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## Chapter 8

### Diversity and Equality in Cancer Care

Mark R D Johnson and Julie Fish

- The context of health inequalities, with specific examples from relevant population groups.
- Exploration of epidemiological, knowledge, care and treatment differences among minority groups or other strands of legally recognized diversity.
- Differing understandings of causes/effects, values and terms such as ‘family’ or partner, among people from diverse culturally defined groups.
- Improving the knowledge, attitudes, behaviour and clinical practice of health professionals dealing with cancer in diverse groups.

#### Introduction

Tackling health inequalities is crucial to improving outcomes and achieving cancer survival rates which ‘equal the best performing countries in the world’ (Department of Health, 2011a). Cancer inequalities, including differences in cancer outcomes (e.g. mortality) and in user or carer satisfaction of cancer care, affect a range of groups including socio-economically disadvantaged groups, black and minority ethnic groups (BME), older or younger people, men or women, people with disabilities, people from

particular religions, and the lesbian, gay, bisexual and transgender (LGBT) community.

Inequalities can occur at any stage of the patient pathway, including awareness of the signs and symptoms of cancer, beliefs about susceptibility to cancer, or post diagnosis outcomes and experiences. The NHS Constitution clearly outlines that there is a core duty to ‘promote equality’ (of access and outcome in health). The *Cancer Reform Strategy* (Department of Health, 2007a) highlighted the significance of cancer inequalities in both morbidity and mortality, including survivorship, and in the experience of health services for cancer, noting that a major challenge to addressing this concern was the lack of evidence. Subsequently, the National Cancer Action Team published its National Cancer Equality Initiative (NCEI) (2010), which summarized the available evidence. They suggested a series of initiatives to reduce cancer inequality, whilst noting that there was still little reliable evidence on the causes of inequality (in any of the equality strands examined), or on effective interventions to reduce inequality.

Inequalities in health are an acknowledged fact, highlighted by reports such as the *Marmot Commission* (Marmot, 2010), which focused primarily on socio-economic aspects. The policy context also includes the growing political and strategic importance of the UK Equalities Act (2010), which came into full effect in 2012. Policy concerns being articulated at a European level must also be acknowledged, and the effects of the possibility of multiple discrimination or impact of membership of more than one disadvantaged category (for example, migrant women, older people with a disability, or LGBT minority ethnic people), known as **intersectionality** (Fundamental Rights Agency, 2013).

This chapter summarizes the key dimensions of cancer inequality, extrapolates from other sources some of the reasons for these inequalities and suggests ways in which these might be addressed. It also illustrates examples of good practice and interventions or projects that appear to have promise. The chapter aims to provoke reflection on the issues and to stimulate professionals to take action and report their findings, to reduce cancer inequality in future.

## **A policy context**

The existence of inequality in health status and in the experience of receiving healthcare has become, despite the intentions of the founders of the NHS, both an established fact and a matter for policy concern. New dimensions of inequality, going beyond the poverty that informed Beveridge's reforms, have become increasingly recognized.

The first major inquiry into **health equity**, commissioned by the Labour Government of 1974–79, (Black, 1980) demonstrated that while the introduction of the NHS had improved the overall health of the nation, there remained widespread inequalities. It concluded that the main cause was economic inequality. Some startling gradients were noted, for example the death rate for men in social class V (unskilled manual workers) was twice that for men in social class I (professional and managerial) and the gap between the two was increasing, not reducing as was expected. This was controversial because the founding principle of the NHS was that cost and income should not be a barrier to healthcare, which was to be 'free at the point of need'.

These findings were reinforced and reiterated in subsequent Government commissioned reports, particularly the *Whitehead Report* (1987), the *Acheson Report*

(1998), and the *Marmot Review* (2010), and in each of these, key mechanisms or dimensions of inequality were found to be socio-economic gradients (i.e. being poor was bad for health) and ethnicity. BME groups consistently showed worse outcomes than white people, even when socio-economic status was taken into account, recognizing that their income was likely to be lower and their residential concentration was highest in areas of deprivation. It does not, however, appear that ethnicity can be simply reduced to a marker of socio-economic deprivation: both issues are important because ‘being Black’ has effects on poverty as well as beyond (Williams and Johnson, 2010).

