

## Culture and health



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### Executive summary

Planned and unplanned migrations, diverse social practices, and emerging disease vectors transform how health and wellbeing are understood and negotiated. Simultaneously, familiar illnesses—both communicable and non-communicable—continue to affect individual health and household, community, and state economies. Together, these forces shape medical knowledge and how it is understood, how it comes to be valued, and when and how it is adopted and applied.

Perceptions of physical and psychological wellbeing differ substantially across and within societies. Although cultures often merge and change, human diversity assures that different lifestyles and beliefs will persist so that systems of value remain autonomous and distinct. In this sense, culture can be understood as not only habits and beliefs about perceived wellbeing, but also political, economic, legal, ethical, and moral practices and values.

Although culture can be considered as a set of subjective values that oppose scientific objectivity, we challenge this view in this Commission by claiming that all people have **systems of value** that are unexamined. Such systems are, at times, diffuse, and often taken for granted, but are always dynamic and changing. They produce novel and sometimes perplexing needs, to which established caregiving practices often adjust slowly.

Ideas about health are, therefore, cultural. They vary widely across societies and should not merely be defined by measures of clinical care and disease. Health can be defined in worldwide terms or quite local and familiar ones. Yet, in clinical settings, a tendency to standardise human nature can be, paradoxically, driven by both an absence of awareness of the diversity with which wellbeing is contextualised and a commitment to express both patient needs and caregiver obligations in universally understandable terms.

We believe, therefore, that the perceived distinction between the objectivity of science and the subjectivity of culture is itself a social fact (a common perception). We attribute the absence of awareness of the cultural dimensions of scientific practice to this distinction, especially for macrocultures and large societies, which define only small-scale, microcultures as cultural. We recommend a broad view of culture that embraces not only social systems of belief as cultural, but also presumptions of objectivity that permeate views of local and global health, health care, and health-care delivery.

If the role of cultural systems of value in health is ignored, biological wellness can be focused on as the sole measure of wellbeing, and the potential for culture

to become a key component in health maintenance and promotion can be eroded. This erosion is especially true where resources are scarce or absent. Under restricted and pressured conditions, behavioural variables that affect biological outcomes are dismissed as merely sociocultural, rather than medical. Especially when money is short, or when institutions claim to have discharged fully their public health obligations, blame for ill health can be projected onto those who are already disadvantaged.

As a result, many thinkers in health-care provision across disciplines attribute poor health-care outcomes to factors that are beyond the control of care providers—namely, on peculiar, individual, or largely inaccessible cultural systems of value. Others, having witnessed the ramifications of such thinking, argue that all health-care provision should, rather, be made more culturally sensitive. Yet others declare merely that multiculturalism has failed and the concept should be abandoned, citing its divisive potential.<sup>1</sup> Irrespective of who is blamed, failure to recognise the intersection of culture with other structural and societal factors creates and compounds poor health outcomes, multiplying financial, intellectual, and humanitarian costs.

However, the effect of cultural systems of values on health outcomes is huge, within and across cultures, in multicultural settings, and even within the cultures of institutions established to advance health. In all cultural settings—local, national, worldwide, and even biomedical—the need to understand the relation between culture and health, especially the cultural factors that affect health-improving behaviours, is now crucial.

In view of the financial fragility of so many systems of care around the world, and the wastefulness of so much of health-care spending, a line can no longer be drawn between biomedical care and systems of value that define our understanding of human wellbeing. Where economic limitations dictate what is feasible, socioeconomic status produces its own cultures of security and insecurity that cut across nationality, ethnic background, gender orientation, age, and political persuasion. Socioeconomic status produces new cultures defined by degrees of social security and limitations on choice that privilege some people and disadvantage others. Financial equity is, therefore, a very large part of the cultural picture; but it is not the entire picture. The capacity to attend to adversity—to believe that one can affect one's own future—is conditioned by a sense of social security that is only partly financial.

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**Systems of value** are political, moral, religious, economic, or social systems of meaning, either overtly expressed or taken for granted.

**Cultural competence** is defined as awareness of the cultural factors that influence another's views and attitudes, and an assimilation of that awareness into professional practice

In this Commission, we review health and health practices as they relate to culture, identify and assess pressing issues, and recommend lines of research that are needed to address those pressing issues and emerging needs. We examine overlapping domains of culture and health: **cultural competence**, health inequalities, and communities of care. In these three domains, we show how inseparable health is from culturally affected perceptions of wellbeing. After examination of these key domains, we identify 12 findings in need of immediate attention:

- Medicine should accommodate the cultural construction of wellbeing
- Culture should be better defined
- Culture should not be neglected in health and health-care provision
- Culture should become central to care practices
- Clinical cultures should be reshaped
- People who are not healthy should be recapacitated within the culture of biomedicine
- Agency should be better understood with respect to culture
- Training cultures should be better understood
- Competence should be reconsidered across all cultures and systems of care
- Exported and imported practices and services should be aligned with local cultural meaning
- Building of trust in health care should be prioritised as a cultural value
- New models of wellbeing and care should be identified and nourished across cultures

We believe that these points are imperative to the advancement of health worldwide and are the greatest challenges for health. Together, they constitute an agenda for reversal of the systematic neglect of culture in health, the single biggest barrier to advancement of the highest attainable standard of health worldwide.

### Culture and health

#### Introduction

On Feb 6, 2013, a crowd gathered outside London's Queen Elizabeth II Conference Centre across from Westminster Abbey. They were there to hear the verdict of the Mid Staffordshire NHS Foundation Trust commission that investigated the causes of hundreds of preventable patient deaths in just one NHS hospital system in the West Midlands between 2005 and 2009. On the day of the announcement of the commission's findings, aggrieved families, policy makers, and members of the press assembled to hear the results. They all wanted to know on whose shoulders the blame for this travesty could be placed. As the crowd listened, the commission's lead attorney, Robert Francis, announced that no specific group or person could be held accountable for such malpractice. The real villain was culture—culture caused these crimes of neglect to occur, and the culture of the UK's NHS was responsible.

As one newspaper put it: "The victims and their families were not happy. The culture of the NHS is not something that can apologise and try to atone. The culture of the NHS cannot be punished for its misdeeds. They wanted to see someone held to account. But the verdict was clear. 'It was', Francis announced, 'not possible to castigate: failings on the part of one or even a group of individuals'. There was no point in looking for 'scapegoats'. The guilty party was the 'culture of the NHS'. It was the culture that had ignored 'the priority that should have been given to the protection of patients'. It was the culture that 'too often did not consider properly the impact on patients of actions being taken'."<sup>2</sup>

However, members of the Care Quality Commission, the group that oversees health quality in the UK, were subsequently charged with participating in a "tick-box culture", "presiding over a dysfunctional organisation" with a "closed culture",<sup>3</sup> and were themselves partly held responsible for the failings of the Mid Staffordshire Trust. Culture, here, supersedes direct actions of nurses and doctors, hospital boards, local and regional health regulators, health policy makers, local and national politicians, and even referring family doctors as sources of blame. Indeed, responsibility is extended to the culture of the very commission established to regulate the effect of cultures of practice on health.

Nowadays, in assessments of health and health-care provision, to blame culture, however defined, is not uncommon. Culture, as this example shows, cannot be merely equated with ethnic group or national allegiance. We all participate in locally defined forms of behaviour that not only produce social cohesion, but that limit our ability to see the subjective nature of our values, our perceived responsibilities, and our assumptions about objective knowledge. In this context, the responsibilities of doctors and health systems, and the priorities of policy makers and researchers, are also collective behaviours based on social agreements and assumptions—ie, on culture.

Such examples show the degree to which culture cannot be ignored by science-oriented clinicians, disease specialists, and policy makers, making clear the need to understand the effect of culture, however defined, on care for one another in the 21st century. To understand culture and what it means is crucial to improvement of health, which is why disciplines that once focused solely on the study of other societies are, now, central to our future health and wellbeing. Today, anthropological and medical humanities approaches to health and wellbeing are necessary to reshape our understanding of how we conceptualise health and what makes us healthy.

#### What is culture?

The anthropologist Robert Redfield once elegantly defined culture as "conventional understandings, manifest in act and artefact".<sup>4</sup> This definition is useful because

it focuses not only on shared understandings, but also on practices that are based on those understandings and that make sense of beliefs held in common with others. Culture, therefore, does not equate solely with ethnic identity, nor does it merely refer to groups of people who share the same racial heritage.

Redfield's definition is also helpful because it does not imply that all members of a group that share languages, practices, and overt expressions of belief automatically share a given value, nor that local ideas can be readily translated across or even within a given group. For example, we can say that a particular society has conventional knowledge about medicinal plants, but clearly this fact does not imply that such knowledge is evenly distributed between all members of that society. Furthermore, local healers could hold specialist knowledge, but the benefits of that knowledge would be available to anyone who visits them for assistance. Moreover, the effects of that knowledge could vary widely across encounters with those healers, and what that knowledge suggests could also vary between various healers themselves when, say, they question a finding or diagnosis. The same applies, of course, to surgeons, nurses, and dentists, and so on. Their practices and values vary broadly, even in western Europe and the USA, where biomedicine is sometimes thought to be uniformly practised. Germans might define low blood pressure as an illness as much as a health benefit; North Americans might use antibiotics to excess; and French people might spend government health funds on spas and homoeopathy.<sup>5</sup>

To say that culture is about shared conventional understanding does not, however, imply that the cultural dimensions of the behaviours of any group of people are always subscribed to or overtly understood from within. For example, a group may perceive itself to care for the elderly while failing to address the actual needs of ageing. Moreover, members can regularly—and wrongly—assume that their own practices are universal, rather than particular. Monotheists, for instance, might customarily think of religion as a belief in God, whereas for many people, religion is not the belief in any single, omniscient being at all. This example is a social convention—something widely evidenced (even assumed to be universal), but not often consciously questioned or critically examined. Cultural systems might, therefore, not be overtly expressed, but their effects can be ubiquitous, including in daily scientific practices. Not only hospitals, but universities, scientific laboratories, global health charities, and government agencies all have their own cultures, although they might seem less obviously cultural than the kinds of cultures anthropologists traditionally study. However, because they are sometimes more covert, their unexamined effects might actually be greater.

More than a century ago, the sociologist Émile Durkheim separated empirical facts (what we see and

evidence) from social facts (what we assume when our beliefs remain unchallenged).<sup>6</sup> For Durkheim, the things we take for granted are foundational to our existence, even if, or perhaps because, we do not always recognise them. They transcend our capacity for self-criticism, yet exercise a continuing effect on us that is inversely proportional to our awareness of them. Indeed, groups of people rarely believe that their moral perspectives are relative, and their awareness of how much their values are cultural only becomes clear when those values diverge from, or are in conflict with, other values that they do not agree with.

The effect of culture might therefore seem overt when a clinician attempts to care for someone from another society, but when we think of how culture affects behaviours in a hospital, we might not view such activities as cultural in nature. When we speak of, for example, the silent majority, we are referring to shared values and categories of thought that survive in a largely uncritical manner; this silent majority is made up of the beliefs, habits, ways of life, ideas, and values of a majority that might not feel the need to express these values overtly because they are not overtly challenged. For this reason, cultural values can become more obvious when members of a group are faced with practices and beliefs that vary substantially from their own. Culture is made up of not merely those variable behaviours and practices that a group understands itself to possess and articulate daily, but those that are covert and taken for granted. Accordingly, anthropologist Fredrik Barth once metaphorically called culture an empty vessel—ie, a concept defined at its peripheries.<sup>7</sup> The vessel's walls are tangible—they separate inside and out, and give shape to contents that might be less easily defined.

Most importantly, culture is a dynamic concept—sometimes overtly expressed, sometimes not openly defined. For example, citizens might rally around national identity in times of conflict, but happily return flags to their cupboards in times of peace. Likewise, they might fundamentally believe in human equality, but participate actively in **prestige hierarchies** in their places of work. Because it is often taken for granted, culture as a category of inquiry is crucial to the experience of health and wellbeing, and the provision of health care.

Culture, then, can be thought of as a set of practices and behaviours defined by customs, habits, language, and geography that groups of individuals share. As the UN Educational, Scientific, and Cultural Organization (UNESCO) affirms<sup>8</sup> in its adoption of anthropologist Edward Burnett Tylor's 1870 definition of culture,<sup>9</sup> we need to find ways to develop a complex understanding of how customs, moral values, and belief systems manifest themselves in particular settings over time. Here, particularly, a medical humanities approach could be used to reshape medicine and health care.

**Prestige hierarchies** are hierarchies created by real or perceived differences in status and authority, and acted out in a defined environment, such as a clinic or hospital

However, the difficulty of acknowledging the importance of culture does not alone enable us to recognise our own cultural assumptions. Indeed, the hardest thing to know in a relative and comparative sense might be one's own culture: what anthropologists call the anthropological paradox. On the one hand, we believe that it takes one to know one; whereas, on the other, we acknowledge that the hardest thing to know is one's own culture—ie, to critique objectively the subjective nature of our own practices.<sup>10,11</sup> This difficulty accounts for why culture remains, for many, a vague concept. By definition, being immersed within a culture can be hard to recognise.

This dimension of culture is seen in the initial NHS example, and is crucial to our major claim: the systematic neglect of culture in health and health care is the single biggest barrier to the advancement of the highest standard of health worldwide. Although we accept, along with the Francis Commission,<sup>12</sup> the accountability of culture for clinical malpractice, we also suggest that examination of culture holds the key to good practice. Not only are the things we find most difficult to examine the things we take for granted. When a society's own objectivity is compromised by local practices and covert understandings, we begin to understand why culture matters in ways that affect us all.

We believe the time has come to revise common views of culture as overtly shared and largely unscientific ideas and practices. Culture can as much concern what we take for granted and do not critique—what we assume is universal—as what we understand at the level of social diversity. We therefore recommend the following definition of culture:

The shared, overt and covert understandings that constitute conventions and practices, and the ideas, symbols, and concrete artifacts that sustain conventions and practices, and make them meaningful.

### Why culture matters

In 1952, the French anthropologist Claude Lévi-Strauss led a study<sup>13</sup> commissioned by UNESCO to address the issue of racism and the threat that it posed to world peace and stability. In the period after World War 2, when colonial values were still common, the project provided a direct attack on ethnocentrism and its assumptions about the superiority of one society over another. Lévi-Strauss “warns against genetic determinism, reveals the fallacies of ethnocentrism and facile cultural evolutionism, defends the rights of small societies to cultural survival, and revels in the intricacies of the symbolic systems of societies to most of his readers”.<sup>13,14</sup> Embedding these concerns into a key UNESCO document by a leading anthropologist assured that the idea of culture would inform contemporary views of multiculturalism, cultural competence, and the value of social diversity. UNESCO's perspective on cultural rights became the foundation of how health rights are now defined multiculturally.

But to defend local cultures, and especially to appreciate how culture affects local ideas about health and related health outcomes, is not always easy. Since Lévi-Strauss' report, UNESCO has struggled to mediate between the need for universal human equality and the right to harbour diverse worldviews, and it has been criticised for its perceived ambivalence. Indeed, its policies (embodied in its 1995 report)<sup>15</sup> reignited the right-to-culture debate by promoting “a relativistic view of development and a universalist view of ethics”.<sup>14–16</sup> In short, the difficulty with respecting local differences while promoting health universalism is that under such conditions, culture can be used “to legitimise not just exclusiveness, but exclusion as well”.<sup>14</sup> Apartheid, for instance, is an intolerable form of multiculturalism—separate but unjust, rather than separate and just.<sup>17</sup>

Although Lévi-Strauss' document<sup>13</sup> provided a basis for decision making about culture, no-one knew at that time how globalisation would affect the dissolution of cultural diversity. The 1950s was the era of salvage anthropology, in which anthropologists were charged to record dying cultures and their local social practices. At that time, people needed to recognise the benefits of indigenous knowledge—of how surgical practices, for instance, might be advanced through understanding the Amazonian use of curare to paralyse muscle tissue.

