realistic evaluation approaches are more reflexive and ask what works, for whom and how.

e.   **Policy analysis and historical analysis studies** examine the evolution of policies, institutions and programs over time at regional, national and global levels.

f.   **Cross-country analysis** involves comparison across multiple country level studies to identify generalisable factors affecting variations in systems and processes using a range of techniques for meta- analysis techniques (Gilson, 2012).

These design options reflect a spectrum of approaches for building new knowledge, ranging from experimental designs that measure reality as 'objective fact' to more reflexive designs, that acknowledge 'reality' as subjective, and that seek to understand 'what works', and for whom.

However, our experience of health equity-related research in EQUINET suggests that this methodological focus tells only a small part of the 'research design story'. As observed earlier, research evidence competes with many other factors and interests that influence changes in health, especially if it contradicts dominant views. It is more likely to be used if it is perceived as relevant for action, whether in processes that generate solutions to perceived problems or to inform and energise action by groups and organisations affected by issues. How this is achieved in part relates to how the questions are set, but also to the design of the research process.

In formal national policy or implementation processes, a review of the national health strategies of nine African countries suggested that research was more responsive to demand when the agendas were jointly set with stakeholders; when clear policy signals and leadership were provided, including on specific areas of debate or conflict that demand evidence; where taskforces or committees facilitated stable, longer-term interaction among researchers, officials and policy processes, rather than ad hoc interaction; where longer term links were built with trusted national research institutions; and where organised and informed civil society motivated demand (Loewenson, 2010). *Box 2* below summarises features of evidence that are seen to respond to the needs of decision-makers.

Box 2. When it comes to research evidence, what do decision-makers look for?

- *Credibility and reliability:* evidence from trusted sources (established through authors' names, peer recommendations, source of research, familiarity of logos and so on).

- *Quality:* current, jargon-free and transparent evidence, which must include what worked and what did not, with recommendations ranked in order of effectiveness.

- *Costed:* discussions that include cost analysis.

- *Contextualised:* evidence presented within a local, national, regional or global context.

- *Timed:* evidence on issues they are already working on.

- *Connected:* where can they get more information?

- *Customised:* evidence that can be reformatted for presentation, passing on to colleagues, printing for their own use, saving and filing, composing a briefing note, etc.

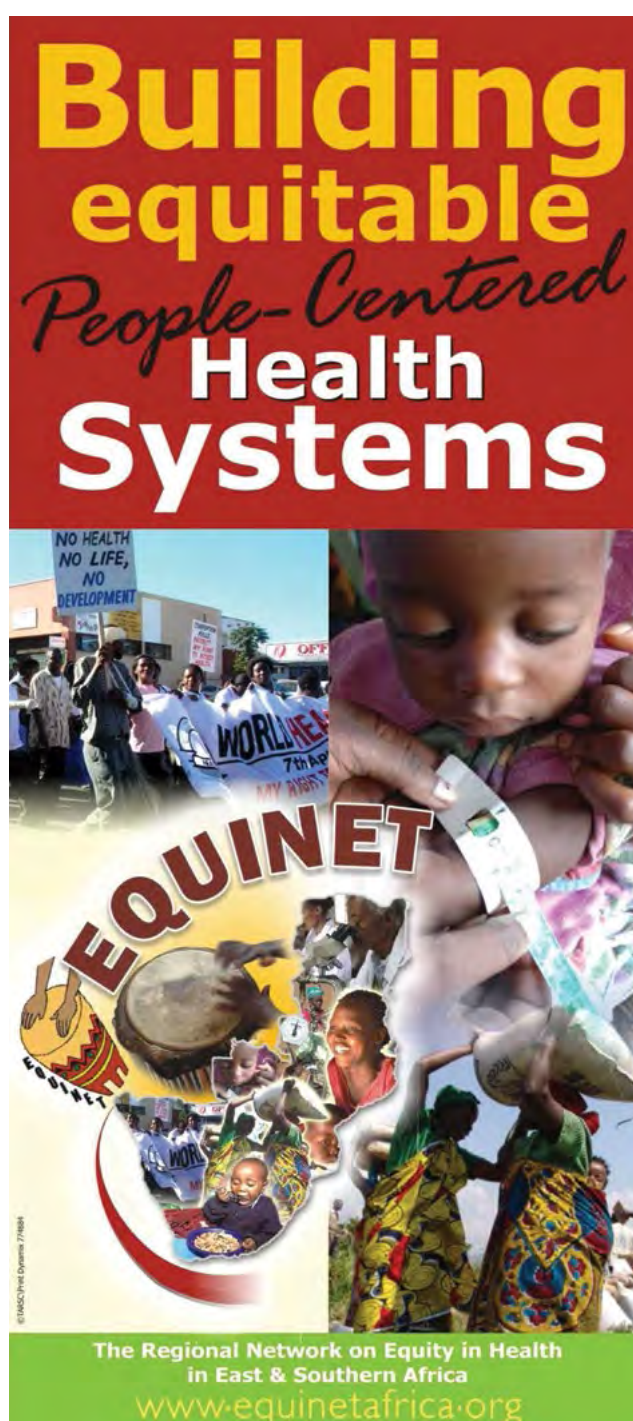- *Mode of delivery:* in electronic format and hard copy (IDRC GEH, 2008).

Research that is inclusive, based on co-production of knowledge with different sets of stakeholders, has the potential to improve policy and public debate. However, our health sectors often do not see their own role in producing knowledge or values. An assessment of national health strategies in eight African countries suggested that while all committed to improved use of research findings for decision-making and action, primarily they used routine administrative data and demographic and health surveys as evidence for strategies and only Ghana's health policy identified the health system as a "knowledge industry" to be developed (Loewenson, 2010).

As noted earlier, equity-oriented change is not necessarily a product of rational, linear policy processes. It also emerges from struggles between competing forces and interests, and depends on strategic capacities to take advantage of brief periods when windows of opportunity open for change. This too can influence what designs are used to build and communicate knowledge (Sisters of Resistance and Rodriguez, 2018; Kelley, 2016; Loewenson, 2010). It suggests a need for research designs that work with and for those who have been marginalised by conditions, to expose conditions and their causes, also that speculate on alternative explanations for these conditions in ways that encourage analysis and action on them.

'Solution-setting' and action research designs are potentially more relevant for these situations than research that ends with raising problems, particularly when the research process itself builds the methods, capacities, power and the networking of actors that are needed for policy or other changes (Theobald et al., 2009; IDRC GEH, 2008).
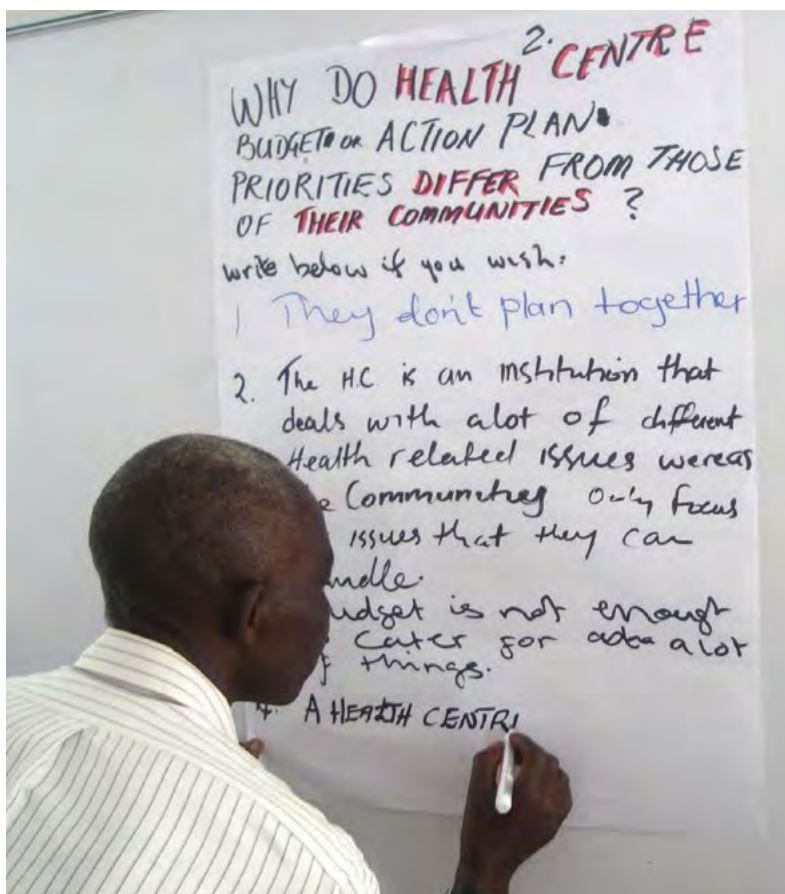
This includes embedding participatory processes in research design more directly with those involved, including in participatory action research (PAR), operations research and implementation research, in the analysis of evidence from monitoring and health information systems, in evaluation research and various forms of system research, ranging from ethnographic and speculative approaches to quantitative surveys. Some research designs more directly integrate learning from practice, such as PAR and implementation research, where learning from action is part of the designs and knowledge is built from action by those actively affected by and engaged in the issues (Loewenson, 2010).

As described further in *Section 5.3* and *Boxes 9, 11 and 13,* EQUINET has since 2005 worked with local communities and organised networks in ESA countries in research designs that involve learning from action to generate knowledge and change, including in the organisation and power of those affected by issues.

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Using spirals of analysis and reflection from action, affected communities, whether commercial sex workers in Malawi; communities in remote and militarised areas of eastern DRC; low income community members in Lusaka; people in informal settlements in Harare or communities in post Ebola Monrovia have collectively identified the problems and situations that are affecting their wellbeing and their causes (and causes of the causes). They use this to stimulate collective reflection, organisation and action or negotiation on the changes they propose, reviewing the results of their actions within the research. It has generated new and transferable insights and built the self-confidence and organisation of the groups to act not only on the issue that motivated the research issues, but sometimes on other issues (Mbwili-Muleya et al., 2008; Chikaphupha et al., 2009; Baba et al., 2009; Kaim, 2016; Jones et al., 2018).