Cancer inequalities are differences between people’s cancer experience and/or outcome that result from their demographic or social characteristics (All Party Parliamentary Group on Cancer, 2009). These social inequalities are collectively known as the **social determinants** of health (Navarro, 2009; Wilkinson and Pickett, 2010; Marmot, 2010) and include:

- Age
- Class
- Disability
- Gender
- ‘Race’ and ethnic origin
- Religion,:
- Sexual orientation (and)
- Gender identity

The NHS of the twenty-first century, under the terms of the guiding NHS Constitution, has a responsibility to ensure that such inequalities are addressed and, insofar as possible, removed. The Care Quality Commission, which is responsible for enforcement of quality standards, explicitly places ‘equity’ under the headings of quality and safety in its guidance, and states,

Equality, diversity and human rights... Providers must consider equality, diversity and human rights in every aspect of their work. You should consider the needs of each person using a service against six key strands of diversity: Race, Age, Gender, Disability, Sexual orientation, Religion or belief. We sometimes refer to this as identifying a person’s ‘diversity’ or ‘diverse needs’. (Care Quality Commission, 2011: 38).

## **Epidemiological inequalities**

These national studies referred to earlier were unable to focus on other ‘protected characteristics’ (Equality Act, 2010) recognized as affecting inequality, beyond noting the well-established fact that men and women tend to have different life expectancies. However, a more detailed analysis of cancer statistics, undertaken for the National Cancer Action Team (National Cancer Equality Initiative, 2010), reported that both cancer incidence and mortality were generally higher:

- In deprived groups compared with affluent groups;
- In older compared with younger people; and
- In men compared with women.

These pictures were more complicated when considering specific cancers: breast cancer is known to have higher incidence in more affluent groups, but mortality is actually higher in less affluent women, including BME women.

It is also apparently well established among health professionals, on the basis of nationally available epidemiological data (Gill et al., 2007), that cancer is less of a threat to people of a minority ethnic background than to the majority ('white') population. Why, therefore, is it considered important to examine issues of biopsychosocial welfare in relation to cancer and ethnicity?

## **Reflective activity**

Consider your initial training and understanding of the biology of cancer: how far were issues of genetically defined 'race' and socio-cultural aspects of 'ethnicity' highlighted in the course texts and lectures?

It appears from closer scrutiny of the data that the prognosis for people from BME groups varies according to both the site of cancer and between ethnic groups. In general, incidence of cancer as a total cause of ill-health and death is lower amongst ethnic minority groups (possibly because of their lower average age), although there are some important exceptions. These are reviewed next, using data from the National Cancer Intelligence Network (NCIN) review (2009).

### **Ethnicity**

Incidence of prostate cancer is greater amongst Black African and Black African–Caribbean men and appears to progress faster, starting at a younger age. There is more liver cancer in South Asian groups as a whole, whilst mouth cancer is more common specifically in Bangladeshi men and women, both of whom have higher rates of tobacco use than average. Chinese groups have a higher overall expectation of cancer, but there are few robust data on specific cancers.

The reason behind this lack of specificity is that the quality of data recording in relation to ethnic groups is poor and this affects the ability of service providers to plan and deliver suitable services (Iqbal et al., 2008, 2009). The situation is even worse in terms of describing the specific needs and experiences of people in terms of their religious beliefs, sexual orientation or any disabilities, largely because such data are not routinely recorded in NHS data in a format that permits analysis (Johnson, 2008, 2012a); however, data on age, sex and place of residence are routinely collected and can be used to look at variations in terms of gender, age group and poverty (indirectly) by association with area-base deprivation index scores.

More specifically, the following key facts or ‘headline risks’ can be deduced from the latest data (National Cancer Intelligence Network, 2009), in relation to minority ethnic groups:

- Black males of all ages were more likely to have a diagnosis of prostate cancer than white males (age standardized Relative Risk (RR) between 1.26 and 2.48, based on different assumptions regarding 25% of patients with unknown ethnicity).
- Black and South Asian males and females had a higher rate of liver cancer than white males and females. (Black ethnic groups: RR 1.47–2.67, South Asian ethnic groups RR 1.47–2.43).
- Black males and black females had a higher rate of myeloma than white males and females. (RR 1.79–2.80).
- South Asian females 65 and over had an increased risk of cancer of the mouth (RR 1.18–1.97), whereas South Asian men may have a lower risk of cancer of the mouth than white men.
- South Asian females aged 65 and over had a higher risk of cervical cancer than white females. (RR 1.15–2.29).