But as globalisation continues, cultural diversity decreases, denying us not only the benefits of genuine differences, but also the different kinds of knowledge that characterised humanity in former times. Many of the estimated 6000 languages still spoken across the world are rapidly disappearing. Many are now only spoken by a handful of people, and a unique mother tongue dies every two weeks.<sup>18</sup> The failure to preserve cultural diversity might not only be incalculable, but also rob humanity of the very alternatives it so desperately needs—not only from the standpoint of indigenous knowledge about the natural world and the cures such knowledge might hold, but also in terms of models of cooperation and trust that have been lost on modernity. As cultural diversity and biodiversity give way to global homogeneity, both other ways of thinking and potentially important ethnopharmacological resources are jeopardised.

Nowadays, issues not recognised when Lévi-Strauss wrote for UNESCO<sup>13</sup> affect how we see the benefits of diversity. There was, for instance, no way of knowing how indigenous rights issues would come to be legally tied to court cases involving the return of indigenous property,<sup>19</sup> or of anticipating how new definitions of culture would encourage racial use of biological markers to establish indigeneity,<sup>20</sup> or of predicting how both would contribute to contemporary stereotyping of health-related behaviours by well-intentioned clinicians and culture mediators working to improve clinical competence.<sup>21,22</sup>

Because of these complex difficulties, many people now maintain that we no longer need Lévi-Strauss' form of structural anthropology, nor the idea of autonomous

cultures, to understand, account for, and acknowledge how meaning is constructed locally.<sup>23,24</sup> After all, how do we engender the moral trust needed to cross ideological boundaries, if not by faith in what the Brundtland report in 1987 called “our common future”—ie, by a focus on our uniformity rather than our diversity?<sup>25</sup> Furthermore, what constitutes culture in a globalised world where differences are often only annoyances to be ameliorated and levelled?

For many people concerned about global health, culture is less important than addressing political and socioeconomic inequality, even perhaps a thing best de-emphasised, if not wholly forgotten. We completely disagree. Worldwide equality can only be achieved by recognising cultural systems of value and countering the idea that local cultures are obstacles to worldwide equality. Indeed, a failure to acknowledge culture leaves its negative effects unaddressed and its positive potential for providing new models of thinking unrealised. Ignoring culture prevents each person from feeling like he or she belongs to a local moral world.

Culture in itself is neither good nor bad. Thinking about cultural systems of value often helps, but sometimes hinders, the amelioration of differences between people. When culture works unchecked to exclude and discriminate, an effort should be made to uncover practices that are taken for granted so that they can be changed. When culture creates moral bonds that increase commitment and empathy, endeavours should be made to understand how those bonds improve wellbeing and health, and how they might provide future models of care.

To dismiss, however, that culture is ever-present—for example, that the universalism of science can be opposed to the local prejudices of culture, or that worldwide goals should take priority over local ones—is to blind us to our own vanity and the exclusionary ways in which even the best-intentioned individual can unknowingly behave. In times of social dysfunction, people with a public voice might come to share more with one another as an emerging culture of worldwide elites (irrespective of their views) than with the incapacitated others with whom they might otherwise share an ethnic, religious, or racial heritage, or with whom they identify morally.

Although suffering and compassion are often discussed, if carers are ignorant of what brings value and meaning to another’s life, it becomes difficult to make life better when illness undermines health. For example, irregular antenatal visits and reluctance to attend common screening tests are well-known issues across the world, adversely affecting maternal and infant health. Findings from a study<sup>26</sup> of south Asian women done in the UK showed that, contrary to health professionals’ beliefs, non-adherence to these visits and tests had little to do with negative attitudes towards antenatal care. Instead, the women merely lacked

informed choice. By contrast, findings from another study<sup>27</sup> in Nigeria showed that women booked their first appointments too late because all clinical care was deemed curative and seemed to offer no advantages for a healthy mother. Here, participation in health care was mediated by ideas about the cultural meaning of care. Finally, in a study<sup>28</sup> of use of folic acid supplements during pregnancy in Arab and Turkish ethnic populations, underuse was associated with economic pressures on pregnant women rather than because participants were neglectful or lacked information. These are just a few instances of how the investigation of stereotypical views of—wrongly presumed—culturally influenced behaviours can have a real and lasting effect on clinical encounters. Unless we address local models of wellbeing that might differ from what we assume to be universal, we have no way of understanding the day-to-day behaviours on which good health and wellbeing depend.

It is important, then, to understand how wellbeing is socioculturally generated and understood, and how cultural systems of value relate or not to notions of health and to systems of care delivery. Because wellbeing is increasingly recognised as both biological and social, health-care providers can only improve outcomes if they accept the need to understand the sociocultural conditions that enable people to be healthy and make themselves healthier—ie, to feel well.

To achieve such an understanding means asking what is lost to health care by ignoring the cultural systems of value of not only patients, but also caregivers, health administrators, charities, and researchers. Thus, in this Commission, we assess how a closer attention to local and worldwide meanings can improve health in a world of burgeoning health-related costs and diminishing resources. We critically examine what is known about how caring for one another succeeds or fails across cultural divides, how cultures of care function or collapse in response to changing values, how health cultures alternately ameliorate or exaggerate inequality and inequity, and how health itself is affected by the presence or absence of general wellbeing in any given sociocultural group.

In this Commission, we assess the nature of cultural competence (how people communicate across cultural divides), the adverse effects of health inequality (how culture can unequally limit opportunities to become healthier), the structure and function of communities of care (how collective activities around health either succeed or fail), and the social conditions that undermine or improve human wellbeing (how personal health relates to the presence or absence of social trust). This Commission is less an inventory of culture-specific definitions of illness and healing (ie, of traditional medical anthropology) than an assessment of why cultural awareness matters in health.

## Cultural competence

### Background

Although an interest in other societies has taken many forms throughout history, examination of how different cultural concepts affect health-related behaviours began only at the start of the 20th century, with the advent of long-term anthropological fieldwork that exposed the diversity, complexity, and continuity of local health-related practices across cultures.<sup>29</sup> One of the earliest clinicians to take up the comparative method for examining the influence of culture on health was William Rivers, the pioneer doctor and social anthropologist who is equally remembered for his work as an experimental psychologist. Rivers both founded the *British Journal of Psychology* in 1904 and became the first person to use double-blind trials in scientific experiments. Ironically, this development of double-blind trials eventually led to the use of placebos to eliminate social meaning from clinical trials, thereby making possible a wholly biomedical field of inquiry. The complete elimination of social affect, it could be argued, is what created modern biomedicine as we know it.

However, for Rivers, culture mattered greatly. He was unequivocal about why culture is important to medicine, stating that health and beliefs are:

“so closely inter-related that the disentanglement of each from the rest is difficult or impossible; while there are yet other peoples among whom the social processes to which we give the name medicine can hardly be said to exist, so closely is man’s attitude towards disease identical with that which he adopts towards other classes of natural phenomena.”<sup>30</sup>

Although Rivers might be credited with laying the foundation for the ethnographic study of culture and health, medical anthropology as a taught discipline is much more recent, dating mainly to the advent of consciously multicultural societies, the decline of overt colonialism, and failures resulting from the unilateral export of untenable models of development across the world. Likewise, the idea of medical humanities can be traced to the 1940s and the work of pioneering medical historians such as Henry Siegerist. Although a thorough understanding of medical humanities can enrich one’s awareness of how health is defined across cultures and over time, medical anthropology in particular shows how systems of medical knowledge are a result of both the natural environments within which cultures develop (eg, the use of particular medicinal herbs) and local understandings of people, the cosmos, and what constitutes acceptable (ethically and morally) forms of behaviour.<sup>31,32</sup> Although medical anthropologists do still focus on exotic beliefs and practices, now they just as often ask how sets of beliefs (both familiar and unfamiliar) affect their illness behaviours in their own societies.

We cannot consider in this Commission the complex explanation of such processes, but the reader should bear

in mind how a basic idea—eg, the notion of divine judgment—can have an important effect on how an individual might deal with, for example, chronic disability.<sup>33–36</sup> Similarly, ways of thinking that at first seem foreign and exotic might seem less so once one understands how complex beliefs and practices overlap to produce coherent and consistent forms of meaning.<sup>37</sup> In many societies—especially those in which malnutrition is ubiquitous—obesity is often mistaken for health,<sup>38</sup> whereas in other cultures (Brazil, for instance) the right to be beautiful (as it is culturally defined) might extend to plastic surgery for poor people.<sup>39</sup>

Beliefs about the body that might baffle physicians—for example, the idea that diseases are the consequences of ancestral actions—might parallel new and emerging ideas in science about epigenetics, symbiosis, disease vectors, or evolutionary principles.<sup>40</sup> Different theories about illness become more familiar as their merits are investigated. This fact explains why many medical anthropologists are clinically trained and why many clinicians take up medical anthropology. When illness is at stake, the appreciation of these factors by caregivers and their ability to communicate with those they care for becomes important.

These are not the only reasons why clinical competence should include cultural competence. By the 1970s, the value of clinical communication and, particularly, caregivers’ understanding of patients’ individual backgrounds, were not only understood, but also quantified. In 1975, the importance of communication for clinical competence was shown by the results of a study<sup>41</sup> that compared effectiveness of face-to-face interviews with both physical examinations and laboratory tests for achievement of clinical accuracy. In 66 of 80 patients (83%) “the medical history provided enough information to make an initial diagnosis of a specific disease entity which agreed with the one finally accepted”. If 83% of all correct diagnoses can be made by taking of a complete medical history from the patient, why are clinicians so often held to brief and often routine clinical encounters?<sup>42</sup> And why has this fact not been taken into account during assessment of the costs and health benefits of what happens in the clinic?

Some say testing has increased for entirely non-clinical, but quite cultural, reasons. *Scientific American* commentator John Horgan puts it bluntly:

“Over-testing undoubtedly stems in part from greed. Most American physicians are paid for the quantity of their care, a model called ‘fee for service.’ Doctors have an economic incentive to prescribe tests and treatments even when they may not be needed. Physicians also over-prescribe tests and treatments to protect themselves from malpractice suits.”<sup>43</sup>

According to Ezekiel Emanuel, the yearly cost of health-care provision in the USA was almost US\$8000 per person.<sup>44</sup> Emanuel invites us to compare this

expense with the entire GDP of China, the world's second-largest economy:

"China's G.D.P. is \$5.9 trillion (compared to America's \$14.6 trillion). So the United States, with a population a quarter of the size of China's, spends just on health care slightly less than half of what China spends on everything...If we continue at this rate of growth, health care will be roughly one-third of the entire economy by 2035—one of every three dollars will go to health care—and nearly half by 2080."<sup>43,44</sup>

But if laboratory investigations are not cost effective, why are they used instead of reallocating resources so that clinicians can spend more time with patients? Is it because health care has become an increasingly predatory business endeavour? Is it because biomedical cultures have become overly devoted to testing practices? In what way, for example, might health-care cultures in the USA be called caring when fees for services become the number one cause of personal bankruptcy?<sup>45</sup> Perhaps most importantly, why has culturally relevant research—now 40 years old—been systematically ignored in restructuring health delivery procedures and delivery costing?

As the authors of the 1975 study concluded long ago:

"Firstly, physicians can allocate the relative time spent taking the history and examining the patient with some confidence, knowing that the extra time spent on the history is likely to be more profitable than extra time spent on the physical examination. Secondly, more emphasis must be placed on teaching students how to take accurate histories in a medical clinic, and proportionately less on showing them how to elicit physical signs. Thirdly, more emphasis must be placed on research into communication between the patient and his physician, and perhaps less emphasis is needed on the development of new laboratory services. Fourthly, there are implications for the planning of medical outpatient departments. There needs to be more emphasis on space for interviewing patients, and proportionately less on space for examining them. Our findings also have implications for the number of follow-up appointments that need to be given to patients who seem to present diagnostic problems. It seems that if the physician is still in considerable doubt about the diagnosis after the history has been taken and the patient has been examined, then laboratory investigations are unlikely to be helpful."<sup>41</sup>

Health economists should quantify the potential savings from allowing clinicians time to gain accurate case histories. Provision of such time would also increase a physician's sense of worth, and might even help limit the high levels of mid-career disenchantment. However, such savings could have a negative effect on investment in for-profit health, where clinical care is routinely exposed to service delivery models and physicians are sometimes referred to as health-care vendors. As this neglected study made clear, saving time in the short term will not translate into saving money.

Despite the age of this study, its findings are still relevant. What health-care delivery culture is being

promoted worldwide by emulating business practices that need immediate financial returns on investment without any responsibility for long-term outcomes? We call for a resurrection of respect for caregivers who are wholly capable of saving money and lives, if given the time to show their abilities to do so.

### Clinical adherence

Although competence is generally understood as the ability to implement recognised standards of best practice, what constitutes competence in medicine is far from clear.<sup>46</sup> Martin Talbot,<sup>47</sup> for example, questions the competence model of medical education, claiming that it sometimes rewards low-level or operational competencies at the expense of "reflection, intuition, experience and higher order competence necessary for expert, holistic or well developed practice". By contrast, Betancourt and colleagues<sup>48</sup> think of competence as a means to address organisational, structural, and clinical barriers to health-care access and provision faced both by physicians and those who seek their help.

Although cultural competence training has roots going back to the 1960s, it almost never figures in the training of public health organisation employees, and has only been formally integrated into medical education since the 1970s, arguably in response to calls for new medical models that address the shifting demographics caused by migration.<sup>49,50</sup> In most training, however, it is not present, even if the view prevails that cultural competence can improve clinical outcomes by addressing the needs of those who are different from whatever dominant sociocultural groups provide care.

Cultural competence and diversity are vaguely defined, poorly understood, and prone to being affected by political rather than educational motives.<sup>51</sup> Conventional understanding of cultural competence that emphasises recognition of racial, ethnic, and linguistic identities shifts clinical meaning away from socioeconomic factors and standard clinical diagnoses. Cultural competence is surely far more than a vague umbrella term that encompasses training in cultural sensitivity, multiculturalism, and cross-culturalism.<sup>52</sup>

Research into diverse health views of speakers of non-native languages has furthered understanding of just how wide ranging health needs are around the world. This research seeks to prevent medicalisation of ethnic groups on the mistaken assumption that because they might fare less well clinically they are less willing to comply with and adhere to treatment regimens.<sup>53,54</sup> Substantial scope exists for further research into these areas, particularly for studies that critically explore how ethnic origin and language proficiency can be rightly or wrongly held responsible for clinical non-adherence.<sup>55</sup> The need for this research is especially clear when health-care providers consult in multiethnic communities, where the need for translation is essential.<sup>56,57</sup> Language mediates most experiences of health-care services for

patients.<sup>58</sup> These services include not only face-to-face consultations with health-care practitioners, but also language-specific medical leaflets, health-related television programmes, and, increasingly, health advice on diagnostic websites and online discussions.

However, intercultural health communication is not only about language translation, but also situated beliefs and practices about causation, local views on what constitutes effective provision of health care, and attitudes about agency and advocacy.<sup>59</sup> It is also about understanding communities of care and how they function at a local level to ameliorate uptake and overuse of expensive services. In one north London community (Tottenham and North Middlesex) studied for this Commission, more than 50% of the community health organisations functioning in 2010 were shut down as a result of government withdrawal of support for their services. Ignorance of the social needs of patients therefore has real knock-on effects. Who is quantifying

the real loss in both social and financial terms, let alone in terms of mortality and morbidity?