The actions taken are diverse, including widening community health literacy, ensuring recognition and functioning of health centre committees, negotiating improved community environments or respectful treatment by services. This is not simply a technical design issue. It implies an engagement with those affected in setting the research questions and the design, considering how this affects the capacities and confidence to produce change. This is particularly important for dimensions of health equity where conditions and explanations may have disempowered those affected from exercising agency, such as in the previous examples. Here the design needs to build critical analysis, discourse and the confidence to act.

Community meeting on health centre committees, Lusaka, A Zulu 2015

Here too an inequitable research system poses a challenge. Researchers from the region may avoid 'risky', less well funded participatory research designs to choose better funded biomedical approaches. Qualitative designs and methods that enable more reflexive processes are often undervalued. We have joined Reidpath and Allotey (2019) and Daniels et al., (2018) to challenge this. Nevertheless, it remains a dominant reality. For example, Makerere University in Uganda face challenges in designing work that strengthens approaches for engaging communities, supporting evidence-informed policy development or testing innovative service options given a demand for clinical trials and a logistically challenging setting (Pariyo et al., 2011). Mixed designs are sometimes used to manage these tensions, combining both reflexive and experimental designs (as for example in *Box 4*). This may yield creative features, discussed later. It may also lead to confusing designs and intense processes for those involved.

In many forms of equity-related research, therefore, the design goes beyond the preparation of protocols that only meet 'scientific' criteria (Tayob, 2019). It calls for creativity in questioning and providing alternatives for criteria that disempower already marginalised groups. It calls for research designs that are attentive to and capture inequalities in ways that do not perpetuate the same inequalities. It suggests designs that contribute to the forms of self-reflection, analysis and feedback from practice that encourage change and strengthen struggles for justice.

5. METHODS USED IN RESEARCH PROMOTING HEALTH EQUITY

The context and design issues raised earlier suggest that research for health equity needs to be rigorous, systematic and creative. As for the research design, the methods may be experimental, using natural differences across time and space or sample surveys with control groups. They may be ethnographic, using observations, case studies, interviews and they may use a range of participatory approaches. The methods may be grounded, discovery-oriented, exploratory, descriptive and inductive or focused on causal analysis and process-oriented, assuming a dynamic reality. This paper does not aim to provide a 'how to' of the different methods. Readers are referred to publications that discuss different methods, such as on health systems and policy research by Gilson (2012); implementation research by Peters et al., (2013) and on participatory action research by Loewenson et al., (2014). We do not restate the significant body of literature on experimental, epidemiological, social science and ethnographic methods for public health research and for social and political analysis.

Underlying these methods are different paradigms of how knowledge is generated, however. Positivist approaches see reality as objective, understood through experimental methods with the intention of sharing generalisable fact. Reflexive and constructivist approaches consider reality to be subjective, understood through methods that systematise and validate subjective evidence and share transferable insights on it. While a specific knowledge paradigm may not in itself disempower or generate inequities, where communities have perceived knowledge systems to dominate or discount their reality, they have used reflexive forms to 'reclaim' their own power over knowledge (Cook and Richard, 1979; Loewenson et al., 2014).

Box 3: Learning from EQUINET research on equity in health and wellbeing for urban youth

A policy perception of an urban advantage is no longer valid for many health outcomes and a focus on urban–rural differentials is no longer sufficient for addressing inequalities in health, especially those emerging from disadvantage *within* urban areas. This has been poorly recognised in the past, in part due to the methods used and the comparison of aggregate urban data with that from rural areas. The literature presents a picture of urban health that is a series of fragments of different, disconnected facets of urban risk, health and care, with limited

direct voice of those experiencing the changes and limited report of the features of urbanisation that *promote* wellbeing. The social distribution of health and wellbeing in urban areas relating to life stage, social cohesion, length of tenure, migrancy, formal status of areas does not easily fit the usual categories in health surveys, and there is little within area analysis in national surveys. The indicators collected are generally negative, focused on morbidity and mortality and not on positive outcomes, or on the assets that may enable them, such as social literacy. Our understanding of how to frame responses is affected by lack of an appreciative inquiry lens and our services are increasingly framed on reacting to disease. The World Health Organisation (WHO) constitution takes a more holistic understanding of health and *wellbeing*, not merely the absence of disease, yet the data we currently measure across ESA countries focuses largely on morbidity and mortality, limiting our understanding of the interaction of psychosocial, material, economic, environmental determinants that affect and promote urban wellbeing. This situation and its dynamic nature is argued to call for a mix of methods and disciplines in research, including those that draw more directly on the lived experience of different groups of urban residents (Loewenson and Masotya, 2018; Photo J Hall, Johannesburg, 2006, CC).

Our research work and experience, such as that outlined in *Box 3*, suggests some key features of the methods that may be important for understanding and acting on the determinants of equity in health and wellbeing. The methods often draw on diverse disciplines and paradigms, apply a system lens and build relationships in the research, empower change agents, use innovative and creative approaches, whilst ensuring that the quality, credibility and ethical nature of the work in line with the methods used.

The next parts of this section discuss these features further.

5.1   Working across disciplines

By the late 20th century many epidemiologists and public health practitioners were expressing dissatisfaction with the limitations of a risk-factor paradigm in public health that overemphasized and organised interventions around individual risk, to the exclusion of other organisational levels of risk. This led to calls for health and disease to be studied at a population level within a socio-political context, to understand the structural factors, social determinants and systems that affect health and access to health care and the social response to these determinants, particularly to address the political and other forces affecting health equity. It motivated new critical thinking, research methods and tools (WHO CSDH, 2008). In our experience much of the work to understand the drivers of inequalities in health and to identify changes to address them calls on a range of disciplines. While the research questions may be focused, the analytic concepts used to answer them may call on multiple disciplines, as in the example in *Box 4* below.

> **Box 4: Exploring the interaction of power relations and different dimensions of vulnerability following devolution in Kenya**
>
> An intersectionality lens was used in Kenya to explore how power relations intersect to produce vulnerabilities for specific groups in specific contexts and to identify the tacit knowledge about these vulnerabilities held by priority-setting stakeholders. Using key informant and in-depth interviews and focus group discussions from across the health system in ten counties, combined with photovoice and participatory research with young people, the research investigated the range of ways in which longstanding social forces and discriminations limit the power and agency individuals are able to bring to health decisions. They found this to be mediated by social determinants of health, exposure to risk of ill health from their living environments, work, or social context, and by social norms relating to their gender, age, geographical residence or socio-economic status. Their findings indicated that while a range of policy measures have been introduced to encourage participation by typically 'unheard voices', devolution processes have yet to adequately challenge the social norms and power relations that contribute to discrimination and marginalisation. They suggest that action to address this involves sectors beyond health to address these social determinants and to identify ways to challenge and shift power imbalances in the processes for priority-setting (McCollum et al., 2019).

In EQUINET work we have used the full spectrum of methods elaborated earlier and do not set a hierarchy that places certain forms of evidence or certain methods as superior to others. As others have also found, enforcing disciplinary and methodological boundaries can be reductive of and exclude alternative knowledge systems and processes and can curtail the complexity needed to address health equity related issues in systems and society (Webster, 2015). We have been aware that doing this may make some of our work less 'publishable' in health journals and have opened space for other ways of reporting findings, discussed later.

Much of our work has sought to dig deeper than single cause-effect relationships to understand deeper structural causes and responses. Hence, in addition to the inclusion of more direct involvement and voice of those affected by issues, we have also had to integrate and overcome the sectoral silos that address the diversity of deficits that affect health through more inclusive approaches, whether through inclusive cities (as argued by UN Habitat); inclusive economies (as argued in African Union economic policies) or social inclusion in governance (UN Habitat, 2015; Loewenson and Masotya, 2018). The significant structural asymmetries, social deficits and inequality in the global economy and their impact on our countries and communities do not only imply 'closing gaps' across and within countries.

Whether in relation to the health consequences of extractive industries, the prevention and control of epidemics, the implications of urbanisation and climate change or the response to a rise in chronic conditions, as noted in *Section 1*, improved health equity is linked to alternative ways of organising society, politics, economy and environment/nature (Boron, 2015; Kothari and Garg, 2014; Loewenson and Masotya, 2018).

Thinking more holistically, and addressing structural and system level drivers of inequity calls for sustained, affirmative strategies and changes that generally cannot be equated with progress in one discipline and sector only. We have gathered significant evidence that tells us this. For example, our 2007 and 2012 Regional Equity Analyses and later work made clear that with economic growth taking place at the cost of intense exploitation of nature and significant social inequality, we can focus neither on economic improvement, nor on short-term gains, at the cost of social and longer term deficits (EQUINET SC, 2007; EQUINET, 2012). Inevitably our discussions on health equity have raised issues that take us outside narrow biomedical paradigms, often outside the health sector alone and increasingly to the balance of policies, systems and resources in different sectors and their effect on current and future generations.

This calls for us to engage with those outside our usual disciplinary and institutional 'bubbles', to bring in new perspectives and disciplines from the sciences and the arts, sometimes going further to synthesise paradigms in transdisciplinary approaches. Such approaches go beyond collaborations across disciplines that each retain their own paradigm. They integrate constructs in a more holistic transcending set of classifications and shared parameters (Picard et al., 2011). It matters whether research enables or disables this. For example, in EQUINET's urban health work, we found that where 'health' has been understood as a biomedical concept due to the increasingly curative and disease focused nature of health systems, using a 'wellbeing' framework supported a more integrated and shared framework (Loewenson and Masotya, 2018)

A mix of methods and disciplines can lead us to question the assumptions held by particular disciplines and wake us up to new lenses for research that can enhance the validity of findings. Being a consortium network, which bases inclusion not on a specific disciplinary or professional group, but on health equity related values and goals, has enabled EQUINET to bring a wide range of disciplines to its work, including epidemiologists, pharmacists, social scientists, nursing and other clinical personnel, architects, urban planners, economists, lawyers, trade specialists, specialists in labour relations, media, theatre, artists, and so on. Working as a network regionally has helped us to tap and share this expertise across countries, as for example in the combination of social science, economic, trade, pharmaceutical and health science disciplines applied in the work on capital flows in health outlined in *Box 5*. This also links with new networks in state and civil society, deepening associational power.

