

# Developing and Evaluating the Practical Application of a Human Rights Framework in Cancer Care

*A brap report for Macmillan Cancer Support*



February 2010



“A big thing then was [pink] breast cancer teddy bears that you could order that could comfort you through the disease. I can’t tell you how much that enraged me. Because I’m really not afraid of dying, but I’m terrified of dying with a pink teddy bear tucked under my arm...”

Barbara Ehrenreich, author of *Smile or Die: The Relentless Promotion of Positive Thinking Has Undermined America*, Holt/ Metropolitan, 2009  
**Speaking on Radio 4, 9am, 11<sup>th</sup> January 2010**



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## 1.0 INTRODUCTION

### 1.1 Aims

In 2009 Macmillan Cancer Support commissioned a group to undertake the first phase of a project to develop and evaluate the practical application of a human rights framework for cancer services. The aim of the first phase of this work was to 'test' how human rights principles can be given practical expression in the context of service-user and staff experience in three cancer care settings ('test sites') – Bury NHS; Merseyside and Cheshire Cancer Network; and South East London Cancer Network. In doing this we have sought to examine how a human rights framework for equalities in cancer care can be developed and populated over time.

The working partnership with the test sites has been exploratory in nature and considers both the generation and practical application of human rights principles in those site-specific contexts. We are extremely grateful for the time, co-operation and honesty of test sites, all of which has helped to formulate the ideas for phase 1 of this work.

### 1.2 The Need for this Project

This project responds directly to the Cancer Reform Strategy (2007)<sup>1</sup> which outlines the direction of travel required over the next five years if England is to deliver cancer outcomes that are the best in the world.

The Strategy suggests that survival rates are improving for some cancers year on year and that patients' experience of care is improving, but not by enough; it also identifies a number of challenges England faces in responding to an increasing incidence of cancer as people live longer. The strategy recognises that there are major inequalities in cancer incidence, uptake of services and outcomes according to people's socio-economic position, or specific aspects of their background and identity. Yet the document is also clear that opportunities for change and innovation do exist, citing the potential to introduce new service models that could help to improve convenience and outcomes for patients.

It is in this spirit that Macmillan Cancer Support initiated and commissioned this work. Building on work already undertaken by the National Cancer Equalities Initiative<sup>2</sup> and the Department of Health<sup>3</sup> it aims to provide

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<sup>1</sup> *Cancer Reform Strategy*, Department of Health (Dec 2007).

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/dh\\_081006](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/dh_081006)

<sup>2</sup> *We Can – Reducing Inequalities in Commissioning Cancer Services – Principle & Practical Guidance for Good Equality Working*, NHS National Cancer Equality Initiative [NCEI], NHS National Cancer Action Team (Oct 2009).

[http://www.cancerinfo.nhs.uk/images/stories/ncei\\_docs/final\\_principles\\_guidance\\_doc.pdf](http://www.cancerinfo.nhs.uk/images/stories/ncei_docs/final_principles_guidance_doc.pdf)

<sup>3</sup> For example, *Human Rights in Healthcare – A Framework for Local Action*, DH (2007 and revised 2008).

[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_073473](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_073473)

practical, on-the-ground approaches to improving equality practice in a cancer care setting using principles of human rights.

### **1.3 What We Did**

In order to develop and test this framework brap worked closely with three 'test sites' identified by Macmillan prior to the commissioning of the project. These were: Bury NHS; Merseyside and Cheshire Cancer Network; and South East London Cancer Network.

Work with the test sites included:

- Exploring the needs of people affected by cancer and how human rights and equality relate in this context.
- Identifying the skills and experience required by health and social care professionals to embed human rights principles within cancer care and assessing any gaps.
- Identifying 'good practice' in implementing human rights principles in cancer care.
- Providing support, training, resources and guidance to test sites to help them understand issues involved in the pilot and work towards project outcomes.
- Talking to test sites to assess the usefulness and feasibility of the human rights framework developed through the project.
- Undertaking broader inquiry to understand how the development of this framework relates to other work and policies in the fields of equality, human rights, health and social care.
- Developing recommendations for the focus of Phase 2 of this project. This includes suggestions for further testing of the ideas presented in the framework (section 5.0 of this report) and proposals for more detailed testing methods.