However, health and culture deserve attention not only from the point of view of patients and health-care professionals, but also in relation to increasingly diverse non-medical staff, including social workers, receptionists, telephone and internet respondents, and care administrators who function as service gatekeepers. These providers might participate in their own professional cultures that are as diverse as or even more diverse than the patients and communities that they serve. The responsibility for advancement of cultural awareness in health-care practice should not be borne solely by those who deliver direct care, nor should responsibility only be seen as a community issue, and therefore non-clinical.

Because competence involves understanding how barriers to better care can be overcome, practices should be improved and more responsive (and responsible) clinical cultures should be created. Competence is highly anthropological, embracing culture less as static and stereotypical than as something always in the making.<sup>60</sup> At its best, cultural competence, then, bridges the cultural distance between providers and consumers of health care through an emphasis on physicians' knowledge, attitudes, and emerging skills.<sup>61-63</sup> Competence is about creation and growth of meaningful relationships.

Competence, therefore, demands attention to both patients' and carers' explanatory models and perceptions of illness and wellbeing. The importance of such an explanatory models approach has been widely recognised and adopted as a structure for competent practice to include the following questions:

- What do you call this problem?
- What do you believe is the cause of this problem?
- What course do you expect this problem to take? How serious is it?
- What do you think this problem does inside your body?
- How does this problem affect your body and your mind?
- What do you most fear about this problem?
- What do you most fear about the treatment<sup>64</sup> (panel 1)?

Frameworks that bridge cultural distance might be the necessary first step in reconciling divergent illness perspectives held by health-care providers and patients; but merely establishing commonalities is not sufficient. Social competence is also relevant when patients and their doctors share knowledge that is taken for granted; when physicians and patients share too common a language for the description of illness and disease, patients might end up with poorer understandings of their disorders, with incorrectly assumed agreement.<sup>77,78</sup> Again, competence is about making relationships meaningful enough to limit the damaging effects of suffering. Mutual understanding provides a foundation for affective caring, but time and space should be provided for such new forms of clinical care to emerge and take root.

#### Panel 1: The Cultural Formulation

The most pressing challenge for mental health therapists working with different cultures is to develop a sensitive and culturally viable method of improving the wellbeing of psychologically marginalised people. The *Diagnostic and Statistical Manual of Mental Disorders* (DSM)-IV<sup>65</sup> (1994) and DSM-IV-text revision<sup>66</sup> (2000) of the American Psychiatric Association introduced, as an appendix, a method that used culture as the main focus for the generation of a clinical rapport between therapist and patient. The 1994 inclusion was the first attempt to promote widely what is now called the Cultural Formulation.<sup>67</sup>

In this formulation, the patient is asked to develop a life story—ie, a culturally embedded biographical narrative.<sup>64</sup> The story forms the focus of the therapeutic environment. Published alongside a glossary of culture-bound syndromes, the formulation can mitigate some of the difficulties associated with psychiatric assessment and diagnoses of patients from ethnic minorities whose frames of reference sometimes differ greatly from those of their therapists.<sup>68</sup> Its application is also effective for treatment of any illness for which cultural differences have an effect on care.

Although the full clinical effectiveness of the Cultural Formulation has not yet been established, results of trials have shown promise for clinicians engaging, assessing, and treating those in need by taking into account local contexts and forms of meaning.<sup>69</sup> Derived from the insights of medical anthropology,<sup>70</sup> the formulation represents an attempt to transcend biomedical frames of reference that are often incompatible with individual ideas of being unwell.<sup>71</sup> As a result of its acknowledged potential,<sup>72</sup> the Cultural Formulation has been integrated into the 2013 DSM-5.<sup>73,74</sup>

Although the new DSM-5 version of the Cultural Formulation enables mental health-care providers to assess the potential effect of cultural factors on development of mental illness, further elaboration (Bloomsbury Cultural Formulation)<sup>75</sup> invites caregivers to establish common ground with patients by providing personal narratives that mirror those of patients. Such reciprocal engagement therapeutically acknowledges both the perceived alienation of those in need and the cultural divide that has to be transcended to achieve good outcomes.<sup>76</sup> This expanded version of the Cultural Formulation therefore directly addresses a continuing criticism of the DSM, namely that it fails to acknowledge its own cultural orientation, maintaining a singular view of the causes and meanings of mental distress.



Competence needs to include knowledge of how to develop new ways to evoke clinical meaning and acceptance that meanings can differ.<sup>79</sup> Whether or not competence involves physicians developing clinical variables that encourage patients to make their own choices,<sup>80</sup> competence in culture needs production of clinical spaces within which misunderstandings can be bridged.<sup>81,82</sup> Caregivers need time to create meaning, saving unnecessary expenses.

Competence is the nurturing of communication between caregivers and patients to remove barriers to care.<sup>50,63</sup> Therefore, cultural competence can no longer be considered only “a set of skills necessary for physicians to care for immigrants, foreigners, and others from ‘exotic’ cultures”.<sup>61</sup> Moreover, cultural competence should not concern itself exclusively with perceived differences. Culture is less successful when it functions as a medium through which medicine translates clinical realities to uninformed others than when it produces new social circumstances that successfully contextualise clinical knowledge. A new technique called the Bloomsbury Cultural Formulation<sup>75</sup> exemplifies such a commitment, and should be reviewed carefully for its potential application in all clinical settings (panels 1 and 2).

### Competence and evidence-based medicine

Although a glaring need exists for cultural competence awareness and training in both public health policy and clinical care, the cultural determinants of health behaviour need to be better understood and compared with prevalence rates that suggest genetic causes of illness in ethnic and racial minorities. Although the central goal of evidence-based medicine is to reduce disease burden through measures that have been proven to be both effective and efficient, it is rarely associated with sociocultural factors affecting disease burden and outcome.

Because values and behaviour are largely socially conditioned, to understand the cultural factors that influence treatment-seeking behaviours and treatment adherence is crucial to maximise health outcomes. A strong evidence base for the treatment of diabetes, for example, enables doctors to reduce the effect of symptoms, but only if patients present themselves for treatment. Likewise, accurate advice on management of diabetes will improve the patient’s health, but only if the patient puts the advice into practice.

Health care, therefore, fails to be effective if patients either do not make use of health care to which they are entitled or do not adhere to treatment regimens. Type 2 diabetes is a case in point—for a disease whose major causes are known (as are rates of mortality and morbidity, preferred treatments, and modes of prevention), compliance is only between 40% and 60% even in the most privileged economies,<sup>89</sup> with findings from studies in Scotland, for example, showing that

only a third of patients adhere to therapeutic recommendations (in the Tayside Region).<sup>90</sup> Evidence-based approaches to practice have long recognised that research evidence and clinical skills alone are not sufficient to achieve optimum outcomes. Treatment decisions often need risks to be weighed, such as the decision between an aggressive or conservative approach to management of a disease by care provider, patient, and health services and funders. Good quality care should therefore integrate “best research evidence with clinical expertise and patient values”.<sup>91</sup>

Even in the narrowest biomedical models of health care some form of cultural competence is needed to frame and present information so that patients can make choices in line with their goals, values, and beliefs

### Panel 2: Medicalisation of culture and mental health

The *Diagnostic and Statistical Manual of Mental Disorders (DSM)-5* of the American Psychiatric Association (APA) preserves the omniscience of the caregiver at the expense of the patient’s understanding. Surprisingly, this criticism has been most strongly levelled not by medical anthropologists,<sup>83</sup> but by the British Psychological Society (BPS) in an open letter to the APA:

“clients and the general public are negatively affected by the continued and continuous medicalisation of their natural and normal responses to their experiences; responses which undoubtedly have distressing consequences, which demand helping responses, but which do not reflect illnesses so much as normal individual variation.”<sup>84</sup>

In effect, the response shows what the BPS felt to be the potential medicalisation of normal behavioural variation.<sup>85</sup> However, the issue is not just about creating illness from individual variation, but also from cultural variation—where otherwise acceptable cultural ways of thinking are themselves redefined as illnesses. Indeed, much of medical anthropology has been devoted to explaining how cultural practices (eg, states of possession) can provide acceptable cultural mediums for expression of anxiety, loss, and helplessness.<sup>86</sup> This difficulty has been identified for decades by medical anthropologists,<sup>87</sup> yet psychiatry continues to assume a position of omniscience with respect to cultural diversity.

To put it another way, what the BPS accused the new DSM-5 of promoting was the medicalisation of human diversity whenever and wherever symptoms seemed to vary from the DSM’s own cultural norms—ie, where symptoms could be identified as subjectively unique. In short, the BPS was openly accusing the APA of falling victim to its own cultural prejudices by defining as symptoms whatever behaviours did not conform to the dominant North American behavioural model from which the DSM emerged, and by allowing for diagnoses that rely on value-laden, subjective judgments that showed little or no evidence of being caused by biological mechanisms requiring pharmaceutical treatment. What is equally difficult is the fact that the DSM’s diagnostic categories, according to the BPS, have no predictive value,<sup>88</sup> leaving as many as 30% of all personality disorders to be characterised as “not otherwise specified”.<sup>87</sup> Such a high percentage creates the risk of defining as an illness any form of behaviour that seems unusual to a psychiatrist lacking cultural sensitivity.

Why has the APA now endorsed as pharmaceutically treatable forms of behaviour that merely seem at odds with North American biomedical models, to the degree that cultural differences themselves now stand at risk of being even more readily medicalised? How should growing concerns about the culture-specific nature of diagnoses affect the APA’s claim that the DSM’s diagnostic categories transcend cultural barriers? In our opinion, worldwide wellbeing goals and the tendency to treat diverse culturally valued behaviours as new illness categories need to be redressed.

about their own ability and the effects of their actions. From the caregiver's perspective, cultural factors cannot be ignored by labelling them as non-clinical or non-evidential because much of what is clinically possible is set by these very factors. Patient empowerment and related self-help strategies are useful only for those who believe that they have the capacity to affect health by taking responsibility for themselves; for those who do not feel—or are not—empowered, quite different strategies are needed to improve wellbeing, and these strategies, in general, rely on opportunities for person-to-person engagement and building of trust.

Because competence is about identification and interpretation of the unknown, it has not been furthered, and might have been hindered, by an exclusive focus on medicine's evidence base. Although development of best practices from what has already been tested is laudable, an obsessive focus on evidence also means valuing what is known at the expense of what is not yet known, what might not be known, or, indeed, what might not ever be clinically knowable. A thing in the making, by definition, cannot be fully known by straightforward recourse to existing formulas or normative theories.<sup>92</sup> Curiosity is key to innovation. Use of normative decision-making techniques can, therefore, have disastrous effects. This issue is shown by many well-intentioned, competence-improving initiatives that teach culture reductively, exacerbating already harmful stereotypes.<sup>92,93</sup>

Although anthropologists try to avoid approaching culture as stereotypical and fixed, many medical educators do not. Medical school initiatives and caregiver training programmes often reduce individual behaviours to broad stereotypical formulas, or at least encourage such stereotyping by applying specific behaviours to categories of people. Broad truths might exist on which such generalisations are based—for example, many German people relate low blood pressure to a weakening of the heart, and fear it more than most. But generalisations should be accepted cautiously, with the realisation that individual responses to norms vary widely. One of our main concerns, then, is the question of whether something as dynamic as culture can be effectively known from within the highly normative theories of engagement that are central to medical education. Culture, including institutional cultures, should therefore be examined carefully and rigorously.

To establish what is and is not culturally normative, broad generalisations run the risk of defining cultural lifeways as themselves pathological, with indiscriminate application of normative stereotypes to diverse beliefs, patterns of acting, and systems of meaning. Sensing the presence of a shared value relates little or not at all to how a member of a society might or might not respond to that value. Cultural competence courses can as much inadvertently strengthen culturally associated stereotypes that physicians hold about patients, thereby making it more difficult for doctors to perceive their own biases and

the effect that these could have on diagnosis and treatment decisions.<sup>94</sup> Training courses need themselves, therefore, to be developed competently.

Cultural competence training at its worst creates an idea of culture as a thing “made synonymous with ethnicity, nationality and language”,<sup>64</sup> and that can be taught as though it can be satisfied using a checklist—do this, not that. Under such conditions, doctors who have been trained in cultural competence can often misattribute cultural reasons to patient issues, rather than recognise that patient difficulties can be equally economic, logistic, circumstantial,<sup>64</sup> or related to social inequality.

Those studying health care need to appreciate what is as yet unknown and the processes by which new knowledge can be obtained. To teach culture as a fixed perspective on illness and clinical behaviour risks the promotion not only of mediocre care, but also of poor strategies to address difficulties that emerge in socially complex treatment environments. Such practices and assumptions are especially harmful because they are exacerbated by health-care students' insecurities about knowledge and evidence. They are also made more harmful when educational hierarchies encourage students to emulate authoritatively their senior doctors who themselves might be at odds with the relevance of culture.

### Mistaking compliance for competence

Many medical students believe that equality of care is best ensured by a doctor's refusal to use ethnic, racial, or religious characteristics as clinically salient diagnostic criteria. In doing so, these students support Dogra's<sup>51</sup> claim that the a priori acceptance of racial and ethnic distinction by doctors is, by nature, problematic. Yet, difficulties arise if doctors insist that patients present themselves in ways that doctors understand as culturally neutral. To ask female Muslim patients to remove their veils during diagnosis, for instance, or to request that a family of Hasidic Jewish patients not bring food into hospital might seem only to ignore the relevance of religious affiliation. But those who find these practices meaningful deem such requests hostile. Although to blame culture is problematic, the fact that culture is factored out of clinical settings might merely show some acknowledgment of the extent to which it is inherently so difficult to assess.

Most students are encouraged to equate competence with achievement of clinical compliance—culturally competent doctors are those who learn to use the **social capital** of patients, families, and communities to achieve measurable clinical results. Such models of care,<sup>64</sup> which increasingly conceptualise doctors as health-care vendors, only succeed when goals set by managers and administrators are similar to those of patients. However, they will not solve issues generated by deep social difference.

Rigid conduits for giving care in which doctors invariably emerge as non-patient-oriented replace personal

**Social capital** is defined as the valued social networks and reciprocal social bonds that sustain human engagement and cooperation

relationships and clinical freedom. Mid-career dissatisfaction and depression are common in health-care workers as patient distrust of providers grows.<sup>95</sup> Care recipients increasingly perceive novel patient empowerment programmes as attempts to devolve responsibilities from caregivers to the patients themselves. For example, packaged service programmes can widen gaps for those who cannot access them, leaving the poor to be blamed while the wealthy are treated as consumers with assets to spend. In HIV public health messages, for instance, patients in high-income countries are repeatedly informed that their infections are manageable and that they are healthier than they might think; whereas campaigns in low-income countries barrage the so-called uninformed patients with messages about how they are less healthy than they could possibly imagine.<sup>96</sup>

Under such circumstances, what can students be taught? In the worst cases, they are taught that patients will agree if doctors speak positively, look the patient in the eye, and exude whatever warmth and closeness might be needed to cajole patients into following therapeutic instructions. Although such enforced behaviours might sway patients under specific clinical circumstances, they do not show clinicians how patients will behave outside of the clinic. And while patient–doctor interactive training can produce an immediate expression of compliance on the part of patients in doctors' offices, doubts about treatment effectiveness can re-emerge soon after patients leave the clinic. Polite patients who go on to ignore the agreement that the physician thought had been established in the clinical encounter are later labelled as non-compliant, when in fact the physician mistakenly thought he or she had convinced the patient to follow his or her instructions. Such misunderstandings do little but reinforce sociocultural stereotypes.<sup>97</sup> Although humanitarian concerns might, then, drive competence training, compliance issues are sometimes viewed as a managerial annoyance.

