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Chapter 1

Epidemic narratives

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In June 2009, the World Health Organization officially declared that the world was experiencing a global pandemic of H1N1 influenza. An initial outbreak of a new virus in Mexico (termed 'swine' flu because of its early identification in pigs and mix of pig, avian and human genetic material) had jumped to humans and was now sweeping the world, hastened by travel and rapid transmission on our interconnected and crowded planet. Soon after the emergence of the virus, the WHO had called the outbreak an 'extreme expression of the need for global solidarity' (WHO, 2009). Pandemic preparedness plans, put into place in many industrialised countries in response to the earlier threat of H5N1 avian influenza, were mobilised at scale. Yet by July, it was clear that the battle to halt the epidemic had been lost. With thousands of new cases being reported every day and scientists predicting a huge rise as the winter flu season kicked in, some governments, such as the UK and US, switched strategy from containment to damage limitation, through a mix of public hygiene campaigns and the handing-out of stockpiled anti-viral drugs such as Tamiflu to reported cases.

Swine flu may be the latest epidemic outbreak to be hitting the headlines, but it is, of course, not the first and it will not be the last. Current global health policy is dominated by a preoccupation with infectious diseases and in particular with so called 'emerging' or 're-emerging' infectious diseases that threaten to 'break out' of established patterns of prevalence or virulence into new areas and new victims (Kickbusch, 2003; Knobler et al, 2006; Foresight, 2006). Such episodes are variously described as outbreaks, epidemics, or pandemics depending on their severity, temporal or geographic reach, or their ability to capture our attention (or frighten us). Of the many risks currently facing the international community, the 'most feared security threat' is that a highly infectious and virulent form of human influenza will develop, causing a global pandemic potentially worse than the epidemic that killed so many in 1918-1919 (WHO, 2007a, p45). But the complete list of significant global health risks that have the potential to become epidemic is long and includes multidrug-resistant tuberculosis, malaria, newly emerging and highly infectious viral diseases such as Ebola, Marburg and Nipah, and a growing worldwide resistance to frontline antibiotics. Addressing such diseases ranks high on almost any league-table of global health policy (Saker et al, 2004; Lee, 2000; Lee, 2003a).

Epidemics can be defined as an increase, over and above what would normally be expected during a particular period of time, in cases of disease within a community or region. Earlier epidemics serve as a sharp reminder of the power of infectious disease to wreak havoc on lives, economy and society. In the 20th

century outbreaks of plague in India 1907 killed 1.3m, and estimates of the numbers killed in the influenza epidemic of 1918-19 range from 20 to 100m. In today's world of mobile people and microbes, the power of infectious diseases has been massively magnified: swine flu has illustrated the capacity for outbreaks to become global pandemics with unprecedented rapidity.

The image of swine flu as a disease emerging 'out of Central America' and going global also evokes earlier events and fears, whether the emergence of SARS 'out of Asia' in 2003, or the emergence of HIV and Ebola 'out of Africa' in the 1980s and 90s. Such fears contrast sharply with 20th century postwar optimism that infectious disease would soon be conquered with a potent mix of sanitary hygiene, vector control (notably through the use of DDT), vaccines, and antibiotics. Notwithstanding what today seem the outsize ambitions of such postwar responses, several disturbing trends of the past twenty years threaten to undermine the successful control of infectious diseases that has been achieved in industrialized nations (Barrett et al, 1998). Firstly, there is a clear increase in the rate at which new diseases (such as H1N1 influenza, SARS, BSE and H5N1 avian influenza) are emerging. At the same time, established diseases, such as malaria, are shifting into new geographical niches as climate change broadens the zones in which vector species (such as mosquitoes) can survive. Finally, newly resistant disease strains, such as drug-resistant malaria, HIV and TB, represent a growing class of re-emerging infectious diseases, which were once considered tractable but now threaten populations anew.

Of these trends, the swine flu outbreak highlights in particular the threat to humans from zoonosis, the process whereby new diseases somehow manage to 'jump' from an animal species to infect human beings. A sharp rise in such zoonotic diseases in the past twenty years is one of the most startling of the findings indicating a growing threat from infectious diseases. Humans and microbes have been evolving together over hundreds of thousands of years, and some new diseases that make their way into human hosts are to be expected. But things are changing more rapidly than such evolutionary processes would suggest. One important study indicates that all new infectious diseases of human beings to emerge in the past 20 years have had an animal source, and that more than 60% of emerging infectious disease events since 1940 have involved zoonoses (Jones et al, 2008; see also Woolhouse, 2008). Such data may point to a dangerous 'phase' shift in the balance between humans and their pathogens, caused by dramatic shifts in population and climate over a relatively short time frame (Wolfe et al, 2005; Wolfe et al, 2007). Recent research reveals multiple causes for this increase, including increased human and domestic animal populations, migration, increased human/animal encounters, habitat disturbance, climate change, deforestation, wars, loss of social cohesion and natural disasters (Morens et al, 2004). Scientists, it is argued, must therefore be poised to discover and identify emerging diseases before they have a chance to spread. 'Virus-hunting' needs investment and profile (Wolfe, 2009a). And infrastructures and resources for surveillance, preparedness, rapid containment,

and protection through public health measures – need to be put in place across the globe.

There is good reason to fear the effects of emerging diseases and the epidemics they can cause. Despite the successes of industrialized nations, the current global burden of infectious disease remains enormous: roughly one-quarter of annual global deaths can be attributed to infectious diseases (WHO, 2004a; Morens et al, 2004). A disproportionate amount of this burden sits squarely on the shoulders of the world's poorest people, as would any future burden associated with emerging infectious diseases. This is no coincidence. The conditions of poverty, such as over-crowding, lack of sanitation, and forced migration, are precisely those which encourage the transmission and persistence of infectious disease. The combination of the massive current burden of infectious disease with the possibility of more bad news ahead (with the added potential for climate change to worsen the global health situation) has mobilized the global health community (Haimes et al, 2006; WHO, 2008a). In recent years, an infusion of new cash and new initiatives—such as the Global Fund to Fight AIDS, TB and Malaria, the Bill and Melinda Gates Foundation global health program, the Millennium Development Goals (especially numbers four, five and six), and the recent revisions in the WHO's International Health Regulations (Dry, this volume)—have transformed the global health policy landscape. The result is that infectious diseases, and the epidemics they can cause, are at the top of the global health agenda.

