

## **Introduction**

### **Global Assemblages of Virtue and Vitality:**

### **Genealogies and Anthropologies of Rights and Health**

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This book explores some of the assemblages of virtue and vitality where the political and moral language of rights are brought together and combine with the knowledges and practices of biomedicine and health. Over the last hundred years or so, rights, health and medicine have been repeatedly associated and assembled in a variety of ways and forms. The concepts of social rights, solidarity and citizenship developed by T. H. Marshall (1950) and others, for example, dominated how medical care was administered in most Western democracies up until the 1970s (Seymour, this volume; Dean 2009; Miller and Rose 2008; Burchell, Gordon and Miller 1991; Collini 1979). According to these social liberal theories of rule, the nation's citizenry had a social right to access medical care made available through the welfare state (Reubi 2012a; Bolton 2008). Another example is the way in which bioethical notions of individual rights and autonomy have progressively informed the practice of medicine and research across the globe from the late 1970s onwards, displacing the social liberal assemblage of virtue and vitality (Mold 2011; Wilson 2011; Reubi 2010a; Stevens 2000). For bioethical philosophies of government, doctors and medical scientists have to respect the right of patients and research subjects to decide freely whether or not they want to undergo particular treatments and experiments (Fox and Swazey 2008; Sunder Rajan 2007; Jasanoff 2005; Tutton and Corrigan 2004). Another more recent example of combination of rights and health has been the increasing prominence of human rights in the field of global public health (Reubi 2011). Indeed, from HIV/AIDS and access to medicines to sexual and reproductive health, human rights

concepts like the principle of non-discrimination and the right to health have come to play a significant role in the regulation of health (Hulverscheidt this volume; Waterson this volume; Nguyen 2012; Zigon 2011; Petryna 2009; Robbins 2008; Biehl 2007).

This collection of essays brings together historians, anthropologists, lawyers and sociologists to explore some of these and other assemblages of virtue and vitality. The aim of these pieces is not to outline and defend a specific rights framework for biomedicine and health. Indeed, there are already sizeable bodies of literature doing exactly that, like the work of Jonathan Mann, Paul Farmer, Paul Hunt and others which advance a human rights based approach to global health (e.g. Schrecker, Chapman, Labonte and De Vogli 2010; Farmer 2004; Hunt 2003; Mann, Gruskin, Grodin and Annas 1999). Instead, the authors in this collection take a social constructivist and critical approach to examine three different aspects of health rights assemblages. Firstly, they look at the ways in which these assemblages are made. For example, in her essay Marion Hulverscheidt analyses the way in which female genital mutilation became framed as both a medical issue and a human rights problem in global health policy in the late twentieth century. Similarly, Hannah Waterson examines how, influenced by international models, AIDS became understood as a human rights issue in Japan over the last ten years. Secondly, the essays in this collection also study the problems inherent to assemblages of virtue and vitality. So, in her chapter, Beatrix Hoffman shows how immigrants to the USA have their access to health care curtailed because of the national nature of the right to health in that country. Likewise, Storeng and Béhague suggest that the way in which evidence-based advocacy has reconfigured human rights discourses in relation to maternal

health has severely limited the possibility of making claims purely based on social justice arguments. Thirdly, the studies found in this collection also examine the influence health rights assemblages have on identities and understandings of citizenship. For example, in her essay, Jane Seymour examines the social liberal understanding of the citizen in relation to health that existed in the UK in the inter-war period. Likewise, Zigon explores how the Russian Orthodox Church's drug rehabilitation programmes, which are based on a very particular reading of human rights, seek to transform participants through practices such as confessions, daily manual labour and talk therapy.

In this three-part introduction, we set the scene for the studies of health rights assemblages carried out in these essays. In the first part, we sketch a possible genealogy of health rights over the last two centuries. Arguing against a celebratory history, we suggest that one of the first combinations of health and rights was the social liberal assemblage articulated around social rights, solidarity and the welfare state. Thereafter, the language of human rights and bioethics, both developed after and to some extent in reaction to World War Two, progressively replaced the language of social rights. This was especially the case after the 1970s, with the rise of bioethical notions of individual autonomy, and after the 1980s, with the rise of human rights talk of non-discrimination against HIV/AIDS patients. In the second part, we explore some of the questions, approaches and concepts articulated in the growing anthropological, sociological and political science literature on health rights assemblages. We start by introducing the concept of 'assemblage' or apparatus of virtue and vitality. We then outline the importance of transnational expert and advocacy networks in the making of health rights apparatuses, survey some of the

problems and difficulties inherent to health rights and discuss the notion of subjectivity in relation to health rights. In the third and last part, we summarise the different essays that make up this collection.