It is not always possible to link rates and established patterns of cancer risk to lifestyle and behavioural patterns associated with ethnicity or specific ethnic groups, beyond the data on smoking and use of oral tobacco. There are few reliable data on lifestyle and diet that can be linked to clinical outcome data; however, early detection has been identified as a national priority, and although levels of public awareness of cancer signs and symptoms are generally low, they are known to be even lower in groups, such as deprived communities, some BME groups and men. This may contribute to lower uptake of screening and later presentation when symptoms arise, and hence to poorer outcomes.

## Sexual Orientation

Differences between the health and other behaviours of LGBT people and the general population may also lead to differences in cancer incidence associated with sexual minority status. There are some forms of cancer that have much higher incidence in LGBT groups, such as anal cancer, which is 31 times more common in gay men who may practice penetrative sex (Knight, 2004). Conditions related to HIV–AIDS, such as **Kaposi's syndrome** (Friedman et al., 1998), are significantly more common among gay men, while some lesbians may have made life choices (including reduced likelihood of giving birth and breastfeeding), which raise the risk of breast cancer (Zaritsky et al., 2010). It is believed that lesbian, gay and bisexual people are more likely to smoke (Tang et al., 2004), increasing their risk of lung cancer. A recent UK study found a two-fold increased likelihood of a smoking history among 18–19-year-old LGB young people (Hagger-Johnson et al., 2013).

Some health professionals and lesbians themselves believe that lesbians are at a lower risk of cervical cancer due to a lower perceived risk of **human papilloma virus**

(HPV) infection because they do not have sex with men (Fish, 2009); however, reported rates of HPV infection among lesbians range from 3.3–30%, with a prevalence of 19% for lesbians with no reported history of heterosexual sex (see Fish, 2009). Campaigners at one time objected to the fact that although vaccination for HPV was being actively promoted for young women to prevent cervical cancer, it was not being made available to sexually active gay men, where they argued that it might help prevent anal cancer (*The Guardian*, 13 June 2012, Society Supplement p. 34). The National Cervical Screening Guidelines now recommend that lesbian and bisexual women should be offered routine screening tests on the same basis as other women.

## **Inequalities in access to care and treatment**

There are geographical variations in the accessibility and availability of certain services, as is widely debated in terms of media coverage. This includes the willingness of local healthcare bodies (at the time of writing, Primary Care Trusts, but probably in future, Clinical Commissioning Groups) to set local priorities and limits on the funding of treatment within the general parameters set by NICE. There are few sources of data, however, that can be relied on to debate this issue, apart from difficulties caused by income, education and language ability (which specifically may affect access to information, depending on the availability of interpreter support: see Kai et al., 2011). It behoves all practitioners and policymakers to reflect on their responsibilities in this respect, and to create and examine local data to ensure they are not discriminating against any of the ‘protected characteristics’ and that their locality represents ‘good practice’.

In general, a poorer experience of care is reported by members of black and minority ethnic groups, men with prostate cancer, and people living in London. This has important consequences, since some analysts suggest that part of the striking variations in mortality can be attributed to later presentation for care, arising from delayed diagnosis amongst deprived groups, older people (at least for breast cancer) and certain BME groups. However, the contribution of any delay in diagnosis to poorer outcomes such as survival rates, and the observed higher mortality amongst men than women, is still uncertain (NCEI, 2010).

While there is little published evidence of discrimination in terms of clinical care, access to drugs and surgical interventions, or other aspects of medical care delivery, it seems that people living with cancer do feel that their identity in terms of ethnicity, gender and sexual orientation – and membership of other ‘protected characteristics’ – might affect the way they are treated or viewed by professionals. This comes out very clearly in terms of the way they feel they have been communicated with. A UK National Cancer Patient Experience Survey (NCPES, 2013) reports that there are consistent patterns of inequality across the data collected. White people, especially those living in less-deprived areas and reporting heterosexual orientation, (sometimes described as the ‘generic majority’ population), consistently felt happier about their treatment than members of the ‘at risk’ groups designated by membership of one or other of the ‘protected characteristics’. In particular, they highlight the following differences.