### **1.4 Structure of this Report**

This report describes the first phase of this project and is split into the following sections:

- The Context of this Project
- About the Project: what we did
- A Human Rights Framework for Cancer Care
- Emerging issues and recommendations

### **1.5 About Macmillan Cancer Support**

Macmillan provides practical, emotional and financial support for all people living with cancer. One in three people in the UK will get cancer and, as

treatment regimes continue to improve, more people will live with the consequences of cancer as part of their daily lives.

Macmillan has set the ambitious target of reaching and improving the lives of everyone living with cancer. As rates of cancer survival continue to rise and the UK population becomes more diverse, it is important that health and social care services are able to support the needs of sections of society that are often marginalised. Macmillan has a clear vision of a health and social care system where equal access to and appropriate delivery of the best quality cancer care services is made available to everyone living with cancer.

## 1.6 About the Project Stakeholders

Anne Coates Tim Elliott	Director of Strategy Team Leader	Bury PCT Cancer Screening and Male Cancers Department of Health Cancer Policy Team
Neil Formstone	Cancer Voice	Cancer Voice (Macmillan Cancer Support)
Harry Cayton	Chief Executive	Council for Healthcare Regulatory Excellence
Surinder Sharma	National Director, Equality and Human Rights Group	Department of Health
Farhat Hamid Christos Pishias Nick Gradwell	NHS Transformation Lead Equality and Human Rights Group Policy Manager - Health	Department of Health Department of Health Equality and Human Rights Commission
Heather Hunt		Equality and Human Rights Commission
Jessica Corner Sandra Clarkson Jagtar Dhanda Hana Ibrahim	Chief Clinician Macmillan Development Manager Inclusion Programmes Lead Equality and Human Rights Projects Manager	Macmillan Cancer Support Macmillan Cancer Support Macmillan Cancer Support Macmillan Cancer Support
Khadija Abbasi Sarah Jackson	Equality & Human Rights Officer Inclusion Projects and Administration Coordinator	Macmillan Cancer Support Macmillan Cancer Support
Simon Oberst	Director of Improving Cancer Services	Macmillan Cancer Support
Paul Mackenzie	Health Inequalities Manager	Merseyside and Cheshire Cancer Network
Paula Lloyd	Associate Director Patient experience	National Cancer Action Team
Joanne Rule Paul Trevatt	Co Chair Macmillan Network Nurse Director	NCEI North East London Cancer Network

In order to support and facilitate this innovative project, Macmillan put together a steering group representing key agencies and interests within the Health Sector. Participants have been as follows:

## 1.7 About brap

brap is a Birmingham-based strategic equalities and human rights charity with an established local, regional and national profile. The organisation was established eleven years ago as a new kind of equalities partnership, bringing together key public institutions and third sector agencies as part of promoting progressive and evidence-based approaches in equalities practice.

From its inception brap has drawn on human rights principles, recognising the growing dissatisfaction with and inadequacies of the traditional 'silo' approach to equalities and the tendency this has to create rigid and narrow interpretations of cultural identity. brap has long taken the view that in an age of 'super-diversity' the notion of a single 'identity' determined by culture, ethnicity or disadvantage is both out of step with reality and potentially damaging.

brap's work covers a range of policy areas – health and mental health, housing, employment, education, and criminal justice, for example – and we also develop operational and 'critical friend' relationships with service providers and delivery agencies in these areas. This enables us to take a unique perspective on both the policy drivers shaping the roles of the public, private and third sectors and also their implementation. This is especially significant in terms of public service delivery.<sup>4</sup>

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<sup>4</sup> [www.brap.org.uk](http://www.brap.org.uk)

## 2.0 THE CONTEXT OF THIS PROJECT

### 2.1 Cancer inequalities

The Cancer Reform Strategy recognises that inequalities in cancer outcomes are experienced by a range of different groups in society and that these inequalities are 'patterned' according to socio-economic group, ethnicity, age, gender, disability, sexual orientation, religious group and cultural beliefs/practices. Inequalities may also vary according to the type of cancer and other factors such as location.

