

“Walking into the unknown”

Survivors and carers speak out on discrimination and
inequality in cancer care services

EXECUTIVE SUMMARY

- 1 Macmillan Cancer Support commissioned this study in order to better understand the extent, cause and nature of discrimination and inequalities in cancer care focusing on individuals who identify themselves as belonging to one or more of four specific disadvantaged groups:
 - Those who experience socio-economic deprivation.
 - People from ethnic minority groups.
 - Older people.
 - People from lesbian, gay, bisexual and transgender groups.

- 2 The research was conducted in late-2010 by Midlands-based equalities and human rights charity, brap, and focuses on three key areas of investigation:
 - The equalities data and processes of 78 hospital trusts across England, Ireland, Scotland and Wales.

 - Contributions from a total of 144 individuals (patients, carers and family members) which illuminate the differential experiences of cancer care for those from disadvantaged groups at various stages of the care pathway: pre-diagnosis/diagnosis; treatment; follow up care; and cure, remission or relapse.

 - The potential for a new framework for assessing discrimination and fairness in care provision focusing on three 'benchmarks': equality of outcomes; equality of relationships; and equality of voice and choice.

FINDINGS

A: Health Trusts' Equality Plans & Processes

- 3 There are distinct limits to the way trusts consider inequality. Analyses focus primarily on health and risk factors – such as lifestyle and other predisposing factors. It is rare for **discriminatory behaviour or treatment** within the system to be examined as a possible contributing factor in unequal health outcomes and relatively little information about specific groups and their experiences is collected.

- 4 Virtually all trust equality plans reference patient engagement and consultation but few offer any real detail about the *consequences* of consultation.

- 5 Only nine of the 78 Trusts surveyed described their work to improve cancer care as part of an overall equality action plan.

- 6 It is rare for trusts to equality-monitor patient complaints – only 14% of the sample examined provided an analysis of complaints by age, gender and ethnicity.
- 7 In this connection the report recommends that:
- a) Trusts’ current focus on ‘risk’ must also include the risk of discrimination. Present policies and processes should be reviewed to ensure that they can and do furnish equality-monitored data which helps understand and address not just inequalities in health outcomes but also inequalities and unfairness in treatment and service provision. Equality monitoring should be a key part of service improvement.
 - b) Complaints procedures must be reviewed so that they work in favour of patients and provide additional intelligence regarding patients’ experience of care.
 - c) There needs to be more ‘real time’ feedback regarding patients’ experiences of care.
 - d) Anti-discrimination training should be incorporated as part of the service’s core vocational training, rather than as a ‘policy add-on’ within equality schemes.

B: Patients’ and Carers’ Experience of Cancer Care

- 8 Patients in all groups reported instances of being treated without dignity and respect, of poor, ineffective communication, lack of compassion and disregard for emotional distress. These behaviours were widely interpreted amongst interviewees, focus group participants and questionnaire respondents as discriminatory.

Pre-diagnosis

- 9 Patients from all groups reported delays in securing appointment for screening or diagnosis, with the worst delays reported by BME patients.
- 10 Patients report hostility from consultants if they reveal that they intend to refuse specific treatments or are investigating alternative therapies.
- 11 LGBT patients and carers in particular report persistent insensitivities regarding their domestic and family life and status of partners.
- 12 In this connection the report recommends:

- a) An assessment of patients' communication needs should be a standard part of the process, with this information following the patient through the system.
- b) Professionals' communication training should be urgently reviewed and its impact on patient experience assessed.
- c) There are specific areas of sensitivity and competence – for example, in handling family and relationship information from LGBT patients – which require significant improvement.
- d) Information provision such as the proposed 'information prescriptions' will only deliver benefits if improvements are made in the provision of one-to-one support, better signposting to advocacy, emotional and practical support, and more effective listening and communication.

Treatment

- 13 Lower socio-economic groups in particular report that their views, opinions and questions regarding treatment are regarded less seriously than those from better-educated, 'posher' patients.
- 14 Many report feeling unequal in the consultant/patient relationship – and of being treated “harshly”, “negatively”, “dismissively” or “coldly”.
- 15 Older people and those from lower socio-economic groups are concerned that decisions regarding their treatment lack fairness and transparency. They frequently feel that they are made unduly aware of the costs of treatment and whether they merit the outlay.
- 16 Those from lower socio-economic groups report struggling with the costs of illness (travel, special dietary arrangements), but also that this means they are less able to have a full voice in shaping and deciding their care options.
- 17 Patients from all of the four disadvantaged groups report high levels of isolation in the system, although this was slightly more marked amongst those from lower socio-economic groups. They report feeling alone, lost, unsupported.
- 18 BME patients continue to report that their cultural needs are routinely unmet, but significantly patients in all four groups also reported instances where their treatment lacked dignity and respect in the most basic considerations of care – e.g. in cleanliness, food choices, advice, comfort and privacy. BME patients and carers report persistent failures in trusts meeting their language or interpretation needs.
- 19 In this connection the report recommends:

- a) Older patients and their carers and families must receive appropriate explanations regarding treatment decisions and feel confident that decision-making is fair, transparent and *in the best interests* of the patient. The emotional impact of treatment decisions must be recognised, and explaining them fully and adequately viewed as a key requirement of effective and compassionate communication.
- b) Health professionals have a key role to play in *enabling* patients to achieve greater choice and autonomy, but must be part of a deeper cultural shift which will make this aspiration a reality.
- c) Culturally-specific needs are important, but health practitioners also need to be clear about what constitutes a ‘special need’ and what constitutes a fundamental requirement of high-quality care. Many of the shortcomings in behaviour and treatment recounted in the report are *basic* failings in the duty of care and compassion.

Follow-up care

- 20 Older patients and carers in particular lack adequate information and knowledge regarding their follow-on care. This is compounded by trusts’ patchy and inconsistent signposting to other forms of support, ineffective communication, and exchanges between professionals and patients planned without due regard to privacy, preparation, or adequate time to digest information and formulate necessary questions.
- 21 Older people who do manage to identify a support group (whether formal or informal) manage better.
- 22 Many patients (especially older and BME groups) reported professionals doing too little to ‘uncover’ information from patients which would have helped in planning follow-on care – in many cases failing to ask questions that would have elicited information that patients, carers or advocates did have.
- 23 In this connection the report recommends:
 - a) Much more needs to be done to assess and improve the patient/health professional relationship to ensure that patients’ rights are embedded within it and that it is a supportive and enabling dialogue. More real time patient experience data could be used to support this process of assessment and improvement.
 - b) Fundamental to patient empowerment is the right to ask questions. Trusts should develop a standard checklist of questions that patients can use to help them formulate appropriate questions regarding their own

circumstances. Such checklists could be developed with the assistance of cancer networks and other patient support networks.

- c) When assessing doctors' performance, more use could be made of patient 'voice' in the assessment process, focusing in particular on where patients feel their rights have been infringed.

At end of life

- 24 Patients in older and BME groups report complex problems regarding lack of information, inability and/or lack of opportunity to discuss end of life options as part of the treatment process, and a lack of 'voice'.
- 25 In this connection the report recommends:
 - a) The 'system' must be able to accommodate culturally-specific needs but it must also ensure dignity, respect, kindness, care and compassion for all, not just in exceptional cases where 'special needs' are identified. An improvement for all would by default bring significant improvements for disadvantaged groups.
 - b) There is a pressing need for patients and their carers to be able to discuss end of life arrangements much sooner with medical teams – in part to help carers, partners and families prepare emotionally and practically, but also to ensure that trusts too are better able to work with families to try and ensure that choice and autonomy can be exercised.

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Full Report

Survivors and carers speak out on discrimination and
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1.0 INTRODUCTION

About this study

We like to think that we live in a society where we all matter equally, and that nobody matters more because they are rich, or less because they are poor.

And yet, health remains one of the great focal points of inequality, as the recently published Marmot Review of health inequalities in England makes clear.¹

For more than a decade, tackling inequalities in cancer care has been a central concern in public health policy. But approaches to addressing inequalities have tended to focus on the risk factors associated with particular social groups and the lifestyle factors that may exacerbate these risks. Emerging evidence suggests that other factors also contribute to inequalities in outcome and this includes *discrimination in service provision*. Indeed, so concerned has the Patients Association become with shocking routine failures in care for some older people it has called for independent ‘patient safeguarding champions’ within hospital trusts and a new independent complaints procedure for the NHS.²

In terms of health care, then, social inequality has two quite different dimensions. Inequality affects the life-chances and health outcomes of disadvantaged groups, and the health service is engaged in a constant effort to better understand the nature and the inter-relationships of these inequalities. But to focus only on the risk factors that ‘bring people into the system’ is to ignore the role that inequality might play once ‘inside the system’. Addressing this is much less comfortable because it requires practitioners to address head-on the central but largely unspoken issue of discrimination and unfair treatment.

And that is the focus of this paper. Macmillan Cancer Support commissioned this study in order to better understand the extent, cause and nature of discrimination and inequalities in service provision focusing on individuals who identify themselves as belonging to one or more of four specific disadvantaged groups:

- Those who experience socio-economic deprivation.
- People from ethnic minority groups.
- Older people.
- People from lesbian, gay, bisexual and transgender groups.

¹ The Marmot Review (Feb 2010): Fair Society, Healthy Lives: The Marmot Review: Strategic Review of Health Inequalities in England post-2010.

<http://www.marmotreview.org/AssetLibrary/pdfs/Reports/FairSocietyHealthyLives.pdf>

² Patients Association (n.d, published December 2010): Listen to patients, speak up for change.

[http://www.patients-association.com/dbimings/Listen%20to%20patients,%20Speak%20up%20for%20change\(1\).pdf](http://www.patients-association.com/dbimings/Listen%20to%20patients,%20Speak%20up%20for%20change(1).pdf)

Who should read this report?

While this research is aimed squarely at policy-makers and health professionals in particular, inequalities in cancer care have the potential to affect all of us – through our families, spouses, partners, friends and colleagues. We hope therefore that the report can reach the widest audience possible, including civil society organisations, community groups, patients’ and service-users’ groups and self-help groups.

A health warning

We are not clinical experts, however, and this is not a clinical report. It focuses on patients’ experiences of cancer care and the impact of this care on their lives and those of their carers and families. It relies heavily on interviews conducted with patients and carers, and the words they used to describe their experiences have not been changed.

We are extremely grateful to the many individuals who consented to be interviewed. Their stories do not make easy reading but they demand to be heard and have not been softened for the benefit of the reader. Like them, we hope that the contributions they have made to this work can have a positive outcome by helping to improve the quality of patient care.

About brap

brap is a Midlands-based strategic equalities and human rights charity with an established local, regional and national profile. The organisation was established twelve years ago as a new kind of equalities partnership.

Our work focuses on equality issues in a wide range of policy and service delivery contexts, including health and mental health, housing, employment, education, and criminal justice, to name just some.

A thank you

We have engaged with a large number of individuals, voluntary and community organisations, cancer networks and health providers throughout the course of this research. They have contributed a wealth of expertise and insight and also helped us reach a large audience across the United Kingdom and for this we are extremely grateful. Thank you, we hope the report does justice to your valuable input.

2.0 WHY THIS RESEARCH?

Cancer inequalities have in recent years become an important part of the public health agenda. In 2000, the government presented a plan for investment in cancer reform, the aims of which were to reduce death rates and improve survival and quality of life.³ In 2007 the Cancer Reform Strategy also prioritised reducing inequalities and pledged that every person would have access to world-class NHS services at every point of the cancer pathway. A closer examination of whether discrimination plays a role in exacerbating these inequalities is clearly significant.

Why these groups?

As noted, this paper focuses on four groups who have been found to experience inequality in cancer care:

- Those who experience socio-economic deprivation.
- People from ethnic minority groups.
- Older people.
- People from lesbian, gay, bisexual and transgender groups.

While some statistical data in relation to the differing experiences of these groups does exist, it is generally acknowledged to be under-developed. This was confirmed by our review of the data held by hospital trusts, as is explained later in this paper. (**Appendix 1** provides a broader overview of cancer inequalities.)

