



SHARPENS YOUR THINKING

Methodology and method

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Chapter 3: Methodology and method

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3.1 Key messages

The capabilities approach to justice claims that inequalities become matters of justice and human rights where they prevent or inhibit someone developing the capacities necessary to live a good life. The Equality and Human Rights Commission has provided a list of ten capacities or domains which are essential to a good life; health and life (or life-span) are two of these. Life-span is essential to a good life because human life that ends prematurely is qualitatively less than if it had run a full course. A reasonable degree of mental and physical health is essential because without it a good life is elusive and sometimes impossible to achieve.

Where people do not achieve the ten capacities or where they do not do so as well as others in society, their lives are diminished. For this reason, we should be concerned about non-achievement of and inequalities in achievement of these capacities. For example, if one group of people has much shorter life-span than another, this should concern us.

The inequalities we find in relation to health and life can be put into a number of categories on the basis of their relationship to fairness or justice:

1. Those generally thought to be natural or inevitable, such as the shortened lifespan of people with some inherited disorders, such as Down's Syndrome;
2. Those that are disputed as being natural versus socially created; for example, whether being a wheelchair user is a disability because of a natural phenomenon, such as spinal injury, or because of social decisions that make the environment hard to navigate by wheelchair;
3. Those generally thought to be socially created, such as shortened lifespan related to social class.

The view taken in this report is that all three inequalities should be viewed *prima facie* as matters of concern. This is probably obvious in the third case but less so in the second

and perhaps not at all obvious in the first. However, few inequalities can be simply written off as natural and inevitable. For example, if people with Down's syndrome have higher rates of death due to cardiovascular disorders, this should be a stimulus to ensure there is good provision for that group and research into treatment. We should look for reductions in the inequality with the main population as signs of improvement in the situation.

For some individuals or groups there might be inequalities about which nothing can be done. An individual in persistent vegetative state can achieve little by way of important human capacities. But these cases are rare and tragic. As a starting point, we should view all inequalities in important human capacities as matters of concern and calls for action.

People are often blamed for poor health and life outcomes on the basis that they have made bad lifestyle choices, such as smoking; in most cases this explanation misses the deeper causes of people's behaviour; for example, working class single mothers are not genetically programmed to smoke more than company directors (and at one time would not have done) so we should look for the causes of this difference rather than being content with the smoking behaviour as an explanation.

Socio-economic status is strongly linked with inequality in life and health. Links to inequality in life and health exist in relation to the seven protected inequality strands that are the focus of the Equality and Human Rights Commission and of this report. Socio-economic status should not be used to 'explain away' inequality in life and health in other strands, such as ethnicity by saying, for example, that the relative ill-health of an ethnic group is due solely to their relative poverty. Again, we should be looking for the deeper causes, such as why an ethnic group is unduly socially deprived and what are the mechanisms by which this leads to worse health and life outcomes.

3.2 Methodology and method

This chapter sets out the methodology and method of this report. By methodology we mean the underlying beliefs and assumptions on which the report rests. In the main these are those of the Equality and Human Rights Commission's *Equality Measurement*

Framework; this *Framework* is, in turn, founded on an approach to fairness, justice and equality that is called the Capability approach (Alkire, Bastagli & Burchardt 2009). Thus the first section of this chapter sets out the Capability approach and the place of life-span and health, which are the focus of this report, in that approach. This section will be of use primarily to those who wish to engage with the discussion and commentary of the report. Those whose primary concern is the bare facts of inequality alone could bypass it.

The second section of the chapter sets out our method. By method we mean the techniques we used to gather the data for this report. This section will probably be of most interest to those who wish to check the origin of the data or who wish to update it for, for example, the next triennial review.

3.3 Methodology: Health and life in the capabilities approach to human rights

Our report concerns inequality across the seven protected strands in the two domains of life and health. The two domains are part of a set of ten set out by the Equality and Human Rights Commission in its *Equality Measurement Framework*. The *Framework* itself is a product of consultation with people and groups across Great Britain but is based in the Capabilities approach to justice developed by Sen and Nussbaum, amongst others (Nussbaum 2006, Nussbaum 2003, Sen 2005). In this section we describe how the domains of life and health sit within the capabilities approach and how capabilities relate to human rights. This will provide the basis for our discussion of inequality within each of the strands in that we will be able to highlight those inequalities that seem to be of greatest concern from a human-rights perspective. We also explain our decision in this report to devote a chapter to life and health inequality in a further strand, that of socio-economic status or class. The section is built around a series of questions, beginning with the question of when we should judge a health or life inequality to be unfair.

Is inequality in health and life due to nature, choice or unfairness?