However, the resulting appearance of a consensus about the risks of global outbreaks hides a set of assumptions—about the nature of the threat and the best way to address it—which may be counter-productive to the goal both of reducing the global burden of infectious disease (in epidemic and endemic forms) and, more broadly, to the goal of creating a more equitable and just world for the long-term. By being more critical about the nature of our understanding of epidemic disease at the global, national and local levels, we can better equip ourselves to deal with disease in all its manifestations, as it affects the world's poorest as well as those with access to the best preventive and curative medicine available.

What follows, therefore, is an attempt to make explicit some of the implicit assumptions that shape scientific and policy perspectives on and responses to epidemics, and global health more generally, today. Indeed in many respects, the story of swine flu as it unfolded during 2009 is a prime example of what Wald (2008) has termed 'the outbreak narrative': [this] begins with the identification of an emerging infection, includes discussion of the global networks throughout which it travels, and chronicles the epidemiological work that ends with its containment (Wald, 2008, p2). It is versions of such a narrative – in the case of swine flu and other recent epidemics – that have underpinned the mobilisation of vast scientific and policy resources and infrastructures. These are aimed at protecting and re-establishing what is increasingly portrayed as global health

security, defined by the WHO as a set of actions which 'minimize vulnerability to acute public health events that endanger the collective health of populations living across geographical regions and international boundaries' (WHO, 2007a). Such understandings of epidemic outbreaks and emergent diseases, albeit with particular nuances, are now well-established in media and public discourse, and in the arguments and strategies of international agencies and many governments.

Yet the outbreak narrative is not the only story to be told about the 2009 events around 'swine flu'. Behind the headlines, and emanating from people, places and perspectives not so prominent in the glare of global policy concern, are a range of other accounts. These include the story from Mexico, of a much longer-established pig influenza, and of the political economy of highly industrialised, intensive pork production methods and worker conditions which may have enabled its spread and species jump. They also include the case of Egypt, where politicians jumped on the World Health Organization's early labelling of the disease as 'swine flu' to call for a mass-culling of Cairo's pig population (Tadros, this volume). Alternative stories also encompass a view of H1N1 as a relatively mild influenza, with much in common with regular seasonal influenzas, and, like these, manageable through routine health care and available drugs – and unlikely to kill if these are used. But while such a narrative was, by late 2009, becoming part of the mainstream in many industrialised countries endowed with effective health systems, others were voicing fears about a different spectre for

other parts of the world: the devastating impact that a 'mild' disease in the industrialised world could have if it emerged, at scale, into places and populations which lacked effective, accessible health care – such as many parts of Africa.

These alternative stories about swine flu highlight how the particular 'outbreak narrative' discussed above is just one among many. How an epidemic is defined, in space and time, in terms of populations, institutions and interventions, depends on who gets to do the defining. There is always more than one way to tell a story, or 'frame' a particular issue. Within alternative narratives, the dynamics of a given disease, what counts as a problem, and to whom, can vary greatly. This extends to the very notion of an epidemic: whether disease incidence is 'unusual' or expected clearly depends on the place, timescale and vantage point from which it is looked at. From a perspective focused on disease specific interventions and biomedical control, epidemics are implicitly linked with the goal of disease eradication. From another perspective, the same diseases could be seen as part of the historical, geographical and social landscape, something to be accommodated when possible and occasionally suffered when not. Equally, the notion of 'emergent' disease clearly depends on perspective: what appears to populations of industrialised nations as an emergent disease from an 'other' place, affecting them for the first time, may actually have been long-established, and lived with, there – as it seems may be the case for 'Mexican swine flu'. But while a sensitivity to narrative reveals a diversity of such

framings, it also demonstrates their relative authority or dominance. In this sense, not all stories are created equal.

In such ways, narratives – in constructing disease issues in particular ways – frequently also construct people and populations, labelling and making moral judgements about them. Thus colonial assumptions about the backward, insanitary customs and lifestyles of poorer African and Asian populations which motivated often coercive public health campaigns in the early twentieth century (e.g. Vaughan, 1991; Manderson, 1996) find their contemporary counterpart in narratives which identify livelihood and lifestyle practices with the spread of disease. Such labelling often accompanies accusation. Some of these linkages explored in the following chapters include: African forest bushmeat hunters and Ebola; Asian poultry farmers and avian flu; people engaged in risky sexual behaviour and HIV; Christian garbage collectors and H1N1; and urban slum-dwellers and SARS (on the politics of disease and accusation, see Farmer, 1992; Farmer, 1999a; and Farmer, 2003).

In these ways, narratives about disease are also deeply intertwined with issues of power and social justice. The perspective from which a disease is understood, who is threatened, who is blamed, and who is called upon to change their ways can have profound implications for what is done, and who gains or who loses. The view of avian flu as a threat to global populations requiring large-scale culling of poultry, and a view of the same disease as a local problem that must be

lived with, has very different implications for the lives and livelihoods of backyard poultry farmers in places like Indonesia and Thailand and those of the inhabitants of industrialized nations.

A central proposition of this book, then, is that disease and epidemics are constructed through different narratives which justify and shape different pathways of response. Narratives, in this sense, are not just stories; they are stories with purposes and consequences. Narratives about epidemics matter because they shape the pathways by which certain responses—of institutions, healthcare practitioners the media and individuals— are justified and come to be dominant, with profound practical and material implications for how ‘successful’ responses are, gauged in which terms, and for whom.