However, active patient and user engagement improve care when other compliance and adherence strategies fail.<sup>98,99</sup> For this reason, social encounters cannot be wholly replaced by technical innovations because in the best cases, student health providers (doctors, nurses, midwives, and therapists) learn that therapeutic encounters are events in which outcomes can be improved by genuine care. They also learn that respect and esteem are key factors to assist patients in discovering new meaning through the suffering that illness creates. Much of social science has devoted itself to showing how new kinds of meaning can be created when patients and carers work together and are mutually respectful.<sup>100</sup>

In view of the brevity of competence training and the limitations placed on health-care providers, one might reasonably ask whether a little knowledge is a dangerous thing. This difficulty is compounded by short-term managerial demands for outputs, creating little time for cultures of care to emerge. To unpack such goal tending

takes time, trust, and patience—therapeutic time for both patients and doctors, but also for managerial overseers who otherwise haunt clinical encounters, leaving caregivers and patients fearful, if not depressed. In this regard, the system needs to change, as health-care administrators and policy makers are in much need of critical study. Such large-scale difficulties in the culture of care are not easily addressed, and new approaches to teaching competence in medical schools therefore vary substantially.<sup>30,101,102</sup>

To rethink cultural competence is a challenge. Cultural competence is caring competence. Not only does it include an awareness of diverse patient needs, it also demands some awareness of medicine's own cultural practices, including its prejudices, assumptions, and institutional values. Those professionals who are at odds with such hierarchies often find their motives questioned. Rural primary care doctors, who openly acknowledge the importance of social work, regularly complain that their treatment strategies are perceived as time-wasting and second-class by hospital-based colleagues.<sup>103,104</sup> Nursing has become so undesirably subservient that some countries cannot survive without a massive influx of immigrant caregivers into their workforces. Even the invention of family practitioner subspecialties has not helped,<sup>105–107</sup> frequently leaving family practitioners to be lumped in with countercultural or other forms of so-called alternative medicine.<sup>108</sup>

In short, cultural competence is the tail end of a much bigger issue involving professional prestige hierarchies, a scarcity of education, and basic cultural ignorance on the part of medical educators. If medical schools need to make ends meet by indirect revenues on grants and profit-making clinical services, and by a dependency on philanthropy, why should they be focused on education, health promotion, or a curiosity about the great unknown that other viewpoints represent?<sup>109</sup> Cultural awareness and competence should not be a secondary concern for health-care trainees, but an essential element of training and research into training—something fully and centrally supported as an educational and research priority.

Medical training institutions need to change if they are to promote clinical competence. Not only should administrators and training staff become more aware of their own cultural practices, but they should take culture more seriously than whatever subspecialties are presently drawing the most attention of those in training. Moreover, they should show clear evidence that such initiatives are substantive and genuinely supported by training staff. Training institutions should stand up for the rights of future caregivers to learn and implement new ways to provide care through training that is extended and exploratory. If professional schools object on the grounds that students already have far too much basic science knowledge to absorb, then new care-mediating professions should emerge on an equal footing in terms of academic status and financial remuneration.

## Culture, inequality, and health-care delivery

### Dynamic inequalities

Societies and groups (cultural, political, or professional) are built on consensus and conventional, often taken for granted, practices. These groups can become vulnerable in periods of great change and when exposed to external and internal stressors. Especially in unstable times, groups tend to focus on social and cultural differences rather than similarities.<sup>110–112</sup> Although the views of individuals within societies, and the practices of those individuals that are based on diverse views, can vary widely, generalisations about perceptions of wellbeing can be measured collectively and become

salient within broad populations as a result of cultural values. Broad cultural attitudes can vary over time and place, just as social determinants of health can vary from culture to culture.

The ancient practice of understanding oneself by differencing ourselves from others is, in part, what makes people social and enables local alliances to emerge.<sup>113</sup> When societies are stable or moving towards stability, they are naturally less concerned about what they perceive to be outside influences.<sup>114–116</sup> However, assimilation of those perceived to be outsiders (however one might define them) becomes difficult in moments of political instability, social insecurity, and crisis.<sup>117–122</sup> Americans who once invited in the tired and poor might attempt to ring-fence themselves after 9/11, and in the UK, Prime Minister David Cameron might even proclaim that “multiculturalism has failed”, asking in turn that physicians become gatekeepers for the identification of irregular migrants<sup>1</sup>.

Indeed, exclusion of outsiders in moments of perceived duress is not limited to nations and majority groups—the same tendency to discriminate is equally evident when health-care workers discriminate against other kinds of health work as less important; when health authorities perceive non-biological interventions as expendable; and when advocates of global health criticise local practices as insufficient or unprofessional. To perceive different cultural practices as sources of trouble occurs especially when those who represent dominant forms of care provision feel threatened and vulnerable. In these circumstances, the biomedical validity of other cultural practices (and notions of health and wellbeing) can be challenged outright (panel 3).

However, although contemporary biomedicine is quick to see itself as universal,<sup>126</sup> in some countries as much as 85% of a population self-medicates without the benefit of biomedical care—ie, do not participate directly on a daily basis in worldwide biomedical culture and the professional networks of biomedical practitioners.<sup>127</sup> Indeed, most people choose their own forms of medical treatments because biomedical provision is absent.<sup>128,129</sup> Although this majority might rely on local, indigenous remedies, inauthentic and out-of-date pharmaceuticals, or products and interventions that have unknown effects, it nonetheless can be made up of individuals who have strong views about wellbeing and health. The idea that biomedicine is able to address the ills of the world is therefore a fundamentally cultural notion. An understanding, then, of how culture plays out in disadvantaged societies and groups can enable people to go beyond simplistic arguments that focus exclusively on the benefits of worldwide financial equality, while also holding important answers to overwhelming health-care delivery challenges (panel 4).

In a healthy society, both outsiders and upwardly mobile professional achievers can nourish, inform, and

### Panel 3: Multiculturalism and the limits of governance

In May, 2012, a regional court in Cologne in Germany defined male circumcision on religious grounds and without medical indication or legally valid consent of the circumcised as bodily harm and thus liable to prosecution.<sup>123</sup> The ruling outlawed a religious ritual central to Jewish and Muslim faith communities on the grounds that state law needed to protect the basic right of children to physical integrity. By doing so, the Cologne court made a continuation of Jewish and Muslim religious life impossible.

In the ensuing debate, health-care professionals argued both for and against the ruling. Mathias Franz (University of Düsseldorf, Germany) claimed that the damage inflicted on the body and the long-term psychotraumatic effects of circumcision outweighed their religious significance. The German Academy for Paediatrics avoided a clear statement, but pleaded in favour of new legal provisions respecting both a child's physical integrity and the religious sensitivities of their parents. The highly respected Deutscher Ethikrat, a committee advising parliament on medical ethics, was unable to reach an agreement on how to reconcile religious freedom with protection of children from religiously motivated surgical practices.

Beyond the importance of male circumcision to both faith communities, the fact that Germany would have been the first and only nation in the world to outlaw the practice weighed heavily in the debate on the fault lines of religious commitment and cultures of care. An all-party committee in the German parliament developed legislation, passed with an overwhelming majority on Dec 12, 2012, that legally protects male circumcision on religious grounds, introducing basic medical requirements for the procedure.

Courts worldwide have studiously avoided adopting the term male genital mutilation in an effort not to confuse the practice with the more debilitating forms of female circumcision (now universally called female genital mutilation), which have affected the lives of roughly 125 million women worldwide,<sup>124</sup> and have been condemned by many Islamic legal bodies, WHO, the World Conference on Human Rights, and the UN. In fact, female circumcision has been outlawed in most countries.

Many followers of the debate believed that the German reversal on similar grounds was mainly a function of the country's historical need to honour Jewish identity practices, rather than the fact that to make male circumcision illegal did more harm than good, or that most German citizens strongly support the need to protect the basic right of children to physical integrity. By contrast, circumcision is promoted in the USA on the grounds that it might prevent HIV.

When does the human right to physical integrity give way to cultural or religious values, or a perceived health advantage? More troubling still, why has legal protection for females been so universally adopted despite actual practice, whereas the male right not to have surgery exists virtually nowhere and has now been legally removed in at least one otherwise progressive political environment? Why has the practice for females continued in so many countries where governments have felt the need to outlaw it but have done little or nothing to prevent it?<sup>125</sup>

reshape conventional practices; in stable times, a society can withstand people who put themselves forward to represent its needs in universities, medical schools, and positions of political authority. However, in moments of cultural insecurity, many citizens will fear both newcomers and the upwardly mobile who could come to be seen as asking more from people in need than they believe that they can give. Under such conditions, a group's altruism is seriously jeopardised by its own social insecurity. Here, both caregivers and educators might find themselves targets of resentment. When a society becomes unstable, people who seek out advancement and prestige—especially in education and in health—can be perceived to have placed themselves above a widespread disillusionment.

Likewise, although individual views of trust vary substantially in any society, broad measurement of trust is possible. Politicians are the least trusted people in many settings, but not in all cultures. Social pressures, and pressures from outside in particular, can be felt collectively and give way to collective action that would be deemed unacceptable in other times and places. When a society is under pressure, it might not be capable of producing the trust needed to tolerate the difference that outsiders represent, or even the insiders who challenge notions of social and economic class through their career and life choices. At the level of culture and health, the tendency is logical: when groups find themselves in flux and unstable, the less fortunate are often not met with empathy, but with impatience and disregard. Simultaneously, the personal gains of the upwardly mobile are, by the less advantaged, easily confused with alien values, and criticised as such.

Especially in contemporary biomedicine, career choices have immediate effects not only on the lives of individuals making them, but also on those being cared for, and on society in general. For example, in a long-term study<sup>104</sup> of more than 240 rural primary care doctors in North America, physicians reported spending up to 60% of their professional time providing non-biomedical attention to patients. These physicians thought that such caring was an important aspect of clinical care. Indeed, they openly resented being treated as less competent by hospital-based and university-based specialists, including not only their supposedly more highly trained peers with greater authoritative voice and professional status, but also health administrators who punished them financially for spending too much time on so-called social welfare.

More research is therefore needed to assess the effect of educating health-care professionals to believe that their best opportunities are at prestigious centres of excellence. In socially and financially unstable times, few health-care workers believe that they have the luxury to be working in remote rural areas, with the dispossessed and poor, or even with elderly people who can seem demanding and burdensome. Away from the bright lights of world-class research institutions, caring

becomes increasingly unattractive and career prospects diminish as career challenges increase in disciplines of care now deemed less promising.

This focus on upward professional mobility has implications on the ground—ie, at the level of basic primary care. First, people who lack influence in health-care provision are not heard. Second, health-care professionals who do choose to work in places of high need and less prestige increasingly pay for that choice in terms of status and economic reward. And finally, as upwardly mobile health-care workers—be they doctors, educators, researchers, or medical anthropologists—succeed, they might be thought of as doing so at the expense of those they purport to represent, participating as much in a society's inequalities of achievement as changing them.

### Sick societies

In the *Problems of the World*,<sup>132</sup> the UN summed up the worldwide price of modernity. Asked to provide single words that corresponded to the difficulties characteristic of various societal domains, respondents painted a sorry picture. For “culture”, the response was “rootless”; for “politics”, “powerless”; for “economics”, both “jobless” and “ruthless”; and for the “environment”, “futureless”.

#### Panel 4: Masking biomedicine

The fact that between 85% and 90% of citizens self-medicate even in countries claiming widespread primary care provision<sup>130</sup> means that what appears to constitute a system of organised biomedical care could well mask both an absence of regulation and a workforce of caregivers who remain almost wholly untrained.

For example, findings from a study<sup>131</sup> in rural Madhya Pradesh, India, show that 67% of health-care providers have no medical qualification whatsoever and, perhaps worse, adherence to checklists and related best practices differs little between trained and untrained doctors. The nature and scope of the issue suggest that merely arguing for more medical providers is inappropriate. Although 70% of rural primary care visits are carried out by providers that have no formal training (15-times as many providers have no qualifications as those who do), training is not even correlated with higher-quality care. Findings from the study, in fact, showed no meaningful variation between the ability of trained and untrained health-care workers to provide an accurate diagnosis or correct treatment.

The assumption that quality of care in rural India is, therefore, higher for trained doctors should be openly questioned so that, at the very least, the culture of primary care in India focuses more on the training and practice of caring than on the availability of expensive drugs and equipment.<sup>131</sup> Findings from this study call for a much broader debate<sup>125</sup> and beg a fundamental moral question: should systems of care be promoted that cannot be implemented or sustained? Furthermore, is self-reporting on the presence or absence of primary care an adequate means of assessing levels of care provision? Is it morally acceptable to expect countries with limited health infrastructure to adopt systems that are not only unworkable, but that also hide the depths of destitution into which so much of the world has fallen? Should WHO reassess standards of health so as to take account of the worldwide absence of clinical competency? How can we work openly to achieve the eight Millennium Development Goals if some of the data for care provision used to assess benchmarks do not take into account an assessment of levels of competency?

**Panel 5: Uncaring cultures**

A third of the world's wealth is owned by 0.001% of the world's population—a new culture of people who owe no personal or country allegiance.<sup>137</sup> They are seen every day in London, New York, Paris, and Hong Kong. Like a Las Vegas gambler, they have substantial bluffing power because their chips are not in the stable reserves of local banks or recorded by any tax collector. In fact, no government knows how much they have available to gamble and bluff others. The crippling effects of hidden money are visible when even the wealthiest countries cannot afford health care for everyone, when otherwise taxed resources remain offshore and out of sight.

However, the creation of communities of care is not merely a matter of taxation of the wealthy, but also of knowing where resources are, where goods are produced unfairly at the expense of poor and disadvantaged people, and where so-called flight capital—hidden capital that is globally mobile—ends up. Here, the difficulty of knowing where that wealth resides is compounded because its location shifts, sometimes daily. Such increasing disparity has led some to describe modernity as the new Middle Ages, in which health care (because it depends on collective good will) often suffers most.<sup>138</sup> If you leave people to sink or swim, they drown if they cannot swim in the first place. A basic capability to affect one's destiny needs to be nourished if people are to empower themselves.

When asked what one word summed up the condition of the modern world, the sentiment could not be more troubling: “meaningless”. Classical social theory offers a term to describe this sense of futility. That term is anomie—an absence or decrease of ethical standards, a kind of “psychological as well as physiological weariness, disillusionment, disappointment, psychic pain, and a tendency to grope at random, which in turn brings on still other crises, until life itself seems ‘intolerable’”.<sup>133</sup> It is a state not only common amongst many groups and societies worldwide, but also pervasive in mid-career health-care providers.<sup>134,135</sup>

Social scientists recognised long ago the dangers of combining social disillusionment with social expressions of ego and self-interest, a danger that can escalate when social conditions seem threatened by what is thought to be the all-consuming needs of minorities and immigrants. At such moments, a group—a community, a culture, or a society—cannot feel confident about its own resilience because it finds itself caught between its own anxiousness and the need to overstate its exclusive identity. At such a time a group is in danger of becoming actively exclusive.

Although we should abhor inequality, the problem of exclusivity might have less to do with levelling inequalities than with recognising inequality in the first place; for equality is always relative. People will often perceive grades of inequality more intensely when they feel insecure. However, since security and insecurity are defined and changed by cultural systems of value, a concern about culture should supersede a concern about social inequality. When societies become wholly undone, people with high social status—eg, academics, doctors, or health activists—can find themselves held in suspicion precisely because they are perceived as having unequal advantage. Here, calls for equality by the advantaged becomes culturally intolerable. Doctors were horrifically

persecuted by Pol Pot's regime in Cambodia during 1975–79,<sup>136</sup> as are Red Cross volunteers in war-torn regions. In many poor countries, caregivers are perceived locally as having unfair prestige and advantage, possessing access to what others desperately need. In a so-called sick society, people can fail to trust the very caregivers whose efforts they fundamentally rely on.