Inequalities in life-expectancy and health are often put down to nature or to individual choices, that people die younger or are less healthy when they inherit certain genetic

tendencies or when they make bad life choices. Were this the case it would seem wrong to speak of these inequalities as unfair, or as violations of human rights. Looking across the seven inequality strands of age, sex, sexuality, trans-gender, ethnicity, religion and disability, there seem to be examples of inequalities that might be explained as a function of nature or choice: prostate cancer kills men not women; lung cancer kills smokers; sickle-cell disease affects black people; old people are more likely to get cancer; people with Down's syndrome are more susceptible to heart disease; and so on. So when should we say an inequality is unjust rather than due to nature or choice? Let us begin by considering ill health due to poor life choices.

In a review of evidence on people's conceptions of the reasons for health inequalities, Blaxter (Blaxter 1997) found that men and women in manual and non-manual work thought individual behaviour is a factor in such inequalities, but that they also blamed poverty (to a much lesser extent) and stress (to a greater extent than poverty but less than behaviour). However, Blaxter also found fatalism with regards to life and health, particularly from manual workers; fatalism in this context is the view that ill-health and mortality is largely a matter of luck and there is little you can do about it. In explaining this, people pointed to factors in the environment that were out of an individual's control, such as dangerous or stressful work. In a study of unmarried mothers, Graham (Graham 1994) found that young mothers smoked believing they had to in order to alleviate short-term stress and possible mental illness, despite knowing that smoking had long-term health costs.

A decision to smoke can be viewed as up to the individual and its consequences that person's fault. But if this were the case we should expect a roughly even spread of smoking across strands and across class. In fact, decisions to smoke are unevenly spread. This could be because of a prevalence of addictive or risk-taking personalities in some groups and areas; but more plausible is that factors in people's life and environment make a pro-smoking choice more likely for some than others. If these factors are to do with social benefits and burdens then we have entered the realm of injustice. In other words, if some groups smoke more because, for example, it is a means of coping with the stresses of unemployment or poverty, then the illnesses of smoking should be viewed as a result of unemployment or poverty as well as individual choice. Hence, for example, the inequalities between rich and poor in relation to lifestyle choices such as smoking and

exercise can be viewed as the result of collective injustice rather than simply the accumulation of a lot of poor choices by the poor and good choices by the rich. An underlying assumption of our report is that the link between choice and injustice is plausible. We turn now from inequalities (wrongly) explained as due simply to choice, to inequalities (wrongly) explained as due simply to nature.

In the literature on disability there is extensive discussion of a distinction between those who view disability as natural and those who view it as socially created. Those who view it as natural would tend to say that, for example, an illness that results in someone being wheelchair-bound is due to nature; it is no-one's fault and is not a matter of justice. We might choose to help the wheelchair-bound by improving access to buildings but this is a matter of charity, not justice. Those who view disability as socially created would say that the illness resulting in being wheelchair-bound is natural but that the creation of an environment in which wheelchair mobility is restricted is not. The difficulties in living experienced by the disabled are due to decisions made about structuring the social environment. Hence, the relative immobility of wheelchair users is an inequality that is unjust rather than natural.

On the other hand, it seems unlikely that all inequalities are the result of injustice. For example, the short lifespan of a child with Tay-Sachs syndrome would occur in any society no matter how fair. Others inequalities might be a product of combinations of nature, lifestyle and unfairness. The high mortality rate of young women with eating disorders could be viewed in this way. It follows that before we set out the inequalities in health and life in this report, we need some mechanism with which to discuss them and to help us sort out inequity from (mere) difference.

The capability approach

This report is based around the *Equality Measurement Framework* designed by the Equality and Human Rights Commission. This Framework is based on the Capabilities approach to justice and human rights developed initially by Sen and Nussbaum (Nussbaum 2006, Nussbaum 2003, Sen 2005). Sen first developed the Capabilities approach as an economic tool by which a nation's wellbeing and quality of life could be assessed. Sen was interested in famine. Famine can be thought to be the product of

shortage in a society; people starve when there is insufficient food. If this were so, the way to overcome it would be to increase a nation's gross national product (GNP) so that it either produces enough food or can buy it. However, Sen's examination of actual famines showed that they were rarely due to shortage; food was available but those who starved were not entitled to it. It follows that GNP is a bad indicator of wellbeing in that nation; GNP could increase in a country experiencing famine but without a change in entitlement the famine would remain.