### Differences between ethnic groups

*Communication:* Cancer patients from all minority ethnic groups were consistently significantly less likely to be positive about some aspects of communication and how

they were treated as patients by NHS staff compared to white patients. This key finding replicates the findings of surveys of NHS patients in other patient pathways, as reported in the annual GP Patient Surveys and other official NHS national surveys of mental health service users and hospital inpatients. This suggests that rather than something specific in the delivery of cancer services, there may be aspects of healthcare in general, less well-experienced or more heavily criticized by some ethnic minority patients. Throughout the NCPES, where there are statistically significant differences between white patients and patients from ethnic minority groups. White patients are almost always the most positive, with black patients being the least positive on six items; Asian patients least positive on six items; and Chinese/other ethnic group patients being the least positive on nine items (NCPES, 2010). Those questions covered a wide range of issues, from information giving (such as whether they received ‘understandable answers’ to their questions), to confidence and trust in nurses, the control of pain and assessment of primary care support. Communication is clearly a crucial part of the process and key to many inequalities (Johnson, 2012). It is worth noting that subsequent rounds of the NCPES have found very similar differences: in the 2011/12 round, 25 statistically significant differences were found between ‘majority’ and minority ethnic groups, all in the same direction and pattern as in 2010 (Macmillan Cancer Support, 2013a; National Cancer Intelligence Network, 2012).

*Patient information:* Access to culturally relevant information about cancer and its signs and symptoms has also been recognized as an issue. There may be an unmet need from BME communities for cancer awareness outreach that is not at present being met through initiatives such as the Ethnic Minority Cancer Awareness Month (EMCAM) or the work of minority-led initiatives such as Cancer Black Care, Cancer

Equality and BME Cancer Communities (<http://www.bmecancer.com>). Existing cancer information may not always reflect multi-ethnicity in terms of images and language (e.g. patient information stating that skin might appear red after radiotherapy) (Hill, 2003). Very few 'generic' mainstream information resources include details of foods that appear more frequently in minority ethnic diets (such as *saag*, *naan*, or *ackees*).

*Religion and spirituality:* There is very little information on differences in cancer incidence, treatment or outcomes by religion, and none at a national level other than what can be inferred from the 2009 National Cancer Intelligence Network report (2009) about incidence and survival by ethnic group. Some equality issues that are explicitly related to religion may be identified. Patients may find it difficult to access health services during religious festivals, for example the Muslim holy month of fasting (Ramadan) can have substantial impact on attendances at cancer clinics. It is important that NHS services work with local communities to address these issues. Similarly, practices such as fasting (which is not confined to Muslim groups) may impact upon cancer treatment and interfere with medication regimes. Many of the issues faced by different religious groups are closely related to ethnicity and culture, and therefore action on many of the issues identified in this section on ethnicity will also have a positive impact on tackling inequalities according to religion.

There is also evidence that religion and spirituality affect psychosocial adjustment to cancer. Research conducted with Black Caribbean and White British patients living in South London boroughs with advanced cancer explored how religion and spirituality influenced their self-reported cancer experience (Koffman et al., 2008a). In this group, Christianity was the only religion referred to. Strength of religious

belief appeared to be more pronounced among Black Caribbean patients. Three main themes emerged from patients' accounts: the ways in which patients believed religion and belief in God helped them comprehend cancer; how they felt their faith and the emotional and practical support provided by church communities assisted them to live with the physical and psychological effects of their illness and its progression; and Black Caribbean patients identified the ways in which the experience of cancer promoted religious identity. Patients from both ethnic groups appeared to derive benefit from their religious faith and belief in God, but the manner in which these were understood and expressed in relation to their cancer was culturally shaped (Koffman et al., 2008a).

*Culture and lifestyle:* A study of breast awareness among women from different BME groups living in London and Sheffield suggests that Asian and Arab women share much in common with the White British socially disadvantaged women, in terms of general poor level of knowledge about breast cancer, notions of breast cancer, personal susceptibility and pessimism about prevention; however, distinct cultural differences were observed between these groups. For the Asian and Arab women, their frame of reference was firmly embedded in a specific socio-cultural-economic context, including cancer beliefs held in their ancestral country and the experience of being a migrant being of particular relevance. These contributed to the development of cultural constraints over the discussion of cancers, engagement with preventative behaviours and with healthcare services (Scanlon, 2004).

## **Reflective activity**

Consider your own lifestyle and 'frames of reference' and discuss with a friend from a different background (ethnic, social class, religious, language or other) what their

‘points of reference’ might be. How might this lead to a professional needing to give you different advice?