Advocates of equal opportunities applaud the focus on and attention to the social determinants of health and the incapacitating of individuals to affect their own futures that results from poverty. How can we expect poor people to be motivated when they lack social capability and opportunity? With respect to inequality, culture is often perceived negatively—ie, as an excuse to not acknowledge straightforward oppression. “Aren't traditional cultures so happy to live with so little?”, the tourist sometimes asks. Indeed, even UNESCO guidelines ask for restricted development in world heritage sites.<sup>15</sup> The temptation is to think of culture more as a barrier to equality than as a method to understand poverty. However, if culture is not thought of as an ever-changing process of creation and maintenance of social alliances—as something always in the making—people might well fail to see how new financial elites form their own cultural networks that increasingly undermine and erode the ability of states to provide basic health care. Indeed, only once new worldwide wealth is understood as a cultural form will we see how disempowered normal forms of health governance have become (panel 5). Although the basis of a healthy society is arguably citizens' trust in governments and institutions,<sup>139</sup> in times of great economic stress and societal change—as when governments implement strict austerity measures—trust can be paradoxically eroded through the very actions designed to enforce fiscal responsibility. This erosion is what John Maynard Keynes called the “paradox of thrift”,<sup>140</sup> and health-care providers would do well to consider his views of the long-term damages of short-term fiscal improvement.

Indeed, when governments design publicly structured systems of health care and social welfare behind which lie for-profit private providers, public trust might be impossible to generate because the main aim of these providers is to compound gains for investors by giving less. This structural relation is precisely the opposite of what Keynes recommended. When publicly funded welfare masks private profiteering, people in need of care cannot establish trust. In fact, they feel betrayed, because quality control is mediated less by strict evidence than by mediocre assessment exercises—that is, by rank advertising.<sup>141,142</sup>

Is the promotion of public–private partnerships in health care by governments and WHO as much in the best interests of recipients of care and communities cared for as they are in the interests of private providers and their lobbyists? Where profits take priority, the fact that health care functions in the public interest is as contestable as its business prospects are undeniable.

**Panel 6: Health tourism and the moral economy of death**

Organ trafficking has often been sensationally compared with cannibalism. After all, when anthropologists first began to examine why some groups of people consume—even symbolically—one another, the belief was that doing so made it possible to embody another's life-force. But just how much of us can be bought, sold, given to, and taken by others? This question is not easy to answer—first, because it is tempered by the cultural value of a long life at all cost, and second, because as technical options for enhancement and replacement advance, supply will never—and by definition can never—meet demand. As science increases its ability to give new life to those with failing tissues and organs through transplantation, genetic modification, and tissue preservation and regeneration, the ethical ambiguities grow exponentially as practices outstrip the moral capacity to adjust.

At stake is not only emergence of new international cultures of commerce, but also the highly unequal and unfair availability and distribution of appropriate matches for both poor people who cannot afford commercially driven treatments and for ethnic minorities for whom appropriate organ matches might be unavailable.<sup>144</sup> In a study in the British West Midlands,<sup>145</sup> for instance, more than 1500 British Asians awaited kidneys while that same subpopulation donated just more than 100. Under such conditions, many go abroad. However, of those who do go abroad, one in three will either die or have their new organ fail, making this cohort four times as likely to die from the procedure as those who stayed on dialysis. But these people seek organs anyway—an issue exacerbated by the fact that some countries use promotion of such services as a form of economic development.<sup>146</sup> Again, the capitalisation of organ buying leads to moral conundrums that societies seem ill-equipped to address.

Because of capitalisation (removal of an exchange from a reciprocal moral economy), an important question exists that few policy makers will face or know how to face: how do we regulate trade in medical services that so disadvantage and

abuse some socioeconomic and cultural groups, and that develop markets for those who can and will pay for body parts of others? Policy makers have historically avoided issues that they are incapable of controlling, resulting in an explosion of minimally regulated or unregulated off-shore health services that only activists and rights advocates seem willing to question. Ignoring these issues has meant that when governments fail to act, individuals and charities need to step in to make a moral commitment to help the disadvantaged—both clinicians becoming social scientists and social scientists becoming clinically informed, if not also clinically trained.

Anthropologist Nancy Scheper-Hughes has been one of those leading the call for social scientists to redefine their professional identities and directly help disadvantaged people worldwide whose poverty leaves them little choice but to sell organs to wealthy purchasers. Libertarians claim that one has the right to sell one's body in free and open markets. But how free is such a decision if brute poverty motivates an irreversible sale, if many die on the surgeon's table, and if people and organs are trafficked to often-unregulated places to serve health tourists with money to spend?

One obvious solution to limited supplies involves enhancing donations, and campaigns promoting donation have been moderately successful. But increasing donations is not a long-term solution to a problem of which organ need is only the symptom: simply supplying more and more organs will not help to answer the fundamental question of whether or not it is always in an individual's best interest to seek out and replace body parts—to live longer, if poorly, on the dead, the dying, and the compromised live donor. Who regulates donation when health care becomes a private industry? And who will address the now-rampant cultural value of survival at all cost, an unprecedented cultural practice that creates a kind of life-through-death that would otherwise never have existed?<sup>147</sup>

Health care has, in many countries, become big business, especially when this business sees bodies as commodities to be exchanged and bartered in all of their parts<sup>143</sup> (panel 6).

In short, no trust in government—so-called big society—is possible with the continuing erosion of local, personal, and sociocultural needs in favour of life under the brighter lights of urban, national, and worldwide stages. The issue here is the dissolution of the welfare state and the damaging effects of present neoliberal thinking about health and wellbeing. Also at risk are nations whose human resources in health care and other sectors are eroded or destroyed by an almost ceaseless draining of skills and services. Large-scale migration now occurs by people seeking specialised health care.<sup>147,148</sup> Abandonment of local health needs in

favour of centres of excellence (and the countries and societies that have created them) should be replaced by new models of excellence, and especially by training programmes that value communities and their local needs. New forms of community health intervention should be created on par with clinical medicine—new forms of caregiving that nourish local systems of value. Therefore, in addition to measurement of socioeconomic determinants of health, cultural determinants of health should also be examined and better understood so that resources can be effectively allocated.

**Structural violence**

If the cultural determinants of health are ignored, hidden aspects of social inequality will be missed. Because when inequality can be latently embedded in institutions and

social relationships, its damaging effects often go unchecked. Social scientists use the term structural violence to describe the link between unequal social structures and actual harm to individuals. Much work on structural violence focuses, as a result, on how poverty, race, sex, and oppression affect susceptibility to disease. Additionally, other broad structural relations become equally relevant. Diffuse, dislocating, and destabilising factors (eg, shifting labour needs, climate change, overpopulation, and resource scarcities) all supersede and therefore shape the capacity of individuals to control their futures.<sup>149</sup>

The concept of structural violence is useful in that it draws attention to how social conditions can substantially limit opportunities and capabilities of individuals, particularly the less fortunate, explaining in broad terms why the world's poor are unfairly burdened by disease and the absence of wellbeing.<sup>23</sup> The concept also shows the inappropriateness of price-costing human suffering. As Yong Kim and colleagues<sup>150</sup> put it:

“because the patients are poor and the treatments expensive, the logic of ‘cost-effectiveness’ had stalled innovation in treatment and control of HIV and drug-resistant strains of TB and malaria...Rather than assume a fixed universe of limited resources that makes only the simplest and least expensive interventions possible in poor countries, we must search for a more appropriate share of rapidly expanding global resources...Any barriers that currently exist to comprehensive global TB control, either in the minds of policy makers or in the ‘real world’, must be brought down.”<sup>150,151</sup>

If policies are guided solely by the perception that financial resources limit what is feasible, disease burdens will grow alarmingly and disproportionately. Multi-resistant bacteria, diabetes, and dengue provide clear examples of how prioritisation of immediate need leads to an absence of public health foresight, focusing on short-term gains while long-term health burdens grow logarithmically and disadvantage people structurally less positioned to transcend oppression. The goal of focusing on structural violence, then, is to address long-term debilitating circumstances by exposing hidden obstacles to increased health equity,<sup>23,152,153</sup> revealing how even clinicians, biomedical researchers, and policy makers can become culturally blinded to the complex social structures that shape the burden of disease.

Ideally, policies that redistribute public funds and wealth<sup>154–156</sup> can directly affect local health outcomes, allowing local ethnographic research to inform better practices, and improving delivery structures that take account of both local and global health priorities.<sup>157</sup> Manderson and colleagues<sup>157</sup> put this succinctly: “a social science perspective on diseases of poverty is critical to ensure that equity remains an underlying principle in policy development, research, advocacy/dialogue, legislation, resource allocation, planning, implementation, and monitoring of programs and projects”.

### Problems with the structural violence model

The root cultural determinants of inequality often remain hidden if suffering is seen mainly as a moral hurdle (eg, unaddressed poverty), or when disease is compounded by the effect of “multiple social stressors (eg, discrimination, malnutrition, stigma, lack of access to medical treatment)”.<sup>158</sup> Everyone lives within hierarchies of authority that are, by definition, unequal (eg, doctor and nurse, or teacher and student), so the question of whether a structure—as opposed to a person—is capable of violence remains moot. A sole focus on structural inequalities might, moreover, too easily attribute blame to disparity itself. As Wacquant<sup>159</sup> said, the difficulty with reducing human strife mainly to structural violence is that it:

“conflates fully fledged domination with mere social disparity and then collapses forms of violence that need to be differentiated, such as physical, economic, political, and symbolic variants or those wielded by state, market, and other social entities...Nothing is gained by lumping under the same heading ‘steep grades of social inequality, including racism and gender inequality,’ that may operate smoothly with the consent of the subordinate with, say, wife beating and ethnic rioting or ‘brute poverty’ with, say, invasion and genocidal policies.”<sup>159–161</sup>

Furthermore, to call attention to inequality and legislate to ameliorate it are entirely different things. Often, attempts to legislate equality have not worked well. More than 30 years ago, Littlewood and Lipsedge,<sup>87</sup> for instance, reported on longstanding inequalities in psychiatric treatment of blacks (African and Caribbean) in the UK. Why do racial minorities (and especially so-called Afro-Caribbean groups) in Britain have much higher prevalences of diagnosed mental illness than the general population? Why are these prevalences so much higher in migrant communities than they are in these groups’ communities of origin? Does the act of living in a different country create mental illness (structural violence in the community), or is the trend to overdiagnose a physician’s concern (the result of latent racism embedded in clinical practice)?

What has happened during the subsequent 30 years? Despite this longstanding awareness and many regulations, discrimination remains almost unchecked. Blacks outnumber other racial groups by as much as 3:1 in some UK psychiatric intensive care units.<sup>162</sup> Similar findings from a study of life expectancy of black Americans showed that racial disparities in the delivery of health care have not decreased substantially, leaving them to live, on average, 6 years less than white Americans.<sup>163</sup>

Decades of work have “documented that whether bounded by ethnic or racial identities, immigrant status, English language fluency, educational attainment, poverty, low socioeconomic status, or urban/rural residence,



minorities and the poor receive less care and poorer quality care than their middle class and educated compatriots".<sup>163</sup> Type 2 diabetes is so common in indigenous communities (more than 50% of men older than 50 years of age for some Native American groups) that local leaders openly describe the sequestration of indigenous people into reservation social housing as a form of cultural genocide. In the Pacific Island Countries and Territories, the situation is particularly worrying, especially when considered against the background of groups in which this illness was once virtually unknown<sup>164</sup> (panel 7).

Although measurement of differences in treatment according to race is still important, the effects of interventions need to be gauged as they relate to the ability of people being treated to make their own decisions. "Unless differences in medical care according to race reflect the quality of care and meaningfully affect patients' survival or quality of life, the existence of racial disparities will remain of far greater interest to social scientists than to policy makers and physicians."<sup>167</sup> If freedom to make decisions is limited by race, then racial disparities should first be addressed and controlled for before disease can be examined racially. In too many instances, racial factors are assumed relevant to disease without controlling for social inequality and its effects on an individual's capability and opportunity.

Despite debate about their meanings and relation to one another, the ideas of agency and social structure are still used in many disciplines to highlight the relation between individual decisions and a person's sense of what is feasible. At an individual level, obtaining and maintaining a minimum degree of agency—that is, an individual's capacity to act on the world—might, in fact, be as or more important than relative status in any given society because perceptions of inequality are always relative and, in unstable contexts, exaggerated in unexpected ways. Many social scientists agree, therefore, that if the aim is to grant every human being a sense of agency, then the expression and exercise of will needs always to be locally contextualised. After all, people will often use their their own agency to deny themselves what is otherwise accessible (food, water, and protection from the elements) when they put aside their own needs in favour of those of their families and friends.

Agency is inevitably structured, although not always structurally established. People's everyday lives and the restrictions on their decision making are, in part, shaped for them by external and internal structures.

Because structures can remain hidden (eg, when culturally driven ideas are assumed within a group holding them to be universal, or when people working to abate inequality themselves subscribe to their own prestige hierarchies), education should be the means to increase awareness of those structures and their effects. Pioneer 19th-century thinkers about health and its maldistribution, such as Engels<sup>169</sup> and Virchow,<sup>170</sup>

regarded those who defended or promoted structures that systematically worked to their advantage and to the disadvantage of others as murderers (eg, for Engels, the Manchester factory owner murdered his employees by exploiting them to the point of making them sick and so shortening their lives).<sup>171</sup> This kind of structural violence is not as controversial if acknowledged in the past or in distant places. However, it clearly applies no less to contemporary financial, business, political, and other elites than it did to Engels' factory owners.

To put this point another way, people's lives are structured by social mechanisms that they are often largely unable to affect, the elucidation of which is opposed by the advantaged.<sup>23</sup> Caste, class, status, sex, ethnic group, age, and gender preference are all examples where hiding difference also involves hiding inequality. In India, the so-called Scheduled Castes (or Untouchables) who make up about 15% of the population continue to be subjected to systematic structural violence,<sup>172</sup> despite the fact that the Indian constitution explicitly prohibits discrimination based on the now-abolished caste system. For example, findings from a field study showed that 10 years after the reforms began in 1951, only 6% of formerly Untouchable families had been able to purchase land compared with 55% of high-caste Hindus and 66% of intermediate-caste Hindus and Muslims.<sup>173</sup>

Libertarians often argue that agency is available to all—a thing we earn through hard work—and some

#### Panel 7: Cultural genocide of indigenous groups

Samoan Airlines has announced that it will introduce extra-wide seats to accommodate the increasing need for such seating by obese passengers.<sup>165</sup> Three-quarters of deaths in the Pacific Island Countries and Territories are caused by non-communicable diseases.<sup>166</sup> According to a WHO report,<sup>166</sup> 60–90% of people aged 25–64 years are overweight in some regions of the Pacific, where diabetes occurs in up to 40% of some populations. Although genetics are important, much of the disproportionate non-communicable disease burden of Pacific Island people is the outcome of cultural disadvantage. Although high rates of non-insulin-dependent diabetes would suggest genetic susceptibility, diabetes prevalence seems more directly connected to rapid lifestyle changes associated with westernisation and the availability of inexpensive, high-energy, low-nutrition foods.<sup>167</sup>

Populations and local cultures evolve symbiotically with their environments. If, for example, Amazonians die from the common cold because they have not evolved symbiotically with a foreign pathogen, social non-adaptation should not be attributed to genetic reasons in the absence of other biological explanations. When cultural explanations provide adequate answers that far outstretch the capacity of biological sciences to offer useful reasoning, ignoring both the limits of scientific explanations and the usefulness of cultural ones would surely be unwise.