Sen suggested, therefore, that judging a nation's quality of life required looking at what its citizens could do and be within the overall restriction of a nation's GNP. One vital element is, of course, the ability to be sufficiently well fed. But there are many others. Slaves could be well fed but could not be said to have a good quality of life; political and personal freedom would be another element in a good quality of life. Judging quality of life thus requires examining a range of such elements. Furthermore these are not fungible; you cannot substitute one for another. For example, you could not make up for a slave's shortage of freedom by giving him more food.

From this criticism of a GNP-based approach to quality of life and this analysis of famine, a theory of justice has emerged. It has long been held that fairness or justice has some kind of link to equality; people should be treated equally in some way. But this is problematic. For example, giving everyone an equal number of vouchers to use on health care would be treating them equally but would seem to be unfair because some need lots and others don't need any. So the key question for Sen in relation to justice is: equality of what? In what way should people who are clearly different in many ways be viewed and treated as equal? This question is perhaps the starting point for all accounts of justice.

There have been many attempted answers to the question. For some it is equality of respect for property rights, for others, equality of respect for property and welfare rights, and for others, equality of certain outcomes, such as wealth. Sen suggests that the important equality is of the capacity to be and to do across a range of characteristic and worthwhile human functions and activities.

The notion of a capacity to be and to do might seem Gnostic or mystical, but it is not. If asked what people need to live well, to flourish, most of us would be able to come up with

a list. The lists would vary but there are likely to be common elements, or at least elements people would agree to once they were suggested. Living a normal life-span, being healthy, being secure from violence and fear, are obvious candidates. Less obvious but plausible are notions of being able to pursue your goals in life, being sufficiently educated and being able to participate in civic and political affairs. It is these that are behind the idea of a capacity to be and to do. A society has a high quality of life to the extent that its citizens (all of them) are able: a) to be - healthy, alive for a normal life-span, secure from violence and fear, and so on, and b) to do - to pursue goals, read and learn, participate in civil life, and so on. Furthermore, and crucial to the account of justice, a society is just or fair to the extent that all its citizens have these capacities. Thus, if one group of people is living much longer than another then this is a cause for concern from the point of view of justice.

We said above that the capacities are of 'worthwhile' capacities and functions; this is an important restriction. Humans have the capacity to do many things that are either trivial or wrong. For example, we might not be too concerned as a matter of justice if some people exercise the capacity to drive Lamborghinis whilst others don't; although we would be concerned if some people's capacity to drive such cars inhibits the more important capacities of others. And we would certainly not want to extend to all the capacity to hurt others for fun.

Deciding what capacities are worthwhile is for Sen and Nussbaum a social process that will develop and change over time. Sen does not provide a list but Nussbaum suggests ten, on the basis of thought and of discussion with others. These are:

- Life - including not dying prematurely
- Bodily health - including nourishment and shelter
- Bodily integrity- including free movement, security against assault, opportunities for sexual satisfaction
- Senses, imagination and thought - being able to use your mind in a characteristically human way following, for example, adequate education
- Emotions - not having emotional development blighted by fear and anxiety

- Practical reason - being able to reflect on life and develop a conception of a worthwhile life for yourself
- Affiliation - to live with others with respect and without discrimination
- Other species - to live with concern for animals and the natural environment
- Play - being able to laugh, play and recreate
- Political and material control of the environment.

Where citizens are unable to meet these capacities to some threshold point a) they cannot truly flourish and b) there is a concern of injustice.

What is the link between capabilities and rights?

How, though, does this connect to rights? Rights are generally explained in terms of entitlements and duties: someone has a right to x if she is entitled to x and if others have a duty to ensure she can x. For example, if I have a right to free speech I am entitled to speak my mind and others have a duty not to prevent me doing so; I have a right to free health care if I am entitled to it and others have a duty to provide it. The free-speech right is an example of a negative right, a right to non-interference; the health-care right is an example of a positive right, a right to a service of some kind. Can we really say that someone is entitled to a full life span and others have a duty to provide it? If so, is it a negative or positive right?

In Nussbaum's capabilities approach, rights and capabilities are closely allied. The ten core capabilities must be realised for a human being to flourish. If we have any moral duties to each other at all then helping others to realise their capabilities to be and to do is at the core of these. The capabilities of others are the foundation of their rights and our duties (as well as our rights and their duties). Taking life-span as a core capability and, therefore, a human right, our duties will lie in both the negative sense (of not taking action that shortens life) and the positive sense (of taking action to remove threats and dangers).

The precise nature of the duties borne in terms of the right to life will vary depending upon the duty holder: the government will have a duty not to kill its citizens and to ensure that

neither do others; the employer will have a duty to protect employees; the health care system will have a duty to protect the populace.