Current concern with epidemics can be seen as another instalment in a long-running debate over how global health funds should be invested. Classically, this debate has been argued in terms of disease-specific programs on the one hand, and primary health care-oriented interventions, on the other. The thirtieth anniversary of the famous International Conference on Primary Health Care at Alma-Ata in 1978, which represented an apogee of the health systems approach, has led to some renewed soul-searching in the international community. The recent publication of the WHO’s annual report, titled *Primary Health Care: Now More Than Ever*, may indicate an attempt by that agency to swing the pendulum back to a focus on health systems strengthening, a year after its 2007 report, A

safer future: global public health security in the 21st century, on the increased security risks associated with disease outbreaks and epidemics (WHO, 2007a; WHO, 2008a). The big difference today is that the players in this drama have changed significantly, with civil society organisations playing a much more prominent role, and charities, the 'new global philanthropy' and public-private partnerships like the Global Fund and Gates Foundation investing far more money than the WHO or most individual nations can.

An approach to thinking about epidemics in terms of narratives and pathways thus provides a distinctive window onto some highly pressing practical and policy challenges. Understanding how epidemics and pandemics emerge and how they might be tackled have become major pre-occupations. Yet, we argue, current approaches are often restricted by implicit assumptions that provide only narrow, partial perspectives on the dynamics and experiences associated with epidemics. Important, multi-scale interactions between disease, ecology, society and politics are often inadequately addressed. Not incidentally, the perspectives of people living with disease are also often neglected. How effective will different responses be, given rapid changes in viral, social and political dynamics at a staggering range of scales, from the microscopic to the truly global? How will responses cope with the inevitable uncertainty and surprise? How will responses themselves feed back to shape the dynamics of disease? And who will gain or lose in the process? These are critical questions, and addressing them is vital to building pathways of disease response that are both effective, responsive to fast-

changing conditions, and socially just. Our central argument in this book is that doing so effectively requires a better understanding and appreciation of the multiplicity of epidemic narratives, and their links with actual and potential pathways of response. At the same time, we suggest that responses that take into account neglected perspectives, and neglected people, will be better for all of us because they will be more likely to address both the long-term and short-term drivers of outbreaks.

This requires bringing to light alternative narratives which may give voice to important yet neglected perspectives and priorities, including those of marginalised people and places. And it requires addressing the social, political and institutional processes through which narratives and pathways arise and are reproduced, and through which some come to dominate. As we argue, meeting contemporary disease challenges requires far greater attention to such social and governance processes, including the relationships between knowledge and power. It requires both an opening-up to acknowledge multiple narratives and pathways, and astute reflection on the potential priorities, trade-offs and complementarities between these in particular disease and social settings.

[a]Focal diseases

Diseases that are novel and threatening to those living in industrialized nations—such as SARS, Ebola and emerging influenzas - have garnered a

disproportionate share of policy and media attention in recent years. HIV/AIDS, understood as an exceptional disease requiring an exceptional response, has attracted resources which dwarf the budgets devoted to other health issues in many African and Asian settings. Yet the fact remains that lower-profile diseases cause far greater damage to lives and livelihoods, especially amongst poorer populations: 750,000 children a year in Africa die from malaria, until recently a neglected disease, and an estimated one in five of all child deaths globally is due to diarrhoeal diseases (WHO, 2008b; Wardlaw et al, 2009). Such diseases and their impacts warrant far greater research, policy and public attention.

This book, therefore, is organized around a paradox. While we argue that disease-specific policies and an epidemic focus tend to obscure narratives emphasizing long-term factors in the causes of epidemics and experiences of multiple, interacting health problems, we have nonetheless organised our book into case studies of particular epidemic diseases. One reason for this is that our contributors' expertise tends to lie within individual disease categories (a fact which itself reflects deep structuring tendencies within health and development studies). More to the point, by taking the bull by the horns in this way, we are also able to show, in some cases, how dominant certain narratives have become. The flipside of this is that having outlined such dominant approaches, our contributors can indicate more strongly what is left out of such accounts. What is left out, as the following chapters show, is often the chronic, the endemic, and the entrenched: the flipside of the exciting, if unnerving image of a fast-moving,

interconnected globe that animates many outbreak narratives. As the following chapters indicate, each disease is subject to a range of understandings, or narratives, with more on-the-ground complexity than a global outbreak narrative can capture.

The book is made up of case studies of seven diseases: Haemorrhagic fevers (Ebola and Lassa), SARS, HIV/AIDS, Highly-Pathogenic Avian Influenza (HPAI), tuberculosis, obesity, and H1N1 (or swine) influenza. These offer an important set of commonalities and contrasts in relation to our core concerns. All have, as we show, been understood as presenting epidemics – at least by some people and institutions, at some times. Several have starred in headline-dominating global outbreak narratives – including Ebola, SARS, HIV/AIDS, H1N1 and HPAI. These five infectious diseases have also been understood as newly-emergent – at least in some analysis. In TB, we have a different kind of case – an ‘old’ and endemic disease which is now re-emerging in new, drug-resistant forms. This is similar to malaria, a case which we do not include, but which is also an old, endemic disease now raising new concerns, as it threatens to make inroads into new areas made hospitable to mosquito vectors by climate change and as drug resistance even to Artemisinin therapies emerges. In obesity, we are looking at a ‘lifestyle’ disease, akin to heart disease, cancer or tobacco-related afflictions, rather than an infectious or communicable one. Yet obesity rates have risen with the speed of a classic epidemic. Taken as a group, this range of cases enables us to test the concept of epidemic quite strongly, viewing it from many different

angles and beginning to dismantle its significant parts. We see that some diseases with similar biological, ecological or epidemiological profiles are addressed very differently, while others which share fewer of these characteristics can nonetheless be grouped together in an analysis of responses.