A word on defining social groups

Definitions of specific social groups are always subject to differing interpretation. To avoid confusion, we set out our usage of the relevant terms below. Interviewees' responses were based on 'self-identification' with one or more of the target groups.

Black and Minority Ethnic: One focus of the research was on the experience and views of black and minority ethnic (BME) patients and carers. We used a broad definition to include any minority ethnic community in the UK, including 'white' ethnic minorities, refugees and asylum seekers, and the Gypsy and Traveller community.

Lesbian, Gay, Bisexual, Transgender: We adopted a broad definition that includes lesbians, gay men, bisexual and transgender people (LGBT). Obviously in some cases respondents reported experiences that related specifically to their sexual orientation (rather than their gender). Yet we found that respondents were happy to identify with this broader category and to say when an experience related to a particular aspect of that identity.

³ DH (2000): NHS Cancer Plan, a plan for investment and a plan for reform.

Older People: We recognise that there is no ‘standard’ definition of older people. It depends largely on the country and context in which it is being used. For example, ‘older’ may refer to pensionable age. For the purposes of this study ‘older’ refers to people who are 50 and over. This is based on AgeUK’s definition.

Lower Socio-Economic Background: As with the other groups, respondents were asked to self-identify with this category and they were not asked to disclose their income level. That said, we targeted particular areas of the country – e.g. ‘Spearhead Group’ localities, the 20% of areas in England with the worst health and deprivation indicators. In a recent report £14,400 a year before tax was identified as a minimum income standard for the UK in 2010.⁴

⁴ JRF (2010): A minimum income standard for the UK in 2010.

3.0 WHAT WE DID – OUR APPROACH TO THIS WORK

Gathering evidence

Our evidence-gathering for this research had a dual approach. Firstly, using desk-based and online research we examined the equalities data and processes of 78 hospital trusts across England, Ireland, Scotland and Wales. Using a smaller weighted sample we investigated data and processes in significantly greater detail.

We focused on an analysis of trusts' equality schemes because these should detail what trusts will do with regard to particular groups. Hospital trusts are required by law to develop and publish an *equalities scheme or policy* and these use a range of data to explore the experiences and outcomes of patient groups. Schemes are intended to cover the needs of all equality groups, but most importantly focus on what needs to be done to achieve parity across the board. Where publically available information did not provide adequate detail, follow-up phone-calls were made to seek clarification.

It is, however, extremely hard to track the *implementation* of trusts' equality plans and to understand progress in trusts' equality *practice*. For example, in many cases trusts state that they monitor patients in relation to race, gender and disability, but we found it difficult to find evidence of this happening, despite undertaking follow-up phone calls to seek clarification.

Interviews and focus groups

Above all, this research is indebted to the patients, carers, family members, partners and service-users who contributed their 'lived experience' of cancer care.

It was important that we reached the widest array of people who might have an interest in contributing and for this reason we offered a range of options for people to engage in the research, including an online survey, face-to-face and phone interviews, and focus groups.

We interviewed 36 people across the four groups, received 33 completed online surveys and engaged with a further 75 people in focus groups. The demographic breakdown of interviewees is shown below:

Nature of engagement	Demographic breakdown				
	BME	Lower socio-economic groups	Older	LGB&T	Totals
Interview	10	9	12	5	36
Online survey	15	8	5	5	33
Focus group	23	20	28	4	75
Totals	48	37	45	14	144

In the case of older people, ethnic minority groups, and LGBT groups, it was possible to identify participants by email, word of mouth and personal contacts through known networks and organisations. But this approach does not work for lower socio-economic groups: by and large, people do not group or ‘cluster’ by deprivation; they don’t belong to special organisations for deprived people. However, by targeting voluntary, community and resident organisations in deprived neighbourhoods (using the Spearhead Group of the 20% most deprived neighbourhoods as a starting point) and by using key community contacts and community outreach, we were able to identify participants. In some cases, contacts established in local organisations spread the message by word of mouth; in some cases we went out and knocked on doors.

The in-depth interview framework asked questions which enabled people to describe their experiences at various stages of the care pathway:

- Pre-diagnosis
- Screening/tests
- Diagnosis
- Treatment
- Follow up care
- Cure, remission or relapse

However, it is important to emphasise that the vast majority of people do not think in neatly prescribed ‘care pathway’ terms, and nor do their experiences necessarily conform to such a schematic. We encouraged people to tell their ‘whole story’ and used prompts where necessary to understand more about their experiences at particular points on the care pathway.

While the total number of participants (144) does not constitute a statistically significant sample and this is an important limitation, the depth and detail of the patient voices represented here goes far beyond what is usual in much health

surveying. It must also be said that the representation of disadvantaged groups is also significantly better than is usually achieved in health surveying, including the most recent National Cancer Patient Experience Survey Programme 2010.⁵

Once we had assured ourselves that formal ethical approval would not be required for this work, we took the step of ensuring that all staff involved in the project were advised regarding the type of support needs respondents might have. During interviews and focus groups, respondents received pre-interview guidance to ensure informed consent and to agree what would be talked about. Respondents were also asked whether they required any guidance or support as a result of taking part in the project.

⁵ DH (Dec 2010): National Cancer Patient Experience Survey Programme 2010 – National Survey Report. <http://www.dh.gov.uk/en/Healthcare/Cancer/Patientexperience/index.htm>

WHAT WE FOUND

4.0 HOSPITAL TRUSTS: EQUALITY PLANS AND SYSTEMS

Trusts' equality schemes and the supporting systems offer the key means whereby trusts identify, understand and address discrimination and inequality and offer the main publicly accessible source of information regarding service provision and priorities for specific groups.

There are distinct limits to the way trusts consider inequality. Typically, analyses focus primarily on health and risk factors – such as lifestyle and other choices which may predispose particular population groups to ill-health or may contribute to unequal health outcomes. It is rare, however, for discriminatory behaviour or treatment *within the system* to be examined as a possible contributing factor in unequal health outcomes. This is reinforced by current approaches to data collection by trusts: relatively little information about specific groups and their experiences is collected.

Most trusts, then, take the view that it is individual experiences, such as lifestyle or culture, which have the greatest impact on health outcomes. Examples of initiatives which illustrate this approach include:

LGBT health inequalities

One trust discusses its staff awareness training regarding LGBT health inequalities. It states that in order to complete this it has carried out initial research into the issues. Its findings primarily focus on lifestyle:

- Mental Health – one-fifth of LGBT people have attempted suicide or have self-harmed.
- One-third have been diagnosed with depression.
- 48% of lesbian women smoke compared to the 22% average in the rest of the female population.
- Alcohol and substance misuse – significantly higher for all types of drugs in the LGBT communities compared to the national average.
- Higher levels of sexual risk taking; higher numbers diagnosed with a sexually transmitted infection.

Ethnic minority cancer awareness

One trust runs an Ethnic Minority Cancer Awareness Week which aims to raise awareness of lifestyle factors and the need for early presenting. Some of the facts it is promoting are:

- Rates of smoking are higher among African-Caribbean and Bangladeshi males, significantly increasing their risk of lung and other cancers.
- 43% of black and ethnic minority women do not practice breast awareness and do not know what to look for when self-examining.
- Chewing tobacco and smoking less will reduce the risk of cancer.

While initiatives such as these are clearly intended to respond to the additional risk factors associated with particular population groups, they are rarely coupled with actions that might help address the discrimination or inequalities these groups might experience *within* the health system.

In many respects this is not surprising because it mirrors the default position from which the equalities practice of recent decades in virtually all contexts has proceeded: gathering intelligence about disadvantaged and marginalised groups to try and identify why they don't fit the service profile, rather than examining services to see why they fail certain groups and individuals.

Indeed, discrimination is rarely mentioned in the schemes we appraised. Very few of the schemes or policies that we looked at could be said to have been established with patients' experience *inside* the service as their primary focus. There is an assumption that once patients begin to receive treatment, services will treat everyone well and that outcomes will be the same across the board. The patient experiences recounted in this report demonstrate that individual experiences of services differ dramatically and that outcomes may suffer as a result of this difference.

Risk factors, then, are only one dimension of health inequalities, albeit a fundamentally important one. But trusts' data collection and equality monitoring processes need to reflect not just the clinical basis of health inequalities but also whether there are inequalities in the *experience of services* which might also contribute to inequitable health outcomes.

Performance monitoring and patient experience?

While most trusts use data to understand the diversity of local health populations, few move from this to the next step of interrogating their performance to establish the *differential* experiences of or outcomes for patients by age, ethnicity, gender or other equality 'markers'.

Indeed, of all the trusts we surveyed, only twelve generate data based on *more than* the ethnic monitoring categories used as part of the census process.

There is some evidence, however, that this is slowly changing, certainly as regards a much greater emphasis on patient experience. We found a small number of trusts now much more actively pursuing patient experience initiatives as part of broader service improvement efforts. These initiatives recognise the importance of staff-patient relationships, the centrality of staff behaviours in shaping that experience, and the imperatives of making greater use of patient experience metrics. There is also a growing awareness that feedback on patient experience needs to be in as close to ‘real time’ as possible. Staff-patient communication and information plays a key role in these initiatives – as it should, because poor and ineffective communication is a key issue in patient dissatisfaction and frustration, as testified by all of the groups we interviewed.⁶

While this is clearly a move in the right direction, it should be noted that emerging practices in patient experience are not yet at the point where *inequality of experience* is considered as a specific factor.

Patient engagement and action

Most trusts undertake patient engagement and patient surveys to further explore issues that impact on patient care. Of the trust equality plans surveyed, only three failed to reference patient engagement. But few equality plans offer any real detail about the *consequences* of consultation – what will be done and what actions taken to improve patient experiences. Only six of the trusts surveyed had an up to date action plan – in other words, clearly demonstrated that they were currently pursuing actions to improve equality.

Cancer Inequality

Given the prominence of national cancer priorities, we were surprised to find that only nine of the 78 Trusts surveyed described their work to improve cancer care as part of an overall equality action plan.

One trust specifically detailed its aims to improve access and take-up of screening services by LGBT groups and those from deprived areas and stated that in the case of the LGBT community this will be done with the support of LGBT organisations.

Complaints

⁶ For example, see: King’s Fund (2010): Transforming patient and staff experience – what works? Conference proceedings at: http://www.kingsfund.org.uk/events/past_events_catch_up/transforming_patient.html

One of the ways in which hospital trusts can monitor patient experience is through complaints made by patients. However, if complaints are not also equality-monitored – i.e. analysed by age, gender and ethnicity (as the National Cancer Equality Initiative [NCEI] does, for example) – then it is not possible to analyse whether specific groups are experiencing differential or potentially discriminatory treatment. In the desk research we undertook, only 14% of the sample of hospital trusts examined provided an analysis of complaints classified according to age, gender and ethnicity.

Some trusts' annual reports, however, do give some detail regarding the types and numbers of complaints received, how they have been acted on and how this has resulted in fewer complaints in that area.

5.0 THE VIEWS OF PATIENTS AND CARERS

As already explained, our review of the data held by trusts in the form of equality schemes and policies shows that attention is paid primarily to identifying what it is about particular groups that prevents or hinders their accessing services – for instance, lifestyle factors, language needs, or cultural or religious beliefs and practices. The gaze is outwards – away from cancer services themselves and towards understanding more about community groups, the people who use services. While this seems both acceptable and reasonable, providers also need to look inward, examining their own behaviours and practices. They need to ask themselves: “Is there anything about our cancer services or our staff behaviour that prevents people from using services, having a good experience, or receiving a good outcome?”

This trend is also echoed in the actions of NHS institutions. Trusts in the main are ‘self-examining’ only in so far as they are focused on getting their systems and processes legislatively compliant. The inward gaze rarely stretches to considering whether specific activities – such as diagnosis and referral systems – or, perhaps more importantly, the behaviours and attitudes of staff, are having a detrimental impact on the experiences and outcomes of patients.