> **Box 5: Exploring the equity implications of capital flows in ESA health systems**
>
> Private health is the fifth most promoted sector in Africa, after tourism, hotels and restaurants, energy and computer services. To understand flows of private capital behind the growth of the for-profit health care sector in southern Africa, EQUINET working through Rhodes University Institute of Social and Economic Research (ISER) and other institutions in the region brought together a range of disciplines and capacities to examine health sector capital flows in and across ESA countries. Despite the minor movements of capital in the health sector in ESA countries, Mauritius, South Africa, Botswana and Namibia appear as the growth points for big capital, with the rest of the region relegated to the margins in terms of large investments. Investment potential exists in the pharmaceutical, hospital and hospital services sectors. However, most new foreign direct investment (FDI) in health is in the pharmaceutical sector often for the production of ARVs to absorb funds from external funders. The pharmaceutical sector has also had the most significant amounts of overt privatisation of all health-related sectors, either through selling fixed assets or transfer of equity. The report argues that South Africa is likely to be the biggest destination for investment in health care, and the major regional source of private FDI flows to the health sector in ESA countries. The team of economists, health system and pharmaceutical researchers showed the implications of this in terms of the commercialisation of and inequities generated within the health systems of the region (Ruiters and Scott, 2009).

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This demand for collaboration across disciplines is growing, rather than receding. As health equity issues emerge in new areas, from macro-issues such as climate change to new areas of genomics and biobanking, the demand for an African lens on the implications for the region calls for us to build such work across disciplines, and to link a range of professionals with those affected by these issues. For example, externally funded genomics research and biobanking initiatives have played a critical role in building capacity for research in this area and for global networking. However, with concerns raised on African researchers having a limited role in decisions on the design and conduct of the research, there are questions on the direction and sustainability of benefit, particularly for those negotiating for the region on these issues.

New global issues, as for local medicine production and other areas of health technology development, demand a deeper regional investment in interdisciplinary collaborations and capacities needed for self-determined research and development practice (Munung et al., 2017).

5.2 Applying a systems lens and creating relationships

In our experience, exploring the determinants of and responses to equity in health and wellbeing takes us beyond individual factors to an analysis of the orientation and capacities of systems, including to deliver on rights.

Evidence from all regions indicates that taking a systems lens is vital to understand how health systems, and the different elements, inputs and actors within them, interact to promote or impede health equity (Gilson et al., 2011).

Yet much health research does not apply a comprehensive system level analysis. Even research that seeks to assess the introduction of innovations that have system wide effects appears to focus on narrow causal pathways between input and outcome, based on assumptions of how all systems operate. Hence, for example, research on performance based financing in health systems has been critiqued for lacking clear evidence on wider or longer term effects on the functioning of systems or the distribution of population level health outcomes necessary to understand their implications for health equity (Brown et al., 2013). The effects that are not covered may have equity implications, such as in shifting burdens and workloads, raising hidden costs or generating particular forms of exclusion (Brown et al., 2013; Loewenson et al., 2018).

A more affirmative framework to promote equity-oriented systems calls for an understanding, such as through realistic review, of what works for health systems, under what conditions and how. For example, we have explored the role PHC-oriented systems play in responses to HIV and access to treatment or in integrating management of chronic conditions; what system features help to retain health workers, beyond specific targeted incentives; what food systems support greater control over health promoting foods at local level, or how systems balance the power across different actors to support equity in the allocation of resources (EQUINET 2012).

Box 6: Exchanging country experiences on the role of essential health benefits in equitable health systems

Undertaken through IHI and TARSC, with ministries of health in eSwatini, Tanzania, Uganda and Zambia, the Essential Health Benefits (EHBs) project raised the usefulness of involving ministry of health personnel as researchers; it brought a policy and practical lens, pointing to the value of embedded implementation research to inform strategic policy and service processes. Key findings have already begun to feed into policy dialogue within the countries involved. The research also raised various areas of good practice in implementing EHBs: in some countries for example, consultative, consensus-building design processes involved experts and implementers and reached out to parliamentarians and the public. This national engagement and ownership of research from the onset and the involvement of people working in the system as lead researchers helped locate the work within the wider system, profile the wider system implications and support the adoption of the findings for strategies that take the diversity of local contexts into account (Loewenson et al., 2018).

Doing this with those more directly involved in the system as researchers, as shown in *Boxes 6 and 7,* whether with health planners at national level or with local communities, civil society and workers in and beyond the health sector, facilitates this wider system lens. It enriches knowledge by embedding analysis within those with more direct experience of their systems.

Box 7: Intersectoral responses to nutritional needs of people living with HIV in Kasipul, Kenya

Ongala et al., (2009) implemented a PAR process in EQUINET that involved representatives of prople living with HIV (PLWHIV), health workers, local community organisations, the provincial administration, the Kenya police, Ministry of Livestock and Agriculture, and the district development office in a district of Kenya. PLWHIV and their organisation used the research to explore their food insecurity, as they were going without food and skipping treatment and medicines. Their research showed the range of gaps in support across the multiple systems that they interact with. Weak community level and service support left people more dependent on individual resources. Weak provision of information on locally available health diets and a fragmentation of initiatives and focus on emergency responses limited the establishment of longer term approaches to food production and marketing. The research triggered responses that cut across systems, including health systems and community groups on information, care and psychosocial support; support for production; and self-help groups establishing kitchen gardens, poultry keeping and market gardens. The work changed perceptions and interactions across different institutions, putting PLWHIV in the centre of a constellation of services for their food security and wellbeing (Ongala et al., 2009).

Systems level research may involve tracking the benefit from financial measures and flows, such as the work by McIntyre at al. (2007) to [assess progress towards equitable resource allocation](#) in four southern African countries that adopted such formulae (Namibia, South Africa, Zamibia and Zimbabwe) and to understand how system features affect such progress. It may also point to analysis of the relationships in systems, doing research in ways that contribute to relationships that bring changes within health systems (Gilson et al., 2011). It may demand sustained interactions to build sufficient trust between those involved to draw honest reflection. The policy analysis work in the region has helped to strengthen the capacities and relationships that contribute to the application of a system lens (Gilson et al., 2011).

Showing the indicators of equity and inequity in health in the region (EQUINET, 2012)

System level analyses are not as simple to communicate as single risk-health relationships or achievement of single targets. In an 'indicator' driven world, one of the ways we identified in EQUINET to communicate and inform advocacy on the system features emerging from equity-related research was to translate them into 'indicators' of progress towards health equity. These 'progress markers' reflected system issues, such as the provision and implementation of health rights in the constitution and of measures to value and retain health workers in local services, or the negotiation of national priorities in bilateral agreements. They were combined as an 'Equity Watch' to monitor and report on progress in health equity in the different countries of the region, and used in advocacy and policy engagement, including with parliaments and international partners (EQUINET, 2012). This engagement motivated further research to better understand system challenges, such as for parliamentarians, in taking up the concept of progressive realisation of the right to health within the oversight and budget processes available to them (London et al., 2009).

Given the level of global influence in health systems, our system lens and relationship building in EQUINET have expanded to include research to support engagement on global health policies and processes (Loewenson and Molenaar-Neufeld, 2015). Here we found a literature on global health diplomacy (GHD) that is fragmented, involving multiple disciplines, but without shared theory or conceptual frameworks and in our region, more focused on descriptive accounts than explanatory inquiries (Blouin et al., 2012). A two-year research project in EQUINET in association with the East Central and Southern African Health Community (ECSA HC) explored factors affecting the negotiations on African interests in health diplomacy in relation to the negotiation of the WHO Code of Practice on International Recruitment of Health Personnel (shown for example in *Box 8* below); the engagement of African governments on performance-based financing; the engagement on local production of medicines and negotiation of regional priorities in the BRICS (Brazil, Russia, India, China and South Africa) forums.

Box 8: The Engagement of East and Southern African Countries on the WHO Code of Practice on the International Recruitment of Health Personnel

The WHO 'Global Code of Practice on the International Recruitment of Health Personnel' (hereinafter called the "Code") adopted by the World Health Assembly (WHA) in May 2010 was the culmination of efforts by many different actors to address the maldistribution and shortages of health workers globally. African stakeholders influenced the development of the Code, but two years after its adoption only four African countries had designated national authorities, and only one had submitted a report to the WHO secretariat.

This research was part of the EQUINET research program on global health to identify factors that support the effectiveness of GHD in addressing selected key challenges to health strengthening systems in ESA countries. The research strategies included an extensive review of literature; a 'fast-talk' session at the 66th World Health Assembly (WHA) in May 2013 involving stakeholders from African countries to gauge views and concerns relating to the Code; a region-wide questionnaire survey implemented in 2013 to obtain views of government informants on issues affecting and measures for managing health workers, including migration of health workers in ESA countries; and three country case studies undertaken in Kenya, Malawi and South Africa concluded in 2014 to provide an in-depth exposition of perspectives on the Code and its implementation. Respondents to the research had been involved at variable levels in the diplomacy surrounding adoption of the Code. Some raised concerns about the final provisions of the Code, including its lack of provisions for compensation or specific provisions on resource transfers, and its voluntary, soft law, nature. The views expressed suggested that African policy interests were not all included in the Code, or not included to a sufficient extent. This was further indicated by content review of the Code against positions stated during the negotiations. This and a changing context since the initial negotiations may have contributed in part to a subsequent weakness in implementation. The findings pointed to the necessary inputs before during and after negotiations to carry positions through, including to implementation, which were discussed with officials and diplomats (Dambisya et al., 2013).

Our content analysis of the evidence from these four areas of global health diplomacy pointed to enablers such as political leadership and champions with clearly articulated policy positions, regional interaction and unified platforms across African countries. It also led us to question, however, the assumption of what is 'successful' in health diplomacy. For example, the adoption of a 'development aid' paradigm suggested that success would be measured in aid transfers. However, this carried the risk of a dominance of remedial, humanitarian engagement in international co-operation on health, with less sustained attention to structural determinants (Loewenson and Molenaar-Neufeld, 2015).

In taking a systems lens, whether within or across countries, our experience suggests that we need to be as clear in our analytic frameworks about the longer term impact on equity of any assumptions of what is a 'successful outcome' as we are on the parameters and methods used.

