Chapter 45
Reflections on Mainstreaming Health Equity in a Large Research Collaboration: "If I can't dance it is not my revolution"

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45.1 Introduction

The concept of health promotion emerged largely in the context of the Ottawa Chapter. This term was an alternative within public health to integrate "action at the levels of individuals, communities and society" (Wold & Mittelmark, 2018, p. 21). This was quite a radical shift. It acknowledged that socio-economic and political factors and inequalities shape health (Woodall et al., 2018). But there are concerns that health promotion has been co-opted by the individualistic machinery of positivism that dominates much public health and biomedicine in general (Smith, 2014). This creates a host of challenges for health promotion practice, including the way in which research is conducted and its potential impact on policy and practice.

This chapter focuses on contemporary health promotion research. The purpose is three-fold. First, to remind readers that a health equity lens adds an invaluable dimension to health promotion practice and research in particular, and public health in general. Getting "equity" right into research can not only save lives and unnecessary suffering, it also saves money. The inequalities exposed by COVID-19 are a reminder that researchers have a critical role to play in eliminating inequalities by producing high-value relevant evidence. Research evidence, along with other types of knowledge and ideas (Smith, 2014), can then be used to develop better-tailored recommendations for policy and practice.

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Second, this chapter aims to highlight one way in which a health equity lens can be organisationally embedded to improve health promotion research cultures and practices. A process that we describe as health equity mainstreaming. In what follows, we analyse the experience of a large English Research Collaboration as it sought to operationalise an equity focus by systematically integrating it in the institutions that govern research: its culture, processes, systems, projects, funding policies and individual practices.

The third objective is around methodology. In this chapter, we draw on our experiences as researcher-implementators in a large English partnership organisation. Our role was to design and oversee an organisational response to the lack of equity focus in much-applied health research, including health promotion. We want to underscore that reflective practice by us was essential to understand better how health equity mainstreaming could work (or not) in practice. The reflective process ran throughout our almost seven years of work with the Leadership in Applied Health Research and Care North West Coast (CLAHRC NWC).

Reflexions included examination of informal and formal discussions with colleagues and observations from attending meetings and delivering capacity-building activities. In addition, we were tasked with leading the internal evaluation of CLAHRC NWC. One of the strategic objectives of the evaluation was to assess whether embedding a health equity focus was achieved. This provided a brilliant opportunity to collect richer and nuanced data on progress. In addition to data from reflections, the evaluation collected data from internal documents (e.g. policies, strategies and minutes of management and SB meetings), monitoring data and data from feedback forms completed by people using the Health Inequalities Assessment Toolkit (HIAT), face-to-face interviews (n = 58) and focus group /workshops (n = 73). These included staff from CLAHRC NWC's partner organisations explained below. Information sheets and consent forms emphasised that participation was voluntary.

45.2 The Setting: CLAHRC NWC

The CLAHRC-NWC was one of 13 such collaborations established across England by the NIHR. They aimed to accelerate the translation of research findings into health policy and practice. Funded from 2014 to 2019, CLAHRC NWC included 36 partners from 3 universities, 5 NHS Clinical Commissioning Groups (CCG), 9 Local Authorities (LA), 17 NHS Provider Trusts and the NW Innovation Agency. In addition, 170 members of the public contributed as Public Advisers (PA). Some of these public partners were residents of 10 relatively disadvantaged neighbourhoods by 8 third sector organisations to join a Community Research and Engagement Network supporting place-base research.

The CLAHRC NWC operated within an English region with some of the starkest inequalities in mortality and other health outcomes. Since 1965, there have been 1.5 million excess premature deaths in the North of England compared with the rest of the country (M. (Chair) Whitehead et al., 2014). This geographical divide has been increasing, driven in part by England's public expenditure reductions and "the systematic dismantling of social protection policies since 2010" (Alston, 2018, p. 23). In this context, CLAHRC NWC acknowledged that the primary causes of health inequalities are not within the gift of researchers to act on. However, it was committed to increase the equity dimension of all its research portfolio to maximise the relevance of findings for front-line practice and policy aimed at reducing these inequalities.