And in addition, the system also ‘defends’ itself by using apparently sophisticated analyses which enable institutions to deny that discriminatory treatment could be a factor. Disastrously poor experiences, for example, are sometimes described as ‘never events’ – extreme occurrences which lie beyond the normal tolerances of error and which therefore ‘don’t count’. But when such events are ‘collectivised’, patterns emerge. The Mid Staffordshire NHS Foundation Trust scandal perhaps offers the most egregious recent example of this.

NCEI research has already indicated that outcomes may be affected at particular points of the ‘care pathway’, highlighting:

- Pre-diagnosis/diagnosis
- Treatment
- Follow-on care
- End of life care

(**Appendix 1** describes these terms are interpreted in the context of this report.)

For this reason we have organised the findings from our patient interviews wherever possible to illustrate lessons in relation to these four points of the care pathway. We emphasise again, however, that service-users rarely if ever conceive of their cancer experience in such neatly constructed terms. Nonetheless, the stories recounted here play a vital role in illuminating real, lived patient experience.

5.1 Pre-Diagnosis and Diagnosis

Patients and carers we spoke to across all four groups experienced challenges and poor treatment at this stage of their cancer journey. Some types of unfair treatment, however, were more likely to be reported by some groups.

Delays

Respondents from both black and white minority ethnic groups reported long delays in securing an appointment for screening or securing an appropriate diagnosis.

A carer for Chinese residents at a care home observed that “diagnosis always comes too late” for people she has cared for. She put this down partly to health providers’ failure to offer adequate interpretation services or to find other ways of communicating (e.g. picture cards). She added:

“When you have cancer, you need to be understood, you need someone you can talk to... In the time I’ve been here ten people have died of cancer, which is all of those that had it. We haven’t had one survivor. Most here are Stage Four already by the time they are diagnosed... It can be touch and go whether you actually get a referral.”

One BME patient said:

“I got lost in the system at the beginning which delayed referral... In my first contact with the doctor he barely looked at me.”

In one case described to us an African woman explained the difficulties she had experienced in securing an appointment with her consultant for further diagnosis following an initial scan (a follow-up to brain surgery to remove cancer and check success):

“I cannot stand. I am wheelchair bound. I need care. I cannot be a mother or wife now and if I need to pee I have to do it in a pad. My carers come in every three hours and thirty minutes. In this time I have to stay in one place. Because of the way I was treated, because the consultant did not bother to look at the results for eight months and I was not diagnosed in time, I am now paralysed from the waist down.

“I fought and fought to see the consultant from the time I had the scan, and I got nowhere. Then eight months later when I saw him he just tells me matter of factly I will need more brain surgery.

“I ask myself why this happened. I went to the hospice and in the hospice I would meet women, white women who I got to know and they didn’t have any problem with getting appointments with the consultant in question and

had very frequent appointments. Yet I had to fight for everything and I do feel that it comes down to discrimination, that I am a black African woman from Cameroon. He saw me as another black person who doesn't know their rights. He looked at me like another black person who can't read and didn't go to school.

"I have lost my profession; I have lost being a mother and a wife. That is what he has done to me."

A smaller number of respondents in other groups reported delays in diagnosis or referral too, particularly those from low socio-economic groups and older people. For example, one interviewee from a low socio-economic background said:

"The specialist (this was six months before diagnosis) sat there, slouched back, arms folded and said, without checking anything, 'you are a rather portly fellow and there lays the answer.' That was it matter of fact, didn't listen to his chest, or ask any questions, that was it. He said go on a diet."

Hostility to patients refusing treatment

Another BME patient explained that a lack of proper discussion regarding treatment options caused protracted disagreement between herself and her consultants:

"Before I had even got my clothes on he was telling my husband that I was going to need radiotherapy/chemotherapy. I felt so frustrated. I was thinking, 'hold on I'm here, you're talking to my husband, not to me!' We left with no information – we were sent home. After diagnosis I really was sent packing with no information."

She researched alternative treatments and chose to use water therapy and a range of supplements rather than undergo chemotherapy. When the consultant realised that the patient had refused chemotherapy, she explained:

"He just said to me point blank, 'you know that you have less than a 50% chance of seeing year five.' It was so awful. I spent about a month really down and I realised I needed not to see the consultant anymore. I dread those appointments."

The experience of two transgender patients also indicated outright hostility from consultants when they or their carers undertook their own research and challenged consultant views on the best treatment options to take.

Dignity & respect

A common experience reported across all four groups at pre-diagnosis and diagnosis was being treated with a lack of dignity and respect. LGB respondents in particular

reported a lack of respect for their private and family life. They reported examples of partners either not being present when diagnoses were given, or partners not being acknowledged as such and instead treated as 'friends'. One LGB patient said:

"Most questions were directed at my partner though I was included in the process, but not necessarily as my girlfriend's partner, but as a 'close friend'. It isn't questioned, but it is assumed you are heterosexual until you choose to make them aware of what you thought was obvious. We didn't always do this as this might add to what was a stressful event by itself. However, the times we did bring it up, it helped us to relax and approach the situation in a much more together way."

An older patient said:

"The registrar just opened the file and said you have prostate cancer. It's aggressive. Any questions? The nurse came in. I was really surprised and didn't really know what to say."

The carer of a BME patient described the lack of compassion a consultant showed when they had given the patient their diagnosis and in encounters following that:

"I would try and get 2 minutes with him on my own to explain this. I just wanted him to understand how desperate I was so that he would show some humanity. But he didn't ever show any humanity, he just treated me like rubbish."

In another example from a lower socio-economic background respondent, a carer whose partner's diagnosis was terminal, said:

"We had very little time with the consultant. He [the patient] said 'so what now?' and she [the consultant] said, 'you can go out to the nurse who has some leaflets for you' and that was it. The nurse told us what the leaflets were, drawing attention to the Roy Castle Foundation and if we wanted to 'leave' anything to them – we couldn't believe it. For once in his life he [the patient] was speechless. We got out to the car and he just handed me the keys – he would normally drive – and said 'well lass, that's a bugger isn't it.'"

Personal behaviour and decency

Many of the accounts of patients' experiences at pre-diagnosis and diagnosis refer not to an inability of the 'system' to cope, but to the poor behaviour and practice of health professionals. In particular consultants or specialists who did not respond to or share information, or who treated patients with a lack of dignity or respect. In those cases where respondents reported a positive diagnosis experience, this too reflected largely on the behaviour of the consultant. One interviewee, a carer for her 79-year old mother, described a more positive experience in this way:

“She dealt with my mother as a person; she was a skilled communicator; she was very caring but wasn’t patronising and she was very good at presenting information; she didn’t make anything seem terrifying.”

Yet in many ways this story was the exception and highlights the gulf that exists between what is good and what is bad in the health system. This same interviewee went on to say:

“When I hear about other people’s experiences I get the feeling that our experience was exceptional, but wouldn’t it be nice if it wasn’t. For my mother it didn’t seem like age was a barrier. But I have always been very particular about my mother’s appearance because of the expectations associated with age. So I’m pretty sure that an elderly lady laid there with dishevelled hair would probably be overlooked or would have less value.”

5.2 Treatment

Respondents in all four groups reported unfair or poor practice in terms of active treatment. Yet there were noticeable patterns specific to some groups. Where they were clearly discernible, these are identified.

Discussing treatment options

A number of respondents from lower socio-economic backgrounds felt that their views or questions about treatment decisions were not taken as seriously as those that may have a “posher accent” or look more “pulled together” – that they were simply not regarded in the same way as better off, more educated patients. One said:

“You have to be a white, articulate, middle class person to be taken seriously. I had no support caring for a loved one who was dying. My family were ignored and made to feel stupid for wanting to know basic information like ‘why are you giving that particular drug?’ You need a lot of money to get any kind of respect and support.”

Some respondents reported difficulties in accessing medical records, an important part of the process when exploring new treatment opportunities. This carer of a BME patient described the uphill battle they faced:

“I was researching other types of treatments, types that are available in Canada in the hope that we might find something that would help or give her a chance of life, or more life. I requested her medical records – I knew we could- and the consultant was obviously annoyed but agreed to get them ready for one week for me to pick me up. When I went to his office to pick them up they weren’t there and I was told he was out of the country for two weeks. This went on like this until 5 weeks later I got them.”

'Appeasing' the power of consultants

The doctor-patient relationship is an unequal one and most of the time we accept this imbalance. But in times of extremis what looks like an abuse of power can cause lasting distress, as this interviewee, the carer of a BME patient, explained:

“At the point that she was given her non-specific diagnosis she was pregnant. The consultant said that even though they couldn't be sure she had cancer that she needed to have chemotherapy. Telling her that it was very likely she would have to undergo a termination as it would damage the baby. But she would not consider this. The consultant didn't even seem to consider her concerns relevant. He was harsh and cold and completely stamped out any hope we had as well as making us feel completely stupid for thinking it a possibility. It's hard to explain but he would sneer and laugh in this way that would completely push us down. The best way I can describe it is that he was mocking us and dismissing us. I would try to appease him and appeal to his power driven side. I'd say 'we're young we don't know what we're doing, we're scared... I would tell him that we wanted his advice... I would submit to him to try to appease him. He constantly tried to make me look small.”

Another BME patient said:

“I was treated very negatively, the consultant said 'people like you want to do these alternative things and then when they don't work you come back, and it's too late by then. When I was told this I was infuriated.”

Scarce resources and the issue of age

A number of older people described a lack of equality in treatment decisions, but in different terms. Their comments concerned a lack of transparency in decision-making and a perception that due to their age the treatment proposed was more likely to be a low-cost and palliative rather high-cost and curative:

“I do wonder and would like to ask the registrar what other treatments I could have... I have read in the Daily Mail health section that you can only have the injections for eighteen months, but I don't know whether this means I can go on to have other treatments...”

“I asked my [specialist nurse] about the decision on my treatment to have the injections and she brought my file in and showed me a letter that had been signed by four consultants. It said that 'due to the patient being 85 we recommend hormone treatment.’

“When it's in black and white like that, and maybe I'm anticipating it, but I'm sure if I was 65 I'd be on a different treatment. I've always been really active; I'm not necessarily a typical 85-year old.

It's like she'd gone beyond her duty and was showing me something that maybe I shouldn't have seen. It was like she was giving the game away, and it was at that point that I thought for the first time 'this is palliative' not curative."

Another older patient said:

"They tell you what treatment you are going on and why it's the best in the world, but I just feel like I don't want to follow all their bullshit. I was put on one type of steroid (the one where your tits grow) which seemed to work, my PSA was above 12 and then it went down to under one. Then they swapped me, no discussion, just decision made. I wondered if it was financial because I had heard rumours about this, and so I asked them, and they said no it wasn't."

Another said:

"After diagnosis the consultant told me that the only cure for my type of cancer was a bone marrow transplant and implied they would be finding a match for me. When I next saw my consultant I asked about a match and he said to me: 'When you get to our age you're too old for a bone marrow transplant' – he told me it was a blunder bus approach.

"I couldn't believe what he was telling me that I was too old. It was like diagnosis pulled the carpet from under my feet and then being told that completely took the carpet from under my feet. Later I complained and he completely denied saying it. I really got the impression most of the time, that they just made it up as they went along."

The issue of allocating scarce resources for treatment in a proportionate and reasonable way is a complex one, and difficult decisions cannot be avoided. And yet, judging from these interviews, it does appear to be the case that patients and carers from lower socio-economic backgrounds are made disproportionately aware of the cash value of their treatment and believe the treatment decisions taken to be financially driven. One said:

"Whether you are up here, or in the gutter, you should be able to get the same drugs."

Another:

"The doctor said to us 'you know these cost £10,000? Do you really want to do this?' But it shouldn't come down to whether you are *worth* the investment. We had been told chemo would lengthen his life, his time left, yet because he was terminal and because we lived on *that* side it felt like

they didn't think it was right for us to go for the treatment. And when it comes to it, life shouldn't be valued or in our case devalued in this way."