The early death of an individual does not necessarily imply the violation of the right to life; getting an inherited cancer that kills is bad luck. However, if the cancer is due to the known presence and acceptance of carcinogens in a workplace by, for example, the relevant Government department, then that should be seen as a human rights issue.

This takes us to the link between inequality and human rights in terms of life expectancy. Avoidable inequality in life expectancy looks unjust; if it is caused by failures on the part of those who had duties to protect the people affected then we can say it is certainly unjust and a violation of rights.

Thus, in the chapters that follow, when we look at inequalities in life expectancy we shall also be looking for evidence of failures to respect the human right to life in this sense; that is, as the right to have the full life you would be capable of in a just society.

As with life expectancy, at first it seems strange to talk of health as a human right rather than, for example, health care. How can people be entitled to health given that it is not in anyone's power to guarantee it? The answer runs along the same lines as that given in relation to life expectancy. People have the right to the best health they are capable of; or, perhaps more precisely, they have the right to the opportunity to achieve the best health they would be capable of in a just society.

There remains a question here of how much resource society has to provide in order for people to meet their capabilities. For example, it might be possible to keep someone alive but only at great expense; is it really a violation of rights to fail to provide this? According to Alexander, Nussbaum and Sen do not address this question adequately (Alexander 2008). He suggests that Dworkin (Dworkin 1992), who is not a capability theorist, provides a useful tool. We should imagine ourselves deciding how to allocate health resources behind a veil of ignorance which denies us self-knowledge of our health and disability status. The allocation decisions we reach behind this veil will be fair. This veil-of-ignorance device is well known in philosophy; Rawls developed it in his account of justice (Rawls 1999). It's a powerful theoretical tool but in practice hard to create a situation akin

to a veil behind which we place real decision-makers. Thus, in this report we leave aside the question of resource allocation. We describe which inequalities are, to us, of concern but do not make a judgement as to whether resources should be allocated to alleviate the problem.

How does the Capabilities approach relate to the Equalities Measurement Framework and to this report?

The *Equality Measurement Framework* has been developed by the Equality and Human Rights Commission as the main tool with which it will assess equality and human rights in Great Britain. It is based on the Capabilities approach and sets out ten central domains in which equality should be examined in judging the fairness of a society. These are similar but not identical to those of Nussbaum. The ten are: life; health; physical security; legal security; education and learning; standard of living; productive and valued activities; individual, family and social life; identity, expression and self-respect; and participation, influence and voice. Thus, for example, if women are not given equal access to education and learning this looks like an injustice, a violation of a human right. An important methodological difference between Nussbaum's list and that of the Framework is that the latter is the product of consultation across a broad range of people and official bodies whereas the former is a product of reflection and theory. However, it is arguable that the lists largely contain the same competencies labelled differently, with the exception of Nussbaum's "other species" competency.

The Equality and Human Rights Commission's triennial review will examine the state of inequality across these ten domains (or competencies) for seven inequality strands protected in law. The focus of our report here is the first two domains, life and health. The domain of life is primarily to do with life-span or life expectancy. Let us introduce these domains in a little more detail.

Life expectancy

Individuals who die prematurely have generally been denied an opportunity to live a flourishing life; humans need to live a full-length life in order to live a good life. Of course, many who have died young have been highly influential and productive. However, their early death has generally contributed nothing positive; their lives

would have been better, their capabilities more realised, had they lived longer. It might be argued that early death is occasionally positive as when people die courageously in some way. But again, although the expression of courage enables us to look back and say this was a good life, it would have been better had early death not resulted from their courageous act. Some people will choose a life of risk and danger as part of their flourishing. Even so, it will be better if the risks do not eventuate, if the risk-taker survives in tact. It is difficult to imagine a real-life analogue of the story of Achilles, who was given a choice of a short, glorious life over a long mundane one, and who chose the former. It seems then reasonable to say that life-expectancy, being alive, is a capability that must be realised for someone to live as well as possible, to be and to do what she can. The British politician Frank Dobson once said:

There are huge inequalities in our society. Poor people are ill more often and die sooner. And that's the greatest inequality of them all - the inequality between the living and the dead (Warden 1998)

All of us will die eventually; but some are far better placed to live long lives than others. In our chapter on class we show that this is a strong indicator for life expectancy. If this is avoidable inequality in life-span then it is unjust.

Health

Human beings need a reasonable degree of mental and physical health in order to flourish. The precise degree will vary between individuals; the physical health required by someone whose life is oriented towards physical activity might be greater than that of someone whose life is primarily intellectual. Further, individuals can adapt to negative changes in physical and mental health and still flourish.