The organisational architecture of CLAHRC-NWC is shown in Fig. 45.1. The Steering Board (SB) included representatives from the NHS, LAs, University Partners and PA with an independent chair. A subcommittee of the SB reviewed project proposals and made recommendations on funding. The Management Team comprised: Director; Programme Manager; Operations Manager; Director of Engagement; Director of Capacity Development and Theme Leads. There were four thematic programme and three cross-cutting themes. In addition, a Public Advisers Forum, open to all members of the public registered as Public Adviser (PA), oversaw the public involvement policy and sent representatives to the SB and the CLAHRC management group.

45.3 The Grand Challenges Faced by CLAHRC NWC

The World Health Organisation (WHO) sponsored Commission on the Social Determinants of Health's report in 2008 triggered a rapid expansion of both research and policy interest worldwide. (European Portal for Action on Health Inequalities, n.d.; WHO, 2018). More recently, the UN Sustainable Development Goals, endorsed by 193 nations in 2015 prioritised action to reduce health inequalities (Strand et al., 2009; Crombie et al., 2005). Many national health strategies now focus on these goals including the WHO's Health in All in Policies framework; the European Union (EU) Health Programme (2014) and the EU/WHO Health 2020.

Today, in the UK, multiple tools, funding streams and policies focus on health inequalities (Department of Health and Social Care, 2019; NHS Health Scotland, 2018; NIHR, 2018; Toleikyte & Colwell, 2020). They all aim to integrate action on health inequalities within planning and services redesign cycles, from assessment prior to implementation, through service design to quality assurance, audit and evaluation of existing services. Yet, they have not been systematically implemented or adopted. Indeed, our previous research did not find any initiatives that sought to embed a health equity focus across a research organisation (Porroche-Escudero et al., 2021). These findings are confirmed by a forthcoming review of English-language papers/resources aiming to strengthen the equity focus in health research, which has found that with notable exceptions (Eslava-Schmalbach et al., 2019; Plamondon & Bisung, 2019) published evidence on the processes and effectiveness of attempts to integrate a health equity focus across research organisations are lacking (Halliday et al., personal communication). Four main reasons for this absence of

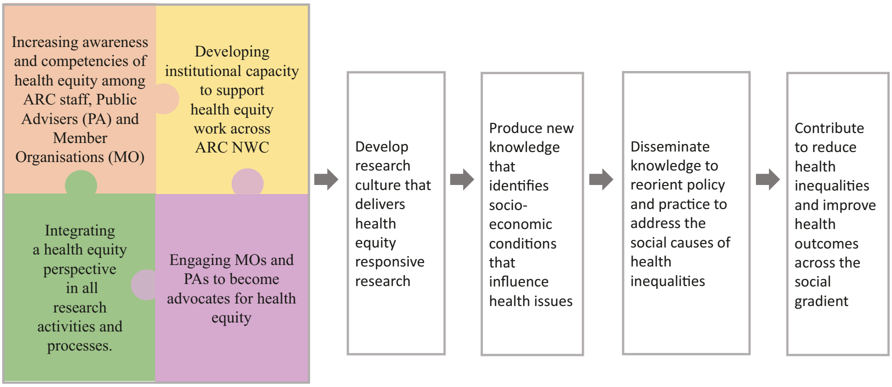

Fig. 45.1 Pathways to health equity mainstreaming

an equity focus in much public health and health promotion research have been highlighted in the literature.

45.3.1 *Individualisation of Disease*

Some scholars argue that public health's primary focus on the material, physiological body creates a false separation between the biological body and the wider determinants of health and neglects issues of agency and socio-economic well-being. (Pérez, 2019). The body is also viewed in terms of risks and disease. Thus, a considerable amount of public health practice and research focuses on how to modify people's behaviours without consideration of the wider social determinants of health that shape these behaviours (Wold and Mittelmark 2018:21; Scott-Samuel and Smith 2015) – a process that has been described as Lifestyle Drift (Popay et al. 2010).