5.3   Empowering change agents

As raised earlier, the collective and conscious power to direct resources towards health needs and values of solidarity are central to health equity. It implies that research that seeks to inform and advance health equity should also advance these forms of power and values. In EQUINET we have seen that this means that wherever possible, those affected by the problem should define the questions, be the primary source of information, the primary actors in generating, validating and using the knowledge for action and the primary direct voice in presenting evidence to those who influence their situations. This is not only a matter of building knowledge, but of doing so in ways that also generate analysis, consciousness and organisation in affected groups. Those who are not part of the affected communities facilitate the systematic, participatory collective processes with the relevant communities to enable this (see for example *Box 9*).

Box 9: Community organising for health in Cassa Banana Informal Settlement, Zimbabwe

Residents of a marginalised informal settlement on the outskirts of Harare, Zimbabwe, were caught between two district councils – one urban and the other rural – where neither council was taking responsibility for providing basic services such as water and sanitation to the community of nearly a thousand people. Intestinal parasites and diarrhoea were rife. Working with TARSC and the Zimbabwe Doctors for Human Rights, the Cassa Banana Community Health Committee (CHC) undertook a PAR for the community to clarify responsibilities and engage with local government to improve their health and well-being. They held community meetings to identify priority health problems and their causes. They developed an action plan, took their findings and proposals to the council meetings and put pressure on them meet their constitutional duties. The CHC monitored and reviewed progress. While this was only partially successful, the CHC gained credibility in the community. Two years into the research, this fractured community was working more collectively in dealing with their water and sanitation crisis, the CHC had built a greater understanding of the social and institutional structures and processes that disempower their community and undermine their health and were developing strategies and alliances to overcome these barriers (Kaim, 2016).

Since the early 2000s, EQUINET has used participatory action research (PAR) approaches through a 'pra4equity' learning network and health literacy activities. PAR transforms the role of those usually participating as the subjects of research, to involve them instead as active researchers and agents of change, learning from action to generate new knowledge, with different procedures for systematising and collectively validating the knowledge (Loewenson et al., 2014). The background and methods for PAR and examples of its use are described in a methods reader we produced with WHO and the Alliance for Health Systems Research (Loewenson et al., 2014) and in a toolkit for using PAR in health (Loewenson et al., 2006).

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The PAR processes were locally facilitated to build transferable insights and local actions on community and health worker interactions in local health systems, on PHC approaches to HIV and AIDS services and other priorities identified by those working in communities and health systems to be shared across the region. The learning network enabled us to mentor on methods and to share experiences, peer review and identify common findings and learning across the sites. This supported activism among those directly affected by health issues and informed regional engagement on shared insights (Loewenson et al., 2014; TARSC, 2009).

While PAR has triggered many local actions and changes, sharing the knowledge and insights from these local experiences to develop the field and widen its transformative impact has been a struggle. Those implementing PAR are often more focused on action than writing. PAR does not fit the usual journal paper format and is poorly understood by reviewers. We have, therefore, provided a space for this on the EQUINET website, including in a PAR portal (*Box 10*), and in exchanges with those implementing PAR in other regions that we meet in wider forums.

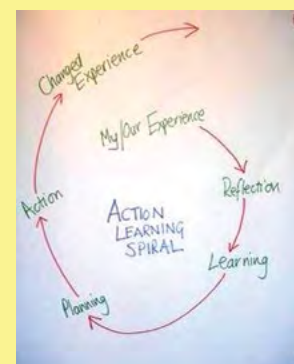**Box 10: Sharing resources on PAR through a PAR portal**

In the evaluation of the Reader on PAR in Health Systems Research many respondents asked for a website to share PAR materials, information and experiences online. There are many existing resources on PAR, but we needed to make it easier for people to find what is out there to support their needs. In response to this, EQUINET set up an online Participatory Action Research Portal. The portal provides information on training courses and guides; PAR methods, examples of tools, and discussions/ guidelines on ethical issues; links to stories, case studies, briefs, videos, text or photojournalism stories of PAR work and facilitator reflections. It also shares information and links to organisations and networks involved with PAR and to published papers and reports.

In these experiences we have seen how research that recognises people's experience and builds their collective analysis has enabled them to contest power imbalances and produce change in systems and institutions. It offers a means to expand social agency and activism and has allowed people to create counter-narratives to dominant characterisations that ignore or undermine them and their health. For example, in rural (Nachingwea) and urban (Kibaha district) Tanzania, people with disabilities and older people explored experiences of socio-political and economic inclusion / exclusion from their own perspectives, collectively

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Box 11: Raising our Voice, Breaking our Silence: Health Workers' Experiences and Needs around Occupational Health Services in Cape Town, South Africa

Industrial Health Research Group in South Africa (IHRG) and a group of unionised health workers used PAR to investigate and intervene in experiences of workplace injury and illness. The project consisted of three workshops, workplace-based investigations, and the dissemination of networking resources among participants. The combination of workplace-based case investigations and the process of critically reflecting on these interventions provided a powerful action-learning experience. Participants were also able to critically examine their own learning experience. Change was evident even in this short term project. Participants' workplace investigations uncovered real cases of workplace injury and illness that had been buried under a culture of ignorance, neglect, silence, and denial of workers' health and safety rights. By uncovering these cases, collectively analysing the issues and engaging authoritative role players, the researchers (being role players themselves as employees and union shop stewards) start to challenge that culture. By raising their voices and challenging patterns of power relations, participants also began to experience change within themselves (IHRG, 2006).

identifying solutions that were applied in their districts and as input to wider policy-making (IHI, undated). As reflected in *Box 11*, we found that social agency was more likely to flourish when PAR was linked to organised groups, and that it can improve the democratic functioning of these groups.

These approaches demand time and facilitation skills, but so too do most processes that advance health equity. They face challenges in building mutual understanding and trust between groups that have built conflict over poor conditions, such as community members who blame frontline health workers for poor services or informal residents and workers who face punitive action from local government workers. PAR processes can support dialogue between conflicting groups, allow for differences to be exposed, interrogated and understood and then addressed.

This is not only an issue between local community members and health or other sector workers. Disempowerment is found in hierarchical health systems that do not listen to or enable their base (Paschal, 2007). It may exist within communities, such as in the gender based differences in work and resources between male and female community health workers (CHWs), as was found in Uganda (Musoke et al., 2018). Beyond PAR approaches, a range of other research approaches, including those in health systems research, can enable those working in and with the systems that affect their health to have a direct and active role in raising and addressing problems and in making improvements in their systems (Loewenson, 2010).

Some situations demand analysis and action at wider levels, as global processes drive health determinants and decisions. This raises new challenges: How does research that seeks to build the power and knowledge of affected communities and groups, who are generally local, include and learn from action on change processes that are often global? How do local changes in organisation, consciousness and voice amplify to global level, without losing their authenticity?

This demands innovative research approaches, discussed further in the next section. These questions are, however, ones that we are continuing to discuss, reflect on and draw learning on in EQUINET from our work in pra4equity learning network and more widely.

5.4   Innovative and creative approaches

Whether to inform policies, to transform the way people understand and act on health, to build collective, solidarity forms of power or to claim rights, we have found that research on health equity makes us 'think outside the box'!

While we use a range of well-known qualitative and quantitative methods, we are also constantly challenged to go beyond traditional ways of doing research and sharing research findings to work in ways that resonate with and engage those we work with. This drives us to be open to innovative and creative approaches (Mtenga et al., 2016).

Many methods more directly engage and involve those affected by inequities in wellbeing. Narrative research enables individuals and communities to tell their own life stories, whether written, spoken or in various forms of visual representation (IHI Spotlight, 2019). The act of telling a story is a deceptively simple and familiar process. However, Colton et al., (2007) in a guide on the approach observed that story telling methods need to pay attention to context and intention and demand time and trial and error to identify the best approach. They need facilitation and context-specific methods to build reflection and knowledge and cannot simply be transplanted in the same form from one setting to another.

Chimamanda Adichie (2009:online) argued in a Ted talk that our lives and cultures are composed of many overlapping stories, warning that if we only hear a single story about another person or country, we risk a critical misunderstanding. *The single story creates stereotypes, and the problem with stereotypes is not that they are untrue, but that they are incomplete. They make one story become the only story...Like our economic and political worlds, stories are defined by ...how they are told, who tells them, when they're told, how many stories are told, and are really dependent on power.*

One use of storytelling is through fictions. Stories that describe imagined events or involve imaginary characters are used to encourage 'speculation'. This is used to destabilise existing, dominant paradigms and narratives which, while appearing neutral, are often constructed to exclude the lives and knowledge of marginalised groups. Through fictions, stories can draw attention to and attend to the gaps that dominant, exclusionary narratives produce.

In participatory research, fictions can forge alternative and different ways of seeing and explaining realities. The learning from such speculation can be synthesised, as in the example in *Box 12*, and collective stories produced that contest the exclusionary effects of dominant narratives. The process allows for complexity. It is not a reductive research process that seeks single cause-effect explanations. It allows for many stories to co-exist and encourages the engagement that brings them into relation with one another. In so doing, it can build a deeper understanding of the situation and multiple entry points for building knowledge, recognising that people in different social situations will hold differing experience and beliefs.

Box 12: Chimurenga's research through speculative fiction

Founded in 2002, *Chimurenga* is a Pan-African think tank and multimedia platform, operating through writing, art and politics. The outputs of Chimurenga include: 'a journal of culture, art and politics of the same name (Chimurenga Magazine); a quarterly broadsheet called *The Chronic*; The *Chimurenga Library* – an online resource of collected independent pan-African periodicals and personal books; the African Cities Reader – a biennial publication of urban life, Africa-style; and the *Pan African Space Station (PASS)* – an online radio station and pop-up studio (Chimurenga, 2019). Chimurenga's research outputs are often unusual, taking the form of exhibitions and radio broadcasts, pavement artworks, and published books, and pop up libraries.