Nonetheless, for all of us, good health makes it easier to live well; and at some point, poor health makes it impossible to do so. Patterns of inequality suggest that some people and groups are denied this right. Again using the example of class, if society were organised differently then those currently at the bottom end of the health gradient could have better health; that they do not look to be injustice and a denial of the right to health.

The *Equality Measurement Framework* gives a number of indicators within each domain which should be examined when assessing the state of inequality in Great Britain. For example, the indicators relating to Life include life expectancy at birth, ages 20, 65 and 80; those relating to Health include percentage who report poor current health status. There are three types of indicator: those to do with outcome, process and autonomy. Outcome indicators are measurements inequality in important outcomes such as life expectancy. Process indicators relate to important processes in civil and social life such as whether you are treated with respect in health care. Autonomy indicators relate to your ability to control your life, for example, whether you are well informed in making lifestyle choices. In our discussion of the indicators within each inequality strand we make use of this three-way distinction.

Not all indicators are meaningful by inequality strand. For example, the Health indicator of percentage reporting a longstanding illness or disability is of little use in assessing the disability strand as the indicator is also the main definer of disability; we should expect 100% of disabled people to affirm this indicator. Other indicators require careful interpretation. The discussion above on the relationship between nature, lifestyle and unfairness in causing inequality shows why. As an example, a higher than average cancer mortality in the disabled might be purely a product of nature, related to the disability itself, or it might also be the result of inadequate screening for those with disability. Our discussion in each chapter draws attention to these subtleties; we try to separate the clearest unfairness from those where further reflection is needed.

Class and its relationship with the seven protected strands

In this report we also examine the state of inequality in relation to socio-economic status, or class. There are two reasons for this. The first is that class is a major axis of inequality in relation to health and life; this has been noted in a large body of research and is the focus of Government-sponsored work, including the recent Marmot Review (Marmot Review 2010). The second is that because of its importance class can hinder recognition of inequality across the other strands. For example, someone might suggest that once you adjust findings for class-effect, inequalities due to ethnicity disappear; and that, therefore, the inequality is all about class rather than ethnicity (see chapter on ethnicity and religion in this chapter). There are at least two problems with this.

The first is that some inequality within the ten domains cannot be simply put down to class; it would remain even if an adjustment for class were made. An example is the difference in life expectancy between men and women. The second is that if an inequality due to, for example, ethnicity, disappears when adjustment is made for class it does not follow that ethnicity is unimportant in understanding the inequality. There is clearly some sort of relationship between class and ethnicity such that one ethnic group is overrepresented in, for example, the lower classes of the National Statistics Socio-economic Classification (NS-SEC). Whilst we may not and cannot say in detail in this report what that relationship is we should not ignore the ethnic element; the picture of inequality should not be assumed to be simple and class-based.

The chapter on class precedes the chapters on the seven other inequality strands. In the commentary on the seven inequality strands we discuss the relationship between the inequalities noted by strand and those noted by class. This relationship is striking in the case of ethnicity, far less so (perhaps partly due to lack of evidence) for other such as Lesbian, Gay and Bisexual people.

To summarise: in this report we identify inequality in the domains of life and health across the seven protected inequality strands. We precede that investigation with a chapter identifying the inequality in life and health related to socio-economic status. In our commentary on inequality identified we attempt to show which is or might be a human rights concern from the perspective of the capabilities approach. We also try to show the connections between inequality related to class and that which occurs in the other seven strands. We do not, however, suggest which inequality should be tackled as a matter of rights; doing so requires an economic judgement that is beyond the scope of this report, namely, whether society should devote resources to the inequality and, if so, how much. We move, next, to a description of the method used to gather the data for this report.

3.4 Data sources

As noted above, the information presented in this report is largely guided by the core set of indicators identified in the EMF (Alkire, Bastagli & Burchardt 2009). Issues of data

availability and comparability have been discussed quite extensively elsewhere (Alkire, Bastagli & Burchardt 2009, Walby, Armstrong & Humphreys 2008) and we therefore highlight just the key issues to be borne in mind when reading the current report. In addition to the core indicator set, we have supplemented the description of inequalities in places with additional indicators, either because data are lacking for the core EMF indicator, or because we feel that additional measures are warranted, for instance where there are concerns that the chosen indicator does not operate well across the sub-groups of interest.

Some quantitative data sources are drawn on extensively across the chapters and we briefly described these below. In addition, each chapter draws on supplementary data sources that are particularly relevant to the strand in question, these are described in the individual chapters. The report also draws on smaller scale research, local and regional studies and grey literature as appropriate where the availability of national level data is limited. Again, these are described in more detail in the individual chapters.