The physical condition of a culture a century ago now thought to be genetically disposed to type 2 diabetes shows how our own prejudices about science outstrip our willingness to see clear evidence. In what sense are genetic dispositions relevant when we consider the degree to which this biologically non-communicable disease is wholly communicable at the level of culture?<sup>2168</sup>

religions (eg, strict Calvinism) might even posit that personal gain is a sign of God's grace. At the same time, human beings have always been able to harm one another—not only through conflict or open war—which is why rights organisations (eg, Amnesty International) so often focus on the absence of individual agency.

However, cultures can also lack agency, and when they do, they are called fourth-world cultures to distinguish them not only as economically disadvantaged members of the third world, but also as socially disadvantaged for being denied basic agency. Organisations such as Cultural Survival and Survival International exist specifically to draw attention to the absence of agency in many cultures (panel 8).

Recognition of who does and does not have agency means recognition that advocates, by definition, have it. Recognition that structural violence is an effect of our blindness to inequality in all its forms at least sensitises people to the need for humility when they have privilege, and the importance of cultural trust when they do not. As Albert Einstein said: "strive not to be a success, but rather to be of value".

### Transformation of economies of health

In that cultures are "conventional understandings, manifest in act and artefact",<sup>4</sup> global health priorities are also cultural because biomedical knowledge is itself an

artifact and outcome of cultural practices. Saying that medical practices are cultural, however, does not mean that they are no less real. Because culture and value are—anthropologically speaking—wholly inseparable, this fact should be acknowledged. Otherwise, members of any society fail to see how we apply equality in one setting (eg, our views of democracy) and thrive on inequality in another (eg, when one personally strives for excellence in the face of mediocrity). The issue, therefore, is not inequality, but how agency and advantage is described and understood when managing the unequal opportunities that disadvantage others.

Although awareness of the cultural dimensions of one's own practices and values is difficult, culture mediates between agency and the structures that provide or limit wellbeing, healing, and health. To the extent that tension exists between the structurally advantaged and disadvantaged, culture provides pertinent sites and relevant narratives for contestation of human values. Any social debate about a government's responsibility for health care will, for example, show not only what is being contested, but also the limits of what is contestable.<sup>112</sup> Because our values are measured against cultural practices that we believe ourselves to share or not share with others, an understanding of the cultural dimensions of our own practices becomes just as important as those of others.

We believe that this observation is crucial to health because it emphasises the cultural dimensions of shared moral choices. We do not mean that morality is relative, but that it is always expressed in relative terms. Cultural systems of value are not wholly abstract. They consist of functional ideologies that have moral consequences, especially when otherwise inalienable rights become negotiable.

For example, in his work on French asylum policies and immigration, Didier Fassin<sup>122</sup> described precisely this moral variation—how the lives and suffering of others are variably governed and altered by tensions over time between repression and compassion. "Why", he asks, should there remain "in societies hostile to immigrants and lacking in concern for undesirable others...a sense of common humanity collectively expressed through attention paid to human needs and suffering?"

How does a moral economy transform? Does variation in a moral economy also produce, over time, a kind of moral epidemiology? Although the term used in this sense is ours, not Fassin's, it does capture a crucial point in his work. This point is that it is much easier to claim the moral high ground from the vantage of socioeconomic and hegemonic stability and privilege than to acknowledge how humanitarian societies can become less humanitarian in the face of social stress. Attention to welfare and wellbeing is sadly negotiable, even in states where the rights to health have been foundational.

Does a stated concern with structural violence, then, present an incomplete picture of the actual needs of

### Panel 8: Agency and fourth-world cultures

'Fourth-world' cultures include traditional societies whose human rights are at risk because their ways of living may differ from those of dominant populations or nations within whose borders they reside—say, Jews in Europe before World War II, or tribal groups in many parts of Amazonia—but the term also may be used to describe members of indigenous groups who are unfairly used in double-blind clinical trials, or who do not sufficiently understand the nature of experiments conducted on them to provide genuine informed consent.

The term 'fourth-world' refers therefore to any disenfranchised groups that lack agency. Even subpopulations can be reduced to fourth-world status when social infrastructures deteriorate. Hurricane Katrina, for example, made clear that once human agency is lost, people can no longer empower themselves. After all, members of poor communities cannot advocate for services when the level of social capital necessary to get a so-called needs designation—a formal petition for help—does not exist.

Viewed this way, health rights apply to cultures as well as individuals. When fourth-world people are thus disadvantaged, they might not only lack agency, they might also be unknowingly victimised. Many clinical trials, for instance, are done in isolated groups that are thought to provide genetically pure samples.<sup>174</sup> Therefore, when data (blood samples, DNA, or experimental cell lines) are collected from such groups, the question of who owns that biological and intellectual property can be hotly contested. Indeed, one of the most important public debates about indigenous rights focused specifically on the possible abuse of rights of a certain culture versus the possible benefits gained from its indigenous biological knowledge by scientists.<sup>175</sup> Here, the question of agency becomes crucial to understanding the extent to which the right to self-determination can exist for groups. Who does and does not have agency extends not just to the right to individual self-determination, but also to the recognition that groups also can have or lack agency.

the socially disadvantaged? Writing on the state of refugees in contemporary France, Fassin cites a startling disjunction between humanitarian law and actual practice:

“In 2004, with 58,550 applications submitted, France became the industrialized country with the highest recorded number of requests for asylum, ahead of the United States, the United Kingdom, and Germany, which until then had been the top three countries for refugees. Yet, in the same year, the rate of acceptance of applications...reached its lowest level at 9.3%. Thus, if we count not the applications submitted but the actually granted refugee status, France...was far behind not only Pakistan, Iran, Tanzania, and Chad...but also Germany, the United States, and the United Kingdom.”<sup>122</sup>

Fassin is acerbic in his criticism: “as with other nations, France is more generous the less it has to bear the cost of its generosity”.<sup>122</sup> Here, Bourdieu’s idea of **symbolic violence** moves the discussion beyond inequality to a consideration of how violence inadvertently occurs when disadvantaged people are wholly disempowered. Allowing for variation in both degrees and forms of agency, Bourdieu<sup>176</sup> shows how an individual’s so-called habitus, or mindset, extends to or limits the predisposition to act—how violence, therefore, takes place, even if passively.

This understanding—how self-motivating and self-sanctioning behaviours move human action for some, and limit it for others—has implications for health care and behaviour beyond the material resources available to people. The assumption that individuals are always moved by self-interest is itself a cultural prejudice that is overturned each time a human being makes a sacrifice for someone else. It also affects attitudes towards distribution and redistribution of resources and an individual’s ability and willingness to have an effect on local circumstances. In Buddhism, for instance, the worst acts of evil are not those committed by criminals as such, but by those who have had the privilege of learning and now use that knowledge inappropriately. Knowledge comes of experience, and suffering can not only have meaning, but also provide enlightenment.<sup>177</sup> Such a view shows that collective suffering—such as that associated with, for example, the killing fields of Cambodia, Sri Lanka, Indonesia, and, most recently, Burma—can also heal when it is acknowledged.

Inequality, then, is only one (even if the most fundamental) part of what limits the capacity of people to control their futures. Identification of socioeconomic inequalities is important. However, inequalities are relative and are not purely financial and economic. Cultural systems of value affect local and worldwide inequalities in much more subtle and complex ways than are often immediately apparent. Care providers, therefore, need to be diligent in recognising how and when they participate in discriminatory practices. Cultural equality—treating others as different but

equal—must become a priority when care providers address the most fundamental challenges in care delivery. Otherwise, the desire to be fair in management of human adversity will remain unfulfilled.

### Techniques of erasure

Michel Foucault<sup>178</sup> argued that confinement of prisoners was dehumanising not merely because containment itself is painful. In extreme forms of confinement, prisoners lack the ability to make the most basic eye-to-eye social agreements with those who imprison them. His concern has direct implications for what a focus on structural violence can miss—namely, the effects of erasure of other forms of meaning, and the assumptions that carers make regarding what constitutes a cure.<sup>179</sup> As Laurence Kirmayer writes:

“for those others who come from far away, and especially for those escaping extremes of chaos and violence, experience is hard to come by and harder to convey. There may be elements of the random and arbitrary that fall outside the possibility of any conventional account, and challenge our need for order and explanation.”<sup>182</sup>

**Symbolic violence** is defined as socially dominant forms of persuasion and coercion that occur without the use of physical force

Kirmayer’s point is not that cultural awareness might be unachievable, but rather that what people find credible in stories of suffering is defined for them by personal values that are never neutral. To provide a proper assessment of suffering, practitioners should come to understand that sufferers of intense structural and political violence are often not going to follow convention by providing emotionally moving illness narratives that fulfil the expectations of their advocates.<sup>179,180</sup> For some well-intentioned therapists, attempts to evoke deep meaning can often be met with silence.<sup>181</sup> Time and again, silence—what cannot be said in clinical settings—reveals much about the limits of social engagement in moments of extreme suffering.

Eliciting clinical responses, therefore, should be tempered by an awareness of what cannot be said. Even the most sensitive care providers might not only miss what is culturally important,<sup>64</sup> but, in favouring some forms of empathic narrative, also wholly eliminate alternative idioms (behaviours at home, at work, and in moments of heightened ritual engagement) that help the patient to make themselves better. If carers cannot become aware of how another’s normality can be medicalised by their own prejudices—ie, acknowledge their own cultural dispositions—they will surely not see which of those dispositions are helpful or damaging.<sup>78</sup>

Such erasure of an individual’s personal and cultural context of meaning is evidenced in the long-term effects of short-term clinical priorities, especially when exchange between carer and patient is minimised. When people overdetermine, confine, or reduce care practices, they not only limit expression of other voices; they also eliminate their own ability to recognise when they have done so. In

the UK, for instance, a much applauded 2010 NHS survey<sup>182</sup> of quality of care for antenatal maternity services improved provider–patient communication by increased use of online advice and related information services; however, the response rate was only just higher than 50%.

Almost 50% of voices were therefore not heard, and those who customarily fall through the net in antenatal (as in any other medical) care were over-represented in the voiceless group. The views of those not represented are impossible to know; but not being represented more or less defines a key dimension of being vulnerable. As many vulnerability assessments stress, those who fall through the net are always invisible when results are based on research participation. Motivation, capability, and opportunity might be buzzwords of behaviour change, but they also hold true for individuals' complete disengagement with services (and their inability to fill out a maternity services survey). The experiences and opinions of those more, and perhaps most, vulnerable were precisely those voices that remained unheard.

The issue of widening health disparities can remain, therefore, even in the face of apparently high levels of satisfaction. As shown by some hospitals reporting high proportions of births from women born outside the UK (as high as 76·4% in Newham Trust),<sup>182</sup> false reliance on data can not only warp views of the effectiveness of care, but also directly erase the very people whose views such monitoring procedures were put in place to protect. How can carers know what they are missing if they position themselves only to listen to what they are prepared to hear?

As ethnographers know better than statisticians, you cannot measure what you cannot evidence—the empty survey form that comes back to school in the backpack of the same vulnerable child it went home with cannot inform; but the study that it is a part of can mislead. Emphasis on data more than basic human interaction—at home, with neighbours, or in clinics—contributes not only to devaluation of personal meaning, but also to widening of health disparities. When once-informative personal engagements are limited or eliminated, methods emerge that sometimes only favour those who make and use them. In rural USA, communities too poor to recruit the necessary social capital to be designated as physician shortage areas not only are not helped, but are also wholly erased.<sup>183</sup> Obvious conditions of inequality are, here, not only hidden; they emerge with a wholly wrong meaning.

Information systems (eg, online appointment and treatment management programmes) establish non-negotiable terms through which a patient's wellbeing must be negotiated. At the same time, the easy flow of information shifts responsibility for care from the caregiver to the individual, who can now be blamed for not accessing what is on offer even if he or she might be incapable of participating in such processes. To understand how violence is overtly expressed and covertly

embedded, research should identify not only how vulnerability is measured, but also how the voices of the vulnerable are inadvertently eliminated.

People of marginal social status risk being culturally under-represented.<sup>184</sup> Norms can be internalised, allowing so-called enacted stigma (shaming) and enacted deviance (blaming) to be displaced or complemented by felt stigma (self-shaming and a fear of being shamed) and felt deviance (self-blaming and a fear of being blamed). Although enacted stigma and deviance can and often do control and govern people with less voice,<sup>185</sup> felt stigma and deviance can be forms of social control in which people police themselves. Personal responsibility to monitor one's risk behaviours includes, by definition, some submission to one's own behavioural conditioning,<sup>186–189</sup> a colonisation by care providers, managers, and insurers of the patient's life and, by implication, a form of communication that is largely one way.<sup>190</sup> Self-monitoring is necessary for health maintenance, but chronic stigma can lead to a sense that one is never actually well.

### Rethinking cultures of care

#### Culture and knowledge

Health outcomes can be improved and money saved if caregivers are allowed time to engage with patients and help patients integrate into care communities. Why have more resources not been invested worldwide to support development of integrated communities of care that bridge the gap between biomedical settings and the diverse needs of multicultural groups? One reason is that increased medicalisation of clinical care throughout the 20th century has limited the role of empathy in health care. An implicit assumption within biomedicine, therefore, needs challenging—namely, that doctors have knowledge, and patients have beliefs. Patients are, of course, implicitly and sometimes explicitly held responsible for corrupting medical knowledge (as when they are blamed for not following instructions). When societies reframe, translate, or merely do not or cannot participate in medical science, patients may also be unduly blamed. Those vulnerable to being blamed make up most of the world's citizenry for whom biomedical care is either unaffordable or unavailable—people who depend on human care for health, instead of on health care per se. At stake are not only biomedical needs, but also the status of rational knowledge systems compared with beliefs held by patients.<sup>191,192</sup> This potential for blame itself constitutes a true source of symbolic violence.

Yet, social scientists have established a framework and body of knowledge through which biomedical claims are also shown to be shaped by a range of political, economic, and cultural forces.<sup>46,126,193,194</sup> Evidence-based medicine and practice are not wholly neutral, objective bodies of knowledge. They are products of specific contexts, and anchored within specific historical frameworks, just as

beliefs and practices are embedded within traditional worldviews.<sup>77,85,195</sup>

Vested interests—including those of the pharmaceutical industry and scientific laboratories, and the biomedical status and cultural identities of researchers and their institutions—establish research questions, study design, sampling techniques, research instruments, data analyses, and interpretation.<sup>196,197</sup> Above all, they not only shape illness categories,<sup>198,199</sup> but also constitute cultural systems of value in themselves. They have their own ethics, conflicts of interests, dynamics of power, and methods of knowledge production that can differ substantially from those of other cultures, sets of values, and the community needs that they should serve. How community health gets regenerated in a world of widespread fiscal and ideological retrenchment presents, therefore, one of the biggest hurdles to contemporary health care. The constant reminder of what cannot be afforded is perhaps the greatest obstacle to thinking about what is possible.