Some patients felt they had been able to secure fairer treatment options as a consequence of having a better understanding of how to navigate the system – and yet even in these instances, the effect on patients' emotional state was damaging:

"For me I was treated...because I needed to be in control of what was happening, that's just me, I was trained as a nurse, so I did as much research as possible but the oncologist didn't want to give me the information, he was patronising, he talked down to me like I was a little girl who didn't need to know. I was labelled a trouble maker. They see themselves as above everyone so they don't have to explain themselves.

"The oncologist referred to me as 'the woman who wouldn't have chemo'. He said I wasn't having it because I didn't want to lose my beautiful hair. I had made an informed decision, it was a social and financial decision, they told me having it gave me a 5%-7% better chance over 10 years. If it had been 30% or 40% I would have had it. I was written off as a trouble maker kicking up a stink."

The value of life...

Being reminded of the 'cash value' of treatment has particular implications for those from lower socio-economic backgrounds who are struggling to meet the financial burden of cancer. Financial constraints mean they have less opportunity to shape the services they receive and ensure they are tailored to meet their needs – and yet this is a cornerstone aspiration of *Equity and Excellence*, the NHS White Paper.

One interviewee said:

"I had to travel to Sheffield (from Birmingham) for radiotherapy. For me and my husband to go twice, which involved staying in a hotel both times, it cost us £700. This just wasn't affordable, but we were told that we didn't qualify for financial support to do this. Sheffield was the only place where I could go for the treatment I needed, so there was no option but to afford it."

Another, a carer whose husband was unable to eat solids, explained:

"With food, staff will say 'try this and try that' and if you have lots of money then this is an option, but if you have little money you can't afford to experiment, but nutrition is so important. They knew we were having trouble and they didn't once tell me that I was entitled to liquid food from the hospital that contained everything you need."

Isolation

Respondents from lower socio-economic backgrounds also reported that they experienced an acute sense of isolation when an in-patient at hospital. And while this wasn't only experienced by poorer participants, it was consistently described by them. Descriptions of this related to a lack of care, a lack of contact and a lack of recognition from staff. For example, the carer of one patient said:

“He was bleeding and urinating and three days later it was still on the floor. Other people had been in and out and were checked on but in the three days we were there nobody offered to wash him or change his bed.”

BME respondents in particular reported repeated failures by nursing staff to cater to their needs. While some of these 'needs' were culturally-specific – language support, for example – more frequently they referred to a basic desire to have fundamental care needs met, such as cleanliness, food choices, advice, dignity, respect.

Patients' requests for additional support – e.g. language – also tend to highlight system (or staff) shortcomings in meeting these needs. This came up time and again in the interviews – and not as isolated incidents but rather as repeated failures to put adequate provision in place or prepare in advance. For example, patients reported numerous instances where staff consistently did not use interpretation services and as a consequence disadvantaged those with English as an additional language. Medical staff's justification for this was often the need for urgency when responding to patients – and yet it was rare for this urgency to be conveyed to the patient.

In many instances cancer treatment is an ongoing process, with planned interactions with the patient to discuss treatment options, or prognosis, and yet pre-planning to ensure that language support or interpretation services are in place for these interactions seems consistently neglected. This further erodes and devalues staff-patient communication and patient engagement and has a detrimental impact on treatment experiences.

While some the examples of 'system failure' described to us had their roots in inequality or 'difference', they were equally – and perhaps most shockingly – also an affront to basic human decency, as is described by this interviewee, the partner and carer of a (post-operative) transgender patient:

“[My partner] was a vegan. [...] Yet the entire time she was in hospital they didn't once recognise this and provide her with the appropriate food, even though we asked for this and went about informal and formal routes to complain. All they could provide her with was jam on toast – and that is not nutritious.

“She needed her wound dressing four or five times a day for the entire time – because the surgeon had cut straight into the tumour – and sometimes she

would be left with the dressing off, exposed to everyone, bleeding and they would return an hour later or longer to redress the wound.

“She’d be pressing the buzzer because she needed to go to the toilet and they would leave her. The toilet door would be left open with no privacy to do things that are necessary post-op. Staff did not understand the physical transformation she had gone through, I couldn’t believe that medical staff could be so ignorant. It was so undignified.

“A lot of this is down to a combination of chaotic systems and discomfort with ‘transgender.’ Her notes stated post-op transgender and yet when Willow talked about difficulties about urinating the doctor said: ‘why don’t you stand up?’ The impact all of this all had on Willow was devastating. She had a huge dislike for the doctor treating her. Nobody talked to her frankly about what would happen to her. She was getting such a bad deal but there was nowhere else for her to go. By the end Willow wouldn’t try to put people right when they referred to her as ‘he’ or made comments that assumed she had a penis, she just wouldn’t say anything.”

Another example from a BME respondent depicts another example of degrading treatment:

“There was a radiotherapist, he was a man, he laughed at me because I was wearing a hijab. I didn’t like it at all. I saw him in the mirror having a laugh, thinking ‘she’s wearing a hijab and this is what we have to do’. I felt very embarrassed.”

5.3 Follow-Up Care

Older patients and carers in particular may lack knowledge regarding follow-up care. They may lack the language to ask appropriate questions, they may be unaware of their entitlements, they may simply be ‘cowed’ or intimidated; perhaps more than anything else, they may also be frightened and distressed. This came over strongly in a significant proportion of the interviews. However, poor information regarding follow-on care options and particularly a lack of information about the impact of treatment on people’s health was found across all four groups. One older interviewee said:

“A lot of how you get treated tells you that old people are past being useful and are taking resource from the government that could be spent elsewhere. And I did feel like this. People do need to know what they are entitled to but very few people do know this. There should be information available at the hospital.”

Another older interviewee (a carer) referred to a lack of information about the side effects of treatment, and a lack of access to support to find out more:

“I’d read about steroid treatment and that Osteoporosis is one side effect – [he] is 70 and so I wanted them to do a bone scan, to see whether it was developing, but when I discussed it he just said ‘you don’t need to worry’. But then you hear that people who go to another centre and who are on the steroids are given bone scans – because they have the scanner. You try and find out information, but a lot of what you can find on the internet or in the paper is terrifying. After all these years you’d think we’d know what was going on, but we still feel like we don’t know why decisions have been made.”

Another said:

“I was given a booklet which listed questions to ask your consultant. I got these out when I went to see my consultant and he obviously wasn’t very happy about it. He kind of had this look about him that said ‘god we’re going to be here all day.’ But my problem is that I don’t know what questions to ask. So if ever a consultant said do you have any questions, I just didn’t know what to ask.”

Another explained:

“I don’t think they treat all people the same, they are not fair and don’t respond to some people very well. I was talking to this woman who I met at the support group. She had mental health issues and really had very bad experiences of going to see her consultant. She was too scared to go back and I know she died recently and I’m sure that she ended up not going for treatment and so her dying had a lot to do with having had a bad experience maybe. Some people are more vulnerable than others and do need more support. I’ve had lots of Asian women, particularly older women, call me to say that they don’t understand what the consultant tells them. There is a real need for good translators.”

In the most distressing instance, one older man, a carer for his wife, described the following:

“My wife had breast cancer and it went into her bones and the consultant did an operation, her spine was collapsing so they put rods fused from her shoulders down to her... But he did it face down and my wife was a big breasted woman, he did it to the curve of her body. When she stood up she was like this (stands with chin pressed to chest), her head was bent down and her mouth was clamped shut. I went to the solicitor he told me I didn’t have a case! He [the consultant] even admitted he had made a mistake but I had no case. His excuse was she was dying anyway we gave her eighteen months

longer – but with what quality of life! I was arrested in the market, I was arrested twice because people were mocking her in public. In all that time nothing has changed, I went to the doctor twice and he said ‘I’ve not got time for you and put his coat on, I had to change doctors.’”

But these feelings are by no means restricted to older age groups. Participants in all four of the groups we interviewed had their own versions of this feeling of helplessness, fear and lack of information. We’ll let this particularly eloquent comment stand for the many there isn’t space to include:

“I never got things explained, radiotherapy burned me, it was never explained why and what had happened. I went to the doctor and he told me ‘you can’t crack an egg without breaking the shell, get on with it’. Nobody said do you need any help; I had to get on with it. I wanted to know what was going on, but I was treated like a child, told to take one day at a time. No one tells you about the extra symptoms tiredness, lymphodima, depression, being up one day and down the next. I thought am I unique, is it the same for everyone? But you’re just walking into the unknown. It’s like you’re at an open door about to step through and you don’t know if there’s a pavement on the other side.”

Benefits of finding a support group

Generally, older people who seemed better able to navigate the system in terms of follow-on care were those who had had the good fortune to meet somebody who had similar experiences and could tell them about it – whether informally, or in the context of a user support group.

“In reality you don’t get a jolt of support. It wasn’t until I started meeting a support group that I found out what things meant.”

Another, somewhat more pragmatically, said:

“I would recommend joining a support group and using the collective power of the group to create change. It also helps to talk to others, it really does. But I think it’s your own fault if you don’t get what you want, if you don’t speak up. There was this old chap, he was insular and asked at the last meeting, if anyone knew who their contact was at the hospital. Now I know that I know mine, so I put my hand up and told him this – and so I think he just didn’t ask. He’s one of those people who keep things to themselves.”

Not recognising additional support needs or involving carers effectively

And yet even when information regarding older patients’ follow-on support needs is available – either from the patient, a carer, or other family members – it isn’t always asked for or acted upon.

One older patient, a woman who felt that her experience of treatment had been a positive one, revealed that her care team did not ‘uncover’ until late in the process (she was undergoing a programme of radiotherapy following earlier chemotherapy treatment) that she lived alone and might require additional support. Following this it was arranged for her to stay in a special unit during the days she is having treatment, travelling home only at weekends.

Another, a carer at a residential home for older people, said:

“Discharge is always bad too. I always ask to be contacted so I can be there when they are discharged. Most of the people need some kind of care package at discharge because they are unable to manage their own cancer care. Invariably I am not contacted and then the person is discharged with no support and no care package. When I ring to insist that it is arranged they say ‘we asked Mr so and so and he said no.’ Well of course he said no... He doesn’t want to cause a fuss and on an awareness level he doesn’t know what a care package is. And there is probably some awareness of this amongst staff.”

These problems were not unique to older people. Another interviewee, the friend and carer of a BME patient, explained the pressure she felt under to get ‘straight answers’ regarding the follow-on care available for her friend:

“I had to prepare so much when we went to see him [the consultant]. I would draw up a checklist of questions, but we never got a straight answer. He made us feel so small, so as time went on I avoided questions and conversations in order to avoid the confrontation. Towards the end she really didn’t want to go to the appointments with the consultant and wanted to opt out, but I wouldn’t let her. We always went.

“At the beginning her brother used to speak up but within eight or nine months he would completely withdraw in those meetings. And everyone would talk through me. But I became more and more scared to talk because of the way he would respond to me, and not because of me, but because every time he did that my friend would lose hope and confidence. I was trying to balance so much, I was terrified of upsetting him. The more he pushed us down the more we became lost to each other and emotionally isolated. And I do blame him for that. I hated myself by that point as well.”

5.4 End of Life Care

End of life care was the area least discussed by patients and carers in our interview group. Those who did touch on this, however, described complex problems primarily concerning lack of information, an inability to discuss end of life care options as part of the treatment process, and a lack of ‘voice’ in the process.

One patient said:

“Once you're out of the hospital, you're left to your own devices – how can the government talk about giving people the choice to die at home when carers are not supported to deal with the consequences of 24/7 care and making very difficult decisions without clinical supervision? You need a lot of money to get any kind of respect and support”.