Subsequent progress reviews of the implementation of the Cancer Reform Strategy were published in 2008 and 2009. The 2008 review<sup>5</sup> noted the need for concerted work to reduce cancer inequalities, specifically by embedding equality and action on inequalities in the workstreams of all CRS initiatives, recognising multiple inequalities, and the need to develop human rights as a key driver for health equalities (in partnership with Macmillan Cancer Support and the Dept of Health Equality & Human Rights Group).

The 2009 review<sup>6</sup> notes that joint work between the National Cancer Equality Initiative and the National Cancer Intelligence Network has led to a much better understanding of the problems faced by different inequality groups, but that a national guide setting out the practical action that needs to be taken at a local level to address cancer inequalities is required and will be published early in 2010.

The All Party Parliamentary Group inquiry into cancer inequalities<sup>7</sup> also concluded that: "It is clear that the impact of inequalities can be profound – not only in terms of incidence, mortality and survival, but also in terms of the patient's experience. The stories we heard from cancer patients themselves were heartfelt, sometimes harrowing, and always persuasive."

### 2.2 Health Policy

Current health policy presents key issues and opportunities for the development of human rights and patient-focused approaches to improving experience and outcomes. This is not a comprehensive review of the current policy environment, but rather an attempt to look specifically at what is significant in relation to a developing human rights emphasis.

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<sup>5</sup> Cancer Reform Strategy: maintaining momentum, building for the future: first annual report, DH (Dec 2008), p.40.  
[http://www.dh.gov.uk/en/publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_091261](http://www.dh.gov.uk/en/publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_091261)

<sup>6</sup> Cancer reform strategy: achieving local implementation: second annual report, DH (Dec 2009).  
[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_109338](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109338)

<sup>7</sup> Report of the All Party Parliamentary Group on Cancer's Inquiry into Inequalities in Cancer, APPG (Dec 2009).  
<http://www.macmillan.org.uk/GetInvolved/APPG/ReportsAndEvents/InquiryIntoInequalityReport2009.aspx>

**(i) High Quality Care for All: The Next Stage Review final report – ‘Darzi’**

The ‘Darzi’ Review represented an unprecedented engagement with the views and experience of the ‘front line’ – patients, carers and clinicians. To that extent it was unsurprising that there was a clear focus on three overarching themes: patient safety; clinical effectiveness; and patient experience.

While all of these have a role to play in delivering the ambition set out for the NHS and in the delivery of a human rights-focused service, it is the idea of patient experience especially that has taken hold, both as a measure for quality and as fundamental to understanding what quality means – not least because this chimes with a growing sense of “...unease about the industrial scale of healthcare, depersonalisation of staff as well as patients, and the vulnerability of patients in our modern hospitals.”<sup>8</sup>

This aspect of the ‘Darzi’ vision, that part which references the significant differentials in quality of care, has been built upon by more recent additions to the policy ‘canon’ which demonstrate a clear and growing lack of sympathy with the ‘accidental’ nature of poor quality care and poor quality outcomes.

**(ii) WCC – World Class Commissioning**

The quality of commissioning and the performance frameworks governing contract outputs and outcomes clearly have significant potential to affect patients’ rights. WCC competencies have the potential to be all about reducing inequalities – or, as some critics have argued, nothing to do with reducing inequalities. The deciding factor will be the interpretation and implementation of these competencies by commissioners. Three issues combine here: the challenge of articulating WCC competencies in relation to a human rights agenda; the challenge of ensuring providers understand their accountabilities in relation to delivering on a human rights agenda; and the challenge of PCTs taking more of a lead as ‘market makers’ with the ability to use their purchasing power to shape new markets.

This is a complex area – not least because PCTs do not have the same kind of public interface with service users that many providers have. Nevertheless, it is fundamental to any system redesign with a focus on human rights that all ‘players’ are seen to operate and co-operate using the same ‘rules’.

This will place an emphasis on commissioning and ‘market making’ and in particular the development of a practical human rights-based approach that is transparent and understandable to commissioners, providers and consumers.