Core data sources used across several chapters:

LIFE:

The Office for National Statistics and the General Register Office for Scotland (GROS) produce regular information on life expectancy, mortality rates and cause-specific mortality. There are some variations between these in the way that information is presented - for instance in the grouping of cause of death ICD-10 codes and the use of age-standardization - which can make direct comparisons of published figures difficult. Furthermore, not all data are routinely presented for England and Wales separately, meaning that patterns for Wales are largely obscured in the larger England & Wales combined data that are presented. As discussed in the individual chapters, life indicators are not available for several of the strands.

HEALTH: morbidity and healthy life-styles

National-level health-focused population-based surveys have been fielded in England, Scotland and Wales over several years, though the series is longer established in England than in the other two countries. These surveys - the Health Survey for England (HSE), the Welsh Health Survey (WHS) and the Scottish Health Survey (SHeS) provide detailed information on health status and health-related life-style factors with information being

collected both via face-to-face interview and a nurse visit. *The Health Survey for England* is an annual survey that began in 1991. All surveys have covered the adult population aged 16 and over living in private households in England. Children have been included in every year since 1995. *The Welsh Health Survey* took place in 1995 and 1998 with a sample of 30,000 adults in Wales, and from 2003 has been run with a yearly sample of 15,000 adults. *The Scottish Health Survey* is a national sample survey of around 8,000 adults and 3,000 children carried out in 1995, 1998, 2003 and 2008. Routine analyses published from the data collected through these surveys vary considerably so that a wider range of information is readily available for England than for the other two countries. The three surveys do not always employ standard analysis and presentation procedures making comparisons across the countries difficult in some cases. Nevertheless, the data sets are deposited with the UK Data Archive allowing further secondary analysis. Selected analyses of the 2008 data from these surveys have been performed for this report. A further source of information on health and life-style factors is the General Lifestyle Survey (GLF), formerly known as the General Household Survey (GHS). This is a multi-purpose continuous survey carried out by the ONS collecting information on a range of topics from people living in private households in Great Britain. The survey has run continuously since 1971, except for breaks in 1997/8 (when the survey was reviewed) and 1999/2000 when the survey was re-developed. The GLF is a module of the Integrated Household Survey (IHS). We draw on data from this survey across several of the chapters.

HEALTH: *Health service experiences (perceptions of treatment with dignity)*

There are two main sources of data on people's perceptions of treatment with dignity and respect in health services. In England and in Wales population based surveys have been fielded - the Citizenship Survey and the Living in Wales survey (to be replaced by the National Survey for Wales in future) - that have included relevant questions. These have been analysed by the equalities strands of interest for this report. In addition, the Care Quality Commission (formerly the Health Care Commission, the Mental Health Commission and the Commission for Social Care Inspection) and Better Together, Scotland's Patient Experience Programme regularly undertake surveys of patients and providers to assess experiences and quality of care. Unfortunately, the standard production of results from these surveys is not particularly useful for the purposes of EHRC's equalities monitoring agenda. This is because the focus tends to be on healthcare organisations - GP practices and NHS trusts - rather than on sub-sections of the

population. In addition, there is no well-organised system of accessing these data for secondary analyses and there seem to be obstacles to releasing the data, especially when variables such as ethnicity are required. For instance, the recently produced summary of findings from national in-patient surveys over time does not include any analyses disaggregated by sex, age or other patient characteristics (Care Quality Commission 2009).

In several cases, we were unable to identify adequate data to examine the EMF core indicator and these data gaps have largely been documented previously. However, we discuss in the chapters that follow some additional data inadequacies that have been identified during the course of our review that warrant further attention.

3.5 Issues to consider in identifying and assessing inequalities

Identifying the 'groups'

The ease with which meaningful groups of people who share certain characteristics and life experiences can be identified varies across the equality strands. For instance, while the great majority of people can be categorised into either 'male' or 'female' and the boundaries of these groups are relatively stable (even if the implications of such group membership are not), this is not the case for ethnic categories or disability categories. Indeed, as discussed in Chapter 7 on Race and Ethnicity, such categories are socially constructed varying across time and place, are not natural or neutral, and are inevitably crude markers of health-related risk (Salway, Ellison 2010, Salway et al. 2009, Bradby 2003). Furthermore, some of the current statutory categories, in particular Black African and White Other, are extremely crude, covering a diverse range of people with differing languages, cultural norms, countries of origin and so on. Caution is needed in interpreting quantitative data that present differences between such artificially fixed 'groups' and we should be alert to the essentialism and reification that can ensue from these approaches.