Another interviewee described the challenges associated with securing 'culturally appropriate' end of life care for BME patients:

“This is a big issue. For many BME people death is a matter of fact, often talked about. Often people don't want to be over-medicated they want to be cognisant. E.g. a Nigerian woman had liver cancer. Her son was distressed that he could not speak to her as she was comatose as dosed on heavy morphine. To the family it looked like the hospice killed her. When people are terminally ill the hospice treatment changes. Our sister did not want this, talking was important. Her husband fought for no morphine but muscle relaxant instead this was not an option regularly offered. Doctor also said there was no point in food as 'she is going' so husband stopped feeding her – doctor must be right. Sister thirsty and sucking on the sponge. Need to recognise food is important to relatives and they could not offer this.”

An account from one transgender patient suggested that her overall poor experience of the system (and of her engagement with her consultant) was so poor that she would no longer engage with the health system even if this resulted in her premature death:

“I don't know what the future holds. I'm now looking into ways to end my life – in a dignified way... There isn't much that is dignified about having a bag put over your head and dying by lethal gas, but at least afterwards you're dead. This is my option now. Another person, who had been treated like I had might not think that death is the easiest option but I do right now.”

The carer of another transgender patient explained that it was only at the point of death that some semblance of equality had been experienced:

“She went onto the hospice ward and spent five months on a ward that most spent one week on or went to for respite. She was frightened of dying, although she knew she was dying. I requested support for her to consider death and to face some of her concerns, but there was nobody for her to talk to. None of the staff recognised her fears, they didn't listen. And you didn't have to listen to her for long to understand that she was scared. It was very strange – that in the last fort-eight hours it's like suddenly the transgender didn't matter. The staff were great and seemed to have this 'equal' response to death, in that very last stage. It's like transgender was no longer relevant.

6.0 KEY ISSUES & RECOMMENDATIONS

“There are two meanings of the word treatment – how you are treated as a person and how you are treated medically. Medically it has been great.”

The interviews with patients and carers conducted as part of this research illustrate beyond question that treatment and outcomes in cancer care differ so dramatically for some individuals from disadvantaged groups that many of the patients we spoke to considered their treatment to be actively discriminatory. These experiences of unfair treatment had a direct impact on outcomes for patients, carers, and families.

In some respects, it is depressingly true that this only serves to confirm what was already known: that inequalities in cancer care exist and that discrimination is a factor contributing to these unequal outcomes and experiences. Where we hope this paper does add value, however, is in giving a loud, clear and sometimes outraged voice to some of the patients involved. They perform a significant service in articulating what that inequality feels like from a patient’s perspective.

A key problem is that of overcoming some of the complex issues involved in ensuring that performance improvement ‘solutions’ are close enough to the problem and that the new data and information they provide can be utilised as swiftly as possible.

The National Cancer Patient Experience Survey 2010, for example, marks a huge leap forward on previously available levels of evidence regarding patient experience and has the potential to be genuinely transformative in service improvement terms.⁷ However, the proportion of respondents from disadvantaged groups replying to the survey would need to be increased – less than 4% were from ethnic minority groups, and just over 1% from ‘non-heterosexual groups’ – and more would need to be done in order for the survey to further illuminate issues relating to discrimination. A repeat survey that better includes groups under-represented in the 2010 exercise and which offers practitioners intelligence regarding unfair or discriminatory practice or outcomes would be a significant contribution to a national perspective on patient experience.

Limitations were also found in some of the other tools and processes this research examined; in some cases the fundamental issue was a more serious mismatch between the available tools and the desired outcomes.

In this section, we summarise the key issues identified during the research and make practical recommendations for responding to these. We do this under two headings:

⁷ DH (Dec 2010): National Cancer Patient Experience Survey Programme 2010 – National Survey Report. <http://www.dh.gov.uk/en/Healthcare/Cancer/Patientexperience/index.htm>

- Trusts and equality plans.
- Practical improvements to the care pathway.

Where it is possible to do so, we identify where recommendations relate to a specific social group and where they are more in the way of ‘generic’ improvements.

In the final section (7.0) we move on to suggest an alternative way of thinking about equality and propose a tentative framework within which health professionals could take greater charge of changing the behaviours and attitudes which reinforce discrimination.

6.1 Trusts and Equality Plans

Key Issues

1. Trusts’ ‘gaze’ remains focused primarily outwards on the risk factors associated with certain social groups, lifestyles and behaviours. There is some evidence that this is slowly changing and that a greater emphasis on patient experience is emerging. Patient experience initiatives are being more widely pursued as part of broader service improvement efforts and these initiatives recognise the importance of staff-patient relationships, the centrality of staff behaviours in shaping that experience, and the imperatives of making greater use of patient experience metrics. While this is clearly a move in the right direction, emerging practices in patient experience are not yet at the point where *inequality of experience* is considered as a specific factor.
2. There is an assumption that equality policies can and will change behaviour and attitudes despite the fact that the available evidence consistently contradicts this view. There is still little explicit linkage in trusts’ policies between health inequalities and poor patient experiences. It is rare for trusts’ equality policies to isolate *discrimination* as a specific factor requiring action.
3. Few trusts systematically interrogate data regarding, say, access, satisfaction and outcomes by age, ethnicity, and gender. Equality schemes do not result in equality monitoring in the fullest sense and they do not achieve ‘equality proofing’.
4. Patient engagement and voice feature heavily in trust plans but rarely are the consequences of this consultation and patient participation spelt out.
5. Trusts’ complaints procedures are rarely equality-monitored and therefore offer little that can help illuminate the causes of poor patient experience, dissatisfaction or unequal outcomes. Moreover, many patients report overwhelmingly negative experiences of attempting to use existing complaints procedures. In all of our research we identified only two examples of where patients themselves had directly challenged what they felt to be unfair or discriminatory practice and in neither case did the service they received improve.

Indeed, in some cases, patients we spoke to explained that their attempts to complain had added to rather than alleviated their sense of powerlessness and isolation in the system. “When I complained, normally the response was denial,” one interviewee said. “So I started to record conversations and take witnesses. I got an appointment with the consultant, he thought to discuss my medication but I said I was there to discuss his comments. He got really aggressive and was about half a foot from my face leaned right over.”

Recommendations

1. The current focus on ‘risk’ must also include the risk of discrimination and present policies and processes should be reviewed to ensure that they can and do furnish equality-monitored data which helps understand and address not just inequalities in health outcomes but also inequalities and unfairness in treatment and service provision.
2. However, equality monitoring is not an end in itself. Its purpose is to enable organisations to assess whether specific equality interventions are working and to this end equality monitoring has to be a key part of service improvement.
3. Complaints procedures must be reviewed so that they work in favour of patients and also so that they provide additional intelligence regarding patients’ experience of care.
4. There needs to be more ‘real time’ feedback regarding patients’ experiences of care. PREMS already offer the basis for this but again represent a solution that somehow fails to get close to the problem, certainly as far as equality of experience is concerned.
5. The potential for discriminatory behaviour and attitudes is recognised in the NHS but largely as a ‘system failure’. Discrimination and a determination to guard against discrimination – to prevent harm, to ensure justice and to uphold medical ethics – should, however, lie at the heart of health professionals’ personal responsibilities. In pursuit of this there may be an argument for incorporating anti-discrimination training as part of the service’s core vocational training, rather than as a ‘policy add-on’ within equality schemes.

6.2 Practical Improvements to the Care Pathway

Key Issues

(a) At pre-diagnosis and diagnosis

1. Some of the problems evident at this stage of the care pathway do seem to affect some groups more markedly than others, but it should also be emphasised that the demarcation between the experiences of different social groups is not as neat and clear as some might desire.

2. Nonetheless, it is also clear that it is at this point of the care pathway that the overall experience and outcomes of many patients is shaped and determined.
3. Some of the key messages regarding consultants and doctors having time to communicate effectively, caringly and humanely seem common across all groups. Too little time to respond adequately to questions, to provide appropriate emotional support at that critical juncture, or to treat patients humanely and with kindness and compassion – these all emerge as strong themes. And it is important to emphasise that while these may be ‘system failures’ (in the sense that the system doesn’t allow sufficient time or resource to do better), they are also personal *human* failures, a failure or inability to respond to the distress and confusion of patients at the point where this is most gravely needed.
4. It is here that the power imbalance in the professional-patient relationship is also most evident. While we acknowledge the inherent difficulties in addressing a decades-long legacy of deference, it is also evident that left unaddressed this authority relationship does have a detrimental impact on the extent to which many patients are able to participate in their diagnosis and get the information they need at this critical stage in their cancer journey. But nor can patient empowerment be a ‘one size fits all’ activity: not all patients are starting from the same point, and for some individuals and groups the playing field must be levelled before they can hope to participate equally.
5. Group-specific problems are most evident in the following instances:
 - BME groups seem to experience the greatest (and most damaging) delays in securing appointments and appropriate diagnoses.
 - BME groups and those from lower socio-economic backgrounds seem more likely to have personal concerns ignored or not taken seriously, thus marginalising their participation.
 - It is also more likely that BME groups and those from lower socio-economic backgrounds will be subject to generalisations and stereotyping regarding lifestyles, cultural practices and other health-risk factors.
 - LGBT groups in particular face significant insensitivity and lack of understanding regarding their family life and partner status.

Recommendations

1. Much of what is needed revolves around improved communication and sensitivity. An assessment of patients’ communication needs should be a standard part of the process, with this information following the patient through the system.

2. Professionals receive advanced communications training and yet the benefits of this are not always apparent at the front-line. Many health professionals view communications training as at best unimportant, at worst an imposition. Communication training should be urgently reviewed and its impact on patient experience assessed.
3. There are specific areas of sensitivity and competence – for example, in seeking and responding to family and relationship information from LGBT patients – where improvements are clearly required.
4. While the standardising of information provision (through the proposed ‘information prescriptions, for example) should be welcomed, this will only deliver benefits if similar improvements are made in the provision of one-to-one support, better signposting to advocacy, emotional and practical support, and more effective listening and communication.

(b) At treatment

1. Across all groups, strong messages emerged regarding dignity and respect and basic human decency and individuals’ failures to achieve the standards expected of them by either system or patient.
2. There is evidence of indirect discrimination or what might be called ‘discrimination by omission’ – for example, a failure to explain entitlements such as access to liquid nutrition if a patient is no longer able to digest solid food.
3. Patients from lower socio-economic groups in particular but also across all four of the interview groups reported barriers to properly discussing treatment options, typically concluding that this was because they were not considered articulate enough, or not ‘middle class’ enough. Education, accent, speech patterns, inter-personal behaviour, personal values and attitudes play a part in determining how approachable *we all are* – but health professionals need to see past this. It is significant how many of our interviewees reporting feeling that they were actively disliked or dismissed by their consultant.
4. A number of group-specific issues are also evident:
 - Older patients are much more likely to feel that treatment decisions lack transparency and are determined by their age. In this regard there seems to be clear evidence in some instances of palliative rather than curative treatment being offered. Older patients and/or their carers are acutely sensitive to this and are likely to make this interpretation even if (as would almost certainly be the case) such a conclusion would be clinically denied.
 - Patients from lower socio-economic groups are also more likely to be made aware of the cost of particular treatments.

- Health professionals seem to struggle more frequently with LGBT patients, carers and partners than any other group to ‘get the basics right’ regarding respect for family life, sexual orientation, partner status etc.

Recommendations

1. Decision-making regarding treatment costs for older patients will become ever more pressing as public finances continue to tighten. Older patients and their carers and families must receive appropriate explanations regarding treatment decisions and feel confident that decision-making is fair, transparent and *in the best interests* of the patient. The emotional impact of treatment decisions must be recognised, and explaining them fully and adequately viewed as a key requirement of effective and compassionate communication.
2. Health professionals have a key role to play in *enabling* patients, but all too often this is not recognised. The general thrust of health policy is towards greater patient choice and autonomy but health professionals need to be part of a deeper cultural shift which will make this aspiration a reality.
3. Culturally-specific needs are important, but health practitioners also need to be clear about what constitutes a ‘special need’ (and therefore arguably requires ‘exceptional’ provision) and what constitutes a fundamental requirement of high-quality care. Many of the shortcomings in behaviour and treatment recounted in the interviews here are not culturally-specific at all but rather are failings in the duty of care and compassion. It is at this point that improving services for one group becomes synonymous with raising quality levels generally.