## **GENEALOGIES OF HEALTH RIGHTS**

In the West, the language of rights has been applied to health since at least the eighteenth century. Although the right to health was not included in the French revolutionaries' Declaration of the Rights of Man and Citizen in 1789, it was added to the list of the state's obligations to its citizens by the Constituent Assembly in 1791 (Porter 1999: 57). For historians such as Lynn Hunt, this period saw the 'invention' of human rights, that is rights that were seen as being natural, equal and universal (Hunt 2007: 20). Although some commentators locate the origin of human rights prior to the Enlightenment (see, for example, Ishay, 2004) the danger, as Kenneth Cmiel noted, is that 'The expansive approach can wind up equating "human rights" with anything "good". Buddha and Jesus now become human rights activists' (Cmiel, 2004: 119). There has been a tendency to point to a seemingly inevitable 'rise and rise' of human rights (Sellars 2002) over the course of history, when, as more nuanced accounts demonstrate (such as Moyn 2010) human rights discourses have actually waxed and waned.

Indeed, the meaning of rights in general, and in the context of health in particular, has changed considerably over time. The birth of human rights is often located in the eighteenth century as it was in this period that rights were conceived of as being universal, applying equally to all men regardless of status – although not to women or

ethnic minorities. Yet, most commentators suggest that from the close of the eighteenth century until the end of World War Two, human rights disappeared from Western political discourses (Hoffmann 2010; Hunt 2007). Rights talk, however, did not go away. Rights remained fundamental to politics, but the nature of the rights being demanded changed. In the nineteenth century, the focus was on the rights of the citizen rather than the rights of man, and attention was directed towards a set of political rights, such as the right to vote. By the early twentieth century, as enfranchisement gradually became universal, citizens' calls for rights were increasingly social in nature. The establishment of welfare states in European nations went some way towards satisfying such demands, as housing, education and health care came to be seen as social rights (Marshall 1992).

Universal human rights, as opposed to the rights citizens demanded of states, returned to global political prominence after 1945. The reappearance of human rights has sometimes been explained as being a consequence of the exposure of Nazi wartime atrocities, or as a result of the heroic actions of key figures such as Eleanor Roosevelt (Glendon 2001). But, as Mark Mazower points out, attempts to establish a new doctrine of human rights succeeded only because nation states were prepared to accept this as part of a broader conception of liberal political thought which maintained that the individual required protection from the state (Mazower 2004).

The post-war turn to human rights manifested itself in a number of ways. Perhaps the most iconic was the United Nations Universal Declaration of Human Rights (UDHR) of 1948. Comprised of 30 articles, the UDHR proclaimed the existence of a series of

civil, political, economic, social and cultural rights, including ‘the right to a standard of living adequate for health and well being of himself and his family, including food, clothing, housing and medical care’ (United Nations 1948). In 1946, the right to ‘the enjoyment of the highest attainable standard of physical and mental health’ was enshrined within the charter establishing the World Health Organization (World Health Organization 1946). The International Covenant on Economic, Social and Cultural Rights (ICESCR), which was ratified in 1966 and came into effect for member countries ten years later, provided legal bite to such declarations (United Nations, 1966).

During this period another set of health rights were established around the use of human beings in medical research. A series of international codes governing medical experimentation were created following the Nuremberg Trials of the Nazi doctors (Weindling 2004; Schmidt 2004; Annas and Grodin 1995). The Nuremberg Code (1947) stressed the importance of the voluntary participation of the research subject, and the Helsinki Declaration (World Medical Association, 1964) asserted that researchers should ‘seek the potential subject’s freely-given informed consent, preferably in writing.’ Although these codes were symbolically very important, they had less immediate impact at the national level than might be supposed. Patients were often used in medical trials in both the UK and the USA in the 1960s without their knowledge or consent (Rothman 1991; Hedgecoe 2009; Hazelgrove 2002). Patients’ rights, whether these applied to the individual or to the wider population, were hard to define and even harder to impose (Mold 2012).