Intersectionalities or 'cross-overs'

In addition to the need to recognise the limitations of working with fixed categories for some of the equality strands, it is also important to be alert to the internal heterogeneity of the 'groups' identified and the ways in which individual outcomes and experiences are shaped by multiple identities simultaneously (Molloy, Knight & Woodfield 2003).

Throughout the report we try to identify cross-over themes and vulnerable groups, and to alert the reader to the importance of not assuming that patterns of inequality always move in the same direction. For instance, in Chapter 8 on Sex and Gender we show how the socioeconomic inequalities in health indicators are not the same for men and for women. Similarly, in Chapter 7 on Race and Ethnicity we illustrate the differing sex inequalities in several life-style factors across the ethnic groups, as well as highlighting the particular vulnerability experienced by older Pakistani, Bangladeshi and Indian women. More examples are found in the other chapters.

Consistency of measures

It is important to note that comparisons between some of the core indicators presented in the chapters that follow may be affected by variations in the question format and codes that have been employed. For instance, the questions used to assess self-reported health vary between the health surveys as well as in the census. Table 1 and Table 2 summarise the key variables derived from the health surveys. Interested readers should consult the survey documentation and questionnaires for more information. Furthermore, there have been some important changes over time in the way that measures have been calculated - most notably for the alcohol indicator - and this means that it is difficult to assess trends over time.

Table 1: 2008 Health Surveys: measures of self-reported health

	Question wording/ indicator computation	Response options	Notes
Self rated health			
HSE	How is your health in general? Would you say it was ...READ OUT...	1 very good; 2 good; 3 fair; 4 bad; 5 very bad?	
SHeS	How is your health in general? Would you say it was ...READ OUT...	1 very good; 2 good; 3 fair; 4 bad; 5 very bad?	
WHS	In general, would you say your health is ... ?	Excellent; Very Good; Good; Fair; Poor	
LLTI			
HSE	Do you have any long-standing illness, disability or infirmity? By long-standing I mean anything that has troubled you over a period of time, or that is likely to affect you over a period of time?	Y/N	Respondents were coded as having an LLI if they responded yes to both of these questions
	Does this illness or disability/do any of these illnesses or disabilities limit your activities in any way?	Y/N	
SHeS	Do you have a long-standing physical or mental condition or disability that has troubled you for at least 12 months, or that is likely to affect you for at least 12 months?	Y/N	Respondents were coded as having an LLI if they responded yes to both of these questions
	Does (name of condition) limit your activities in any way?	Y/N	
WHS	Do you have any long-term illness, health problem or disability which limits your daily activities or the work you can do? (Include problems which are due to old age)	Y/N	
Common mental health problem			
HSE/SHeS	GHQ Score - grouped	0; 1-3; 4+ (4+ indicating probably CMD)	Derived from individual GHQ questions
WHS	SF36 Mental health score (norm-based)	no cut-off	Derived from individual SF-36 mental health questions and normalised

Table 2: 2008 Health Surveys: Health-related life-style factors

	Question wording/indicator computation	Response options	Notes
Smoking (not currently smoking)			
HSE/ SHeS	Do you smoke cigarettes at all nowadays?	Y/N	
WHS	Which one of these best describes you?	I smoke daily I smoke occasionally but not every day I used to smoke daily but do not smoke at all now I used to smoke occasionally but do not smoke at all now I have never smoked	Used to smoke and never smoked responses combined.
Alcohol consumption (within government guidelines)			
HSE/SHeS /WHS	Maximum daily consumption within guidelines: Number of units consumed on heaviest drinking day in past week: Derived from a battery of questions on types and amount of alcohol consumed	Women up to 3 units or >3 units Men up to 4 units or >4 units	One unit of alcohol is 10ml by volume of pure alcohol. 2006 revised questions including information on glass sizes and types of alcohol. Revised conversion factors.
Fruit and vegetable consumption (5 a day)			
HSE/ SHeS	Grouped portions of fruit & vegetables yesterday (last 24 hours): Derived from a battery of questions on the amount and type of food consumed.	0; 1<2; 2<3; 3<4; 4<5; 5<6; 6<7; 7<8; 8+ (further recoded into Y/N for 5 or more portions)	One portion defined as 80g. Fruit juice, pulses and dried fruit each count only as one portion.
WHS	Eaten 5+ fruit or vegetables the previous day - binary derived variable from a battery of questions	Y/N	Methodology similar to HSE and SHeS . Changes introduced this year to ensure comparability.
Overweight & Obesity			
HSE/SHeS/WHS	BMI : derived from height and weight measures taken in interview.	18.5<25; 25<30; 30<40; 40+	
Exercise (meets government guidelines)			
HSE	Number of days per week any moderate+ activities for 30 mins+: derived from the enhanced physical activity questionnaire, bouts of exercise of 30 minutes or over included and summed.	< 20 or 20+ occasions of moderate or vigorous activity of at least 30 minutes duration in the last four weeks (i.e. at least five occasions per week on average).	Respondents questioned about up to 4 main activities in the past 4 weeks. The summary measure incorporates three basic dimensions (frequency, intensity, duration) of overall physical activity level.
SHeS	Number of days per week any activities 30 mins +, bouts of 10 minutes or more included (sports = moderate if effort): Derived from a number of questions on type, duration and frequency of activity	>1; 1-2; 3-4; 5 or more	Methodology same as HSE but shorter bouts included in summation.
WHS	Activity in past week met government guidelines: derived from questions asking about light/moderate and rigorous exercise or physical activity in the past 7 days. At least 30 mins moderate or vigorous exercise on 5+ days in the past 7 days.	Y/N	Shorter and simpler set of questions that in HSE or SHeS