(c) At follow-up care

1. Across all groups, it seemed the case that personal experience of the relationship with consultants tended to be at the extreme – or at least, is remembered only at the extremes, perhaps: the relationship is either really good, or really bad. There seems little in the middle.
2. Virtually all of the patients who commented on this, irrespective of social group, again testified to the fact that powerlessness, lack of information, lack of time to ask appropriate questions and maybe even difficulties in *formulating* the right questions, are amongst the most depressing difficulties they face and a significant cause of anxiety.
3. Signposting and referral to, and information about, support groups and networks varies dramatically from trust to trust. And even when patients do manage to access appropriate support networks and are provided with checklists of the kind of questions which will help them get the information they need from their consultant, this is sometimes regarded negatively by consultants.

4. Some of the group-specific problems include:
- Older patients in particular may lack information regarding follow-on care; they may lack the language or aptitude to ask the ‘right’ questions which will elicit the information they need.
 - Older patients seem to do better when they find an appropriate support group – this includes feeling better emotionally, being better able to navigate the system, and being better able to draw on mutual support.
 - Amongst BME groups there was a greater tendency for patients’ care plans to fail to take into account additional language, communication or support needs. As several interviewees explained, often support needs which would have been evident from the outset had the right questions been asked became apparent to their medical team only at (or even after) the point of discharge.

Recommendations

1. Much more needs to be done to assess and improve the patient/health professional relationship to ensure that patients’ rights are embedded within it and that it is a supportive and enabling dialogue. More real time patient experience data could be used to support this process of assessment and improvement.
2. Fundamental to patient empowerment is the right to ask questions. Health professionals – in addition to patient advocacy groups and support networks – have a key enabling role to play in this. Trusts should develop a standard checklist of questions that patients can use to help them formulate appropriate questions regarding their own circumstances, thus increasing the likelihood that they will elicit the information they require and also strengthening personal autonomy and participation. Such checklists could be developed with the assistance of cancer networks and other patient support networks.
3. When assessing doctors’ performance, more use could be made of patient ‘voice’ in the assessment process, focusing in particular on where patients feel their rights have been infringed.

(d) At end of life

1. The circumstances of death, and especially whether the carer, partner or family feels that their efforts achieved the least suffering possible and the ‘best’ death the circumstances permit, are a paramount issue. This is what those who are left behind must live with, and issues of dignity and respect, of compassion, kindness and human decency predominate here, and they do so irrespective of social group.

2. There are some group-specific issues, however:
 - Those who feel – as the carer of the transgender patient did – that ‘difference’ was a cause of discrimination right up until the end, find this especially hard to live with and it is likely to colour their attitude towards every part of the medical profession.
 - Older people, especially those who lack support at home, may be prevented from exercising choice in the kind of death they wish for. Their inability to exercise the last kind of autonomy open to them makes them especially vulnerable.
 - Some BME groups may also have other cultural preferences regarding the period of death, wishing, for example, to take a much more active role in supporting a dying patient – offering food, giving water, talking – than is possible when that patient is heavily sedated.

Recommendations

1. The ‘system’ must be able to accommodate culturally-specific needs but it must also ensure dignity, respect, kindness, care and compassion for all, not just in exceptional cases where ‘special needs’ are identified. An improvement for all would by default bring significant improvements for disadvantaged groups.
2. There is a pressing need for patients and their carers to be able to discuss end of life arrangements much sooner with medical teams – in part to help carers, partners and families prepare emotionally and practically, but also to ensure that trusts too are better able to work with families to try and ensure that choice and autonomy can be exercised.

7.0 THINKING ABOUT THE FUTURE

While improvements at particular points of the pathway could be made which would help prevent discrimination and inequality, it is worth emphasising that most patients we spoke to do not think in terms of ‘care pathways’, nor do they typically isolate specific moments or ‘interventions’ when they regard their experience as being particularly poor. Indeed, the King’s Fund has concluded that, “Patients do not naturally differentiate between aspects of care or rank them in order of importance. Everything about the process is a manifestation of the greater whole.”⁸

The experiences so powerfully described by patients here dramatically reinforce this view. The way that people ‘view’ and ‘experience’ the healthcare system is shaped by more than what happens to them at one singular point of the care pathway or with one particular healthcare provider. A particularly poor and discriminatory experience at screening stage, for example, may affect the way patients feel about treatment they receive much later on in their cancer journey. If particular forms of good equality practice are not reinforced throughout the whole care pathway (not just at those points described above) and if they are not enacted across healthcare providers, there is a risk that patients will disengage. In fact, we recorded a number of examples of where patients chose to ‘opt out’ of further care due to inequality experienced earlier on in their cancer journey.

Consequently, we believe that any process aimed specifically at addressing discrimination and unfair treatment in the health system needs to have two complementary characteristics:

- First, it needs to be flexible. It needs to work *across* the care pathway, lending itself to application in a wide range of contexts – as capable of assessing and testing the fairness of performance at the system level as it is to testing and assessing fairness at the level of the individual task, intervention, patient and staff member;
- And it needs to be significantly more agile and quick to use, furnishing feedback that is as close to ‘real time’ as possible.

We said earlier that the key issue seems to be that important aspects of equality are not measured and performance is not managed in a way that encourages improvement. The emphasis is on measuring ‘inputs’ (for example, equality schemes in place, or interventions to increase access for specific equality groups), but patient ‘outcomes’ are not routinely assessed in terms of equality and nor is this a measure that is typically used to drive service improvement. The unequal experiences of patients and the relationships they have with staff are not valued or measured in terms of equality. Similarly, the system has not yet found a successful approach that

⁸ King’s Fund (2008): Goodrich, J., & Cornwell, J., Seeing the Person in the Patient: The Point of Care Review Paper. http://www.kingsfund.org.uk/publications/the_point_of_care.html

enables it to identify (and take action) when the ‘voice’ of some of the most vulnerable patients is limited by personal capacity/ability or the effects of discrimination.

What we are proposing here – albeit in a limited and exploratory form – we believe has the potential to get closer to the problem, and to do this more quickly.

A framework for assessing fairness

Basically, what we are proposing is a fairly simple framework for assessing fairness. It is based in part on the ‘Equality Measurement Framework’ developed following the Equalities Review undertaken in 2007.⁹ For the sake of simplicity, we call this framework:

- Equality of outcomes.
- Equality of relationships.
- Equality of voice and choice.

This closely mirrors the themes we used to aid discussion and interviewing during the course of this research. Participants were encouraged to reflect on three particular aspects of their relationship with services. We described these as:

- **Outcomes** – i.e. what did the experience result in, how did the outcome of their treatment effect and impact on their health and wellbeing and on other aspects of their life?
- **Relationships** – i.e. how did the system and/or NHS processes treat them? Were they treated with dignity and respect? Did how they were treated ‘feel fair’?
- **Voice, choice and control** – i.e. were they listened to? Who did the choosing? Were the options available to patients adequate? Would patients have chosen what actually happened to them? Did they feel in control of decisions made about them?

To explain this better we have included three hypothetical case studies (below) which represent patients’ experience in relation to inequality of outcome, inequality of relationships and inequality of voice and choice.

⁹ See: Equality and Human Rights Commission – Equality Measurement Framework:
<http://www.equalityhumanrights.com/key-projects/equality-measurement-framework/>.

Equality of outcome

Nathan and John have the same type of cancer, at approximately the same stage. Nathan is 62 and is put on a course of chemotherapy to attempt to cure the cancer. John on the other hand who is 82 is told he is not suitable for chemotherapy and instead he will be put on a course of steroid injections to keep the cancer 'at bay'. John is a fit and active 82 year old who thinks he is strong enough to withstand a course of chemotherapy. However the consultant is not willing to discuss this and will not refer him for the chemotherapy.

As a result John did not receive chemotherapy and has now been informed that his condition is terminal. Nathan on the other hand is now in remission. This is an example of inequality in **outcome**.

Equality of Relationships

Lara and Lisa are both waiting to see the radiographer. Lara is seen by a woman radiographer at her request (both a man and woman radiographer are available on this day). Lisa on the other hand, who is post-op transgender is told by the receptionist that she doesn't need to see a woman radiographer despite her request for one. The receptionist says to her colleague (within earshot of Lisa), "I've seen it all now, she'll be fine with Nigel, I've got more important things to worry about."

This makes Lisa feel degraded and humiliated. Being treated with a lack of dignity and respect compared to others, or other types of discrimination and unequal treatment are inequality in **relationships**.

Equality of voice and choice

Susan and Dipali are in the same hospital ward suffering from cancer. Dipali is Pakistani, and her Pakistani consultant Mr Hussein talks mainly to her husband (who is her main carer) when making decisions about her treatment. He feels this is 'the way people from our culture prefer it'. However Dipali is not comfortable discussing all aspects of her treatment and condition with her husband. On the other hand, Mr Hussein discusses Susan's treatment decisions directly with her.

Dipali feels that she has no voice in the system, no choices open to her and no control over her treatment. This is inequality in **voice and choice**.

*

There will obviously be some overlap between these different types of inequality, but we think that in the future a framework like this could help to make it clearer where and how inequality and discrimination operates within the system. This would make it easier to do something about it.

These different aspects of people’s relationship with services have their own ‘status’ because it is not sufficient to have equal outcomes without having a voice or choice, or to have equal outcomes in the absence of fair relationships based on dignity and respect for the patient. Tackling discrimination is *hard* to do, and we need to develop more sophisticated ways of understanding where and when to intervene to address it.

As well as increasing the ‘profile’ of previously under-explored aspects of inequality, we also hope that this will lead to a better understanding of where poor relationships, or a lack of voice and choice in the system can lead to *poorer outcomes* for patients. It is important to recognise that treating patients with a lack of respect can actually lead to disengagement from the system and lower survival rates for those that experience it. (This resonates strongly with health secretary Andrew Lansley’s recent announcement on new NHS performance measures which will emphasise patient outcomes over “process-led targets”).¹⁰

Much of this report has included examples of patient experience that demonstrate inequality and/or discrimination. However, we have saved two for this last section to demonstrate the strong impact inequality in relationships and inequality in voice and control can have on patient outcomes. We make no apologies for reporting these examples in some depth as they help to demonstrate the cumulative effect of unfairness across whole cancer journeys. We think the case studies speak for themselves.

The effect of Inequality in Relationships

“There are two meanings of the word treatment, how you are treated as a person and how you are treated medically. Medically it has been great.”

A general pattern in many of the instances of poor treatment we identified was that it occurred when patients do not ‘fit’ with a particular view of what patients are (or should be) like – white, middle class, under 50, heterosexual, not transgender. When patients do not ‘fit’ they lose out or opt out.

¹⁰ See The Independent (17/12/10): New measures to replace NHS emergency targets.
<http://www.independent.co.uk/life-style/health-and-families/health-news/new-measures-to-replace-nhs-emergency-targets-2162907.html>

This example describes part of the cancer journey of a transgender patient and the effect poor and unfair relationships with staff ultimately had on her health and wellbeing

“They treat you like shit. All you want it to get the right medical care and get better.”

From the first visit to the GP, the patient felt that her ‘identity’ was under scrutiny:

The GP was trying to ‘read’ me. Do you know what I mean by that saying? It’s where someone is trying to work out what you are. The way he looked at me, the way he talked to me. I was being ‘read’ because I was a transsexual.

After admission to hospital for routine surgery, preliminary blood tests show that the patient has a ‘massive infection’:

He just starts examining me and umming and ahing, but doesn’t tell me anything at all. He then told me that it might be cancer, just like that. He didn’t ask how I was feeling. I was completely shocked. I just left the hospital.

The patient goes on to explain the nature of the other ‘treatment’ she receives at this time, and her inability to address it at this particular point:

It starts off with funny looks and referring to me as ‘he’ even though I am a woman called [XX]. But when you have just been told you might have cancer, just like that no warning, the last thing you have the strength to do is complain or insist they treat you with respect.