These outputs often involve fictions. For example, a recent publication 'Who Killed Kabila II' is an in-depth investigation into 'power, territory and creative imagination' in the Congo, conducted through stories written by Congolese writers and those drawn from countries historically involved in conflict in the country. Each of the writers was invited to respond to the question in the title, situating the assassination of Laurent-Désiré Kabila in relation to the underlying struggles from their understanding, whether over minerals, local and regional politics or other issues. As the editors describe the outcome, *…who killed Kabila is no mystery. It is not A or B or C. But rather A and B and C. All options are both true and necessary – it's the coming together of all these individuals, groups and circumstances, on one day, within the proliferating course of the history, that does it* (Chimurenga, 2019:online)

Such 'retelling' of stories from different lenses may be done in many ways. For example, in Saidiya Hartman's latest work, storytelling has been used to re-investigate archives, including from police records, to uncover the unrecorded or excluded histories of black women in the early 1900s in the USA (Hartman, 2008). Through a method termed 'critical fabulation', Hartman revisits historical records, reading between the lines and finding stories that differ from the dominant narrative presented. In her work, black women can be seen to be actively crafting lives outside the limits of the 'respectability' of the time that sought to subjugate and control their bodies.

In our own work, we have actively engaged in struggles for social justice that seek to reframe and claim rights, such as work in Uganda by CEHURD in relation to abortion and women's control over their bodies (Juuko, 2017). Emerging as we have from a recent past of inequalities in law on the basis of race and still engaging on legally defined inequalities on the basis of gender, sexual orientation, beliefs and other factors, this form of reinvestigation and reanalysis of evidence has resonance for our region. Hartman's work, gathered in a book *Wayward Lives, Beautiful Experiments*, re-tells stories from such records of people who 'rebelled' against what they saw as unfair laws to create ways to thrive against the odds, opening the mind to speculate on alternative histories and narratives on what *could* have existed. This can generate insight on sources of inequality and changing socio-political constructs of what is unfair.

This reflection and analysis does not only have to be in written form. In forum theatre, participants devise and perform a scene enacting (in a fictional manner) a problem they experience and a solution for it. Once the performance is over, those present are asked if they agree with the solution, or if other solutions might be found. The scene is then performed again and at any point any participant can replace a performer in the scene to try to change the course of events towards their desired solution. The other performers must respond instantly, in character, to the newly created situations. While the situations created are fictitious, people use them to generate dialogue on problems, to make explicit and explore power dynamics and to rehearse and build confidence in potential responses to these problems (Boal, 2008).

The widening accessibility of visual and information technologies opens many opportunities for research innovation. Digital images and mapping enhance exchange on local realities; social media (blogs, tweets and others) provide new methods for communicating experience for collective analysis; mobile phones facilitate communication and pooling of evidence across wider social networks and the internet has been used for exchanges on diverse realities (IDS 2013). Community photography, sometimes called 'photovoice' has been increasingly used in research (Sutton-Brown, 2014; Wang, 2006; Kaim, 2016). Videovoice' puts video cameras in the hands of community members to collect visual data, as have participatory GIS mapping and Google maps.

In our Eye on Equity work (*Box 13*), for community members the camera seemed to open new channels of communication, raising issues that were buried, opening new areas of dialogue and interaction within the community and giving them new power to more widely communicate their often hidden realities with authorities and politicians, without the limitations of language.

Box 13: Keeping an Eye on Equity: Using photography in equity-related research

In 2008-2009, a number of teams in EQUINET's pra4equity network used photography to communicate realities emerging through various PAR and health literacy processes underway. Photography was used as a tool for visual literacy and to support reflection and action. In seven sites from different ESA countries, a community member and facilitator attended a regional training workshop in photography skills to embed photography within work on strengthening people's power in health. It was vital for the photos to enlarge the lives of the people involved, to show the diversity of views and to allow both painful and hopeful images to surface.

The process aimed to pose probing questions, give visions of solutions and encourage action. The engagement around the photos started before a single photograph was taken. It began by working with people in the community to formulate questions and explore the answers. The photography was embedded and used within this over seven months. The community level photographers also shared photos across the group in the region, using the internet for feedback and support and then choosing images that best communicated and stimulated discussion of the health issues raised and the actions taken.

In 2009, the community photographers met to review the experience, the lessons learned and the way forward. In this session and in other forums where the photographs have been exhibited with the stories of change to stimulate discussion, they have shown the power of different kinds of evidence in catalyzing action on health equity. As one person commented: *From other sources of evidence I imagined reality. From the photos I saw reality.* An EQUINET book 'Eye on Equity' presents the work and opens discussion on the role of community-based photography as a tool for change (Eye on Equity team, 2009; Photo A Baba, DRC, 2009).

Technology on its own is not automatically a tool for a research practice that addresses power imbalances and inequity. It depends on the questions asked, the wider methods for analysis, interpretation, learning from the tool, where these processes take place and how they connect with and are reported and used by affected communities.

We have seen photovoice used to present images of people as victims of situations in exhibits in distant forums, with no processes for local reflection and action. Catalani and Minkler (2010) cautioned that using photography cannot be assumed to shift power to communities. We found from our experience that we need to reflect on whether and how the use of photovoice deepens understanding of conditions and their causes and changes community confidence, power, organisation and voice in engaging those who influence their lives (Kaim, 2016).

Cell phones doubling as cameras are now in many people's hands, offering significant potential for innovative research approaches. However, they can and have been used to extract data from local areas to be analysed in far-away countries, and have led to information being captured in such short phrases that it over-summarises life (de Bruijn and Nkwi, 2014; Omanga and Mainye, 2019). These effects are not inevitable: mobile phones have also been used by Nuba people in Khartoum for exchanges in messages that reflect poetic traditions of their culture (de Bruijn and Nkwi, 2014). The same may be said of the internet. It has significant innovative potential, but is not a neutral technology. It reflects dominant, often high-income country information and knowledge through its search engines, terminology and algorithms (Bristow, 2017).

The caution is not with the technologies themselves, but with what interests and purposes they are being used for and how they are being used. This challenge is thus to use them for advancing organisation and knowledge for health equity. For example, the internet offers an opportunity to overcome the local specificity of participatory research findings in a context where African health and health systems are increasingly affected by global policies and processes. Crowdsourcing in global policy has been used to draw evidence from countries, using this for analysis done far from the sources of evidence. Online courses have helped to disseminate information globally, but the information and perspective disseminated is often that of institutions in high-income countries who have the means to set up such courses, integrating a wider number of communities into these knowledge systems. We found that many current e-platforms do not facilitate the collective analysis, action and review in PAR that empowers people (Loewenson, 2014). Added to this, cost and digital literacy barriers generate an inequity on access to the communication technology infrastructure (Terry, 2009; Pade-Khene, 2018).

Yet the internet has significant potential to support and amplify knowledge for health equity, and there is a growing abundance of digital tools for research. It can expand access to often under-represented publications from the continent through digital libraries and provide online forums for raising questions and evidence (Barringer and Wallace, 2014).

For example, Mzalendo.com, a volunteer project that 'keeps an eye on the Kenyan Parliament', puts parliamentary Hansards into simpler language for Kenyans to enable citizen participation in government processes. In 2010,'Uchaguzi', developed by 'Ushahidi' provided channels for citizens to report electoral offences that were then sent to the electoral authorities or security personnel for action (Bergnethum, 2014). Live data from twitter exchanges can provide an indicator of public behaviours and moods, such as to understand food consumption preferences and patterns (Dixon, 2013). WhatsApp has been used in urban neighbourhoods to distribute and discuss information in neighbourhood programs and can generate a sense of community and collective presence (Dixon, 2018).

Recognising both the potentials and the challenges, in 2017-19 we developed, implemented and reported research using PAROnline in EQUINET. We did this to use the internet more explicitly for research that would generate knowledge for health equity by and with those more directly affected by issues, as described in *Box 14* overleaf.

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Box 14: Exploring how target-driven funding affects comprehensive PHC through online PAR

While transformative, PAR is often local in nature. With African health systems influenced by global policies and funds, EQUINET used the internet to implement PAR online in five ESA countries as 'PARonline'. Performance-based financing (PBF) is one such global process. It is the transfer of money or material goods conditional upon taking a measurable action or achieving a predetermined performance target. There has been little systematic evaluation of the system-wide effects of PBF, or of its impacts on PHC. Given the longstanding policy commitment to PHC in the region, our PARonline research thus asked: How is the use of health targets in PBF affecting health workers professional roles, work and interaction with communities and their ability to deliver comprehensive PHC? Twenty-one participants from seven sites in five ESA countries, including health workers from primary health centres, community members in health centre committees (HCCs) and country site facilitators from national health civil society met online and also held offline local discussions with an average of 19 community members and 15 health workers per site. TARSC acted as facilitator. This community of researchers found that from the lens of local health workers and communities, the current application of PBF falls short on comprehensive PHC. While aiming to strengthen bottom-up accountability in services, neither HWs nor community members felt empowered by PBF, feeling their views and evidence to be disregarded and seeing themselves as implementers of targets defined at higher levels. We observed real trade-offs between PBF and the way comprehensive PHC is funded and delivered. Being selective can be efficient, but can also leave gaps in the system. In our various online discussions, we saw how similar our situations were in different countries and how exciting it was to share common experiences ....*like being in the same room together!* We were able to see common experiences and issues across countries and to develop shared solutions. While there were challenges, especially as this was a 'first-time' trial of an innovation, the online participant researchers valued the structured sharing of experience and analysis across countries: *To me what I found new is having a research done in many countries at the same time...I learnt that African countries share the same challenges.* It took people out of their local settings and made links across countries, building a sense of what is regional and common, to build understanding of our differences, expose ignored issues and to identify and advance as a regional group across countries shared proposals for change (Loewenson et al., 2019).

Beyond the specific methods, noted in *Box 3*, our uptake of innovation may also be achieved in the research design. In our work on health equity with urban youth, for example, we used iterative cycles of review and compilation of diverse forms of evidence, including internet video, visual and written media and modelling, with participatory review and validation by young people from diverse urban settings. We drew on different disciplines, integrating multiple concepts and sources of evidence to co-design new knowledge around shared concepts and a holistic paradigm drawn from lived experience (Bai et al., 2012; Loewenson and Masotya, 2018). The design itself thus aimed to be aspirational, affirmative and intervention oriented. For priority determinants identified by youth, we showed videos sourced from the internet of practices that address these issues in other countries, to stimulate reflection and learning from these responses, and using a grounded thematic approach to capture the emerging themes. In civil society forums and dialogue with local council officials, the youth facilitated discussion with officials and the wider community (Loewenson and Masotya, 2018).

5.5 Ensuring quality, credibility and ethical practice

Whatever the research question and whatever the methods chosen, they should be systematic, transparent, rigorous and validated, so that the knowledge produced can be shared and applied.