## Differences in relation to sexual orientation

In the 2010 NCPES, respondents were asked to indicate their sexual orientation (as heterosexual, bisexual, gay or lesbian, or other sexual orientation) for the first time. Significant numbers of respondents (5%) said they preferred not to answer (a specific answer option) and a more substantial number than usual did not answer the question at all (8%) – this compares to only 3.7% who failed to answer the question on gender. It is possible that significant numbers of people who were not heterosexual reacted in this way to the question, and that cancer patients who were not heterosexual are undercounted in the data. Only 800 patients (1.1%) overall chose one of the response options other than heterosexual. Analysis showed significant differences in the experiences of cancer services between LGB and heterosexual patients, and again the minority – LGB – patients reported less positive views in relation to 15 questions, specifically those which asked about communication and the way they were treated by staff, such as ‘Did you get understandable answers from the Clinical Nurse Specialist all/most of the time’ and ‘Did you feel Hospital staff always did everything they could to control (your) pain’ (Department of Health, 2013, pp. 116–117). Worryingly, many LGBT patients felt depersonalized and were significantly more likely to reply negatively to statements such as:

- Patient was told sensitively that they had cancer.
- Doctors/nurses did not fail to tell patient things they wanted to know.
- Patient never felt treated as a set of cancer symptoms rather than as a whole person.

It is possible that there is a strong association between those respondents who defined themselves as non-heterosexuals and other variables known to influence patient opinion. For example, non-heterosexuals are significantly younger than the heterosexual respondent group. It is also possible that in 2010, which was the first time on any NHS survey that this question has been asked, people may have been reluctant to answer (as was the case when the census first asked about 'race'). It takes time for survey participants to feel assured that their confidentiality cannot be compromised. An alternative explanation is that they were uncertain how to answer the question: it appears that the London Metropolitan police attempted to monitor sexual orientation among staff, and significant numbers of respondents did not understand the term 'heterosexual' (personal communication, 2006). Nevertheless, it is important to recognize the differences of view between heterosexuals and non-heterosexuals and to note that 11 of the 15 questions on which non-heterosexuals have less positive views on cancer treatment relate to communication and (broadly) the respect and dignity with which the patient was treated.

The subsequent rounds of the NCPES, as with the analysis by ethnicity, found a continued pattern of relative disadvantage affecting those classified as 'non-heterosexual'. Although in 2011/12, response rates had improved slightly for questions on sexual orientation, the proportion belonging to non-heterosexual categories was the same, and the reported analysis shows only a collapsed 'non-heterosexual' category without differentiating between groups (National Cancer Intelligence Network, 2012). One factor of relevance that does emerge from the new questions asked in 2011 was that lesbian/gay and other sexual minority groups were significantly more likely to express a willingness and enthusiasm for participation in cancer research studies,

suggesting at least that they appreciated the opportunity to express their views, and perhaps reflecting an awareness that research can lead to improved treatment.

### Differences between age groups

People with cancer in both the youngest and oldest age groups (16–25 and 76+, respectively) often have less positive views about their treatment than those in the middle-age groups. There are 42 separate issues on which there are significant differences between age groups as a whole in the NCPES survey and there are clear themes in relation to young patients, related specifically to ensuring that explanations of treatment, condition, tests and so forth are given in a fashion that recognizes the lack of hospital experience which many of this age group will have at the time they start treatment. As far as older people are concerned, there is strong evidence that fewer of them have easy access to clinical nurse specialists and fewer of them receive information about financial help and benefits than is the case for other age groups. In other respects, there are few definite areas of inequality in cancer attributable to age differences that could be addressed by health practitioners or policymakers, except to ensure that any assumptions about the natural history or likelihood of disease, or worth in terms of need for treatment are not based on preconceptions relating to the age of people at risk.

### Patients with long-term conditions or disabilities

Disability encompasses a wide range of issues from mental health to learning disability and sensory impairment, as well as physical disability. There is no national information on variations in cancer incidence, treatment and outcomes for people with a disability, although there is some evidence for increased incidence of cancer associated with some mental illnesses (although people living with schizophrenia may

have a lower incidence of respiratory cancers). This is associated with increased cancer mortality. People with intellectual disabilities appear to have a similar age-standardized incidence to the general population, although patterns of incidence may be different and screening uptake for those with learning disabilities and mental health needs seems to be lower than the general population. People with physical disabilities may also experience barriers to screening and those with learning difficulties or other communication impairments may struggle to express changes to their health, potentially complicating and delaying diagnosis. (Issues relating to intellectual disabilities and mental illness are more fully discussed in Chapters 9 and 10).