By the 1970s, the language of human rights was being used by non-governmental organizations and other actors to make demands at the national and international level (Moyn 2010). In health, action coalesced initially around the concept of primary health care, which aimed to provide health services at the community level (Brown, Cueto and Fee, 2006). Primary health care was the focus of the Alma-Ata conference in 1978, and the resulting declaration proclaimed that health 'is a fundamental human right' (Alma-Ata 1978). Human rights language was used throughout the 1970s and early 1980s to advance the development of primary health care (Cueto 2004) and also in attempts to address the social determinants of health (Irwin & Scali 2007), as well as in specific health campaigns, such as those against breast milk substitutes and the dumping of pharmaceutical drugs on markets in developing countries (Hilton 2009).

Health as a human rights issue was propelled further onto the global agenda in the late 1980s and early 1990s in the wake of HIV/AIDS. The work of the American physician, Jonathan Mann, has often been seen as being central to the conceptualization of HIV/AIDS within a human rights framework (Fee and Parry 2008). Mann's research on AIDS in Africa convinced him that the epidemic had social and economic causes as well as infectious ones. Mann developed the WHO's first Global Strategy on AIDS based on human rights principles, emphasizing non-discrimination against people with AIDS and equitable access to health care (Gruskin, Mills and Tarantola 2007). Human rights principles were put forward as a tool for the analysis of AIDS and as means to address the many problems it posed (Tarantola 2008).

During the mid-1990s, a range of other health issues, such as reproductive health, mental illness and disability, were also conceptualized as human rights matters (Gruskin, Mills and Tarantola, 2007). Indeed, the health human rights agenda continued to expand into the first decades of the twenty-first century. Health rights outcomes became linked to international development, as seen within the Millennium Declaration and the resulting Millennium Development Goals (United Nations 2000a). In 2000, the United Nations Committee on Economic, Social and Cultural Rights issued a General Comment on the Right to Health, expanding at length on the right to health contained within the ICESCR (United Nations, 2000b). A Special Rapporteur on the right to health was appointed by the UN in 2002 to report on global efforts to ensure everyone has the right to the highest attainable standard of physical and mental health.

Yet, despite such developments, it is not possible to point to a clear narrative of progress around health rights. As will be discussed in greater detail below, complexities and anomalies remain. The United States, for example, refuses to ratify the ICESCR for fear of generating a legal right to access to health care for its citizens. As Anne-Emmanuelle Birn notes, even if the right to health care was guaranteed worldwide, ‘the right to health – as opposed to the right to health care – will still be far from achieved’ (Birn 2008: 37). In part, this is because the meaning of health rights and health as a human right continues to be contested. Demonstrating how and why such contestations remain is one of the central themes of this book.

The key to solving such a puzzle is developing an understanding of where health rights and the notion of health as a human right came from. The history of health rights is relatively underexplored. Although the history of rights, and human rights in particular, is an expanding area of historiographical enquiry (Cmiel 2004), few of these texts make reference to the history of health rights (Moyn 2010; Hoffmann 2010). There are useful overviews of the development of health as a human right (Birn 2008; Tarantola 2008; Gruskin, Mills and Tarantola 2007; Marks 2002) and work on the WHO and the right to health (Meier 2010; and in this volume). To situate health rights, the exploration of the use of health rights language in a range of temporal and spatial locations is required. This book aims to provide such a fine-grained analysis.

## **SOCIAL THEORY, HEALTH AND RIGHTS**

There is a growing anthropological, sociological and political science literature on health rights assemblages – from the research on bioethics (e.g. Reubi 2012a; Mold 2011; Fox and Swazey 2008; Sunder Rajan 2007; Stevens 2000) to the work on human rights and AIDS (e.g. Zigon 2011; Robins 2008; Biehl 2007; Kavita 2006; Nguyen 2005; Epstein 1996) and access to medicines (e.g. Ferraz, 2009; Petryna, 2009; Abramovich and Pautassi, 2008; Gloppen, 2008; Oleson, 2006). In this section, we outline some of the questions, approaches and concepts articulated in this literature – many of which are addressed, used and further developed in the essays that make up this collection.

### **Assemblages of Virtue and Vitality**

The related concepts of mentalities and apparatuses of government developed by Michel Foucault (2004a; 2004b) and others (Legg 2011; Dean 2009; Miller and Rose 2008; Li 2007; Valverde 2007; Agamben 2005; Rabinow and Rose 2003; Deleuze 1992) are powerful tools to help make sense of existing combinations of the moral and political language of rights with the knowledge and practices of biomedicine and health. Mentalities of government are forms of rationalities made up of moral and philosophical propositions, institutions, forms of expertise, scientific statements, intellectual categories, laws and administrative measures, architectural environments, techniques and practices organised in complex assemblages or apparatuses.