How this is achieved depends on the research design and methods applied. The health policy, systems and participatory research often used in equity analysis for the reasons described earlier are often criticized as being too context specific and not rigorous. However, this often reflects efforts to apply criteria used for methods within a positivist paradigm to the research methods underpinned by a relativist paradigm.

This is more fully discussed in the methods readers on health systems and policy research by Gilson (2012); on implementation research by Peters et al., (2013) and on participatory action research by Loewenson et al (2014). The criteria used to judge research quality and rigour differ between paradigms of knowledge. Action researchers have identified five types of validity in line with their assumptions and goals: outcome, democratic, process, catalytic and dialogical validity, reflecting respectively how far the research addressed its purpose, met process and social standards of the research process, was able to catalyse change and generate discussion on the insights raised (Ozanne et al., 2008). Whereas validity is assessed in positivist research from the sampling method, data collection instruments, 'blind' researchers and appropriate statistical analysis, critical theory and constructivist approaches considers issues such as the inclusion of participants, the trustworthiness of the analysis, the level of active questioning and checking during the inquiry; the processes for interpretation and collective validation and statement of assumptions used that may influence interpretation (Gilson, 2012).

Without going into the detail of these methods, discussed more fully elsewhere, what is important is to ensure and be judged on rigour and quality in terms of the research paradigm used. For PAR, for example, the question may be: did it build the collective confidence and action that generated and brought learning from change? In our work, we have sometimes observed externally applied benchmarks of research quality being used to discount people's presentation of their realities. We were constantly asked, for example, to 'prove' the harms of reduced public spending on health and fee charges in structural adjustment programs in ways that would meet experimental research standards, with our reports of harm discounted on grounds of research rigour. A decade of adjustment-related reforms later, these concerns started to accumulate in published research, yet the harms had by then affected millions of people (Loewenson, 1993; Thomson et al., 2017). Evidence from local actors and communities may be questioned more rigorously than that articulated by global actors. A statement that no fragile state had met a single Millennium Development Goal cited by the World Bank in 2011 was widely repeated and used, even after the Bank itself said in 2013 that this was not true (Denney and Domingo, 2015).

Beyond being relevant, the 'standards' and 'benchmarks' for evidence should not silence voices whose experience needs to be heard: Perhaps a precautionary principle should apply to give the benefit of doubt to marginalised groups when they report harms to health. The absence of evidence should not be a reason for inaction on inequities, such as having to repeatedly prove that social participation in health systems has benefit, when it is a right. We need to recognise that the criteria used to make judgments of research quality and rigour are themselves developing as the understanding of diverse knowledge systems grow. In working on health equity we are thus conscious of the need to review the quality of research, but also in judgements of quality, to ask who is making the judgement, whether they understand the paradigm applied and what criteria they have used.

HCC members in South Africa reviewing policies on their status, 2017

As for all forms of research, research on health equity also needs to address ethical concerns and for those involved in research to understand and plan for the environment and capacities that affect ethical practice, including those relating to communities, researchers, policy contexts and resources. Research ethics aim to set standards to protect the dignity, rights and welfare of research participants, and principles of beneficence, justice and autonomy are central. There are other texts that detail ethical procedures in health research (WHO, 2011b). However, the aims and features of equity-related research discussed earlier have specific implications for ethical practice.

For example, whatever the research approach, the relative power relations in the research process calls for clarity on this dimension, on whose interests are driving the process, on how privacy and information that communities or individuals do not want to disclose are managed, how evidence and analysis is documented and reported and how unfavourable or negative information is managed, so it is not buried (Knott, 2018).

Research may invite marginalised peoples to speak only about their 'pain' and 'deprivation' and not their assets and ideas. Communities may *tolerate* this because of an understanding or assurance that stories of damage will produce benefit and because they are rarely heard in other processes (Tuck, 2009). This can, however, position such communities as passive, associating vulnerability with them personally, rather than with their conditions (such as in the often used term 'the poor' rather than people living in poverty) and ignoring their aspirational character and agency (Omanga and Mainye, 2019). Efforts have been made to prepare ethics guidelines that avoid this, as exemplified for the San Community in *Box 15,* or in how community evidence is used (*Box 16*). Working with young people adds further ethical demands to protect them and to provide how they participate, benefit and express themselves, including in decisions (Delgado, 2006).

Box 15: Setting an ethical research code with the San community

The San of South Africa are one of the most researched communities in the world. Their indigenous knowledge and genetic makeup have been of great interest to researchers as they are ancestors of the first hunter-gatherers in Africa. While the media and researchers have continued to want to engage with the community, TRUST, a global initiative that seeks to reduce exploitation in North-South research collaborations, alongside the San Council created a contract to protect the community from exploitation, and to ensure that the San also benefit from any research. Together with the San people, in 2016 TRUST produced a paper outlining a locally driven Code of Ethics for involving San people in research involving a range of organisations in southern Africa. Referencing the original research and media contract, this is now being finalised into the first indigenous-developed ethics code in Africa (Harmon, 2016).

Box 16: Strengthening ethical community engagement in contemporary Malawi

Although community engagement is increasingly promoted in global health research to improve ethical research practice, moral ambitions for community engagement reported in the literature and guidelines are sometimes disconnected from their narrower practical application in health research. Nyirenda et al., (2019) argue that in practice, less attention is paid to engaging communities for the 'intrinsic' value of showing respect and ensuring their participation in research design. More attention is paid to engaging communities for 'instrumental' purposes to improve community understanding of research and ensure successful study implementation. Against this backdrop, from review of literature and engagement with various research stakeholders, they raise ways of strengthening ethical engagement of communities and developing guidelines for community engagement in health research in Malawi. They suggest that participatory community engagement in health research demands collaboration, consultation and communication from the onset of research (Nyirenda et al., 2019).

Here too the wider research system may itself generate inequities. Institutional ethics reviews are viewed as sometimes being more tailored to securing institutions from malpractice suits than to ensuring ethical judgement and practice (Bhattacharya, 2014; Storeng and Palmer, 2019). They are critiqued for ignoring inequalities in voice in research design and funding, in access to publication, in gender imbalances in time and resources for research and publication, in the relationships and roles of senior and junior personnel and so on (Mose, 2019). Externally funded research may raise tensions over findings that critique the benefactors of research and may lead researchers to modify findings to avoid this or funders to ask researchers to omit negative results in commissioned evaluations (Fuh, 2019; Storeng and Palmer, 2019). Communities report 'research fatigue' from repetitive and duplicated studies that do not bring them benefit (Kalinga, 2019).

In international projects, local researchers raise that international research (and international researchers) may not provide resources for measures needed to respect social customs or adequately value the labour that local counterparts perform in enabling them access, and in translating and facilitating sessions for those less familiar with the context.

The preference for experimental designs and the format of applications for review often lose the diversity of forms of knowledge and knowledge processes and locate research relationships within a singular conception of what quality scholarship looks like (Musila, 2019). Review board processes do not take on the wider ethical challenges raised above, or guide researchers who face them. This may unfairly bias research practice away from the new ideas and approaches from lower income countries and communities. We have, for example, faced challenges of ethical review boards having a poor understanding of PAR. Bhattacharya (2014) argues that review boards should be reflexive about research and should open lines of dialogue between reviewers and researchers to discuss and strengthen board knowledge of the diverse fields and contexts and researcher knowledge of how to apply ethical principles in different forms of research (Bhattacharya, 2014). For PAR, for example, ethical principles have been proposed in various forums that EQUINET has reviewed in the pra4equity network, to apply in its own work (Loewenson et al., 2014, *Box 17*).

Box 17: Ethical principles for PAR as adopted by the EQUINET pra4equity network 2014.

In 2014, at a side meeting at the Global Symposium on Health Systems Research, the pra4equity network adopted a set of ethical principles drawn from international codes of practice and from review by PAR researchers from all regions internationally. Fifteen principles were adopted for all involved in PAR, whether facilitator or community. These are shared before beginning PAR and consent forms signed undertaking compliance by all involved with them, with regular opportunities to review and check they are being followed and clear channels for raising grievances at all stages. The principles include a commitment to create conditions for meaningful participation of people whose voices are often ignored and to mutual respect for the language, traditions, values, standards and voice of all groups. They indicate commitment to clearly identify the basis for participant involvement, to ensure equitable benefits and to agree on the responsibilities of all involved from the outset with review over time. In line with general ethical principles, it includes measures for informed consent and respect for the autonomy, privacy, dignity, knowledge and experience of the people involved and for opportunities to withdraw at any stage. At the same time, given the nature of the process, there are additional commitments to enable all participants to contribute meaningfully to decision-making and other aspects of the process, to recognise and work with conflicting rights and interests; to work towards addressing power imbalances, to be open to challenge and change and prepared to work with conflict. Provisions ensure built-in mechanisms and procedures for how negative findings and adverse impacts will be dealt with and for clarifying nature of and involvement in reporting and for the ownership and publication of findings.

While ethical principles need to be clarified for different types of research, wider questions of fairness and ethics in research collaborations have implications for how far equity issues are exposed and whose 'voice' is heard.

The interests that inform funders and researchers north and south may differ. Local researchers, often positioned as junior partners, have less influence and their views are given lower value than prominent external 'experts' (Kalinga, 2019). This is even more pronounced for community researchers. Southern researchers are excluded from the often northern-based spaces for where findings are discussed, due to inadequate funding for their travel and restrictive visa conditions. Visa processes have become significant hurdles, with high costs of and travel to submit visa applications, inconsistent decisions on applications and gender discrimination, where women are asked to provide documentation about marriage and children whereas men are not (Bailey, 2019). UK visa refusals are issued at twice the rate for African visitors than for any other part of the world (Bailey, 2019). The resulting situations, such as the 41 Africans denied visas to speak at the 2018 African Studies Association conference, raise ethical and equity issues about whose voice is heard in global knowledge systems (Fuh, 2019; Mose, 2019; Bristow, 2017).

6. REPORTING RESEARCH

While reporting is often perceived as a final stage in the research process, as raised earlier, our experience and earlier sections suggest that communication and engagement of affected communities, relevant people and institutions take place throughout the process, especially when they are the researchers.

