1 Health Rights and Social Movements: An Introduction

While much research on the Covid-19 pandemic has focused on collective action against Covid-19 vaccinations, less attention has been paid to struggles aimed at defending and promoting the right to health (but see Carpiano et al., 2023; della Porta, 2023; Mylan & Hardman, 2021; Venizelos & Trimithiotis, 2024). Over the course of the pandemic, health and healthcare emerged as key demands put forward by social movements, mobilising health workers, patients and citizens. In general, the contentious politics of health rights have addressed issues relating to the public provision of healthcare, environmental health, the social determinants of health, occupational health and safety, and the neoliberalisation of the health system. The pandemic also sparked debates about medical power and biopolitical control, fuelling demands for the democratisation of decision-making within health systems and for universal and free access to health services. Building on earlier traditions of health movements, the pandemic elevated the right to health to a dominant frame, linking existing collective actors with newly constituted ones with the aim of addressing the immediate pressures of the health emergency while envisioning future alternatives. While social movement organisations at the local and national levels converged on the right to health, using care and healing as a bridging frame, at the transnational level campaigns were developed around patents on vaccines.

This Element focuses on two major campaigns that sought to ensure equal distribution and free access to Covid-19 vaccines. Considering these campaigns as examples of contestations of global health politics, we will analyse their organisational models, repertoires of action and collective framing, while also assessing their outcomes within the complex set of opportunities and constraints that the Covid-19 pandemic presented for social movements mobilising for access to vaccines.

In what follows, we will present these transnational campaigns against patents on the Covid-19 vaccines as part of the broader tradition of Health Social Movements (HSMs) (Brown & Zavestoski, 2004). Having conceptualised Health Social Movements as a distinct category of social movements, the section will briefly introduce some of the key characteristics that define these movements in terms of their multiple repertoires of contention, broad and fragmented organisational coalitions, and diagnostic and prognostic frames. Highlighting the global dimension in the definition and defence of health rights, the section will identify opportunities and constraints for transnational social movement campaigns. The section will conclude with a brief presentation of the selected case studies, the research methods and sources used, followed by an overview of the volume.

Conceptualising Health Social Movements

Health Social Movements (HSMs) have been conceptualised as a distinct category of social movements, defined as 'collective campaigns to bring about change in medical and public health policy, beliefs, research and practice' (Taylor & Zald, 2013: 550; see also Brown & Zavestoski, 2004). HSMs often challenge stereotypes about the genetic, physiological and psychological origins of health and illness, questioning their causal relationships and exposing their social, political and cultural determinants and implications (Banaszak-Holl et al., 2010; Christou, 2022a; Taylor & Zald, 2000).

While social movement studies have sporadically examined health-related movements, research has revealed the fact that they are not only largely heterogeneous but also greatly fragmented in terms of their organisational structures. Waves of protest have developed broad critiques of mainstream medicine as well as specific diagnostic categories and curative practices associated with particular conditions. HSMs have targeted public health institutions as well as pharmaceutical companies and other commercial, yet relevant, actors. From an organisational perspective, this fragmentation of protest along the various dimensions of health highlights the relevance of coalition building for HSMs, but also related challenges (Epstein, 2010; Taylor & Zald, 2013).

This fragmentation is evident in the diverse repertoires of action, shaped by the social and political backgrounds of the claimants and the decision-making levels they target. Examples of this heterogeneous set of contentious forms include strikes launched by the labour movement involved in the health sector (Galanti & Naughton, 2023), direct action tactics by environmentalists (Brown, 2007), awareness-raising and self-help within feminist milieus (Barone, 2024) and civil disobedience undertaken by the gay and lesbian movement(s) of the 1980s and 1990s (Stockdill, 2013), to name but a few. More generally, HSMs aim to raise awareness and/or challenge experts through cultural events and communication campaigns, put pressure on public institutions through marches, petitions and lobbying, target pharmaceutical companies and public figures through naming and shaming campaigns, and often use legal strategies to challenge opponents in court. Tactics of self-help and mutualism have proliferated at the local level, more disruptive protest campaigns have targeted the national level, while insider strategies have dominated the transnational level. In general, Health Social Movements have been more visible on the streets when health crises have hit hard, as in the case of the HIV/AIDS pandemic.