I wanted to put a complaint in, but then they mentioned cancer and I was too shocked.

Following this the patient was admitted to hospital to undergo bone marrow tests, she described a situation that left her feeling worthless, although the indignity of this experienced was eclipsed by the discomfort and trauma of the cancer ‘experience’, the nature of the experience prevented the patient from speaking out.

It was excruciating. The most painful thing I have ever experienced. I asked before the procedure and they [the nurses] said it might be ‘a bit uncomfortable’. I was referred to as ‘he’ by the staff.

The doctor that did the procedure arrived and said hello. That was the *only* thing he said to me, and he didn’t look at me once.

I felt I was no part of what was happening. I was really shaken, I was gripping the side of the bed, my knuckles were white and tears were streaming down my face.

In the end I couldn't take anymore and I said stop, please just stop. The nurse said to me 'the needle is out and the doctor has left. He's gone.'

In this description the patient described feeling 'no part of what was happening' to her, yet this was her body.

The patient was eventually prescribed a 'miracle' drug that would suspend and hold the cancer, but the side effects - which weren't explained – became unmanageable.

I was in terrible pain and discomfort, it was totally debilitating and the quality of my life was so bad.

The worst one was this feeling of being unable to breathe. It was really strange. It was like I would forget to breathe and then this voice would say 'breath, remember to breath' and I'd take the biggest intake of breath. It was terrifying.

The doctor said he couldn't do anything about it. Didn't seem to be concerned and didn't offer any type of help. Yet very recently I found a paper that had been written by one of the doctors at the very hospital I went to that was on what I had experienced.

On another occasion the patient visited a pain specialist to discuss her options. The appointment took an unexpected and unwelcome turn.

He then said out of the blue: 'there's always euthanasia, you can go to a clinic in Switzerland.'

I complained and he denied saying that he had refused to prescribe me anything and that he had suggested looking into terminating life in a humane way.

Here the patient's complaint was met with denial, in the following extract, the patient explains how she tried to get round this in future encounters.

I started to record conversations and take witnesses. I got an appointment with the consultant, he thought to discuss my medication but I said I was there to discuss his comments. He got really aggressive and was about half a foot from my face leaned right over. And refused to comment on what I asked him about. Then I played back his comments, as I had recorded them and it took the wind out of him and he became less aggressive.

From then on when I went to visit the consultant on two occasions there was somebody else in the room, they were never introduced, and things were discussed in front of them that I was not comfortable with.

On reflection, the patient was fairly convinced of the motivations for treating her in this way.

Do you think that someone who isn't transgender, who isn't a bit 'weird' would have got this 'special' treatment? Is this special treatment reserved for people who are going through or have gone through gender reassignment?

There was a doctor at the cancer centre who would always say to me: "you're very tall for a woman" it was a really barbed comment. He was more concerned with my gender transition than my cancer. I wanted to give him a bloody good shake.

I am hardly impartial. But if you add up everything that happens to you, a very clear pattern emerges – and it very wearing.

This had a devastating effect on the outcomes the patient received from the service she had been provided. As a result of the type of inequality in relationships the patient experienced, she was left with very few options.

Another person, who had been treated like I had, might not think that death is the easiest option but I do right now. Maybe I'll go back and try to fight the system and play it. The consultant definitely doesn't want that – they are saving a lot of money – by giving me the 'special' treatment.

The effect of Inequality in voice and choice

Understanding the amount of 'voice' somebody has or the choice somebody has over their lives and care is obviously quite a complex subject. Constraints on choice aren't just created by the health system and staff (e.g. staff coercing patients or not listening to them, or a lack of choices of different types of treatment). Patients may also face 'personal' constraints, such as a lack of self-confidence, or particular entrenched behavioural patterns that prevent people sharing their views. This raises important questions about how the NHS can help patients to exercise independence, choice and control. This is why we asked questions to try and explore both of these types of constraints.

We recorded a number of examples of patients not having voice or choice in the system. We encountered people who:

- Knew their situation wasn't good, but didn't want or didn't feel able to improve it.
- Felt they had no choices available to them in the system (a lack of service options).

- Felt there were no choices available to them due to structural constraints – e.g. a lack of money or family support.
- Wanted to improve their situation but couldn't contribute equally to the decision-making process.
- Were 'pressured' or 'forced' into making a particular decision.
- Were provided with insufficient information.

These different aspects of voice and choice are important to patients and can affect each other. Patients may have 'voice' and a place to describe their needs and express their concerns, but with a lack of choices available to them (in terms of possible treatment options, for example) they may still disengage.

Examining voice, choice and control in this level of detail could help institutions to understand whether a person is bound by a lack of money, has a lack of support, or is not able to make decisions for themselves. All of which would require different interventions to help them. This analysis moves beyond the relatively 'light touch' approach to gauging patient experience used in patient surveys. It is important to understand why and how people lose voice, choice or control in the system and how this affects poor outcomes.

This account, by a young BME carer, describes how the struggle for voice and choice become central to the experiences of the patient, the experiences of her family, and the role of the carer

"She didn't want the consultant to treat me that way because I was her voice. She didn't want him to lose respect for me."

My friend started out going to appointments on her own – did this for 3 months – but she didn't have the confidence to voice her concerns.

My friend said to me she felt very confused. She said to me "they are too clever" "they make me feel stupid." She used a Bengali word that roughly translates as 'guinea pig' – she felt she was their guinea pig

Once she told me this I went to every single appointment with her from that point forward. I just didn't want her to get lost in the system; I didn't want her to be one of these people who get lost in the system.

Over the course of their experiences, voice becomes something that has to be fought for.

At the beginning her brother used to speak up but within 8-9 months he would completely withdraw in those meetings. And everyone would talk through me. But I became more and more scared to talk because of the way that the consultant would respond to me, and not because of me, but because every time he did that my friend would lose hope and confidence.

I was trying to balance so much, I was terrified of upsetting him.

The following excerpts illustrate the role of the consultant in closing down carer and patient attempts to voice concerns, ideas and questions.

The consultant offered the patient a procedure, which both carer and patient, in previous conversations, had clearly stated would be inappropriate. It dawns on the carer that they are not being listened to.

The consultant said that he could operate by taking flesh from her thigh and using it to cover the wound on her cheek. He said that it would make her more attractive and would mean her children would be less scared when they looked at her.

We couldn't believe that he said these things. They are not things we had discussed and we made it very clear that if the operation was only to mend something on a superficial level that we weren't interested.

We explained that every procedure took it out of her and that if he thought that it would have any impact on health or cancer then we would do it, on his advice but if it was purely superficial. We said can this help her? She made her position very clear. So it didn't go ahead....

The worst thing he said to us – and it really fuelled our doubts in him – was at the end when he said to us “well if you had taken the face surgery I might have been able to cut the cancer out”

When he said this we were too stunned to say anything. It's one of my biggest regrets that I didn't. But we all became scared to say anything, because of the repercussions. We couldn't question anything.

On another occasion, the consultant dismissed the carer's attempts to explore potential treatment avenues.

I took the research I had done to see what he thought of two possible treatments and he wouldn't look at it, kind of flapped it away and said don't waste your money.

In the following the carer explains how she was left reeling by what she describes as intentional unethical practice, which resulted in both carer and patient agreeing to chemotherapy that 'he [the consultant] had always been set on us going for' but that they [carer and patient] had been absolutely convinced was not an avenue they wanted to pursue.

I remember it all so clearly, I remember every detail, and I have gone over it so many times as it just makes no sense. He took the ground from beneath us and then gave us our only option. He made us think it was our only option.

We all went into his room, but before we'd even sat down he just said 'the treatment didn't work.' As soon as he said that it felt like everything changed. We were all so uncomfortable, it took us ages to sit and no one spoke.

Within a few minutes he moved on to chemo but we hadn't even started to comprehend that the drug which we hoped was working wasn't. So within 5 minutes it was decided and we'd signed the paperwork.

We had no time to think about it. We were numb.

It wasn't until the next day when we were waiting while she had chemo that her brother said 'he didn't answer the question, what are we doing, this is a mistake.'

It was inhumane the way he played that day. He was persuasive "I'm on your side" He landed one bombshell on us and then another and then he put chemo in front of us.

Impact on outcome

The carer summed up the role of the consultant in taking voice away, and the impact that this had on her and her friend's mental and physical wellbeing.

He made everything a complete nightmare, but he was all we had, so we didn't ever wake up from it.

I would try to appease him and appeal to his power driven side. I'd say we're young we don't know what we're doing, we're scared. I would tell him that we wanted his advice. But this didn't ever work.

I would always prepare so much when we went to see him. I would draw up a checklist or questions, but we never got a straight answer. He made us feel so small, so as time went on I avoided questions and conversations because to avoid the confrontation. The more he made me look small, the more he pushed me down, the more my friend would lose confidence.

Towards the end she really didn't want to go to the appointments with the consultant, she didn't see the point, she wanted to completely opt out, but I couldn't let her do that.

The carer provided an account of her friend's experience on the first anniversary of her death. The impact of their experiences was clearly still taking a huge toll on the carer.

I keep wondering whether I'm looking for someone to blame. It can make you irrational sometimes but he was the one person who could make things okay – not go away – but okay, instead it felt like he was our arch enemy. I would have to gear myself up to see him, I didn't sleep and I became so anxious to see him.

In many cases patients did not do anything about discrimination or unequal treatment, *because* of their lack of voice, choice and control in the system – they felt coerced, they felt there were no other options available to them, they did not have the self-confidence necessary to challenge. This lack of voice in the system or lack of control over decisions comes precisely when patients are most vulnerable and have least control over other crucial aspects of their life – their health, their economic and employment prospects, domestic circumstances, childcare. The potential for reputational and organisational damage is coupled with a system that struggles to respond to discrimination through its formal complaints processes, this is an especially damaging combination.

Using a 'fairness framework'

Such a framework offers a way not just of thinking about how the care pathway operates and performs, but also for thinking about and identifying discrimination. If you can spot it, it's easier to fix. Perhaps more importantly, it offers a framework within which personal behaviour and attitudes can be assessed and modified.

We are only at the very early stages of thinking this through, but it is already evident that there are various ways that such a framework could be used in relation to key policy aspirations, including those set out in:

- Equity & Excellence: Liberating the NHS White Paper¹¹ and the two associated consultation papers:
 - Liberating the NHS: Greater Choice and Control – a Consultation on Proposals.¹²
 - Liberating the NHS: An Information Revolution – a Consultation on Proposals.¹³
- Transparency in Outcomes: A Framework for the NHS.¹⁴

¹¹ DH (2010): Equity & Excellence: Liberating the NHS, White Paper.

http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_117353

¹² DH (2010): Liberating the NHS: Greater Choice and Control – a Consultation on Proposals.

http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_119651

¹³ DH (2010): Liberating the NHS: An Information Revolution – a Consultation on Proposals.

http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_120080

¹⁴ DH (2010): Transparency in Outcomes: A Framework for the NHS.

http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_117583

- Healthy Lives, Healthy People: Our Strategy for Public Health in England.¹⁵
- Equality Act 2010¹⁶ and The Equality Strategy – Building a Fairer Britain.¹⁷
- Cancer Reform Strategy Refresh.
- Issues identified by NCEI in its report Reducing Cancer Inequalities, Evidence of progress and making it happen.¹⁸
- Plans of the CQC (and others).

These key policy objectives share five broad aspirations:

- Outcome-focused – an emphasis on outcome measures not process targets.
- Increased emphasis on the quality of patient experience.
- Enhancing the voice and responsibility of patients and carers
- Improving the evidence-base so that inequality and discrimination are better understood, prioritised and responded to.
- Lighter touch, risk-led and outcome-focused regulation.

Very briefly, we consider the relevance of the proposed framework against each of these.