These cases also highlight how disease definitions and characterisations can shift over time. They show how diseases come to be seen as epidemic, when they do, and how diseases may cross the boundary between epidemic and endemic multiple times. Each case study works to show how defining a disease as epidemic has implications for the most vulnerable members of a given population. HIV/AIDS, for instance, has been variously understood as a global pandemic, as a series of localised epidemics with distinct characteristics (Piot et al, 2009), and – most recently – as a chronic disease amenable to long-term therapy. Ebola, may look like a new, emerging disease from the perspective of populations of industrialized countries who feel threatened by it, but for many Central African forest people who have lived with the disease for generations it is more endemic than epidemic. In short, whether a disease is considered old or new, endemic or epidemic depends on the perspective from which it is viewed. The cases we have chosen highlight these shifting definitions, and the social and institutional processes which underlie them and flow from them.

[a]A pathways approach to epidemics

What, more precisely, do we mean by a narratives and pathways approach to epidemics, and how does the book develop it? In the following sections, we elaborate some key features (see also Leach et al, 2010). We combine a recognition of highly complex social-ecological-disease dynamics, with a constructivist view of how these come to be known and elaborated in policy and practice. We highlight how in certain cases, key narratives come to be overwhelmingly dominant in terms of what policies get implemented, while in others, superficial consensus masks a varied group of self-interested actors, with little practical effect. Diversity of narratives, we argue, is a key feature of the policy landscape for a given disease. At the same time, we recognize that there can be important gaps between the strength of the rhetoric used to convey a given narrative, and the practical, or material, effects of such an account, in terms of actual policy implementation. Put another way, while some narratives translate into pathways, others do not. Some remain merely rhetorical; others remain marginalized or even hidden. We introduce political and institutional issues important to considering why narratives take particular forms, which come to dominate, when and how; and whether and how they become linked with particular pathways of disease and response. And we consider the question of interplay between different narratives in particular settings.

[b]Complex dynamics

Humans and bugs have evolved together over hundreds of thousands of years; epidemics have always been a part of this shared history. A complex mixture of underlying conditions and precipitating events – biological, ecological, epidemiological and social – contribute to their emergence. Today technological interventions such as drugs, vaccines and other public health measures also contribute to the course an epidemic takes. Epidemics are thus part of complex, dynamic systems in which social, ecological and technological processes are inter-coupled (Leach et al, 2010; Bloom et al, 2007).

Appreciation of this is, we suggest, an essential starting point to understanding and dealing with epidemics. This requires broadening our perspective beyond the confines of particular disciplines, linking the medical and epidemiological perspectives which have tended to dominate analysis with insights from other fields, from disease ecology and environmental studies to anthropology, history, and science and technology studies. Our overall approach in this book is based on a commitment to integrating insights across disciplines, complementing recent social science work on global health, epidemics and emerging diseases (Kaufmann, 2009; Janes and Corbett, 2009; Castro and Singer, 2004; Singer, 2009; Nichter, 2008). The contributors bring a diversity of social science backgrounds, in some instances combined with training in medicine or ecology and on-the-ground development work, thus offering a range of perspectives within a broadly shared agenda.

Although mindful of the dangers of counterposing a dynamic present to a more static, stable past, it does appear that the acceleration of a range of biological, social, ecological and technological processes during the last half-century has contributed to contemporary epidemic challenges. These processes include the evolutionary dynamics of pathogens, as viruses and vectors exploit niches that become available through environmental, demographic and livelihood changes. There is growing evidence of the capacity of pathogens to rapidly evolve, challenging linear views of the relationship between human and disease ecology. HIV, for example, can generate more than 10^9 virions per day. Its mutation rate is around 10^{-4} mutations per nucleotide, some 10,000,000 times the rate for human DNA. Each affected person hosts a vast and genetically highly diverse virus population, posing immense targeting problems for the immune system and any conceivable drug treatment.

There are more people—and more domesticated animals such as poultry, pigs and beef—in the world than ever before and they are moving around at unprecedented rates. Both this growth and this mobility affects disease dynamics in complex and often unexpected ways. Much attention has focused on the more than two billion air journeys a year that make the isolation of a disease outbreak an increasingly formidable task.¹ But in some countries internal rural-urban migration is equally important. For example, 80-100 million Chinese constitute the so-called 'floating population', who work in the more prosperous urban areas and typically return to their family homes in poor, and possibly relatively isolated,

rural areas at least once each year to celebrate the Spring Festival. Similarly, according to conventional epidemiological models, bigger and more mobile populations increase the likely number of individuals infected by a given disease, and the probability that new pathogens or new strains of existing pathogens will arise via spontaneous genetic mutation within those human hosts. But the assumptions built into such models do not always reflect how specific social and cultural factors can significantly affect contact rates and disease transmission dynamics. Contact rates across population members can differ greatly: 'super-spreaders,' individuals with very high contact rates, can have a big impact on the course of an epidemic (Lloyd-Smith et al, 2005). As work on HIV/AIDS has shown so clearly, these social and cultural factors apply at all scales, from the most intimate aspects of bodily comportment and behaviour, to intra-household, community and wider societal norms and practices (Edstrom, this volume).