Framing is also key for health movements, as they use powerful justice and rights frames. Given the fact that these movements need to address the stifling effects of certain grievances and sentiments – similar to those related to disease

or extreme poverty (Gonzales Santos 2024) – they need to develop cognitive and emotional strategies that are capable of translating individual experiences into political grievances, destigmatising collective identities and mobilising affected constituencies (Christou, 2022a). As such, health movements have been instrumental in the development of our health systems, advancing health rights, shaping curative practices and influencing research agendas and diagnostic categories. This has implications for the framing processes they employ and the outcomes they achieve, as

> [c]ollective subjects can be created in the name of health . . .. Health movements often disrupt stereotypes about the genetic, physiological and psychological origins of health and disease, questioning their causal relationships and exposing their social, political and cultural determinants and implications. They actively create new associations from existing assemblages, effectively transforming the private experience of illness into a public issue. (Christou, 2022a: 2)

In doing so, HSMs respond to specific challenges and opportunities related to the structural and cultural characteristics of the health arena, as activists must navigate both state paternalism and the commodification of health within the market. In addition, HSMs are shaped and constrained by a specific material health infrastructure and an immaterial bioethical-legal framework (Christou, 2022b).

Health Movements, Health Systems and Health Rights

Health Social Movements have not only confronted, but also influenced, practices and conceptions relating to health and medicine. They have not only challenged medical science as the 'dominant epidemiological paradigm' (Brown et al., 2012: 24) but also informed it from its earliest steps. They have also been central to the co-development of our health systems and the current human and health rights frameworks as we know them today.

As early as the nineteenth century, social reformers, urban planners and physicians mobilised against the unhygienic living conditions of the urban poor, which often triggered deadly epidemics like cholera, linked to rapid urbanisation (Winslow, 1943). Efforts to contain contagion led to identifying 'filth' as a disease carrier – an idea that predated germ theory and laid the groundwork for public health agencies focused on disease prevention through social reform (Singer, 2009). Alongside these developments, experts advanced more holistic views of health, tracing disease to socio-economic conditions rooted in capitalism (Hamlin & Jones, 1998; Waitzkin, 1981). These insights informed early demands for universal rights to a 'healthful existence' (Engels,

2009), forming the basis of modern epidemiology and the socio-economic rights central to contemporary public and global health (Gaffney, 2018).

In the nineteenth and twentieth centuries, grassroots movements also developed claims to health. The emergent labour movement mobilised for health and safety in the workplace and, when successful, influenced paradigmatic industrial reform (Satre, 1982). In Europe, the emergence and consolidation of the working class and its representatives led to the establishment of public health systems, themselves either a product of direct labour victories or of necessary compromises aimed at appeasing class conflict (Gaffney, 2018; Webster, 2002).

Despite the progress marked by these political developments, in terms of both health outcomes and healthcare infrastructure, the Spanish flu pandemic that spread across the globe in the aftermath of the First World War further challenged the strained state of both the healthcare system and society as a whole. Combined with food shortages and unemployment, the Spanish flu triggered intense collective responses, sometimes leading to revolutionary moments. Official responses to the Spanish flu built on the momentum of a growing reform movement and included the introduction of public health services and the centralisation of public health administration. Such was the impact of the flu on the configuration of health systems that historians claim that 'the epidemic was a better campaigner for reform than any politician's speech' (Jenkins, 2007: 337).

The end of the Second World War, on the other hand, ushered in a new era of global governance, including in the field of health. Not coincidentally, at its inception, the United Nations (UN) voted to create an international health organisation to promote global cooperation in the name of public health (Cueto et al., 2019). With this mandate, the World Health Organization (WHO) has promoted a transformative vision of public health, asserting that 'the highest attainable standard of health' is 'one of the fundamental rights of every human being' (WHO, 1948).

Although it was linked to the traditions outlined earlier, this rights-based approach went beyond traditional medicine, proposing a broader definition of health as 'a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity' (ibid.). This definition subsequently structured the WHO's social medicine and reform agenda, which emphasised that '[g]overnments have a responsibility for the health of their people which can only be discharged by the provision of adequate health and social services' (ibid.).