45.3.2 *Epistemic Violence: Lack of Meaningful Involvement of Members of the Public*

Recently, feminist activists in Latin America have reinvigorated debates about public health definitions of risk. For instance, Paz and Ramírez Paz and Ramírez 2019) argue that the concept of risk is concerned with "acting in the present to modify the future and reach a desired situation". The problem, they point out, is the unexamined implicit and explicit assumptions underlying definitions of "what a desirable future should look like". Thus, they encourage public health researchers to confront the following questions:

> who desires *that* future? What actors speak? Which ones are voiceless? For whom is it desirable? Who benefits? Who loses out if interventions are undesired and enforced without consent? (Paz and Ramírez 2019:91–92, our own translation)

This lack of representation and involvement of those who will be affected by health-related research constitutes a clear example of what Spivak calls "epistemic violence" (Spivak, 1994, p. 76). It goes against the very foundational values of health promotion (Woodall et al., 2018) and health research in general (Fundación Soberanía Sanitaria et al., 2019; NIHR, 2019).

45.3.3 A Lack of Equity Focus Is a Form of Violence

Corbin raises an additional, yet interlinked challenge (Corbin, 2016). Although equity is integral to public health practice and research, the focus on behaviour/lifestyle change draws attention away from the need to generate local evaluative evidence for what is working for health equity and what is not. In other words, research and evaluation research often fail to assess "the negative impact of implementing new interventions or technologies on health inequalities" (Eslava-Schmalbach et al., 2019, p. 3) for specific socio-economic groups.

Similarly, research designs often fail to produce evidence to support and influence decision-makers and practitioners to act on the causes of health inequalities that are amenable to local action and to avoid actions that may increase inequalities. Thus, it is not surprising that Corbin asks whether researchers are part of the problem by not actively and explicitly considering equity in their projects (Corbin, 2016, p. 740) and, wonders whether we "are reproducing the exact inequity we seek to mitigate?". As Elie Wiesel reminded us in his acceptance speech for the Nobel Prize in 1986 in Oslo "We must always take sides. Neutrality helps the oppressor, never the victim. Silence encourages the tormentor, never the tormented".

45.3.4 Lack of Expertise to Design Equity-Sensitive Research

Another reason for the absence of an equity focus in health research is the lack of local expertise and confidence on how to include a health equity framework throughout the research process, from the ideas phase through research design and implementation to dissemination and how to do this in ways that involve relevant communities and professionals working with those communities.

This situation is in part caused by the paralysing idea that the upstream socio-economic causes of health inequalities are "too hard" or "too complex" to tackle by researchers, and can only be addressed by political action (Metzl & Hansen, 2014) and by different understandings of health inequalities and its causation (McMahon, 2021a, 2021b).

45.4 The CLAHRC NWC Equity Lens Journey

45.4.1 Beginnings

A recognition of the complex factors discussed above shaped the CLAHRC NWC's early strategy for action to integrate a routine health equity focus in their work. The collaboration started with four well-defined actions. First, it articulated an explicit commitment to reduce health inequalities in the official funding bid and related documents such as promotional materials and the website. This is important because what gets said, gets counted and accounted for (Sen et al., 2007).

Second, it endorsed a definition that recognised that inequalities in health cannot be tackled without fully understanding and addressing their wider social determinants. This marked a shift from the dominant framings of health inequalities in the health sector as individualised "lifestyle-centric" to recognise how "organisation and structural factors are the cause of social inequalities that affect health outcomes" (NIHR CLAHRC NWC, 2013, p. 8).

Third, it appointed a "specialist team". This included a senior researcher (JP) with an international track record of work on health inequalities to take responsibility for the health inequalities agenda from the point the original funding bid was developed, and a researcher (APE). Their role was to develop and implement a method to support the integration of equity into all CLAHRC's work and establish systems for monitoring progress.

The Health Inequalities Assessment Tool or HIAT (www.hiat.org.uk) was developed as the vehicle to support its strategic aim of embedding a health equity. The HIAT was novel in several important ways. Its development was informed by findings from a rapid review to identify interdisciplinary resources, tools and theoretical papers that could support researchers to integrate equity in their work. It had a strong focus on social determinants of health and public involvement throughout the research process. It provided guidance for a wide range of research activities (e.g. evidence synthesis, applied health research, implementation, knowledge mobilisation and capacity-building). It aimed to stimulate self-reflection in teams with a series of questions to foster debate. And finally, it was co-developed with members of the public and staff from its partner organisations including Universities, the NHS and local authorities as well as experts with international experience of health inequalities (Porroche-Escudero & Popay, 2020).