Human-animal demography also affects zoonosis, the process whereby disease passes to humans from other species. A relatively recent editorial in the *Lancet* ('Avian influenza', 2004, p257) states that 'all new infectious diseases of human beings to emerge in the past 20 years have had an animal source.' Given the huge reservoir of known and unknown pathogens in animal species, the number of such diseases has been predicted to increase (WHO, 2004a). Both wild and domestic animals are implicated in zoonosis. Thus for example the HIV-1 virus is assumed to have evolved from a very similar virus found in the wild chimpanzee species *Pan troglodytes troglodytes* (Gao et al, 1999), while a variety of

haemorrhagic fevers in African forest settings are associated with wild animal reservoirs in rats and bats. Domestic animal examples include the recent H1N1 'swine flu', while it has been argued that 'integrated pig-duck agriculture, an extremely efficient food production system traditionally practiced in certain parts of China, puts these two species in contact and provides a natural laboratory for making new influenza recombinants' (Morse, 1995, p11). While the wild populations of most species have been tending to decline in numbers, growth in domestic livestock populations has been rapid, mirroring that in the human populations which consume them or their products. In China, meat production has been increasing at a rate of nearly 8% per year for the past 25 years, with much of this increase occurring at the level of the 100 million peasant household-run farms, which still account for nearly half of all livestock production in the country despite a rapid growth in industrial scale farming operations (Li, 2009, p222).

The emergence and transmission of zoonoses are, then, also shaped by changing food production and livelihood systems that alter the intensity of contact between domestic animals and between people and animals. Where wildlife disease reservoirs and vectors are involved, environmental and land use changes that affect human contact with these become key. Attention has focused, in particular, on the environmental impacts resulting either from the 'invasion' of areas which have previously been sparsely inhabited or from radical changes in land use. For example, Greger (2007) associated the emergence and

spread of zoonotic hemorrhagic fevers in South America with the clearance of forests for crop or livestock cultivation over the second half of the 20th century. Lassa fever and Rift Valley Fever have been linked to deforestation and population shifts in Africa (Morse, 1995). Here the contributing political-economic dynamics have varied from dam construction to diamond mining and logging. For instance as roads have been driven into isolated and remote areas, increases in population and commercial activity to support logging operations have resulted in an upsurge in demand for bushmeat, wild animals killed, butchered and sold locally for food. It is now widely believed that this practice may have been responsible for the initial transmission of the HIV virus to humans and that the transmission of a range of retroviruses is 'a regular phenomenon and a cause for concern' (Wolfe et al, 2004, p932). Climate change, it is argued, is likely to bring further influences to ecosystem and land use patterns with major implications for disease emergence (Patz et al, 2005). The force of these interacting social, ecological and microbial processes has been termed 'socioemergence,' to indicate the inextricable linkages between supposedly social and natural realms (Hardin, forthcoming).

At different moments in history, technologies such as vaccines, drugs and even controversial chemicals such as DDT, have given hope for disease control and even eradication (achieved triumphantly, and so far uniquely, in 1977 for smallpox). By insinuating themselves into the complex dynamics of epidemics, these tools can also lead to new disease patterns, some of which are relatively

benign while others pose serious new risks, such as drug resistance. The emergence of MXDR TB is a case in point. Evidence of growing malarial resistance to artemisinin therapy is another; in this case recommended combination therapies, designed to avoid resistance, have proved very difficult to implement in fragmented, pluralised, health systems and social conditions in parts of Africa and South-east Asia. In Thailand and Cambodia, for example, the continued use of mono-therapies appears to have enabled resistance to emerge (Dondorp et al, 2009).

Thus the outbreak of epidemics, and their spread and impact, relate to how pathogens interact with a complex of social, technological, and environmental processes. These processes are highly interdependent and often context-specific. They are characterised by non-linear patterns of changes across time and space – including those that have the potential to turn small scale local epidemics into large scale global problems. Epidemics implicate a diversity of spatial scales – from the individual diseased body to the globe – as well as temporal ones, as short-term outbreaks interact with longer-term predisposing conditions, stresses and drivers. Some disease drivers and effects involve short-term shocks – as in an ecosystem ‘switch’ that triggers a sudden epidemic outbreak – while others involve longer-term trends and stresses. And disease responses themselves can feed back to shape these dynamics. We suggest that recognising such complex dynamics is a necessary starting point for understanding and dealing with epidemics.

This complex interaction of multiple dynamics—biological, demographic, ecological, economic, social, political, and cultural—operating at different scales and at different speeds results in deep uncertainties, and often ignorance, about likely outcomes and their consequences. It has been observed that all recent pandemic threats have taken the world by surprise. While it is often implied that this is because of lack of knowledge, poor scientific understanding, and inadequate surveillance systems that can be rectified by more knowledge, more science and more surveillance, we suggest that an appreciation of complex dynamics makes uncertainty and surprise inevitable. Building disease surveillance and response systems that are resilient in the face of such uncertainties is a major challenge.

[b]Framing and narratives

Crucially, though, different people and groups in society tend to understand and experience these dynamics in very different ways. The scientific perspectives of epidemiologists or ecologists, or the analyses of social scientists, offer only some amongst multiple ways of thinking about and representing disease drivers, impacts and why they matter. Other understandings may be linked to different policy networks, field practitioners, government spokespeople, international agencies or NGOs, or to networks or epistemic communities (Haas, 1992) that connect them. Different understandings again may emerge from the experiences,

knowledge and perceptions of people living with diseases on a daily basis, or as related to the influence of media, religious or other groupings. How epidemic problems are understood also relates to location, wealth, livelihood, gender and other factors which shape people's vulnerability both to disease, and to the effects of particular kinds of response. All accounts are thus in some senses partial and positioned (Haraway, 1988) - a point which also applies to the brief outline and exemplification of complex dynamics in the previous section. Reflexively, we must acknowledge that this could have been written in other ways, shining light on the issues from different angles.

It is such different ways of understanding disease dynamics, and their links to responses, that we explore in this book through the ideas of framing and narratives. By framing (Leach et al, 2010) we mean that system boundaries are always open to multiple forms of interpretation. Depending on which actors (working within which institutions and political contexts) are doing the framing, different forms of knowledge, different entities, and, indeed, different problems, will be considered relevant. Those which are framed outside can become effectively invisible when approaches and solutions are considered.