Building on these definitions laid out by the WHO, the UN also included the right to health in its Universal Declaration of Human Rights, stating that

> Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control. (United Nations, 1948)

Thus, while the WHO sought to broaden the definition of health to link it to human rights, the UN sought to outline health rights through the multiple and complex determinants of health and universalise them as human rights. The definitions and links established by the two international organisations have had a significant impact on human rights over the past century. They have influenced international law and provided a conceptual framework and benchmark for international non-governmental organisations (NGOs), civil society and social movements to mobilise in their defence and promotion.

These health rights' claims would also be taken up by HSMs and NGOs intervening in health, even as they themselves were undergoing significant changes in line with broader socio-political trends. More specifically, during the 1960s, HSMs acquired the characteristics of what have been termed New Social Movements (Melucci, 1985). Notable examples of this shift include the women's movement's critique of medical and health systems as male-dominated and ultimately sexist, and collective resistance in the name of women's rights (Bracke, 2017; Maraboutaki, 2021) as well as the anti-psychiatry movement, which united medical professionals and patients against the dominant psychiatric logic and practice in Europe and the United States (see Crossley, 2006).

The definition and establishment of health rights paved the way for the WHO's Alma-Ata Declaration in 1978. Alma-Ata brought health equity to the forefront of the international political agenda and established primary healthcare as central to achieving the WHO's goal of 'health for all by the year 2000' (Litsios, 2015). According to Halfdan Mahler, then Director-General of the WHO,

> [h]ealth for all means bringing health within reach of everyone in a given country. And 'health' means a personal state of well-being, not just the availability of health services – a state of health that enables a person to lead a socially and economically productive life. 'Health for all' implies the removal of barriers to health – the elimination of malnutrition, ignorance, contaminated drinking water and unhygienic housing – as well as the solution of purely medical problems such as a shortage of doctors, hospital beds, drugs and vaccines. (Mahler, [1981] 2000)

Concerns about access to diagnostics, vaccines and therapeutics, as discussed in this Element, are thus intimately linked to the advent global health governance and were first articulated in the context of the Health for All campaign. The

failure to meet the campaign's agenda by 2000 led to the creation of the Peoples' Health Movement in the same year, which has become the most important civil society network in global health policy, and a defender of access to medicines (Narayan et al., 2020). These concerns gained centrality with the spread of the HIV/AIDS pandemic in the 1980s, and even more so after the signing of the World Trade Organization (WTO) Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) in 1995, which aimed to standardise and harmonise intellectual property rights across sectors and countries.

HIV/AIDS activism evolved in two key phases: the first aimed to destigmatise the virus and affected communities while advancing research, and the second, following the TRIPS agreement, shifted focus to access to new therapies hindered by patents. In the Global North, this activism was largely driven by the LGBT community (Epstein, 1996; Graf, 1992; Stockdill, 2013), whereas in the Global South, it involved a broader coalition of affected communities, the poor and international health and human rights NGOs (Biehl, 2007; Ferraz, 2021; Heywood, 2009). This later phase gave rise to the Access to Medicines (A2M) movement – a loose network of Civil Society Organisations (CSOs), activists, legal scholars and health experts advocating against restrictive intellectual property (IP) rights in the name of health equity. Over three decades, A2 M has collaborated with governments, global institutions and generic drug manufacturers to lower medicine costs in Low- and middle-income countries (LMICs), beginning with HIV/AIDS and expanding to other global health areas.

While issues of access to lifesaving products and technologies dominated much of the global health agenda in the 1990s and 2000s, the global financial crisis of 2008 spurred contestation in a new direction, targeting 'health system neoliberalism' (Gaffney & Muntaner, 2018). This has been defined as the depletion and privatisation of the health system, and the shift in focus from primary prevention to the more profitable secondary and tertiary levels of care. As a consequence, anti-austerity HSMs have often combined protest tactics in support of public ownership and provision of healthcare, improving working conditions in the sector, and protecting and improving the quality of the services it provides, with direct social actions (Bosi & Zamponi, 2015) of healthcare and/or pharmaceutical provision. These campaigns often involved collaboration between healthcare workers and users behind defensive and/or propositional strategies in the name of better health for all (Christou, 2022b; Galanti & Naughton, 2023; People's Health Movement, 2014).

In sum, Health Social Movements have been involved in dynamic and transformative interactions with medical science, health systems, curative practices, diagnostic categories, biomedical and pharmaceutical innovations,

and have been consequential in the development of international health and human rights frameworks.