Fourth, the CLAHRC Steering Board (SB) requested mandatory HIAT assessments for all activities seeking funding support from CLAHRC, including interns and PhD students in an attempt to systematise the use of the tool.

45.4.2 Awakenings

Halfway through the CLAHRC 5-year funding term, the team took stock of progress made on the core objective of integrating the equity lens across the collaboration. The limitations of the approach were becoming apparent. The team started recognising that a focus on health inequalities was the golden thread that must run through the CLAHRC – a cultural change agenda as much as a technical endeavour. Elaboration of some of these limitations may provide important insights/lessons for others wishing to integrate health equity in research collaborations.

When CLAHRC NWC submitted its application to the funder it stated that it would "tackle health inequalities through improvements in excellent applied research and implementation to enhance quality of health, care, patient experience and outcomes" (bid p.4). The successful proposal suggested that health equity would be a cross-cutting issue and a CLAHRC-wide responsibility. It identified management of the four research themes as the primary site for monitoring and assessing the impact of activities on inequalities. But four factors that diluted the message that health inequalities were a CLAHRC-wide responsibility were apparent.

First, the location of the equity lens plans in the funding proposal may have been problematic. Work on health inequalities was described within the Public Health Theme alone, potentially suggesting that it was the primary responsibility of this theme. Second, although health inequalities were mentioned at several other points in the funding proposal, its prominence varied significantly across the descriptions of specific themes. Third, there was no explicit strategy or road map developed by the CLAHRC management group on how the focus on reducing health inequalities would be embedded across the organisation. Fourth, CLAHRC's conceptualisation of the requirement for embedding a health equity focus across an organisation was too narrow, focusing solely on a technical approach: awareness raising through training and developing a toolkit and rolling out its use across the collaboration.

The combination of these factors resulted in a fragmented and reactive approach to the equity integration "project" with mixed results and frustrations. For instance, the first wave of research projects that began before the HIAT was developed had to "retro-fit" a focus on health equity. There was an understandable reluctance amongst some research staff to engage in this process with enthusiasm. In addition, the two-member HIAT team did not have the capacity to contact, support and chase every single project to carry out a HIAT assessment, let alone to assess whether the assessment was a ticking box exercise or a valuable learning process.

Senior management in CLAHRC tried to address these issues by taking a more proactive approach. Significantly, the health inequalities team was required to provide training and individual advice to all staff, PhD students and PAs. They were allocated a dedicated budget for training, dissemination activities and the development of resources such as a HIAT website and training materials. Alongside these attempts were made to strengthen the degree of transparency and accountability in the HIAT reporting and monitoring processes. For example, the SB requested that quarterly progress report templates be modified to include a section for reporting on the extent to which a focus on health inequalities had been integrated into activities following an initial HIAT assessment.

45.4.3 The Epiphany: Why Didn't We "Walk the Talk"?

As CLAHRC NWC matured over the first five years, the official line was that it took health inequalities seriously. To its credit, we witnessed a remarkable increase in health equity values and sensitivity over the years. Yet, we did not see parallel increases in actions to integrate a systematic health equity focus throughout research projects and activities. But after three and a half years this was a feeling without evidence.

The team was forced to think again about its progress eighteen months before the end of the five years funding period when progress on integrating an equity lens became a key element of an internal evaluation of CLAHRC NWC. The evaluation process provoked an epiphany. We began thinking of the problems described by professionals working in the arena of gender mainstreaming and we could relate to them. Then, we began thinking of the problems we had with the single technical focus on training/capacity-building and mandatory use of tools. Why was it that so few teams "walked the talk" (without being chased or lured by us)? What would it take to close the gap between CLAHRC's values and researchers' practices?