Recognising diverse framings in this way complements those traditions of work in medical anthropology and sociology which have long appreciated the significance of diverse worldviews about health. Whether discussed in terms of medical or therapeutic pluralism (Kleinman, 1988; Johannessen and Lazar,

2006) or diverse cultural models (Hewlett and Hewlett, 2008) it is well established that such understandings can encompass not just bodily and social dimensions of disease, but also their wider political dimensions (Williams and Calnan, 1996; Leach and Fairhead, 2007; Rose, 2006). Yet much of this work stops short at identifying competing worldviews and their social and political origins; their implications for policy and action are more rarely spelled out. In contrast we are interested specifically in how perspectives and worldviews come to inform and justify particular sorts of action and pathways of intervention and response.

This is where narratives come into play. Particular framings often become part of narratives about a problem or issue; simple stories with beginnings defining a problem, middles elaborating its consequences and ends outlining the solutions (Roe, 1991). Importantly, narratives justify and often become interlocked with particular institutional approaches to addressing health problems, and particular kinds of intervention; they become part and parcel of epidemics governance. Today, such governance arrangements are themselves increasingly complex and multi-scale, encompassing international agencies and global public-private partnerships, governmental and private sector institutions, and a variety of civil society and patients' groups.

For instance in the case of pandemic threats, various versions of an 'outbreak narrative' tend to dominate. These run along the lines that 'the global threat of a

pandemic and its consequences for massive mortalities and economic costs require substantial investments in surveillance, drug stockpiling and intervention in areas of the world where outbreaks originate, in order to protect us all.' This focuses on a particular framing of 'the system' and goals (global, aimed at protecting/reducing mortality amongst global populations), a particular interpretation of disease dynamics (sudden emergence, fast-changing, far-reaching spread) and a particular version of response (universalised emergency-oriented at-source control, aimed at eradication). Such a narrative has been typical of both the human health and veterinary international responses to HPAI and haemorrhagic fevers, for example, and has underlain at least some of the response to swine flu. This narrative calls upon particular kinds of knowledge and expertise – notably formal science and epidemiology – in diagnosing and solving the problem. This in turn has given rise to the plethora of initiatives and associated institutional arrangements focused on early warning, risk assessment, intensive surveillance, outbreak monitoring, pandemic preparedness planning, rapid response teams, contingency plans and so on.

There is nothing inherently 'wrong' with this narrative (both in terms of problem diagnosis and solutions), and there are many merits to the sort of response infrastructure that has been built. Yet in practice, there are several problematic tendencies. First, selective narratives can omit crucial factors and elements of dynamics that may be essential to effective and resilient responses, amidst the complexities of epidemics. Second, diverse narratives can undermine each other,

in ways that may lead to practical problems in implementation. Third (and in some degree of tension with the second tendency), in practice a few narratives tend to dominate, to the exclusion of others. Not surprisingly, these tend to be the narratives of powerful actors and institutions. In dominating, they may obscure alternative narratives which may provide valuable, complementary solutions.

Such alternative narratives may well be less coherent and explicit than those associated with powerful health governance arrangements. There are many alternatives to the emergency-response, 'outbreak' narrative. They include more localised, developmental models, which focus on active intervention in a particular setting to reduce disease risk and exposure. They include narratives about the longer-term changes, in environment, social conditions, or health systems, which underlie the emergence of particular outbreaks, linked to arguments and strategies to address these. They include narratives which give far more weight to 'indigenous' cultural models of disease causation, associated with particular logics and practices as to how transmission risks might be reduced. They also include stories where suffering, from disease and marginalisation, are part of a way of life, which, if not necessarily celebrated, is necessarily accommodated and integrated into the identity of a particular group. This variety of story-telling about illness and health brings with it a salutary diversity of understandings and responses. Taken together, all these narratives can help us to question our assumptions when it comes to the 'right' or 'best' way to tackle the serious challenges of disease in all its manifestations.

Narratives interplay in ways shaped by politics and power. Not all lead to response pathways. Some may remain marginalised or even hidden. The interactions between different narratives and the practices linked to them may involve convergence, complementarity, contestation, overt clashes, hard choices and trade-offs, or even a drama of dominance and resistance – as sometimes occurred, for instance, where local people have refused or resisted top-down public health campaigns that failed to meet their concerns (e.g. Yahya, 2006; Leach and Fairhead, 2007). How such interactions unfold clearly depends very much on context – of disease, of place, and of social and political setting. It also depends on histories and memories of past disease and intervention experiences. What is clear is that such interactions may, in turn, feed back to shape the dynamics of response, forcing a modification of pathways. For instance, local resistance to top-down imposition of health technologies may force approaches to be adapted. Emergent drug resistance – unanticipated in an internationally-sponsored roll-out, but plausible within narratives giving more weight to the uncertain consequences of pharmaceutical-microbial-market interactions in weakly-regulated health systems – might derail the best-laid epidemic response plan, forcing new strategies. Or, over time, initially contested narratives might come to converge, enabling new, more inclusive pathways.

It is these shifting narratives and pathways around epidemics, their interactions in today's complex world of health governance, and the implications for dealing with

epidemics and related challenges that are the central concerns of this book. How might the challenges posed by emerging and re-emerging diseases in a context of endemic poverty and illness, population growth and climate change be understood and met in ways that address both short-term and long-term needs of all the people of the world, including the very poorest? This is an ambitious question that brooks no tidy answers. The chapters that follow provide a sense of solutions that are available if we make ourselves both more critical of and more receptive to the narratives that shape our responses.