Outcome-focused

Equity and Excellence and the accompanying *Transparency in Outcomes* both emphasise the importance of an outcomes focus for future service improvement in the NHS. The fairness framework we propose emphasises the importance of assessing outcomes by equality group to understand whether all are benefitting equally from what the NHS has to offer.

However, the framework goes further than that and suggests that it is important to identify and measure those aspects of patient/staff relationships and patient voice and choice that have a particular impact on patient outcomes. While it is now increasingly acknowledged that process-driven targets have not resulted in improved outcomes, there is a role for understanding how and when particular processes may also contribute to unequal outcomes. This would also be relevant to the Cancer Reform Strategy Refresh in offering an equality and discrimination-based analysis of why some groups present later and die earlier. The research reported here has already demonstrated that such an analysis is capable of illuminating patient experience at particular points on the care pathway.

¹⁵ TSO (2010): Healthy Lives, Healthy People: Our Strategy for Public Health in England. http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_122252.pdf

¹⁶ TSO (2010): Equality Act 2010 http://www.equalities.gov.uk/equality_act_2010.aspx

¹⁷ Government Equalities Office (2010): The Equality Strategy – Building a Fairer Britain. <http://www.equalities.gov.uk/pdf/GEO%20Equality%20Strategy%20tagged%20version.pdf>

¹⁸ DH (2010): Reducing Cancer Inequalities, Evidence of progress and making it happen . http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_114353

Increased focus on quality of patient experience

A focus on ‘equality of relationships’ could also help identify where patients are not being treated fairly by staff. The NHS Outcomes Framework suggests that overarching indicators for ensuring people have a ‘positive experience of care’ will be based on common themes from patient surveys (access/waiting; safe/high quality care; information/choice; closer relationships; cleanliness and comfort).

Collecting more sophisticated data that allows comparative analysis by equality groups would clearly be necessary to any performance management regime refocused on patient experience. But even this would be incomplete without also identifying the attitudes, behaviours and ‘failure points’ where discriminatory treatment can (and is) creeping into the system. Again, the proposed fairness framework would make a direct contribution by helping to identify these points and the behaviours and attitudes which contribute to them.

Our analysis of ‘equality of relationships’ involved analysis of a range of domains of patient experience and we think that using analysis like this in the future could to add value to future patient experience indicators in the future in respect of identifying discrimination in cancer care. These included:

- Spotting where and how staff treated patients with a lack of dignity or respect (this means different things to different patients – what did this ‘look like’ in practical terms)
- Identifying when staff used stereotypes or offensive language to describe patients and when patients felt humiliated, harassed or bullied by the way staff spoke to them (e.g., referring to transgender patients as the opposite gender to which would they would like to be referred). Also identifying where patients feel victimized (unable or unwilling to complain about discrimination for fear of reprisals).
- Understanding when staff made un-founded assumptions about the needs of patients due to their background or identity (e.g., that person doesn’t need pain relief because he hasn’t said anything to me)

Generally speaking this would require a more sophisticated analysis of different ‘types’ of discrimination (e.g. direct, indirect, harassment and victimization) within the system.

Enhancing the voice and responsibility of patients and carers

Equity & Excellence: Liberating the NHS and its two associated consultation papers emphasise the importance of “putting local communities at the heart of public health” and empowering individuals so that they can make healthy choices.

In order to deliver on these aspirations, a lens through which to understand inequality of voice and choice will be required, a framework for analysis that is more sophisticated than those used previously. Previous approaches to understanding inequality of voice and choice have tended to focus on whether particular excluded groups have been consulted (e.g. 10 BME patients and 7 disabled patients were consulted). Or headline patient survey results have identified the degree to which different groups (when analysis is possible) feel involved in their care choices or receive particular types of information.

However, in the policies described above, we are noticing an aspiration to address individual level barriers to autonomy, with a focus on the interplay between personal circumstances, issues of self esteem, capacity and the actions of NHS professionals. To achieve this we need to understand barriers to equality of voice and choice in more detail (e.g. examining where and how patients feel coerced by health professionals, examining where and why patients have less confidence to challenge or question decisions made by professionals and the role that discrimination plays in this process). The proposed fairness framework will contribute by helping to identify the circumstances in which patients are *disempowered* by discrimination and unfairness.

In order to be able to exercise choice and greater personal responsibility, patients must also be able to exercise autonomy.¹⁹ Fairness and non-discrimination are central to this, as is levelling the playing field to ensure that individuals can participate equally in their care and the treatment decisions this entails.

Improved evidence-base

The NCEI report *Reducing Cancer Inequalities, Evidence of progress and making it happen* recommends that more data on equality issues should be collected in order to inform action to tackle inequalities and measure progress. To support further improvement on cancer equality, a series of metrics have been developed to enable the measurement of progress on issues where there is a proven link with inequality. Currently the metrics used in the cancer equality portal focus heavily on patient outcomes (incidence, survival, mortality, symptom awareness, screening uptake, cancer waits, prevalence), although patient experience data by equality group is also an equality metric.²⁰ NCEI recognises that there is still much to be done to ensure that better and more consistent data is collected to understand patterns of inequality in these areas and NCIN will continue to develop the evidence base.

The Cancer Patient Experience Survey has further highlighted differences in experience across some equality groups. However, there are a number of challenges still to be responded to:

¹⁹ For a more detailed question framework to examine issues of 'equality of autonomy' see CASE (2009): Burchardt, T., Evans, M., Holder, H., *Measuring Inequality: Autonomy – the degree of empowerment in decisions about one's own life.*

²⁰ www.ncin.org.uk/equalities

- There are still relatively low numbers of respondents for particular excluded groups which makes it difficult to draw statistically significant conclusions about their experience. But this also reinforces the view that only large numbers count and that atypical ‘outlier’ experiences can be discounted.
- The analysis indicates that BME groups, older patients, LGB patients and those from socially deprived backgrounds are more likely to respond negatively to particular questions. However the analysis of *group experience* is limited.
- Questions are analysed quantitatively, and are based on aspects of care and treatment that are “known to be important to patients”. But as our interviewees demonstrate, it is entirely possible for all of the aspects of care covered in the survey to be present, while patient experience remains poor, unequal and unfair. However, open, patient comments in addition to the data were also collected and have been shared with each trust.

There is clearly some convergence between what patient surveys currently record and what we are proposing in this framework for understanding equality and national surveys do have an important part to play in understanding wide-scale patterns of patient experience. However, as the findings from this research demonstrate, more qualitative and richer data that explores different aspects of inequality can help to identify where and how discrimination happens within the system *and the consequences of that discrimination* for patients’ outcomes.

Light touch, risk-led and outcome-focused regulation

In the future, public authorities are likely to be encouraged to identify and prioritise key equality actions arising from their public duties under the Equality Act 2010. Less attention will be placed on regulating to identify whether or not public authorities have particular schemes or processes in place, focus will be placed more heavily on outcomes, and whether there is a clear and persuasive narrative around choosing particular equality priorities.

Our proposed fairness framework shifts the emphasis from that of the largely abstract ‘system’ and its functioning or malfunctioning and instead focuses on clear, practical issues such as staff-patient relationships and the behaviours and attitudes which have the greatest impact on the quality – and *equality* – of that relationship.

The fairness framework could also assist in moving towards fully outcomes-focused regulation in that it offers a way of analysing the factors which contribute to outcomes, moreover doing this with a clear emphasis on patients’ rights and anti-discrimination.

APPENDIX 1

A broader view of cancer inequalities

“There is a clear survival gap between the most and least deprived”²¹

The National Cancer Equality Initiative (NCEI) collects data regarding the age, gender and postcode of individuals diagnosed with cancer. This is then used to analyse incidence, mortality, survival and other measures.

Cancer mortality from all cancers between 1999 and 2003 was 70% higher among the most deprived men and 40% higher among the most deprived women when compared to the least deprived groups.²² While affluent women are more likely to be diagnosed with breast cancer, for example, women in lower socio-economic groups are 5-10% more likely to die from this form of cancer.²³

Combined disadvantage – being poor, old and from an ethnic minority group – also means that you are less likely to survive cancer. While late presentation or failure to attend cancer screening services contribute to this,²⁴ research carried out as part of the NCEI 2010 does indicate that “similar patients from different socio-economic groups *receive different treatment* within the NHS [emphasis added]...”²⁵

Britain is an ageing society and by 2034 it is forecast that 23% of the population will be aged 65 or over and just 18% aged 16 or under.²⁶ According to the NCEI just over half the cases of cancer diagnosed in 2003-5 in England occurred in people over 70, and over one-fifth in people over 80 years old.²⁷ Cancer survival decreases with age and there is evidence that older people’s cancers are investigated and treated less intensively.²⁸

Britain is also becoming more ethnically diverse and by 2051 it is forecast that 20% of the population will be from an ethnic minority background – up from 8% in 2001.²⁹ Already, in some boroughs of London, ethnic minority groups make up over

²¹ NCEI (2010): Reducing Cancer Inequalities, Evidence of progress and making it happen.

²² NCEI (2010): Reducing Cancer Inequalities, Evidence of progress and making it happen.

²³ Cancer Research Campaign (1999): Davey, C., Austoker, J. & Macleod, U: Reducing Inequalities in Breast Cancer; A Guide for primary Care.

²⁴ Cancer Research UK (2006): Cancer and Health Inequalities: An introduction to current evidence, p.18. See also: British Journal of Cancer (90, 1367-1373): Coleman, MP., et al, Trends and socio-economic inequalities in cancer survival in England and Wales up to 2001, p.1372. This indicates that lower socio-economic groups use NHS services less due to differences in knowledge, awareness or beliefs regarding the need for medical attention.

²⁵ Ibid p.7.

²⁶ Office for National Statistics (June 2010): Aging: fastest Increase in the ‘oldest old’.

<http://www.statistics.gov.uk/cci/nugget.asp?id=949>

²⁷ ONS (2010), *ibid*, p.13.

²⁸ ONS (2010), *ibid*, p.13.

²⁹ School of geography, University of Leeds (2010), Working paper 10/02: Wohland, P., Rees, P., Norman, P., Boden, P., & Jasinska, M., Ethnic Population Projections For The UK and Local Areas, 2001-2051.

http://www.geog.leeds.ac.uk/fileadmin/downloads/school/research/projects/migrants/WP_ETH_POP_PROJECT/ONS.pdf

75% percent of the population.³⁰ There are different types and prevalence of cancer within ethnic minority groups, and variations in incidence between ethnic groups. The first national report on cancer incidence and survival by ethnic group was prepared jointly by the National Cancer Intelligence Network (NCIN) and Cancer Research UK in 2009. There is some evidence that environmental factors and lifestyle also play a role in determining risk of particular cancers in ethnic groups.

³⁰ The Guardian (21/01/05), What the Maps Don't Show:
<http://www.guardian.co.uk/uk/2005/jan/21/britishidentity12>

APPENDIX 2

Defining the ‘care pathway’

Pre-diagnosis & diagnosis	<p><i>This might involve:</i></p> <ul style="list-style-type: none"> ⇒ Visiting the GP / health clinic with early health concerns ⇒ Visiting the GP / health clinic with later stage health concerns ⇒ Referral to a specialist to explore / discuss concerns ⇒ Attending hospital for screening / tests ⇒ Visiting a consultant / specialist to receive a diagnosis
Treatment	<p><i>This might involve:</i></p> <ul style="list-style-type: none"> ⇒ Preliminary discussions with a consultant / specialist about treatment options ⇒ Attending a hospital to receive active treatment ⇒ Undergoing surgery to remove or take out the cancer ⇒ Staying in hospital
Follow up care	<p><i>This might involve:</i></p> <ul style="list-style-type: none"> ⇒ Discharge from hospital / discussions regarding care options outside of the hospital ⇒ Palliative care ⇒ Visiting a specialist to discuss success of treatment and potential future options
End of Life	<p><i>This might involve:</i></p> <ul style="list-style-type: none"> ⇒ Discussing your end of life options with a consultant / specialist nurse ⇒ Admission to a hospice ⇒ The acquisition of appropriate care to die at home