Concerned with the direction of human conduct, these mentalities and associated apparatuses make it possible to constitute something as an object of thought, identify it as a problem and devise strategies to intervene upon it. We suggest that combinations of rights, medicine and health are best understood as such mentalities and apparatuses of government and, accordingly, term them assemblages of virtue and vitality. Before outlining some of the advantages of thinking with these twin concepts, we give two examples of such assemblages.

The first example is the assemblage of social rights and blood transfusion developed in post-war Britain and lauded by Richard Titmuss in *The Gift Relationship* (Titmuss 1970; cf. Reubi 2012; Reubi 2010b; Fontaine 2002). At the heart of this apparatus were the concepts of social solidarity and the welfare state: citizens had a right to receive blood for transfusion from the welfare state when needed and, in return, had a duty to give their blood regularly to ensure that the national blood bank was adequately stocked. In addition to these social liberal concepts, this assemblage was further made of and characterised by: the National Blood Transfusion Service, a

centralised, state-run agency part of the NHS and responsible for the collection, storage and redistribution of blood of the British territory; medical knowledge about ABO and Rhesus blood types, laboratory technicians and cold storage rooms; and propaganda specialists and educational films to ensure that the public was educated about blood transfusion and aware of the importance of becoming a blood donor.

The second example is the assemblage of human rights and HIV/AIDS that emerged at the end of the twentieth century (cf. Robbins 2008; Biehl 2007; Nguyen 2005).

This apparatus is constructed around the figure of the responsible patient – someone who seeks information about and manages his or her disease; someone who is an active member of patient support groups; and someone who advocates for more public awareness about the disease and increased funding for research. Other defining features of this assemblage comprise: public health prevention campaigns; provision of condoms and needle-exchange programmes; human rights notions of non-discrimination and non-stigmatisation of people living with HIV/AIDS (PLWAs) and of the right to health and access to antiretroviral treatments; and HIV/AIDS screening tests, counselling specialists and community health workers.

There are many advantages of thinking and narrating combinations of rights and health through the twin concepts of govern-mentalities and apparatuses. First, it enables researchers to avoid following lawyers in thinking that health rights are only norms and institutions and examine instead the rich assemblage of knowledge, socialities, spaces and practices that make them up (Kurasawa 2012; Reubi 2011). Second, it allows researchers to emphasise the different meanings of health rights across time and space and explain this by pointing at the changing arrangements and

assemblages of which they are part (Douzinas, 2007). Third, it enables researchers to analyse how health rights are transposed and adapted to new cultural and geographical contexts by examining the ways in which their assemblage are transformed (Allen 2011; Ong and Collier 2005).

### **Making Health Rights**

For anthropologists, sociologists, historians and political scientists working on health and rights, the assumption is, of course, that health rights assemblages are not pre-existing but have to be made – a protracted and difficult process that necessitates a lot of efforts and perseverance. A key driving force in the production of health rights apparatuses are transnational networks of experts and advocates (Reubi 2012b; Merry 2006; Riles 2000; Keck and Sikkink 1998; Hass 1992). These networks are coalitions or communities of professionals with a recognised expertise in a specific area. One characteristic of these networks is that their members develop and share a same ‘style of thinking’ – a combination of knowledge, values and practices that allow the network’s members to identify problems that need addressing and suggest particular explanations, analyses and solutions. Another distinctive trait of these networks is their transnational character. Their members are all part of a highly educated, cosmopolitan elite that lives in different countries, speaks more than one language and works for international institutions like the UN, the World Bank or the WHO, NGOs, think-tanks, universities and other civil society groups (Goodale 2009; Merry 2006; Guilhot 2005; Chatterjee 2004; Dezalay and Garth 1998). Furthermore, while members portray these networks as horizontal and non-hierarchical, they are frequently dominated by particularly charismatic leaders or political entrepreneurs (Robins 2008; Nguyen 2002; Keck and Sikkink 1998). Similarly, although members

will come from a variety of disciplines, lawyers will tend to be a strongly represented disciplinary group in the networks (Reubi 2012b; Dezalay and Garth 2012).