Of course, some of the answers to these problems lie in the complex social dynamics discussed earlier that reach well beyond the CLAHRC. But we discovered that CLAHRC had the power to address some of these. As we drew on a rich body of work on gender mainstreaming, normalisation process theory and implementation science our understanding of the internal triggers for change grew. Our definition of progress expanded to included consideration of "what was done" and "how things had to be done" to mainstream an equity focus into the fabric that binds a research organisation together: its culture.

The evaluation helped us to see in full technicolour that we were trying to navigate this minefield blindfolded, without a clear roadmap of how the health equity integration objective had to be operationalised. Our suspicions were confirmed. Technical fixes based on training and mandatory HIAT assessments and reports were not enough to transform people's readiness to "walk the talk". We realised that delivering health equity responsive studies required a systematic approach to transform the very roots of the "institutional context of research".

From that point on, CLAHRC NWC started using the language of "mainstreaming": first amongst senior management but slowly it has filtered through to all parts of the organisation. The partners in the CLAHRC received further funding under the new name of the Applied Research Collaboration (ARC) NWC and are taking forward a new "mainstreaming" approach to the health equity integration. The ARC NWC has produced a Health Equity Mainstreaming Strategy and Action Plan, the first roadmap of its kind for a collaborative health research organisation. Important stepping stones to mainstreaming an equity lens at institutional level are highlighted in Fig. 45.1. They include: (i) building knowledge, competencies and capabilities to support health equity work amongst all groups in the organisation (ii) building and communicating a body of expert knowledge to influence policy and practice; (iii) strengthening mechanisms for health equity mainstreaming within the organisation and in all research activities; and (iv) engage member organisations and members of the public to become health equity champions and co-produce research. However, this new approach is not without its own challenges – as we discuss elsewhere (Porroche-Escudero et al., 2021).

45.5 Conclusions – Into the Future

We have taken the title of this chapter from US feminist anarchist Emma Goldman's famous quote, "If I can't dance, it's not my revolution". Because a health equity focus, like dance, is essential to develop public health research that has the potential to be revolutionary. Our understanding of revolutionary is captured in the Oxford English Dictionary definition: "a dramatic and wide-reaching change in conditions, attitudes, or operation" to greater social justice.

Equity-sensitive research is revolutionary because it gives priority to the voices and experiences of those who will be affected by the implementation of research-based evidence. These are primarily the communities of interest and place that are bearing the brunt of social inequalities in health, but it also includes many front-line practitioners working with these communities. The practical wisdom they accumulate from the lived experience of oppression and powerlessness has much to offer health research yet it is routinely ignored. It is revolutionary because it would always assess whether interventions, trials, policies and practices are having differential impacts across social groups and include an assessment of negative as well as positive impact. And it is revolutionary because it is designed to produce evidence to influence decision makers and practitioners to act on the structural causes of health inequalities that are amenable to local action. The revolutionary potential of equity in research aligns well with the health promotion ethos.

All those involved in health promotion research need to move beyond limited technical approaches to strengthening the equity focus of research: primarily capacity-building initiatives and tool usage. We need to recognise that this is a mainstreaming agenda aimed at transforming the very roots of the "institution of research" (i.e. researchers, research organisations and research funding bodies) which dictates what constitutes appropriate research, including preferred methods and issues. (McQueen, 1991). The global health research community has to embrace a systematic approach to effect change in the culture of institutions of research, ensuring that we build expertise and confidence so that thinking and actions on the wider structural determinants of health are integrated into all activities involved in all stages of the research process from prioritisation to knowledge mobilisation.

We hope that our reflective lens offers two interlinked examples of how this may be done. First, our reflective journey showed the complex steps that led the CLAHRC NWC collaboration to where they are today in relation to health equity mainstreaming. Second, our work highlights the importance of reflexivity in the practice of applied health promotion research as it strengthens methodological designs and data interpretation. Reflexivity was critical for us to understand the nature and diversity of disciplinary assumptions and values around health inequalities and to attend to context, language. It helped us to recognise and enquire into what we did not know, what we could improve and what information we needed to monitor and evaluate progress in embedding a health equity.

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