For the wider audience beyond those directly involved, a range of communication channels can be used (Mtenga et al., 2016).

Aspiring parliamentarian signing a pledge card on medicines in Malawi
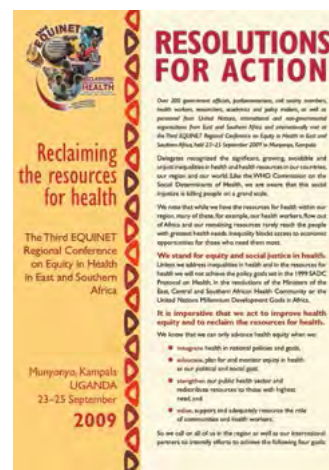
From its inception, EQUINET has made an explicit effort to publish authors and profile work from the region, to enhance the presence and use of this often less visible work (Nyamnjoh, 2004). We use different strategies, including reports, policy and technical briefs, discussion papers, papers in scholarly peer reviewed journals, reviews, visuals, stories, conferences, seminars, workshops and books all found open access on the EQUINET website. Anecdotal evidence suggests that policy-makers and senior officials appreciate and use the briefs to make the case for specific actions. Some of the more successful forms of dissemination have been in videos and radio (*Box 18*). The intent has remained the same: to advance the message on equity in health to those who influence change, whether in knowledge and advocacy alliances or in policy dialogue and practice. As these 'audiences' vary depending on the issue and processes, it has been important to communicate within processes and in forms that are more accessible for them.

Box 18: Building empowered communities for health: A film on health literacy and participatory approaches to health in Zambia

Health literacy empowers people to understand and act on information to advance their health and improve their health systems. Based on participatory reflection and action approaches, it goes beyond just knowing about health and health-care, to acting individually and collectively to advance health. It includes processes that support people driven action and engagement in health systems. Lusaka District Health Team in Zambia has implemented PAR work since 2005 to inform health literacy and improve communication between health services and communities, working with TARSC in the pra4equity network. In 2012 the Ministry of Health adopted a proposal to scale up the work in Lusaka to national level. This video describes the origins and development of the work from the voices of the many different actors from communities, health workers and policy level that played a role in it (TARSC, Lusaka District Health Management team, Ministry of Health Zambia, 2013).

Here too there are equity concerns in the system itself. With the academic publishing infrastructure largely northern funded and based, most papers are led by authors from high income countries and many studies done in low- and middle-income countries are either not reported or are reported in journals not yet indexed in bibliographic databases (Musila, 2019; Chu et al., 2014). This is compounded when journals are not open access, placing a cost barrier on readers from low income countries. It is ironic when work on health equity is published with cost barriers. Our work in EQUINET is open access and with others, we support the principle of open access publishing for all journals to provide online access to articles free of charge (Terry, 2009; Matheka et al., 2014). At the same time we have seen that promoting the more formal publication of research authored from the region needs specific support. We have mentored and supported researchers to improve their writing skills and promoted special issue journals, such as the African Health Sciences vol 9 special Issue 2 in September 2009, based on health equity work in Uganda and a co-edited special issue of the Journal of Global Health Diplomacy on Africa with TARSC featuring research papers from the research on GHD. Our newsletter, with over 220 issues and 12 000 publications in a searchable database, intends to profile, share and support uptake of research on health equity from the region.

While published products provide one form for dissemination, they often do not have the impact and opportunity for feedback and validation that face to face engagement and presentation have (IHI Spotlight May 2019). Whether in learning platforms, review meetings, community reviews or more direct involvement in participatory research, face-to-face interactions facilitate direct discussion of how research can be used, as described for example in *Box 6*. They build trust and interest in the findings and proposals and motivate use of the evidence. For example, Tanzania's dialogue on the 2012/3 Equity Watch report motivated inclusion of equity indicators in routine data analysis and equity input to the analytical report for mid-term review of the Tanzania Health Sector Strategic Plan III (IHI, MoHSW, TARSC, 2012; Mamdani et al., 2015).

These forums allow for a diversity of people and disciplines to come together around findings and proposals and generate ideas and energy on proposals. The EQUINET conferences, held about every five years, have done this at greater scale, bringing together diverse streams of work and people to frame shared resolutions for action and stimulating new thinking on future research agendas. Unfortunately with the costs and climate impacts of these processes, the limited resources are now used more for smaller, more focused meetings or for engaging in other processes in the region, such as the ECSA Health community Best Practices Forum (Dambisya, 2019). The latter provides a unique gathering of health officials, researchers, civil society and professionals to exchange evidence on key policy issues in the region, and offers space for panel discussions and side events for more detailed discussion on key issues. Yet for EQUINET, notwithstanding the reasons, not holding the large cross-cutting gatherings loses the energy and awareness they generate around equity.

In engaging with the diversity of stakeholders that play key roles in health equity issues, we have seen how important it is to understand the stakeholders, their contexts and interests and the decision-making processes we are engaging with. This may call for force-field and stakeholder analysis to identify more systematically the most influential actors, to orient messages for them (Crew and Young 2002; Daivadanam et al., 2019; Bennett and Jessani 2011; Mtenga et al., 2016).

Box 19: Reporting evidence for choices on health financing in east and southern Africa

EQUINET commissioned a desk review of options for domestic health financing to inform policy actors on the positive and negative implications of the different domestic health financing options being explored, advocated and implemented in the region. The desk review covered domestic public health financing options, including mandatory national health insurance; social health insurance, community-based health insurance, voluntary insurance, earmarked taxes, wealth taxes, other direct/ indirect taxes and other sources. The brief presented issues to consider in choosing and implementing options (as shown in the table) from the perspective of equitable progression towards universal health coverage. Noting that specific country contexts affect these decisions, the brief also provided information on the conditions and administrative implications for each option and the immediate/ short term and longer term issues to be addressed in ESA countries if the selected option is to support equitable progression towards universal health coverage and health system strengthening (Doherty, 2019).

The table below summarises how these different options perform relative to key features for UHC.

Key: For the feature in the column, the circle reflects the extent to which the option addresses that feature: Green circles = positive; Orange to red = negative with red more strongly negative. Grey = neutral or variable; Black = generalisation cannot be made.

For example, in an our assessment of domestic financing for health, shown in *Box 19* on the previous page, rather than 'tell' policy actors what to do, we aimed to provide information on options and equity consequences of choices, to support informed decision-making, given the political nature of choices on health financing. Understanding these stakeholders and processes is, however, easier to do when the relationships with the multiple actors are not simply linked to research as an event, but are rooted in various forms of ongoing interaction, directly in co-producing research, or indirectly in steering committees or in other processes.

While this interaction can be demanding, it is less so, when embedded in existing processes rather than as a separate activity. For example, taking our evidence on the significant deficits in public health in the extractive sectors and proposals for reforms to law and practice into civil society platforms like the Alternative Mining Indaba and the SADC CNGO Southern African Civil Society Forum have amplified and connected the work with broader platforms and constituencies.

CSOs at the 2017 Alternative Mining Indaba

This is also the case for other constituencies, such as in the work on GHD, where EQUINET has partnered with the ECSA HC through the Strategic Initiative on Global Health Diplomacy, raised earlier. High level seminars for ministers of health and senior officials on the side-lines of the ECSA Health Ministers Conference and workshops held with prospective delegates prior to the WHA have facilitated the use of evidence from the region in global negotiations (see *Box 20*). The involvement of the Africa group of diplomats in Geneva in these workshops and in identifying and reporting on priority issues have further strengthened these forums.

Beyond these interactions with civil society and state, we have also engaged with parliaments. Malawi Health Equity Network in Malawi and Community Working Group on Health in Zimbabwe have, for example, engaged with parliamentary committees on health on the Abuja commitment of 15% government financing allocated to health.

Box 20: Regional engagement on evidence for global health negotiations

Since 2010, the ECSA HC has convened several regional meetings on GHD, with EQUINET (SEATINI and TARSC) and other partners. As one of these pre-WHA meetings, in 2016 the issues on the 69th WHA Agenda were discussed, with inputs from regional research work and diplomats. The meeting included senior officials delegated or responsible for health diplomacy from the region, diplomats from the Africa group and technical personnel from EQUINET and other partners. The meeting prioritised WHA agenda items that were most pertinent to

Regional GHD meeting delegates 2016

the region. Delegates also reviewed an assessment of GHD work and made recommendations for further strengthening the regional work and capacities on GHD, including mentoring new cadres to build wider capacities. The meetings thus used research evidence to inform negotiations and to identify future GHD priorities and review the development of capacities and the work on GHD in the region (ECSA HC, EQUINET, 2016).

Research that
supports health
equity
Reflections
and learning
from EQUINET

Participants at the 2018 NEAPACOH Conference

Since 2005, we have had a common interest partnership with a network of parliamentary committees on health, with the network evolving into an Africa-wide Network of African Parliamentary Committees on Health (NEAPACOH).

It is also becoming increasingly important to engage audiences outside the region. Interactions with SADC, with the East African Community (EAC) and with the African Union and their official committees and parliamentary forums have been important for formalising regional policies and for feeding into global processes, while noting the consistency of interaction needed to sustain change in often slow-moving policy change processes and with changes of personnel in these bodies. Interactions with global civil society such as the Peoples Health Movement and in south-south platforms with other regions have also strengthened advocacy on shared issues.

Two decades of work and a diversity of network institutions show the importance of a consistency of presence and interaction with diverse groups in generating entry points and channels for reporting and engaging on health equity. The different issues and levels of action and engagement have implied a diversity of interaction, built within the research and made possible by the diversity of constituencies in the network. The strategic nature of these interactions implies that they are not simply a matter for how to frame or shape reports or other media. They are an issue for ongoing critical evaluation and review in terms of how we envisage producing equity-oriented change.

Engaging globally adds the challenge of efforts to reach out and amplify evidence on health equity from the region in a noisy world, where policies are discussed and finalised before they reach open public forums. It is easy to leapfrog into global processes and lose one's base. The power relations that lead to the inequities we raised in *Section 1*, while global in nature, call for work that is grounded in evidence and voice from communities and local systems and links across countries to provide a regional perspective. Yet the dynamic changes taking place at global level raise a demand to understand and amplify evidence and voice on health equity from the region within global processes and to generate greater understanding of and more proactive, earlier engagement with these processes.