Cancer patients taking part in the NCPES survey were asked if they had other long-term health conditions (LTC). On 48 questions there were statistically significant differences of opinion between those patients with a long-term condition or conditions and those without one. In almost all cases the patients with long-term conditions were less positive. Insofar as is possible to look at individual long-term conditions, it is clear that patients with mental health conditions and those with intellectual disabilities were very much less positive than cancer patients without long-term conditions of any kind, and less positive than patients with other kinds of long-term conditions. Again, there were complaints about depersonalization: people felt that they were being treated as a set of cancer symptoms rather than as a whole person, and that communication and respect were lacking in their treatment. People with disabilities, especially those characterized as having intellectual disabilities, are at particularly high risk.

## **Reflective activity**

Look for examples of ‘Easy Read’ documentation designed for people with an intellectual disability and consider whether this style of approach would help with your practice, or in informing other so-called ‘hard-to-reach’ groups, especially across language barriers. Good practice examples can be found on the website of the charity Action for Real Change (<http://www.arcuk.org.uk>)

## **Differences in attitudes or behaviours among patients**

A key element in understanding inequalities and variations in uptake or response to treatment and prevention programmes is that people do not all have the same values or understandings. Ethnicity is a complex concept, which includes elements of a number of ways in which people think of themselves and live. These include language, religion and culture – and that last concept might include different understandings of what is meant by ‘family’ and the responsibilities or roles of family members, as well as drawing on different musical or artistic traditions and having access to different pools of knowledge. For minority groups defined by a history of migration (e.g. ‘South Asian’ peoples), this will include awareness of patterns of diseases and treatments or outcomes drawn from other countries. This is also true for people whose migration (or parents) came from other European countries, as well as the more usually described ‘BME’ groups.

Similarly, people defined by their sexual orientation or age will have different understandings of family relationships and different experiences that will affect the way they think and behave, or indeed, the ways in which professionals may respond to and treat them. For example, for LGBT people, some research has suggested that their partner or carer was not seen as a legitimate person to be involved in decision-

making about treatment and care, and were often overlooked by clinicians and other health professionals (Fish, 2010; BRAP, 2010).

An under-reported issue in relation to cancer treatment is the potential threat to **fertility**, which has very specific implications for younger women, but has also been raised in controversies relating to men's ability to store gametes (semen) for future use. Treatment, especially with toxic drugs or radiation therapies, can lead to infertility, and beliefs (or values), stereotypes and knowledge all affect the way this may be discussed and resolved. A study specifically looking into this issue (Chattoo et al., 2010) found that gender was seen as an important consideration, as was life stage, in discussing treatment options. When ethnicity was discussed, it was often in terms of generalized assumptions, assuming homogenous communities, in addition to a strong sense of minorities being the 'other'. Professionals could interpret similar responses very differently according to the cultural and ethnic background of the patient and often felt ill equipped to respond to the needs of a multi-cultural society.

This issue can become even more salient within the context of families of South Asian origin due to the assumptions professionals have about their family culture being patriarchal, oppressive and intrusive. In fact, people from minority cultures exhibit considerable flexibility and sophistication in approaching such concerns. For example, Islam does not in fact prevent men from using sperm-freezing, although South Asian families may have different understandings of kinship roles and expectations, and sometimes feel exposed to greater peer pressure (see Culley et al., 2009). For women, **gamete storage** is a more complex and time-consuming procedure that could significantly affect onset of treatment and it is important that these matters are raised early and discussed sensitively. It is also important to note

that similar issues (and problems of professionals' feelings of comfort in discussing them) arise in relation to people in LGBT relationships (Hinchcliffe et al., 2005). Although that paper relates primarily to sexual health, it may be that cancer professionals need to discuss with LGBT patients how their cancer might impact on their sexual health (e.g. lesbian sex following cervical cancer, or sex between men following anal or prostate cancer).