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<sup>8</sup> Goodrich J & Cornwell J: *Seeing the person in the patient – The Point of Care review paper*, Kings Fund (2008). [http://www.kingsfund.org.uk/research/publications/the\\_point\\_of\\_care.html](http://www.kingsfund.org.uk/research/publications/the_point_of_care.html)

### (iii) **QIPP – Quality, Innovation, Productivity and Prevention**

To date this is the primary policy and methodological instrument to support the sustainability of performance improvement in the NHS in the context of reducing investment.

QIPP accesses the principle of quality via ideas about the productivity of the health care system:

“The focus on **innovation** as the key driver for **sustained quality** improvements and unlocking **productivity gains** calls for a system wide focus on designing and implementing more efficient and productive services that do not compromise on the quality and safety of patient care but rather **enhance the patient experience**.”<sup>9</sup>

But QIPP is also concerned with the role of consumer voice in innovation – as a source of ideas, as a partner in co-design and in the wider context of understanding what patients and communities value, and what adds value to the public sphere (the ‘place making’ role of NHS institutions).<sup>10</sup>

### (iv) **CQUIN – Commissioning for Quality and Innovation**

CQUIN schemes are payment agreements between commissioners and providers, where a “modest” proportion of provider income is conditional on quality and innovation.

CQUIN is potentially the most significant of the emerging levers to secure quality from a human rights perspective because:

- It is concerned with the negotiation of metrics and data improvement.
- It is concerned with incentivising performance by making payment contingent upon performance.
- It is expanding rapidly in scope and has the potential to expand significantly further.

Pilot schemes in 2009-2010 made 0.5% of income contingent on achieving agreed goals, this rises to 1.5% in 2010-2011.

More recently, the Secretary of State has indicated that up to 10% of trusts’ income will be linked to patient satisfaction<sup>11</sup>. In the context of competition and co-operation rules this 10% would apply to the market as a whole.

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<sup>9</sup> Taylor, J: *In the Driver’s Seat*, NHS Institute for Innovation and Improvement, (July 2009).

<sup>10</sup> There is a need, as *Practical Steps on the SHA’s Duty to Innovate*, puts it, to: “Amplify the voice of the service user as a driver of service delivery innovation.” NHS Institute for Innovation and Improvement (February 2009).

<sup>11</sup> NHS 2010-2015: from good to great. Preventive, people-centred, productive – NHS 5 Year Strategy, DH (Dec 2009).

It is difficult to see why this should represent a limit on any scheme to incentivise performance. In the future financial climate, schemes that incentivise performance that are contingent on the delivery of good patient experience could be extended as a lever for change and would most likely be applauded by the public.

#### **(v) Quality Accounts**

It is proposed that performance in relation to quality improvement would be published in Quality Accounts as part of the process of annual reporting.

In his forward to *The Framework for Quality Accounts* (DH, September 2009),<sup>12</sup> Professor Sir Bruce Keogh, NHS Medical Director states:

“The published evidence suggests that public disclosure does not generally drive improvement through the resulting actions of patients or commissioners. Rather it is the organisational response that providers put in place in order to improve their record on quality that drives improvement.”

A recent example of this strategy is in Mid Staffordshire where the combined ‘challenge’ of improving quality of delivery and patient voice generated a real ability to shift long-standing cultures that have been tolerant of poor care and devastatingly bad outcomes.<sup>13</sup>

#### **(vi) PROMS – Patient Reported Outcome Measures**

PROMS are concerned with patient satisfaction pre- and post- a clinical intervention.

They are relatively safe measures, because they are not based on ‘patient experience’, instead they focus largely on whether clinical outcomes were successful. Their value in this sense would be immense in the context of high-risk clinical environments.

#### **(vii) The NHS Constitution**

While the Constitution contains a number of commitments that have a bearing on patients and human rights, generally speaking it operates at a level far above that at which patient experience is formed – their hour-by-hour treatment and the significant differences in the behaviours of those caring for them.

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[http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh\\_10987](http://www.dh.gov.uk/en/publicationsandstatistics/publications/publicationspolicyandguidance/dh_10987)

<sup>6</sup>

<sup>12</sup> [http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH\\_105304](http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_105304)

<sup>13</sup> “Campaign for courage underway at Mid Staffs”, Health Service Journal, 14th January 2010.

However the Constitution does codify rights and also provides 'headlines' for the levers that are emerging through QIPP and CQUIN to secure patient protections and participation.