The function of these expert and advocacy networks is two-fold in relation to health rights assemblages. Firstly, they help make them up (Reubi 2012b; Rushton 2010; Shiffman and Smith 2007; Merry 2006; Keck and Sikkink 1998; Hass 1992). This involves the articulation of new knowledge. A good illustration is the already mentioned work of Jonathan Mann and his colleagues at the WHO and, later, at the Harvard School of Public Health in devising human rights principles for public health, from AIDS to sexual and reproductive health (Fee and Parry 2008). Secondly, it also involves research into and the problematisation of new issues. An excellent illustration has been recent attempts by both lawyers and anti-smoking advocates to reframe and present tobacco control as a human rights issue (Reubi, this volume). Finally, making a health right assemblage also involves attracting the attention of both the public and those in power. To do so, expert and advocacy networks will generally frame an issue to make it comprehensible and meaningful, run public campaigns, reach the media as well as lobby governments. The international campaign run by the Treatment Action Campaign (TAC), Medecins sans Frontieres (MSF), Oxfam and others to draw attention to the plight of PLWAs in South Africa and the importance of access to cheap anti-retroviral drugs is a good example of such work (Olseson 2006).

Besides making health rights assemblages, expert and advocacy networks also help disseminate them (Goodale 2009; Robins 2008; Merry 2006; Keck and Sikkink 1998). This involves, of course, disseminating information about health rights to government officials, local business leaders, human rights advocates and community

organisers. It also encompasses lobbying and pressurizing governments, multinational corporations and others to adopt the new policies and monitoring compliance. This is often done through campaigns and embarrassing those in power by showing the distance between discourse and practice. Furthermore, disseminating health rights involves translating them and making them both comprehensible and attractive for local actors with their particular cultural sensitivities and interests. In that sense, expert and advocacy networks are ‘mediators’ (Robins 2008: 15) who translate or ‘adjust the rhetoric and structure’ of health rights assemblages ‘to local circumstances’ (Merry 2006: 135). As Merry explains:

Appropriating global [health] rights frameworks and translating them to fit into particular situations ... often means transplanting institutions and programs such as [patient groups, treatment possibilities, human rights rules and so on]. This is at heart a process of translation across boundaries of class, ethnicity, mobility and education. Intermediaries [like NGOs or social movement activists] who translate global ideas into local situations and retranslate local ideas into global frameworks play a critical role in the process. They foster the gradual emergence of local rights consciousness among grassroots people and greater awareness of national and local issues among global activists (Merry, 2006: 134).

Of course, these dissemination and translation efforts are not always successful. As we see in some of the chapters in this volume, local actors with differing interests or worldviews often resist the rationales and practices associated with health rights assemblages successfully (cf. Lynteris, this volume; Zigon, this volume).

## **Problems**

In contrast with lawyers and public health experts' enthusiasm for and celebration of rights (e.g. Schrecker, Chapman, Labonte and De Vogli 2010; Birn 2008; Tarantola 2008; Hunt 2003; Mann, Gruskin, Grodin and Annas 1999), the aim of many sociologists, anthropologists and political scientists has been to uncover the problems and failures inherent to health rights assemblages. This is generally done in a critical humanitarian spirit with social scientists using their research to criticise existing injustices and improve society (e.g. Das 2007; Farmer 2004; Kleinman 1995; cf. also Wilkinson 2012). These scholars have identified a range of issues inherent to health rights assemblages, from the overly biomedical understanding of the right to health (Greco 2004) to the Western cultural bias inherent to human rights discourses (Goodale 2009; Fox and Swazey 2008). Here we examine three issues which have been most discussed in the literature.

The first of these critiques is that health rights assemblages are just another form of power and domination (e.g. Zigon 2011; Goodale 2009; Sunder Rajan 2007; Guilhot 2005; Hardt and Negri 2000; Dezalay and Garth 1998; Fisher 1997). These authors question whether human rights lawyers and public health advocates really are a benevolent force purporting to protect those most vulnerable from abuse. The critics are, as Goodale (2009: 93) has argued, 'sceptical about the well-intentioned activism of the cosmopolitan elite' that make and diffuse health rights. There are two main reasons for this scepticism. First, many of these authors argue that the new class of professional legal and moral experts that has come to dominate health rights assemblages both disempower victims by speaking for them and bureaucratize the language of rights through standardised moral principles, formal procedures and

routinized practices (Reubi 2011; Holden and Demeritt 2008; Sunder Rajan 2007). Second, many of these authors also point out that this new class of professionals are in cahoots with the forces of Empire (Guilhot 2005; Hardt and Negri 2000; Dezalay and Garth 1998). As Hardt and Negri (2000: 36) argue, ‘humanitarian NGOs’ such as ‘Oxfam and Medecins sans Frontieres’ are ‘some of the most powerful pacific weapons of the new world order;’ they are ‘the charitable campaigns and the mendicant orders of Empire.’