As people face cancer and the end of life, the social, cultural and therapeutic role of food takes on an increasing significance. This has not been widely researched, or reported, but one small study involving older Chinese people resident in the UK investigated their beliefs about the influence of food on cancer and its role in supportive cancer care. The analyses revealed four main themes: (1) food as 'therapeutic'; (2) food as 'risky'; (3) food as supportive and comforting; and (4) beliefs about the lack of culturally appropriate and acceptable food in hospitals. Expectations about the lack of Chinese food and the poor quality and perceived unsuitability of 'Western' food were regarded as major concerns in relation to hospital admission (Payne et al., 2008). It can be assumed that similar beliefs and feelings may also be expressed by members of other groups used to a distinctive 'traditional' diet.

## **Relevance to practice**

It is important to recognize that although much of the earlier text reports concerns, inequalities and feelings of exclusion associated with belonging to BME and LGBT (and other 'at risk' minority) groups, there have also been a number of examples of 'good practice' and interventions designed to address these and provide an improved experience and outcome for members of these groups. At present, most of these are still only at the stage of being researched or evaluated in pilot sites, but as they are

increasingly reported in appropriate formats, providers and commissioners of services will find pressure to adopt them into regular provision (e.g. Nottingham City and County PCT, 2011; Fish, 2012). Readers, therefore, should seek out newly reported research and evaluation studies, and ensure that their practice is able to reflect the lessons learned. Specialist journals, such as *Diversity & Equality in Health and Care*, or relevant charities like Stonewall will probably be the first place to report these, and may also note new studies as they start. Key to this will be ensuring collection of appropriate data relating to ethnicity, sexual orientation, disability and other ‘risk factors’ for inequality, and performing audits to ensure that differences are *not* invariably associated with inequalities.

## **Reflective activity**

Consider any research activity or audit that you are involved in or have the opportunity to conduct. Would it be possible to include ethnicity or sexual orientation in this? What would you expect to find?

A number of Government initiatives have been introduced following the *Cancer Reform Strategy* (Department of Health, 2007a) that aim to reduce cancer inequalities and improve the survivorship of patients with the poorest outcomes. In 2010, the NCEI produced a principles and practice guidance document for good equality working, which outlined ten good practice principles:

## **Principles for good equality working**

1. There is an evidence base
2. Work is targeted and specific
3. There is community engagement
4. There is service improvement and innovation

5. Interventions are tested and refined
6. There is a process to measure effectiveness
7. The work is led by champions working in partnership with others
8. The work is evaluated
9. Sustainability is built-in
10. Learning is shared

Since the NCEI was established in 2008, a number of good practice examples can be found:

- NCAT Cancer Awareness newspapers targeted at African and African–Caribbean, South Asian and Irish communities, along with guidelines for Wellbeing Boards and GP Commissioners have been uploaded and published through their website (<http://www.ncat.nhs.uk/our-work/improvement/equality>)
- Other NCAT campaign materials developed as part of the ‘Cancer Does Not Discriminate’ programme can be found on the websites of partner agencies (see Principles for good equality working 7) such as:
  - the RAFFA site working with faith communities (<http://www.raffa.org.uk/health-and-wellbeing/>)
  - Stonewall (<http://www.stonewall.org.uk> for LGBT groups)
  - Breast Cancer Care (<http://www.breastcancercare.org.uk/>) and Cancer Research UK (<http://www.cancerresearchuk.org/>)

## **Chapter summary**

Equality issues should be embedded throughout cancer services rather than being a token gesture. Taking three of the principles as exemplars, we highlight the developments made in efforts to reduce cancer inequalities. These identify the need for robust research evidence and, to this end, the NCEI has been instrumental in developing the evidence base for cancer among groups who experience inequalities.