[a]Epidemic narratives and pathways in cases and contexts

As we have discussed, epidemic narratives and response pathways are deeply interlocked with processes of governance. Chapter Two sets the scene for those to follow by linking a set of dominant narratives about epidemics and infectious disease with what is often called the architecture, or organizational landscape, of global health policy. In particular, this chapter explores the effect of landmark revisions in the WHO's International Health Regulations, that entail significant changes for the way epidemics are governed at a global scale, embracing unofficial sources of information for the first time. Issues of coordination, integration and harmonization have accordingly come to the fore as the amount of data—and global health actors—has increased exponentially. The chapter analyzes how this new organizational and informational landscape and the framing of epidemic disease interact. Centrally, it explores what effect that

interaction has on the ability of the global health community to respond to disease threats of all kinds. It suggests that neither organizational complexity or 'openness' nor rigid lines of command-and-control can ensure resilience in the face of unpredictable risks. Instead, methods are needed to encourage feedback and integration between competing narratives of health and disease. Yet the character of these narratives, and the challenges of their interaction, vary greatly according to disease and context – as the next seven chapters explore.

Haemorrhagic fevers, the topic of Chapter Three, have come to exemplify popular ideas about highly contagious and often gruesome illnesses that emerge 'out of Africa'. Associated with wildlife vectors in forested environments, viral haemorrhagic fevers such as Ebola, Marburg and Lassa fever were the subjects of outbreak narratives in the 1990s, justifying rapid and sometimes draconian international policy responses and control measures. Leach and Hewlett contrast these first global outbreak narratives and the cultural models that inform them, with three other narratives that highlight outbreaks as deadly local disease events, as matters best managed with local cultural practices, and as requiring longer-term insights from both ecology and social science approaches. The chapter shows how each of these narratives highlights different temporal and spatial scales, validating different kinds of knowledge, and assigning cause, blame and vulnerability differently. Each suggests different pathways of response, involving different combinations of actors. Discussing the institutional

and power relations which have shaped their interaction, the chapter concludes by addressing both the potentials and the challenges of integrating them.

In Chapter Four, Bloom turns to Severe Acute Respiratory Syndrome (SARS), which has achieved iconic status as a potentially disastrous outbreak that was successfully controlled by a coordinated public health response. SARS emerged in Southern China in late 2002 and by August 2003 had caused 8422 cases and 916 deaths in 32 countries. After a short delay, the governments of affected countries and the international community mobilised a major response, which successfully contained the outbreak. Once the epidemic was controlled, its influence lived on in the form of competing narratives and their influence on the direction of development of national and international health systems. This chapter outlines three versions of the narrative about “*a big epidemic which might have been*”, addressing the preoccupations and interests of the international health community (and especially the WHO), the Chinese Ministry of Health and other policy actors in China, and, finally, the growth of a partnership between China and the international health community in matters of health governance. This chapter illustrates the high political cost to a national government of being seen to have responded inadequately to a new disease. It also provides an example of an effective multilateral response to a global challenge, when powerful forces in the United States favoured unilateralism. This chapter outlines how particular narratives about SARS influenced both the reform of China’s health system and the global response to potential epidemics.

The next two chapters, by contrast, explore a major pandemic which, for a variety of reasons, was not successfully controlled at the outset – HIV/AIDS. The overarching story of HIV/AIDS tracks some major shifts, from emergent zoonotic disease, to 1980s epidemic, to global pandemic, and finally to what some now characterize as a chronic, manageable disease. With this ‘older’ status providing an interesting counterpoint to other cases, the chapter by Edstrom tracks how such epidemiological shifts have co-evolved with contested perspectives on the social causes and consequences of AIDS, and what to do about it. Authored by a scholar who was personally involved with AIDS policy and grassroots activism throughout much of this period, the chapter ties a taxonomy of different narratives and approaches around HIV/AIDS to an overall historical account. This demonstrates how attitudes and approaches – in assigning agency and responsibility, prioritizing and targeting prevention and treatment, and locating the disease as an exception or a part of broader health and social systems - have shifted over time. In particular, the chapter explores how different narratives emphasize issues of risk and threat, justice and vulnerability in different ways. Yet these approaches operate in parallel as well as in series, generating a picture of a series of contested narratives, linked with different (though sometimes overlapping) sets of actors and institutions. The chapter reflects on the challenges of balancing the importance of both individual choices and agency, with larger-scale processes of population mixing, mobility, inequality and change.

The next chapter explores in particular the role of exceptionalist thinking in shaping HIV/AIDS narratives in specific settings in South Africa where the disease is said to have become 'hyper-endemic'. In particular, it considers how practical is it to concentrate on counselling and individual patients' rights in relation to HIV testing when rates of infection are so high and resources so scarce in these hyper-endemic regions. Macgregor examines the durability of the exceptionalist narrative in relation to HIV/AIDS at the same time as she reveals how rhetoric can be simply that, with practical action often diverging significantly from official procedure. Two case studies illuminate the complexity of on-the-ground interventions. The first focuses on the vexed issue of social assistance for people with HIV, and whether the disease should be defined as a disability even if people remain healthy, revealing the limitations of simple binary definitions such as chronic versus infectious disease. The second case study explores the changing roles of lay counsellors in the testing and management of HIV, demonstrating further how changes in the prevalence of the disease, and the resources available to fight it, make it impractical to meet minimum 'requirements' for informed consent. Whose interests, Macgregor asks, does the exceptionalist narrative serve? And which other perspectives on this complex hyper-endemic situation are not being heard?

Different ways of representing and responding to risk and uncertainty are a feature of epidemic narratives. The next chapter picks up on this particular theme

through the case of avian influenza. Scoones examines the role of risk and uncertainty in three overlapping 'outbreak' narratives which have framed the international response. First, a strong narrative links veterinary concerns with agriculture and livelihood issues, where responses have centred on veterinary control measures and industry 'restructuring' to increase biosecurity and reduce risk. Second, there is a human public health narrative. Here a combination of drugs, vaccines and risk-reducing behaviour change dominate the response. Finally, there is a narrative focused on pandemic preparedness, where responses focus on civil contingency planning, business continuity approaches and containment strategies. Each outbreak narrative is associated with particular professional, disciplinary, procedural and institutional parameters which define the way incomplete knowledge about the future – and so notions of risk and uncertainty - is approached. Across these narratives, surveillance is a common theme, and is defined and designed in particular ways, informed by these outbreak narratives. Using Stirling's framework for exploring incertitude, the paper argues that these narratives make potentially dangerous assumptions about the applicability and reliability of a risk-based surveillance-based approach to managing epidemics. The chapter concludes with a set of challenges for the recasting of surveillance for emerging infectious diseases which take on board these lessons from the international response to avian influenza.