#### Community culture and health

When services are reduced or denied on the grounds that they cannot be sustained for whatever reason, insecurity is likely to prevail. Tolerance is rarely sustainable in insecure social settings where consensus, social agreement, and basic trust are put at risk. This decreased tolerance is evidenced not only in moments of extreme social suffering, such as wars and epidemics, but also when systems of health care are radically re-engineered, even in the interest of innovation (eg, when non-governmental organisations restructure health-care delivery in developing countries, or when politicians enact policies that are designed to transform radically a system of care). Indeed, the cost of innovation can be high because many informal and fragile networks disintegrate when systems of support collapse or are withdrawn.<sup>200</sup>

The challenge of innovation in cultures of care is, therefore, directly exacerbated by social stress. In times of stress, the number of people who survive destabilisation and successfully transform their practices and ways of thinking can fall because social stress not only has a direct effect on tolerance to perceived outsiders. Stress also reduces the actual number of caring relationships a person can tolerate.<sup>201</sup> Merely forcing cutbacks to induce innovation is, therefore, potentially wrong in many ways, as large-scale political oscillations can introduce change while undoing outstanding systems of trust. Hence, one important issue with enforced innovation is that it often comes with ethical and moral costs that are wholly unacceptable.<sup>200</sup> When systems of care, for whatever reason, become less stable, the question of how health-care communities—that is, cultures of care—can be regenerated becomes crucial.

Substantial research into building health communities has been carried out, not least into the circumstances that gave rise to the world's single largest health-care provider, the UK's NHS. Surprisingly, its origins were neither national nor English. In fact, the basic structure of the NHS was adopted in 1948 from a plan begun in Scotland in 1913 (and set out formally in 1936) to attend to the neglected health needs of rural poor in the Scottish Highlands and Islands after the longstanding social collapse caused by the Highland Clearances of the 18th and 19th centuries.<sup>83</sup> A system of health care for all was an innovation that grew from a brutal disaster that led to a regional community health innovation. What made this plan successful was that it was neither wholly local nor wholly national. It did not force communities to deal on their own with the redistribution of scarce national resources—dividing dwindling assets and requiring communities to get on with things. Nor did it expect members of rural and remote communities to see their futures as non-local, as dependent on the draw of urban areas where better services and opportunities for advancement would be supported in the name of excellence.<sup>202</sup>

In fact, the system worked (not only in urban settings, but for the most isolated areas of the UK) for three reasons. First, it embedded and incentivised health-care providers sufficiently to enable otherwise fragile communities to re-emerge and survive. Second, it increased the status of rural doctors through its inducement practitioners scheme. And third, it enabled doctors to become advocates for the communities they served. These basic strategies should be emulated, and resources should be devoted to understand them better. The designers of the NHS recognised that care is a person-to-person exchange that can be disrupted easily when community is eroded or advocates' loyalties and aspirations are in conflict. For instance, removal of patients with Alzheimer's disease from homes to care homes shows that disorientation is a risk factor for vulnerable people irrespective of health status.<sup>203,204</sup> 100 years on, those same Scottish communities still consider having a primary care doctor the key to making a community viable.<sup>205</sup>

As the world becomes less culturally diverse, fewer models of caring are available. However, much can be learned from traditional cultures about caring,<sup>107</sup> from traditional institutions about innovation to meet essential needs, and from new institutions of care that emerge around diverse cultural values. How different individuals, families, and communities give care should be carefully studied.<sup>107</sup> For example, all societies need to rethink how families can make possible more dignified ways of ageing when increased life expectancy changes populations and social priorities. Furthermore, when necessity demands innovation at the local level, new ways of caring sometimes emerge that can provide promising solutions to otherwise insurmountable needs

elsewhere, making it possible, at times, to build a successful health-care system from an idea generated locally (panel 9).

However, in multicultural settings, a special need exists to be open to new models of care; a group's views of what is feasible can often be limited by what it might already assume to be immutable. If clinical care alone does not sustain health, clinical care embedded in relationships of social meaning does—that is, not only in community in a demographic sense, but as it makes possible face-to-face consensus on suffering, tolerance, altruism, and goodwill. Success demands complex social skills that are not well replaced through technical innovations in communication.<sup>208</sup>

The first half, therefore, of creating affective communities of care involves gaining an understanding of a community's sense of what is feasible. However, socially generated wellbeing is the other half of clinical care that decides a population's willingness to shoulder social burdens and emerge with dignity and respect for having done so. Wellbeing is about sustainability, trust, and continuity. It is not an indicator to be measured economically, even though some think that public trust is itself measurable.<sup>209</sup> Social security cannot be generated in the absence of social trust when security is defined only as the economic advantage over others. Application of business models to health cultures of care is therefore difficult and potentially dangerous (panel 9).

However, because health businesses often do employ well-intentioned people, private enterprise can sometimes provide useful innovations that are in the public interest, as long as they can maintain a strong financial base. Conflict-free altruism does become possible for businesses, but mainly when their market shares are immune to hostile pressures for profit, as when charitable trusts own a controlling interest in a company. The

#### Panel 9: Cultures of care

In apartheid South Africa, what has come to be known as the Pholela experiment<sup>206</sup> helped establish a model for culturally sensitive primary care and the idea of cultural competency. Under the direction of its founders, Sidney and Emily Kark, the Pholela Health Center provided integrated community care to the poorest Zulu people in the eastern province of Natal (South Africa). Offering culturally sensitive clinical care and attending to food, housing, and sanitation, the centre helped generate new interest in social epidemiology and, to an extent, what is now called medical anthropology.<sup>207</sup> Pholela also provided a model for community health centres around the world. Although the study of alternative ways of caring can provide new models of how to meet diverse needs, such research can also alert us to new forms of clinical meaning that might have been lost on modern biomedicine. As health care and the role of health-care workers is reassessed, potential contributions of other cultures should not be underestimated.

difficulty with strategies that rely on private investment for public wellbeing is that businesses more often fall vulnerable to profiteering. Indeed, they may even at times be sued by their shareholders if they do not put legitimately accrued profit-making ahead of altruism, no matter how seriously they take corporate social responsibility. Although profit can incite productivity, it cannot induce altruism unless the charitable efforts of business are protected from financially motivated decision making; competitive gain is never a gain without another's loss,<sup>201</sup> otherwise gain is not competitive. The danger with making health a business is that the financial gains are potentially infinite, while the losses to wellbeing might prove irreversible.

Illness needs (what patients need to get better) do not, in this sense, lend themselves to simple cost-benefit considerations, which is why courts remain so busy dealing with health neglect. If public-private partnerships are to serve communities, new ways to establish trust need to be developed that are not mediated by financial demands of shareholders or the prestige cultures subscribed to by policy makers and global health leaders. We believe that the trend towards favouring public-private partnerships in care needs to be rethought so that the responsibility for health-care needs can be reconsidered at the level of social trust.

Corporate health culture (in which private companies provide health care for profit) should, then, be required to embrace systems of ownership that do not merely reward aggressive financial practices at the cost of altruism. When needs are defined as marketable provisions, businesses that serve the needy act in predatory ways, which is why the public health goals of some health-care providers can be legitimately questioned, despite support for care commissions and other overseeing bodies. Providers need to be careful about how they harness social capital as a method for further reductions in support of failing health-delivery cultures.

As evidenced by the history of the NHS, if communities of care are to re-emerge, patients need advocates—non-conflicted ones—as much as they need drugs. Patients are much more willing to burden their suffering when that suffering has shared meaning. For this reason, health cannot be separated from culture. Indeed, health-care provision can only be advanced by a reassessment of, and renewed interest in, the role of culture in health.

The importance of culture for the future of health care lies not only in policy formation, but also in policy implementation.<sup>210,211</sup> The activities of those providing services have a large effect on delivery.<sup>212</sup> Health-care workers have much control over the allocation of rewards and sanctions; without this discretion, the health-care system would collapse under the weight of its own rigidity. This discretion, however, often benefits or harms particular groups or individuals, and so increases both horizontal

inequality (when neighbours and even family members compete for the same few services) and vertical inequality (when inequalities are created by advantages of income or social class). Overworked, underpaid, and undertrained providers can render empty universal political declarations on the future of health, as shown when so many worldwide health goals are unfulfilled, such as WHO's Alma Alta decree—*Health for All by the Year 2000*.<sup>213</sup>

Where are such issues being acknowledged? Developments in culturally informed biomedical approaches, such as the Movement for Global Mental Health and the 10/90 gap of the Global Forum of Health Research (10% of research expenditure on the poorest 90% of need), show the danger of capitalist societies and market economies imposing fiscally driven biomedical templates on the understanding and treatment of illness.<sup>214</sup> They also show (in their dogmatic approach to public–private partnerships) just how culturally driven mainstream ideas are about global health needs, global health provision, and the concept of global health itself.

Recognition that different societies and disciplines have vastly divergent ways of understanding and measuring health and illness should be included in medical education and care provision worldwide.<sup>215,216</sup> Likewise, work should not be devalued if carried out in locations that are perceived to be less rigorously controlled.<sup>217</sup> Researchers and policy makers often fail to prevent assimilation of practices and findings from other countries precisely because their own prejudices and practices are largely cultural in nature.<sup>107,218–220</sup> Ideas about suffering and healing need an examination of how knowledge is culturally negotiated in clinical practice.<sup>64,221,222</sup> Understanding, for example, how non-adherence to pharmaceutical therapies is less a function of unwillingness to adhere than of an absence of informed choice provides just one example of a mistaken assumption about clinical behaviour. Until a full analysis of caring communities is provided and clinical encounters are better understood, using exclusively financial models to scale up service delivery will continue to fail at providing genuine care.<sup>223</sup>

### Migration and communities of care

Although migration can substantially improve quality of life, when instability forces a transition from one culture to another, destabilisation produces both opportunities and vulnerabilities. On the one hand, health outcomes of migrants explain the urge to migrate. Bangladeshi women, for instance, can increase their life expectancy by a decade or more by migrating to Europe.<sup>224</sup> Cypriot migrants can expect to live as long and as healthily as those who stay in times of peace provided they migrate into families and stable communities. Otherwise, their health outcomes are worse.<sup>225</sup> These conditions are mediated, moreover, by so-called hyperdiverse worldwide environments in which communities are continually reshaped.<sup>226</sup>

On the other hand, vulnerability increases exponentially when family networks and the heritage that they embody cannot also migrate. This effect needs to be accounted for, particularly in hyperdiverse environments where new alliances need to be made rapidly, and where individual opportunities emerge at the cost of secure, extended sociocultural networks. Recruitment of allies in unstable moments is crucial to survival for migrators, especially when the behaviours, rituals, and artifacts of culture disappear. This fact is made clear by the high rates of mortality and morbidity attached to those who migrate into new environments lacking family and ethnic ties. Heritage is more than a polite celebration of a sense of belonging. As a stabilising device, it provides public self-definition and acknowledgment.<sup>227,228</sup> Culture is, in part, heritage because the artifacts (both material and ideological) that constitute culture define an individual's sense of belonging.

Despite the fact that culture is embedded in heritage, governments are often unwilling to place a high priority on heritage (both in the context of the arts and in the sense used in this Commission). In fact, some measures of wellbeing entirely omit cultural heritage. One reason for this omission is that the social benefits of culture and heritage are, by nature, unstated and difficult to quantify.<sup>229</sup> We believe that this oversight is a mistake with real effects on the wellbeing of individuals and whole populations.

Findings from a population study<sup>230</sup> in Norway of more than 50 000 adults, for instance, showed that participation in creative cultural activities was associated with good health, satisfaction with life, and low anxiety and depression, even when the data were adjusted for confounding factors. Many other examples show the effect of engagement with cultural activities on levelling health inequalities.<sup>231–233</sup> Continuing health-care reforms that shift responsibility to local communities will change how health-care and social care services are delivered in the future.<sup>234,235</sup> New models advocate a shift from cure to prevention, encouraging local communities and people to take collective responsibility for their environments and capacities to affect public health. Such reforms will need a multiagency approach, with increased reliance on third-sector organisations that can assist communities where governments fall short, especially when oppression, psychiatric trauma, and irregular migration exist.<sup>236,237</sup>

Studies of health-care delivery cultures—particularly of their embedded structures and potential inequalities—will help to conceptualise the entire therapeutic pathway, including not only the physician's practices and clinical techniques, but also the patient and the patient's sociocultural values and patterns of behaviour.<sup>238,239</sup> The allocation of health-care resources should thus be informed by an awareness of how different cultures of care variably improve health and wellbeing, and how diverse social communities interact with systems of caregiving.

## Findings

We have 12 key findings that together constitute a research agenda for culture and health.

### Medicine should accommodate the cultural construction of wellbeing

Medicine has been a triumph of the biological sciences. Biomedical approaches to health and wellbeing have contributed to important reductions in mortality and morbidity worldwide, but they are yet to adjust to the strong effects of culture on health-related behaviours and outcomes. Health is as much about caring as curing. Caregiving has now reached a crucial transition, where a different approach to disease and illness will be needed for further advances in health and wellbeing. Although WHO's new *Health 2020* agenda<sup>240</sup> has identified wellbeing as one of its six domains to monitor, its acknowledgment of the complexity of doing so demands that it rethinks the role of the medical humanities in improving our understanding of the drivers of human wellbeing.<sup>241</sup>

Health is not just the absence of illness or disease. Health should be promoted more broadly, encompassing positive wellbeing, its origins in cultural value systems, and its maintenance through social processes that affect biological wellness. As WHO claimed more than 60 years ago, "health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity".<sup>242</sup> Narrow definitions of health based solely on biomedical status do not address adherence and limitations to adherence. To prevent disease, behaviour change is needed from those who can change, and those who lack social capability should not be left unassisted. To meet these needs, care structures should be reframed at the level of local cultural values. Such reframing will not only need broad policies that recognise the importance of culture to resolve the huge waste created by non-adherence, but also the creation of models of care that take seriously the importance of community health mediators, however they might be defined.

### Culture should be better defined

Culture is not merely defined by national, ethnic, or racial affiliation. Culture consists of conventional understandings manifest in actions, institutions, and things. Culture is key to the practices and behaviours of organisational structures and professions, including the health professions; the health priorities of individuals, groups, and systems of health delivery; and the practices of professionals that bring together or alienate givers and receivers of care. In this context, culture also includes the collective practices of the ill and disabled, and the advocacy groups they participate in and that represent them.

Systems of health-care delivery and the practices that they promote should be studied as cultures, with the

goal of reassessing what matters in health and perceived wellbeing. Studies of culture in medicine should not be overlooked in favour of a sole focus on the ethnic group of patients and how local practices affect adherence. Short-term management priorities should be augmented by long-term investments in wellbeing promotion, and worldwide organisations established to promote health should embrace culture less as a mistaken influence on biological health than as a key determinant of health and wellbeing. WHO's *Health 2020* agenda and so-called health-in-all-policies approaches are important steps in this direction. However, organisations that drive these initiatives should address their own biomedical biases and limitations. To say that culture matters while continuing to favour wholly biomedical research and policy does little to alter the longstanding and deep neglect of the cultural determinants of health and their importance to health outcomes and equity.

### Culture should not be neglected in health and health-care provision

The systematic neglect of culture in health is the single biggest barrier to advancement of the highest attainable standard of health worldwide (availability, accessibility, acceptability, and quality). The cultural practices of individuals and groups served should be better understood and acknowledged so that care systems can adjust practices in the interest of promoting wellbeing and reducing waste. At present, the provision of health care and social care is insufficiently sensitive to culture and does not adequately account for the norms and values of both those who use care services and those who deliver health care.

As of yet, we know little about how patients' cultures affect their attitudes toward wellbeing, but also how and why particular cultures of health-care delivery develop within hospitals, clinical practices, and other health-care delivery settings. The role of culture in wellbeing should be as high a priority as funded research in clinical medicine. Health-care providers should also acknowledge their own cultural values and consider them as such, and organisations should invest in understanding how their practices and values are cultural. Culture is not something that irrationally limits science, but is the very basis for value systems on which the effectiveness of science depends.