1. The National Cancer Intelligence Network (NCIN), for example, has recently produced a report about ethnicity and lung cancer, which shows that Bangladeshi and White men have higher rates of lung cancer than Indian and Pakistani men (Jack et al., 2011). The data will enable targeting campaigns within these communities to raise awareness of risk factors and reduce smoking.
2. Engaging with communities and diverse groups to understand the reasons underlying poorer experiences of care is essential. NCAT has established the national *BME Cancer Voice*, which incorporates both Asian and Black groups to support improvements in the experience of those affected by cancer in BME communities and develop more personalized interventions. It aims to raise awareness of cancer and its signs and symptoms, and access to screening programmes by people from all BME communities through carefully targeted campaigns, including the NCAT Cancer Does Not Discriminate campaign, aimed at raising awareness of cancer in BME communities.
3. With regards to service improvement and innovation, there is a project funded by the ESRC, which aims to develop knowledge among cancer and social care professionals about breast cancer in lesbian and bisexual women. Working alongside the charities Breast Cancer Care and Macmillan Cancer Support, the project aims to develop organizational cultures and practices in cancer and social care services. Breast Cancer Care produced a policy briefing document, which raises awareness about risks, diagnosis and time of presentation, access to information and treatment and access to emotional support (Dhami, 2011). It makes recommendations for Cancer Charities, professionals and commissioners of cancer care and policymakers. As a result, Breast Cancer Care now collects sexual orientation data for their volunteers and plans to do so for everyone that uses their services. They will use these data to see patterns of service usage and if there are any differences that can be attributed to equalities issues, and implement the recommendations in their policy work. In the work with Macmillan Cancer Support, cancer and social care professionals attended a seminar that

examined differences in the research evidence about any form of cancer in LGBT people, and included a Macmillan GP-led discussion about differences in cancer experiences. A service user and carer also spoke about their cancer journey. In workshop sessions, a number of case studies were discussed and these were developed to form a new resource for professionals working in cancer (Fish, 2012). Most cancer professionals are committed to promoting equality, but in order to do so they need resources to support them in delivering good practice and an evidence base on which to underpin their interventions.

## Reflective activity

Consider the relationship between cancer care and the social inequalities:

- Age
- Class
- Disability
- Gender
- ‘Race’ and ethnic origin
- Religion
- Sexual orientation
- Gender identity

What can be done about health service providers’ lack of knowledge about LGBT and BME issues?

What might LGBT people or those from religious and cultural minority backgrounds fear about health professionals?

What concerns do professionals have about LGBT or religious-distinctive patients?

Are differences between ‘diverse’ groups (whether defined by sexual orientation/sexuality, gender, age, disability, ethnicity or faith) the result of accident, an artefact of the data or due to discrimination?

What is the responsibility of the individual practitioner to understand the needs of members of groups, as defined by these dimensions of inequality?

## Key learning points

- The incidence of some forms of cancer is lower among BME groups; however, the prognosis may be worse than for other groups – some cancers are much more common in certain groups of LGBT people.
- BME patients report less positive care in relation to information giving, confidence and trust in nurses, control of pain and assessment of primary care support.
- LGBT patients are more likely to report that they are not treated with dignity and respect and that they felt depersonalized in healthcare interactions.
- Older patients are less likely to say that they had received information about financial help and benefits than their younger counterparts.
- Patients with mental health conditions and those with learning disabilities were less positive about their care and reported feeling depersonalized.
- The cancer care community needs to create a healthcare environment that is welcoming of diversity and includes training in effective communication with inequality. As such, diversity should be integral to Continuous Professional Development.
- It is important to develop a knowledge base of local and national resources for inequality groups in order to signpost people with cancer, their families and carers to longer term support through treatment and follow-up.

## Recommended further reading

Lethborg, C. and Posenelli, S. (2010) ‘Improving psychosocial care for cancer patients’, in P. Bywaters, E. Mcleod and L. Napier (eds.), *Social Work and Global Health Inequalities*. Bristol: The Policy Press. pp. 198–208.

Navarro, V. (2009) ‘What we mean by social determinants of health?’, *International Journal of Health Services*, 39 (3): 429–441.

Wilkinson, R. and Pickett, K. (2010) *The Spirit Level: Why Equality is Better for Everyone*. Harmondsworth, UK: Penguin.

Williams C, and Johnson M.R.D. (2010) *Race and Ethnicity in a Welfare Society*. Maidenhead, UK: Open University Press/McGraw Hill.

Note: selected ‘grey literature’ reports about cancer inequalities on open access can be found at the CERP Portal (<http://www.cancerinfo.nhs.uk/healthcare-professional/cerp>)

## Selected websites exhibiting Good Practice/Further online resources

<http://www.cancerblackcare.org.uk/>

<http://www.bmecancervoice.co.uk/>

[http://www.ncin.org.uk/about\\_ncin/default.aspx](http://www.ncin.org.uk/about_ncin/default.aspx)

<http://www.bmecancervoice.co.uk/images/ncat%20health%20supplement%20issue%201.pdf>

<http://www.cancerinfo.nhs.uk/>