We have discussed and made some efforts towards a more 'bottom-up' global engagement on health equity, such as with similar values-based south-south partnerships and connections with the African diaspora, drawing on the diversity of capacities and processes in and online resources of the network. Others are already doing this in a more sustained manner. From as early as the 1990's, for example, the Committee for Academic Freedom in Africa (CAFA) involved thinkers within and outside of the continent who interacted over 15 years and produced newsletters to amplify African thought and actions on African academic freedom in and beyond the continent. The Chimurenga project (*Box 12*) is a further product of creative connections between Africans on the continent and in the diaspora.

This too is a work in progress, where we are reflecting and building learning from our own actions. As a network grounded in the region that has used a consistent presence over the years to expand the reach of work and build diverse voices on health equity in local areas, countries and regional spaces, we are still on a learning curve on how to take this to global level, without losing our roots and perspective.

7. CONCLUSIONS

Catalysing change to advance health equity has brought us together from diverse organisations, countries and constituencies in EQUINET. Whatever our discipline or sphere of work we have come together on the basis of equity values. Research is not the core focus of most of our members in the network, and in a world and region of persistent and widening structural inequalities, the question is justly raised: can research make a difference?

We wrote this paper to gather our reflections from our experience, work and interactions on what kind of research practice promotes health equity, both in terms of the positive features, experiences and learning as well as the challenges and areas for further reflection and action.

The paper raises many features of research that are not necessarily unique to research for health equity, but have been used for it. Understanding the context and predicting, understanding, listening and relating to the institutions, processes and people involved informs the research questions and design. Equity-related research has used a mix of methods for building new knowledge, from experimental designs that measure reality as 'objective fact' to more reflexive designs that acknowledge 'reality' as subjective, and that seek to understand 'what works', and for whom.

The questions asked demand a spectrum of methods without placing certain forms of evidence or certain methods as superior to others, acknowledging the range of knowledge paradigms and processes needed to address the complexity involved in health equity-related issues in systems and society. Whatever the method, the research needs to be rigorous, systematic and creative, with judgments of quality and validity based on the specific research approach used. A range of forms of media and publication are needed to share findings and proposals from research, particularly forums and ongoing interaction that enable face-to-face engagement, review and validation by stakeholders.

However the challenges to health equity and the opportunities to advance it within our region call for certain features and forms of research. Even while policies have been articulated and knowledge generated on the inclusive economic policies, comprehensive public services and rights-based approaches to addressing social inequality, our realities are increasingly driven by a global economy and a regional response that is generating instability, environmental and social costs; increasing extraction and export of natural resources; rising levels of precarious labour, social deficits and destruction of cultures. Our public institutions have become weaker and even basic forms of wellbeing commodified, disrupting cohesion, solidarity and collective agency.

Like others working on health equity, we recognise that we are on a consistent learning curve on how to link research with the strategic issues, opportunities and forces for equity-oriented change in the region. It starts with what questions are asked in research and who asks them. This is driving research questions and work to expose the deficits and inequalities arising, the determinants of these inequalities and the drivers of these determinants.

The questions and priorities for research emerge from a strategic analysis of trends and from the communities in the diversity of constituencies in the network. The demand from this is for more than a narrative on problems, but work that explains and shows alternatives to a disempowering narrative that 'there is no alternative'. The questions that inform the work described in the paper arise from this: *How do communities and countries reclaim the resources for health? How do we reclaim our states as protectors and promoters of public interests and universal public services? How do we claim social rights and rebuild shared interests and solidarity?*

These questions take us outside narrow biomedical paradigms, often outside the 'core curative care business' that the health sector has retreated to, calling on us to question the inevitability of the status quo, the choices made in health and other sectors and their effect on the wellbeing of current and future generations.

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The conditions in our region generate more, however, than the issues to focus on. We recognised from the formation of EQUINET that power relations are central to inequities in health. The design and methods we use for health equity do not simply intend to generate new knowledge, they seek to engage in different ways in the power relations that generate these inequalities. We understand that knowledge is not neutral – the way it is generated may empower or disempower those affected. It means thinking critically about who raises the questions, who designs, does and uses the research, how research is done and how those directly affected by issues are involved.

These issues contribute to the consciousness and self-confidence people have to act as a form of power *within;* to the ability to act and influence change, or the power *to*; or to strengthen collective action, or the power *with*. Research for health equity has the opportunity in its design and methods for people to affirm and validate their reality, generating reflection on causes and building alternative explanations, analysis, self-confidence and organisation to intervene and to learn from action. How far these opportunities are reflected and outcomes achieved from our research is a matter for our continuous review and reflection.

In this paper, we describe many ways that those affected by problems, whether communities, frontline workers, managers, parliamentarians, negotiators or others can be the primary actors, both as a source of evidence and in generating, validating and using their knowledge for action. Whether through implementation research, appreciative inquiry, realist review, benefit incidence analysis, and the many other forms of research we describe, we have seen common features of such research in drawing on diverse disciplines and paradigms, applying a system lens, building interactions, relationships and organisation for change through and throughout the research and empowering change agents inside affected communities and systems at different levels.

PAR provides a particularly powerful means for people to create counter-narratives to dominant characterisations that ignore or undermine them, transforming people from objects to subjects and strengthening strategic action and review. We are on a continuous regional learning curve on this work, including how we embed PAR within the democratic functioning of social organisations and how we amplify the organisation, consciousness and voice from largely local PAR processes to engage global level drivers of inequity, without losing their authenticity.

We are also constantly challenged to use creative ways of doing and sharing research to take advantage of the opportunities from technology and innovation and to embed work more directly in processes that are accessible to those involved and that provide a channel for their own voice. There are exciting methods and capacities to draw on, that allow for complexity and the inclusion of diverse lenses. They include narrative research, 'fiction', theatre, using photography, videos, cell phones, online media and Whatsapp. The technologies used are themselves not neutral, and need to be embedded in research processes that show the other features described.

When doing this work it excites, reveals, generates energy and many collective 'aha' moments. But it also exhausts, demands many hours of time, absorbs those involved in social processes and often takes researchers and facilitators outside the mainstream of research practice. Those involved not only need to be creative in the design and methods, but also to sustain multiple interactions, while multitasking within under-resourced institutions and settings.

We do this while needing to engage in and contest a global research system that itself has inequities and that reflects diverse interests. It implies engaging funders, ethical review boards and 'project leaders' in high-income countries trained in a singular conception of what quality scholarship looks like on the value of the system level, cross-disciplinary work and reflexive research approaches. Southern researchers face travel, visa and other restrictions rooted in class and racial barriers, excluding them from often northern-based global processes, with inadequate domestic investment to drive self-determined research agendas. Researchers in the region are often positioned as juniors and secondary authors in international programs, undervaluing their contribution. Many indexed journals do not provide space for the qualitative, reflexive or participatory methods used, do not see learning from practice as generating transferable learning and

place cost barriers on readers from low-income countries. Stepping outside the comfort of mainstream ideas and paradigms can risk career paths, resources or even personal security. Many researchers withdraw in frustration for better funded biomedical research, evaluation consultancies and other more traditional postings. For others there is the double task, whether explicitly or implicitly - researching on inequities and challenging inequity in research systems.

Having a consortium network has enabled us individually and institutionally to advance creative work and to address some of these challenges. As EQUINET is not based on specific disciplinary or professional groups but on equity-related values and goals, we have gathered a wide range of disciplines, lenses and constituencies in our work. Valuing the experience and direct involvement of those affected by the conditions that generate inequities within countries has brought interactions between diverse constituencies in processes that build organisation, alliances and engage some of the imbalances in power and voice that drive these inequities.

Working regionally has helped us to tap and share this expertise and experience across countries. It has brought us rich interactions with policy and system actors and deepened our shared networking and associational power. It has stimulated us to explore alternative ways of doing research to reflect shared values, informed by diverse ideas, cultures and struggles and by a rich past of engaged analysis and activist scholarship in our region. Being in a network has facilitated various forms of support, resources, exchanges and publications for more self-determined research collaboration and confrontation, has promoted the quality and visibility of our publications and provoked us to be more creative and consistent in our use of them.

While the paper shares our experience and reflections of the features of a research practice that advances health equity, a context of intensifying commodification of and deficits in wellbeing suggest no room for relaxation and a constant need to critique and reflect on this. The network, a steering committee of diverse actors and the interactions we have provide a means to collectively do this.

We see new challenges and demands. Our region is changing, encountering new opportunities and challenges. This calls on us to nourish but not be over-comfortable in old relationships, alliances, methods and practice. We need, for example, to connect with young people, with our growing diaspora population, with new forms of art and science, new questions and ways of generating knowledge if we are to amplify evidence and perspective in a noisy world on how to understand, catalyse and advance equity in health and wellbeing, for now and for the future.

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Equity in health implies addressing differences in health status that are unnecessary, avoidable and unfair. In southern Africa, these typically relate to disparities across racial groups, rural/urban status, socio-economic status, gender, age and geographical region. EQUINET is primarily concerned with equity motivated interventions that seek to allocate resources preferentially to those with the worst health status (vertical equity). EQUINET seeks to understand and influence the redistribution of social and economic resources for equity-oriented interventions. EQUINET also seeks to understand and inform the power and ability people (and social groups) have to make choices over health inputs and their capacity to use these choices towards health.

EQUINET implements work in a number of areas identified as central to health equity in east and southern Africa

- Protecting health in economic and trade policy
- Building universal, primary health care oriented health systems
- Equitable, health systems strengthening responses to HIV and AIDS
- Fair Financing of health systems
- Valuing and retaining health workers
- Organising participatory, people centred health systems
- Promoting public health law and health rights
- Social empowerment and action for health
- Monitoring progress through country and regional equity watches

EQUINET is governed by a steering committee involving institutions and individuals co-ordinating theme, country or process work in EQUINET from the following institutions:TARSC, Zimbabwe; CWGH, Zimbabwe; University of Cape Town (UCT), South Africa; CEHURD Uganda; University of Limpopo, South Africa; SEATINI, Zimbabwe; REACH Trust Malawi; Ministry of Health Mozambique; Ifakara Health Institute, Tanzania; Kenya Health Equity Network; Malawi Health Equity Network, SATUCC and NEAPACOH