Validity and meaningfulness of measures across groups

A further issue that warrants some consideration is whether the indicators chosen operate similarly across the groups being compared. Can the differences observed be taken as evidence of real difference in the outcome or experiences of the groups or are they rather an artefact of the way the data collection procedures operate in the different groups? These issues have been particularly highlighted in some areas, for instance the assessment of mental well-being across ethnic and linguistic groups (Sproston, Nazroo 2002). However, more generally it has been argued that men and women assess and report their health differently thereby making comparisons of self-reported health difficult (Doyal, Payne & Cameron 2003) and it is likely that these factors are relevant across all the equality strands to a greater or lesser extent. Qualitative studies can usefully supplement quantitative work to increase our understanding of how health is understood and evaluated by different groups of people. However, there is a need for greater validation of some of the indicators that are routinely used to describe and monitor inequalities in health.

Size of effects, statistical significance and importance

While throughout the report we have tried to indicate where the differences reported between groups are statistically significant, it is also of interest to pay attention to the size of the effects and to reflect on their importance at a population level. In different parts of the report we present differences as well as ratios between groups. As discussed in Chapter 8 on Sex and Gender, these measures can sometimes show quite different patterns and it is important to reflect on their implications. It is also worth considering how many people are affected by a particular inequality. There is also the issue of persistence of the inequality in question and whether other inequalities also cluster together in particular groups, as well as the knock on implications an inequality may have for other aspects of people's lives. What factors make an inequality a cause for concern? What factors suggest that an inequality should be a priority for action? These are challenging issues that must be borne in mind when considering the evidence that has been compiled in the chapters that follow.

Meaningfulness of comparisons

The EMF is premised on drawing comparisons across 'groups' within the equality strands - for example comparing men to women, or comparing people identified as 'Bangladeshi' with those identified as 'White British'. There are a number of areas of caution that are warranted in relation to drawing such comparisons:

- Always taking a particular group as the standard against which the other group(s) are compared can serve to normalise that group, implying that the other groups are abnormal and problematic.
- Comparing to a standard group can also conceal important health issues if there are no apparent differences between the groups. It is important to look at absolute levels as well as relative differences.
- Drawing comparisons may not be meaningful if the issue in question affects the two groups completely differently or if the standard is a poor model against which to compare the other group(s). An example here is where male-female comparisons suggest that Scottish women are advantaged but comparisons with women in other parts of Europe reveal their shockingly worse health profile. A further example is the indicator 'Deaths from non-natural causes for people resident in health or social care establishments' which might be explored for older people as compared to younger people. In practice, there are so many factors that distinguish the circumstances of older people who are resident in such institutions from younger people that any simple comparison of the indicator is meaningless.
- Comparisons between the aggregate groups may conceal important heterogeneity within the groups, for instance by socioeconomic status.

Confounding factors and causal pathways

Simple comparisons of indicators across groups tell us nothing about underlying causal factors or possible routes of intervention (Salway et al. 2009). The groups in use in this report are markers for a whole range of factors that have potential explanatory power. It is important that we avoid slipping from simply *describing* differences into *explaining* them when the necessary data are not in place. This is a particular concern in health inequalities work since there is often a tendency for people to fall back on essentialist genetic/biological or culturalist explanations that tend to blame those who are

disadvantaged rather than seeing causes in the wider structural inequalities of our society. Each chapter that follows has made an attempt to discuss the evidence for the possible causal factors that could explain the inequalities presented. In most cases our understanding is very poor and there is clearly an urgent need to do more to understand and seek ways of addressing the Life and Health inequalities evident in Great Britain as well as to systematically expose and monitor them.

3.6 References

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