The Covid-19 Global Critical Juncture and Its Discontents

As shown earlier, epidemics and pandemics have often triggered health rights mobilisations and changed the field of opportunities and challenges in which HSMs operate. This was also the case with the Covid-19 pandemic, as health and care were advanced as central demands, mobilising health workers, patients and citizens more broadly (Christou, 2024; della Porta & Lavizzari, 2022). Indeed, as we will show in the rest of this Element, the pandemic provided an opportunity for the (re)mobilisation of A2M. Building on earlier traditions of Health Social Movements, the pandemic juncture not only remobilised constituencies and milieus active in the defence of health rights, but also had an impact beyond such groups, drawing broader social movement milieus behind the health rights' framework (Christou, 2024; della Porta, 2022; della Porta & Lavizzari, 2022). A broad reference to care was linked to the importance of public health services, with the recognition of the indispensability of care workers, but also to forms of care that became part of our everyday lives during the pandemic, as well as to forms of mutual aid and solidarity networks (della Porta, 2022). In what follows, we will discuss how the Covid-19 pandemic represented a critical juncture for health movements in general and for A2 M activism in particular, providing discursive opportunities to challenge the existing and long-contested system of patents for health-related products and technologies (Collier & Munck, 2017; della Porta, 2022). The global dimension of the challenge, together with the unequal distribution of the costs of the pandemic – both within and between countries – gave rise to hopes of global solidarity and commitments to shared solutions.

These hopes and commitments on the part of world leaders became important resources for the remobilisation of A2 M and the expansion of its audience. Although A2 M focused on vaccines as the primary and most important tool to contain the spread of Covid-19, it used the critical juncture of the pandemic to advance broader critiques of the patent regime, including the system of knowledge production and appropriation, the public funding of private profiteering, and of course the socio-economic and global inequalities that affect access to medicines.

As we will show, the links between the evolution of HSM campaigns at the transnational level during the HIV/AIDS and Covid-19 pandemics are evident in the networks mobilised, the core strategies employed and the collective framing employed, building on the right to health. Despite the virological and

epidemiological differences between the two pandemics, they brought about opportunities (and threats) for global mobilisation and cooperation in the name of health. Given the global nature of health challenges, the protest campaigns are often characterised by an upward scale shift (on the concept, see Tarrow and McAdam 2005), targeting big corporations and international governmental organisations that, in this like in other policy areas, increased their regulatory competences but not their democratic accountability, triggering a parallel growth of a global civic society as well as transnational protests (Boli & Thomas 1999; della Porta et al., 1999; della Porta & Tarrow 2005; Smith et al., 1996). Different international institutions offered distinctive opportunities to social movements, that often engaged transnationally in the attempt to change domestic policies through so-called 'boomerang effects' as social movements sought international-level allies to put pressure on domestic institutions (Keck & Sikkink, 1998) through insiders strategies but also open contestations, as in the case of the counter summits of the Global Justice Movement, for which health rights were already central (della Porta et al., 2006).

Similarly to the HIV/AIDS pandemic, Covid-19 acted as an 'emergency critical juncture', bringing the right to health back to the fore and reintroducing debates on the social determinants of health, disease, environmental health, public health and primary care. What is more, the Covid-19 pandemic gave rise to calls for scientific democratisation and transparency, and to struggles against state arbitrage and control. Finally, the pandemic reopened and publicised the debate on medical and scientific knowledge and advanced existing critiques of the appropriate role of the public and private (i.e. pharmaceutical) sectors in it, especially with regards to vaccines for Covid-19 (see della Porta et al., 2024).

As the pandemic was a global challenge, the demand for access to medicines required mobilisation on a global scale. We therefore trace A2 M activism at this critical juncture by analysing two transnational contentious campaigns during this period of emergency (della Porta & Tarrow 2005; della Porta 2022). As the campaigns against patents for Covid-19-related products, innovations and therapeutics addressed multilevel targets and constituencies, the analysis of the patent system and its discontents provides a lens through which to study health rights protests at the national, transnational and international levels.

Moreover, given that several international organisations are involved, this analysis allows us highlight the specific opportunities and threats posed by organisations as diverse as the WTO, the WHO and the EU. In addition, the fact that these major campaigns against patents on health-related products developed in times of emergency further reinforces the relevance of critical junctures for social movement studies. By looking at transnational campaigns,