The second most debated problem inherent to health rights assemblages is their close relationship with neo-liberalism (e.g. Mold 2011; Wilson 2011; Zigon 2011; Goodale 2009; Sunder Rajan 2007; Merry 2006; Waldby and Mitchell 2006; Scheper-Hughes 2001). For many human rights lawyers and public health advocates, health rights are deemed to be a bulwark against the dangers of neo-liberalism, from privatisation to user fees (e.g. Schrecker, Chapman, Labonte and De Vogli 2010; Forman 2008; Tarantola 2008; Hunt 2004). Social science research has shown this assertion to be problematic. First, it demonstrates that health rights and neo-liberalism presuppose and advance the same figure of the subject: individuals, who are both free and responsible in relation to their health, bodies and lives (Zigon 2011; Waldby and Mitchell 2006; Scheper-Hughes 2001; Cooter 2000). This, of course, limits the protection health rights can offer against neoliberal policies. Second, social science research also shows that health rights tend to be articulated around nation-states, which are the ultimate bearers of health rights obligations (Reubi 2011). In contrast, health rights are rather toothless in relation to transnational corporations – the neo-liberal actors par excellence.

The third and last problem is the judicialization of health rights (e.g. Reubi 2011; Biehl, Petryna, Gertner, Amon and Picon 2009; Ferraz 2009; Petryna 2009; Abramovich and Pautassi 2008; Gloppen 2008). Litigation, especially in Latin America, has become an increasingly popular method for realising the right to health and, especially, the right to access to pharmaceuticals. At the start, these legal suits were focused on providing cheap access to anti-retroviral drugs and benefited the majority of the populations in the countries where the suits were successful. But, with time, an increasing number of claims have focused on new high-cost drugs for rare diseases. These are generally filled by patient organisations with the help of interested pharmaceutical companies. As a consequence, the costs associated with pharmaceutical assistance have sky rocketed and the focus on high-cost drugs for rare diseases has tended to favour a few middle-class claimants to the detriment of standard treatments for the wider population. In other words, the judicialization of the right to health has led to the widening of health inequalities.

### **Subjectivities**

An important part of the anthropological and sociological literature on health rights assemblages explores how the latter have reconfigured the ways we understand ourselves and others as subjects and citizens (e.g. Reubi 2012; Zigon 2011; Robins 2008; Nguyen 2005; Kavita 2004; Nguyen 2002). Building on the work of Michael Foucault and others (e.g. Dean 2010; Rose 2007; Foucault 2004; Hacking 2002; Isin 2002), this literature examines how the knowledge, experts, organisational forms and techniques that make up health rights assemblages transform our modes of being. For this literature, there is no universal, fixed subject in relation to which one can govern. Instead, it holds that notions of subjectivity and citizenship that exist at a given time

and place are progressively constituted through a process of subjectification. This process sees human beings constitute themselves through the adoption and use of knowledge, practices and techniques derived from medico-political apparatuses such as health rights assemblages (Douzinas 2007).

Health rights assemblages have brought into being a range of new subjectivities and notions of citizenship over the last century. Two of these seem to have been particularly dominant in the West (Reubi 2012a; Reubi 2010b; Rose and Novas 2005; Novas and Rose 2000; Rabinow 1996). The first one, which prevailed until the late 1970s, is the citizen with social rights and social duties. As mentioned above, this figure of the citizen was the product of social-liberal theories of rule developed by thinkers like Keynes and Beveridge and articulated around the notions of ‘welfare’, ‘social solidarity’ and ‘society’. In the case of unemployment, illness, accident or old age, this social-liberal citizen was cared for by the welfare state. In return, he or she had an obligation to contribute to the working of the welfare state and both trust and submit to its experts. The notion of the blood donor is typical of the social-liberal subject: he or she is entitled to receive blood from the state when needed but is also expected to give his or her blood whenever deemed necessary by physicians. The second dominant figure of the subject in the last century is the active, autonomous and responsible individual. This subject, a product of neo-liberal theories of government based on notions like ‘markets’ and ‘entrepreneurship’, has been predominant since the early 1980s. This individual is responsible for his or her health and expected to plan actively for the improvement, or at least maintenance of his or her health. Neo-liberal subjects do so by informing themselves on the Internet, discussing their care with their doctors and buying private insurance schemes on the market.