Chapter Eight focuses on tuberculosis, and the recent emergence of multidrug-resistant strains (MDR-TB). It thus addresses a disease which is both 'old', with a

long latency period and also increasingly an element of the 'outbreak' oriented approach to global health. Nightingale considers the transformation of tuberculosis as a result of the interaction of social, microbial, ecological and technological processes. Following a discussion of early perspectives on tuberculosis and its shift from being framed as a threatening epidemic to a more controllable disease, the chapter gives sustained analytical attention to the more recent history of tuberculosis, including the co-emergence of HIV and MDR TB in the 1980s. In relation to MDR-TB, Nightingale discusses the rise of three narratives which are shaping responses. In the first, MDR-TB is understood as a potential national security threat, with marginalized groups such as infected Russian prisoners posing risks to global populations on their release. In the second, structural problems in healthcare globally which allow drug supplies to dwindle and treatment programmes, such as 'Directly Observed Treatment, Short Course' (DOTS), to falter are to blame for the growth in infection rates. According to this narrative, focussed technical solutions, backed up with sufficient funds and decisive government intervention, represent the best pathway to success. Finally, a 'structural violence' and rights-based narrative draws attention to issues of social justice, emphasizing context-specific interventions rather than generic top-down approaches. Throughout, Nightingale considers the relationships between poverty/inequality and pathogen evolution, and, as with the chapters on HIV/AIDS, their varying emphasis on vulnerability versus rights in relation to marginalized groups (such as prisoners and the homeless).

Obesity, the subject of Chapter Nine, has been encountered in many societies in many eras, but has only recently emerged as a key public health policy issue. Certain politicians and policy-makers have called obesity a 'lifestyle' disease of industrialised societies, and a modern 'epidemic.' Millstone therefore draws into the book's comparative frame what has been labelled an epidemic of a non-infectious disease, and moreover one emerging primarily out of North America and Europe rather than the less-industrialized world. Many of the disagreements about appropriate responses to the obesity epidemic focus on the attribution of responsibility – both for causation and for remediation. Positions taken in those debates vary across time, cultures and interests, and they are compounded by macro-social changes and culturally diverse perspectives. One important axis in the debate is marked by two competing framings: one that attributes responsibility for rising rates of obesity to individual choices and actions versus a contrary perspective that locates responsibility in features of the social and economic environment. A second axis concerns competing views on the potential role for governments: one narrative suggests that governments might have to intervene actively and extensively, while a contrary view argues that governments should play only a very limited or vanishingly slight role. As the chapter explores, these competing narratives have been put forward by different groups of actors – from scholars and activists to governments and the food industry. Issues of political economy are key in explaining the interactions between them, and the relative power of the response pathways associated with them at any given time.

Our final case study explores the dramatic response to the novel influenza virus H1N1, commonly referred to as swine flu, in Egypt. Tadros reveals how global outbreak narratives play out in national settings, with surprising consequences. In response to the perceived threat to its human population, in June 2009 the Egyptian government implemented a mass culling of all the nation's pigs following the declaration of an imminent global pandemic. These pigs were owned by Zabaleen, garbage collectors who were also members of the country's Christian minority. The Zabaleen used the pigs to sort and dispose of huge amounts of the nation's organic waste, supporting an informal but effective system of neighbourhood recycling and garbage disposal. Once the pigs were killed, garbage collection in the city effectively ground to a halt, leading to piles of rubbish accumulating in the streets; the phantom threat of swine flu being contracted from pigs was replaced by the real threat of illness caused by rotting waste. This chapter explores the nature of the mainstream narrative, propounded by members of the government and the mainstream media, that supported this severe response. In this dominant narrative, both religious justifications (about the inappropriateness of keeping pigs in a Muslim country) and scientific arguments for the cull were put forward. Tadros also reveals the neglected accounts of the Zabaleen about the effects of the cull on their lives and livelihoods, which were severely curtailed by the loss of the pigs.

In our concluding chapter we integrate the seven disease clusters considered in the book (Haemorrhagic fevers, SARS, Avian Influenza, HIV/AIDS, TB, obesity, and H1N1 influenza) into a comparative frame, explore cross-cutting themes, and draw out implications for the governance of epidemics and epidemic threats, now and in the future. By drawing these diverse cases together, we are able to offer a new set of reflections on the science, politics, governance and implications for social justice of epidemic responses. Approaches to dealing with epidemics, with endemic disease situations, and with the broadest questions of primary health need, we argue, to be more unified. While the language of integration and harmonisation has become prominent in global health policy circles, we suggest that so far not enough practical action has been taken to create responses that take into account the broad effects of illness and diseases on lives and livelihoods across the globe. Such an analysis is meaningful and necessary both because it is more socially just, and also because it is more likely to respond successfully to the complex multi-scale interactions that shape disease dynamics. Long-term changes and the lives and livelihoods of the poor matter even in situations where powerful policy narratives emphasise epidemic 'shocks' and top-down, rapid response. These alternative perspectives, we argue, need to move from the marginal into a mainstream where they too can shape pathways of disease response. By highlighting implications for researchers, national and international institutions, we aim to facilitate reflection on how the construction and implementation of responses might become more effective and sustainable for all the world's population.

[a]Notes

¹Source: <http://www.oag.com/oag/website/com/OAG+Data/News/Press+Room/Press+Releases+2006/OAG+Review+of+2006+030606>