### Culture should become central to care practices

Competence in culture is not a secondary aspect of health promotion and medical treatment, but a key feature of human wellbeing. Sensitisation to the norms and values of those who use care services is essential if professionals are to improve adherence. Health-care providers cannot usefully present information to patients if patients do not understand the merits of adherence to treatment within their existing values and



concerns. Although person-centred care has been embraced by WHO in its *Health 2020* policy framework, the question of how its mainly biomedical focus will be reshaped is unclear. Implementation of a medical humanities approach across WHO will need serious examination of its own prejudices and prestige hierarchies because these very hierarchies might be largely responsible for its longstanding diffidence to the role of culture in health.

Cultures of health-care providers (norms, values, practices, and prestige hierarchies) need to change if professionals are to retain their influence on the practice of health care—from a narrow focus on immediate working environments to a broad understanding of the culture of biomedicine and its role in improving or limiting population health. Because culture affects clinical relationships and outcomes, patients should also be given the educational resources and information to understand how to adjust their own behaviours to improve health and wellbeing.

#### **Clinical cultures should be reshaped**

Caregivers cannot improve patient wellbeing in the long term if they cannot develop cultures of care. Clinical systems should be redesigned to cultivate social engagement between caregivers and patients, and between caregivers' and patients' cultures (such as advocacy groups). These new forms of engagement should develop in conjunction with local provision cultures. Such a redesign could take the form of a reconfigured medical home for patients, but the effectiveness of any reconfiguration should not only be measured in terms of clinical outcomes. Effectiveness is equally dependent on functional outcomes and patient satisfaction. To encourage behaviour change, people need to work together across cultures of care.

Expensive procedures and management cultures should be discouraged so that money can be spent on actual care. The cost-benefit of such a transformation should be measured to shift the emphasis of health care from for-profit activities to caring ones. Local communities need to generate cultures of care that are focused on solutions rather than problems. Behaviour change should extend not only to a focus on prevention, but also to the re-education of science and business establishments about the value of research into cultures of care. Affect should be considered an important influence on health, with positive affect being something to strive for. To spend scarce resources on more oversight rather than provision will exacerbate the impotence of health-care systems worldwide to create positive change.

#### **People who are not healthy should be recapacitated within the culture of biomedicine**

Because non-adherence often results from an absence of capability from patients, clinical practices should be

modified for those in need, rather than marketed to the wealthy. When patients lack ability, they become disproportionately incapable of participating in their own improvement, meaning that the cost of caring does not rise proportionately for those with resources, but it does rise substantially for society. Profit making should not be assumed to encompass altruism because the two are not always compatible.

Building trust should become a major focus of health-care policy. The long-term costs of short-term financial decisions on health should be replaced by the study of how health care can be reshaped to make both behaviour change and wellbeing its central focus. When public organisations mask private gain, those who would otherwise contribute to the public good lose trust in collective action and turn instead to strategies for improving self-worth. When resources are limited, self-worth loses its collective and cooperative meaning, invariably becoming self-centred. Health care cannot continue as the most profitable industry in local economies, and limits should be placed on the predatory nature of medical profiteering on the backs of the weak and vulnerable.

#### **Agency should be better understood with respect to culture**

Intercultural health communications are about not only language proficiency, but also a people's beliefs about what constitutes effective health care and their personal capacity to prevent illness and influence illness outcomes. Although subjective somatic complaints (eg, levels of pain, or perceived weakness) are often negatively attributed to culture, somatic problems that result from emotional stress can be a basis for forming trusting and caring bonds when carers are aware of the origin and meaning of such complaints, and if they have a strategy to address them.

New caregiver-patient relationships that improve access to information about self-management strategies, and related behavioural practices that encourage patients to participate in self-improvement, should be nourished. If a caregiver has time to speak with patients, not only are better judgments about what forms of personal empowerment work for them possible, but doing so also saves time and money that is wasted on misuse or underuse of funded educational programmes and treatments. In this sense, personalised medicine may be, in fact, not only cost effective, but cost saving. Patients should therefore be educated on how they can empower themselves within their local cultures and the cultures of care that serve local needs. Emerging medical information technologies should be used to create new modes of patient participation in health maintenance; however, these technologies are not a substitute for face-to-face care, especially for those in need who may lack the capacity to care for themselves. Studies are needed to establish how new technologies (internet resources, social

networking sites, and online patient self-management initiatives) empower some patients and alienate others. Forms of communication that encourage adherence should be used to cultivate clinical trust, and straight-forward strategies to locate and respond to health vulnerabilities should be developed and implemented.

### **Training cultures should be better understood**

The training of caregivers needs to change substantially. Medical hierarchies and medicine's hidden curriculum of prestigious imitation (hierarchical attitudes, values, and perspective taught implicitly to caregivers) should be openly acknowledged so that clinical students and staff can spend less time reporting to superiors and more time engaging with patients and understanding their needs. Teaching communication skills should not be optional (conveying implicitly or explicitly to students of health care that such training is less valued). Students need extensive training in culture to understand the importance of creating communities of care by finding common ground with patients. New values are needed to reduce waste through better adherence strategies and negotiated caring. An understanding of how culture works for patients alerts caregivers to the importance of caregivers' assumptions and the importance of understanding the practices and limitations of the professional culture of health-care delivery in which caregivers participate. Caregivers cannot know the importance and pervasiveness of their patients' cultures if they do not recognise their own cultural assumptions and biases. If medical students cannot learn to care, then new professions in cultural mediation and local community health advocacy should be developed and prioritised.

### **Competence should be reconsidered across all cultures and systems of care**

Culture is crucial to the sustainability of local health-care systems, and the strengths and weaknesses of care practices. Competence in health-care delivery can be improved through studying the wellbeing practices of other cultures. Some stable and progressive health systems (eg, New Zealand) have introduced guidelines and stringent cultural competence requirements for health-care professionals.<sup>243</sup> The effects of such guidelines should be studied. The destabilising consequences of health-care brain drains and worldwide shifts in professional opportunities should also be monitored to establish the effects of health migration on local cultures and their systems and care. Competence awareness, therefore, means not only the introduction of more exploratory thinking into care training to increase awareness of the importance of culture in caring, but also an understanding of how worldwide priorities and health migrations can undermine value-based local caring by eroding fragile resources.

### **Exported and imported practices and services should be aligned with local cultural meaning**

Culture is the most important factor in the promotion of global health. Policy makers in high-income countries should be aware of the effects of exporting treatment, pharmacological remedies, and untenable delivery models to poorer countries. Capacity building in public health should augment heroic relief strategies. Where relief is urgently needed, the strategies of capacity building should be mediated both by honest assessments of indigenous capacities to respond to global health interventions and by an open acknowledgment of waste by elitist cultures in high-income countries that export practices that are neither locally relevant nor sustainable. Worldwide salvation dramas should be replaced by honest analyses of local capacities to respond to international recommendations and interventions. Export of untenable ideologies has harmed people in need and increasingly damaged the willingness of fair-minded people worldwide to participate with the best of intentions in health interventions that they now see as heavy handed and arbitrary. Such a change of perspective will require that WHO review its skills, as recommended in a Chatham House Report.<sup>244</sup>

Those who influence global health and wellbeing should temper their idealism with options that are real and feasible. They should, moreover, be prepared to invest in vulnerability assessments and informed allocation of scarce resources, with local expression of worldwide standards of basic wellbeing as their main focus. Although an evidence base synthesises and prioritises what is already known, these evidence bases should be augmented by a value base that encourages examination of other and new ways of thinking.

### **Building trust in health care should be prioritised as a cultural value**

New worldwide economic alliances and cultures of offshore health-care provision can weaken the capacities of nations to chart their own health-care destinies. When weakened nations and political institutions become incapacitated, they not only become dysfunctional, but also disillusion citizens from participating in health-improving initiatives. As personal mobility becomes increasingly released from local meaning, disjunction between what people value morally in their daily lives and perceive to be the values of society at large can diverge sharply. This disjunction in values places people at odds with their daily practices and encourages selfishness and personal gain rather than care for others. WHO and the large health charities should rethink their views of public-private partnerships, advocating such partnerships only when and where altruism can be safeguarded from hostile profiteering.

Long-term damage resulting from what seem to be short-term gains should be examined carefully and their effects on trust accounted for. Policy makers should step

back from short-term cost-controlled objectives and ask how trust emerges over time. Instead of governments presenting a publicly structured system of welfare behind which lie for-profit private providers about whom patients know nothing and in which they express no trust, new models of care should be sought, carefully assessed, and either modified or replicated.

### **New models of wellbeing and care should be identified and nourished across cultures**

In this Commission, we present a new opportunity to remodel medical practices by stressing the importance of culture and its effect on wellbeing. Medical practice needs to account for how cultural values and related heritage can be better understood and nourished in the interests of health. Engagement with the idea of culture can enable a change in health-care planning and delivery, from a focus on medical technocracy to humanity; from biomedical cures to the uses and misuses of such potential cures; and from often unrealistic magic bullet research to improved wellbeing. To live up to a health-in-all-policies approach will not mean merely to claim the relevance of wellbeing in WHO's Health for All ideology in its yearly health reporting,<sup>245</sup> but to augment its focus on economic inequality (eg, as defined by the 2011 Rio Political Declaration on the Social Determinants of Health)<sup>246</sup> with an acceptance of the cultural determinants that affect the very priorities of global health organisations, charities, and funding agencies.

Taking proper account of culture is essential to advance people's ability to care for one another. All possible avenues to understand and nourish wellbeing should become the highest health-care priority and publicly supported and funded at least as much as new biomedical research.

### **Conclusion: lives to be valued**

Health is a core human concern, even if it is not consciously considered, or is valued only for instrumental reasons. Everyone wants to lead a fulfilled life that is free from illness and disease, even if tending to disease can itself be a catalyst for hope and happiness.<sup>247,248</sup> In view of worldwide inequalities, emergence of improved caring should be inseparable from freedoms that all societies should provide.<sup>249,250</sup> Such freedoms, in turn, should allow human beings across race and gender divides to conceive of futures beyond abject poverty and chronic suffering.<sup>251,252</sup> After all, few patients care about disease indicators such as blood pressure or lung capacity unless these indicators are connected to themselves and their life goals.

Once ill, a person cannot assist in his or her own curing unless he or she possesses the capability, opportunity, and motivation to adjust effectively to create new forms of wellbeing.<sup>248</sup> Disease prevention is therefore often inhibited by an unwillingness to acknowledge the immanence of illness. Behind the commonplace statement that the goal

of health care is to improve health and eliminate disease is a wider context in which prevention needs to be learned; for creation (or restoration) of wellbeing demands that patients have options that are real to them and that encourage them to live lives that they have reason to value.

Biomedical interventions often, but not always, provide the best ways of dealing with the disadvantages that disease and disability create; they offer the prospect of bringing a person back to full health, rather than merely enabling that person to function despite ill health or impairment.<sup>156</sup> However, an understanding of the effects of sociocultural processes on biological ones has been largely neglected and should become a main focus of research. Now, perhaps more than ever before, mutual convergence of biological and social sciences creates new opportunities for revising our understanding of how sociocultural factors affect biology, and not just the other way around. Changing parameters of specific areas of scientific research have resulted in recognition not only of the deep relation between culture and biology, but also of the way in which social behaviours and environmental factors can turn on and off biological and genetic processes. Immunologists, virologists, neuroscientists, and epigeneticists are now becoming increasingly aware not only of how life itself creates a background against which biological processes unfold, but also of how local biologies create unique forms of illness and health.<sup>253-256</sup>

Proponents of the social model of disability argue that the disadvantages that individuals with impairments have are caused mainly by the way that social environments adjust to disability. For example, deafness was not necessarily a disadvantage on Martha's Vineyard (North America) 100 years ago, where, as a result of several generations of congenital deafness, nearly everyone was able to communicate through sign language.<sup>257</sup> Indeed, many now argue that disability can assist in developing entirely new skill sets.<sup>258,259</sup> Social and psychosocial factors underlie how one can live productively and creatively with what others might label a disadvantage. Caregivers need to recognise both the role of culture in biomedicine and science, and the need for the social sciences to be more critically engaged with scientific value judgments.<sup>40</sup>

The failures of health-care provision are magnified by the cultural assumption that biomedical practices—being scientific and evidence-based—are value free, that culture is something that scientists themselves do not have, and that culture hinders science. If biomedical culture does not acknowledge its own cultural basis or incorporate the relevance of culture into care pathways and decision making, then the waste of public and private resources will continue to cripple health-care delivery worldwide. If the culture of biomedicine remains only one of evidence-based practice, expectation of adherence, hierarchies of treatment, and disease cause, many barriers will go unrecognised. And if a

**Panel 10: Key questions for culture and health**

- How does health-care delivery have to be restructured to prioritise the promotion of wellbeing and acceptance of its sociocultural origin?
- How can health priorities (personal, clinical, societal, and financial) be made to account for and adjust to the effect of culture on human behaviour (the culturally mediated behaviours of patients and providers) and the damaging effects of ignoring the effects of culture on curing of illness and advancement of wellbeing?
- How can physical and perceived wellbeing be improved if beliefs, norms, behaviours, and practices are not understood and acknowledged?
- In view of the damaging effects of clinical non-adherence, the waste it creates, and the inaccessibility of clinical care for some people, how can health-care providers become better and more effective if they are not culturally competent?
- If most accurate diagnoses can be made by taking of careful case histories, how can caregivers be allotted more time to develop trusting relationships with their patients and the vulnerable populations that they serve?
- How can caregivers understand patients' capacities for participating in patient-driven health improvement if caregivers are prohibited from, or not interested in, gaining a full understanding of patients' needs?
- How can a caregiver know what a patient is trying to do unless he or she knows what that patient expects to happen?
- How can doctors and nurses in training learn to value what is not yet known about culturally generated wellbeing if they are only judged on their ability to relate to an evidence base that values its own outstanding knowledge resource above negotiated caregiving?
- How can the study of health-related practices in other cultures best be supported so that successes can be shared worldwide and vulnerabilities can be appropriately assessed and responded to locally?
- What are the direct and indirect effects of the inadequate delivery of health care in disadvantaged and incapacitated communities?
- Can private self-interest contribute to trust, general health, and wellbeing when competition for scarce resources prioritises personal gain over shared wellbeing?
- What are the key drivers of positive change in care, and how can these drivers be improved to better humankind both locally and worldwide?

patient's opportunity, motivation, and likelihood to adhere to medical instructions are not taken into account, poor outcomes will ensue, scarce resources will continue to be wasted, and diseases will proliferate.<sup>260</sup> The illnesses of poor people are now everyone's illnesses. Behaviour change is not only for the poor and needy.

However, behaviour change is only part of the reason why culture matters crucially to health. Like the socioeconomic determinants of health, behaviour change is a major driver of health, but it is highly susceptible to cultural variation, the health of a collective at large, and the commensurate willingness of individuals to participate in collective action. When members of a society lack the capacity for self-reflection—ie, when people find it difficult to assess their own dysfunctional practices—they become vulnerable to choosing bad meaning over no meaning. In such societies, governments and prestige hierarchies may need to change more than people because our collective difficulties are less about the absence of

resources than the ability to control and use those resources. If governmental cultures have themselves become inoperable and incapacitated, then these governments themselves should also change their behaviours.

Such deep and complex societal issues in culture and health require an entirely new health agenda based on new delivery priorities and a major shift in related research (panel 10). To share disease burdens, a revised strategy for cultivation of collective trust is necessary. This project must, by definition, be cultural; for whether healthy groups produce social welfare or welfare states create healthy groups depends on a society's sensitivity to welfare itself. New models will, therefore, emerge in unexpected ways. It is for this reason amongst so many others that attention to the relation between culture and health presents us with both our biggest challenges and deepest hopes for humankind.

**Contributors**

All authors contributed text and collected and analysed data. Many sections were written and multiply revised by more than one author. ADN rewrote the final draft.

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