Of course, these forms of health and biomedical subjectivities do not come into being in a vacuum, but develop alongside and mix with pre-existing notions of the subject. This is all the more so when subjectivities generated elsewhere are transplanted to new socio-cultural settings (Robins 2008; Merry 2006). These foreign forms of the subject will generally encounter resistance and go through a process of translation to adapt them to the new settings (Zigon 2011; Reubi 2010b; Robins 2008; Nguyen 2005; Kavita 2004; Nguyen 2002). For example, when transfusion medicine was introduced in Singapore after World War Two, the social-liberal figure of the blood donor was adapted to fit the local governing elite's project to develop and modernize the newly independent city-state: citizens were entitled to receive blood and in return were expected to give their blood as part of the local nation-building efforts (Reubi 2010b). Similarly, the neo-liberal figure of the responsible, active 'therapeutic citizenship' that was developed as part of the fight against HIV/AIDS in the West was partly transformed and associated with religious forms of subjectivity when transplanted to places as different as post-soviet Russia and post-apartheid South Africa (Zigon, this volume; Robins 2008; Nguyen 2005).

One cannot discuss the relationship between health rights and subjectivities without mentioning those that remain excluded from these rights (Fine 2012; Douzinas 2007; Rancière 2004; Asad 2003; Isin 2002; Agamben 1998; Arendt 1951). As Douzinas (2007: 96) has explained, 'the privilege[d] subject of rights ... has been a white, well-off, heterosexual male, who condenses in his person the abstract dignity of humanity'. In consequence, he argues, 'rights have been denied to [the] people' that do not fit this picture and are 'routinely portrayed as uneducated, uncivilised or simply unworthy of

the privileges of the fully human' (Douzinas: 97). Categories of people who have been denied health rights are many. Women in the past and present have often seen their reproductive and sexual rights curtailed in the name of morality, tradition or culture (Hulverscheidt, this volume). Similarly, the privilege of claiming health rights was, until the process of decolonisation in the 1950-70s, limited to particular racial groups (Hoffman 2011). More critical today, perhaps, is the persistent discrimination of health rights in relation to nationality and citizenship (Hoffman, this volume). Although the exclusion of many categories of people from health rights continues, it is important to note that, as Rancière (2004) has argued, these categories are subject to political contestation and change (cf. also Hoffman, this volume). Health rights, as this book will demonstrate, are not static entities with fixed boundaries and consequences.

### **Summary of Chapters**

The ebb and flow of health rights over both time and place is a critical theme of this book. We begin, in Part One, by exploring the discourses that surround health rights, citizenship and subjectivity. As discussed above, health rights did not begin with the UDHR or the establishment of the WHO, but were connected with much older discourses surrounding citizenship, social solidarity and the nation-state. In her chapter, Jane Seymour discusses the place of rights in relation to the provision of health care in Britain during the early twentieth century. She suggests that reciprocal responsibility, and not rights, were central to good citizenship and thus good health. Such an understanding points towards a social conceptualization of health rights and responsibilities conferred upon the citizen, not universal rights available to all humans. Indeed, as Beatrix Hoffman demonstrates in her chapter, discourses of

citizenship can be used to restrict health rights, and particularly access to health care. Focusing on the USA in the later twentieth and early twenty-first centuries, she explores the position of unauthorized immigrants in America with respect to health care. Health care for immigrants has long been a contentious issue, and though unauthorized migrants have been able to use emergency care since the late 1980s, they do not have access to the programmes that provide health care for elderly or indigent American citizens. In the United States health rights are thus linked to citizenship, with unauthorized immigrants deliberately excluded. In his contribution, Jarrett Zigon further explores the relationship between health, rights and citizenship. In the first part of his essay, Zigon unpacks the political subject imagined in the work of Western political philosophers and lawyers who are favorable to the universal language of human rights. In particular, Zigon outlines the universal figure of the subject that underlies Michel Ignatieff's theory of human rights: the individual that has a capacity to stand outside his or her own socio-cultural context and freely reflect, decide and act. In the second part of his contribution, Zigon explores the ways in which the Russian Orthodox Church (ROC) uses the language of human rights as part of its drug rehabilitation and HIV/AIDS prevention and treatment programmes. Interestingly, he shows how Ignatieff's political subject is lost in translation, as the ROC reconfigures human rights as a tool to transform drug addicts into good, neoliberal Russian citizens.

The problematic making and remaking of health as a human right is explored in greater detail in Part Two. In his chapter, Benjamin Meier charts the transformation of the right to health through the development of international health frameworks and institutions. Beginning in the late 1940s, with the UDHR and the establishment of the

WHO, and concluding with the response to HIV/AIDS as a human rights issue in the 1980s, Meier plots the changing nature of health as a human right at the international level. As the tools and objects of global health governance evolved, so too did the notion of health as a human right. This was not, however, an uncontested process: the human right to health was a place where many political tensions, including those between Cold War adversaries and rich and poor nations, were voiced. The establishment of the notion of health as a human right at the global level opened up the possibility for specific issues to be conceived of as human rights problems. In her chapter, Marion Hulverscheidt considers how and why Female Genital Mutilation (FGM) came to be seen as an abuse of human rights. She demonstrates that the framing of FGM as a human rights issue in the 1990s was only the most recent approach to the practice. In the late nineteenth century anthropologists ‘discovered’ FGM, but saw it as a custom to be described, not as an abuse to be condemned. During the 1960s, doctors emphasized the potential health dangers of FGM, and in the 1970s, feminist groups saw it as a violation of women’s rights. The construction of FGM as a human rights issue has not, Hulverscheidt suggests, completely taken over from these older discourses. Another example of the making of human rights is offered by David Reubi. In his contribution, he explores how a network of public health experts and human rights lawyers have sought to frame tobacco control as a human rights issue over the last ten years. Reubi describes in detail the efforts made by this network to construct a right to tobacco control and have it accepted within both the tobacco control and the human rights fields. He also shows how, for this network of experts, human rights are a strictly legal concept interpreted by lawyers and a way to access to powerful, judicial monitoring and enforcement mechanisms. This, Reubi argues, is contributing to the current judicialisation of the right to health.

Resistance to, contestation of and the translation of health rights are considered in greater detail in Part Three of the book. In her contribution, Hannah Waterson examines the ways in which people living with HIV in Japan have engaged with human rights discourses to shape policy and practice. HIV was initially considered to be a disease of ‘others’, principally foreigners and gay men, helping to foster a restrictive approach. Echoing the response to HIV/AIDS at the global level, gay groups and other NGOs began to use human rights discourses to press for less discriminatory policies. Waterson’s chapter also serves as a case study of the ways in which the local and the global interact to transform and transpose the human rights discourse, calling into question the very universality of human rights. Katerini Storeng and Dominique Béhague raise additional problems with the rights discourse in their essay which examines the utilization of rights discourses by activists and others to frame a specific health issue, in this case safe motherhood. They explore the changing nature and relevance of rights talk, particularly as new discourses, such as that around evidence-based policy and practice, have come to the fore. Drawing on ethnographic research within the safe motherhood community, Storeng and Béhague argue that over the last 20 years, the rise of ‘evidence-based’ advocacy in global health has led to a resistance and move away from the language of rights. They also show how, where the language of rights has remained important, its very meaning was changed, to bring it in line with the evidence-based ethos. These reformulations notwithstanding, there are scenarios that appear to remain resistant to the language and practice of human rights. In his chapter, Christos Lynteris considers the response to the SARS epidemic in China in 2003. The rights of individuals suspected of carrying the virus were quickly restricted in order to prevent the disease

from spreading, a practice commonly employed across time and space. Lynteris shows how, in China during the SARS outbreak, the language of rights was, despite numerous tentatives, unable to impose itself. Instead, a biopolitical rationale intended to restrict the movement of migrant workers was the dominant discourse and remained so throughout the outbreak. In this scenario health was not a right, but rather a duty to the state.

There is a sense then, in which Lynteris' chapter returns us to our beginning, with responsibilities and the role of the state remaining relevant at the opening of the twenty-first century just as they were at the start of the twentieth. The essays in this collection show that languages of citizenship remain important both in understanding where health rights came from and how they operate in local and national contexts. Constructing health as human rights issue was a contested and incomplete process and one that had often unintended effects. Moreover, the technical discourses surrounding the systemization and implementation of health as a human right may themselves further transform the notion of health rights. The changes over time and space in the meaning and application of health rights pointed to by this book are unlikely to be the final formulations of this dynamic concept.

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