### **(viii) CQC – Care Quality Commission**

The CQC registration process will require providers to regularly solicit and give effect to the views and experiences of patients and carers in demonstrating their approach to patient care and quality. The main focus of the registration process will be on the outcomes and quality of care for people using services. Questions and prompts for inspection and assessment staff in relation to equality and human rights will be developed for all of these outcomes. The CQC will also focus on issues affecting the workforce that may have an impact on the quality of care being delivered and the experiences of people using services (e.g. equality related legal duties as an employer).

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These recent policy changes represent an apparent toughening of the stance on achieving the ambitions set out in the 'Darzi' report.

They speak as much to a reinvigoration of purpose and culture as they do to the technocratic and structural aspects of NHS and wider market design.

The trajectory of 'patient experience' and what is evidenced of that experience suggests that this is the opportune moment to seek to generate a new order of contract with patients – an offer that might deliver a practical expression of the NHS Constitution in a way that is immediately beneficial to patients, staff and carers.

### **2.3 Health Service – Structural & Market Changes**

Over the last decade large parts of the broad structure of the NHS have become more fixed, with the advent of PCTs, World Class Commissioning, and the development of – and now deadline for – the establishment of Foundation Trusts.

While this has been a protracted and at times apparently tumultuous process the structural roles of commissioner organisations and an acute provider market, with significant/total independence, is in place and could not be readily challenged in the coming period as national investment tightens.

Equally the credibility of generating local investment models is probably better entrenched than at any previous time.

These arrangements have been reinforced by recent market interventions by the Department of Health – most notably the marginal cost payments/tariff for extra-contractual activity.

In using consumer experience as a key determinant of payments it is likely that CQUIN will be equally significant, with a potential to have a direct impact on the viability of organisations.

The Operating Framework 2010-2011 places an emphasis on non-payment for 'never events' (i.e. largely preventable patient safety incidents that should not occur if available preventative measures have been implemented). This is another example of a toughening of delivery mechanisms to achieve 'Darzi' outcomes.

What happens with, for, and to patients is becoming more central to the way that judgement will be exercised across all domains. It is worth noting that this is not only about the operating assumptions or principles of engagement of organisations – increasingly it is about their **behaviours**, as those are demonstrable.

The exception to this 'modernisation' has clearly been the position of community services, after attempts to enforce a speedy outsourcing of PCT provider activity were abandoned in 2009.

However there is clearly the intention to bring community services into line – so that they are formed as part of a market and subject to the same internal and external rules as other 'NHS' providers.

Community services by their very nature are complex delivery systems in comparison to commissioning and acute sector organisations. This is not about the services that they deliver, but rather about the degree to which they are able to attach institutional value and broad organisational purpose to the often wide range of separately focused activities and 'client groups' with whom they work.

While the Department of Health is prepared to countenance any future structural variation/business model as long as the proposal can demonstrate leadership in the delivery of systems and services, 'new' organisations would nonetheless be required to achieve the same targets in terms of patient experience and satisfaction as would be set for an acute service provider. They would become subject to the same market levers, and again these would focus on their **behaviours** rather than solely their ability to analyse or describe their populations.<sup>14</sup>

This creates a huge opportunity, as there is currently little understanding of the most effective system levers and trading currencies that might deliver the dynamism that is expected from these changes.

Three key areas will be:

- The closing of the 20% productivity gap that currently affects community services.

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<sup>14</sup> "Plan A for meeting increasing demand is scaling up in community", DH Industry Day – 12th December 2010.

- Gearing up to meet the challenge of ‘closer to home’ care – at any given time 30% of occupied hospital beds do not need to be occupied.
- Using a credible vehicle for generating trading currencies that might converge the interests of commissioners, the provider and the consumer.

This last is potentially the singular contribution of a human rights framework to supporting a business and demand led future in the NHS market – in so far as it might enable the demonstration of key organisational and staff behaviours across an organisation.

## 2.4 Patient Involvement

Over the last decade there has been some uncertainty about the purpose of patient voice. A range of formal mechanisms to ‘involve’ patients and the public within health and social care have helped to highlight instances of dissatisfaction. However these mechanisms have arguably not generated the level of capacity to critique systems of care that was originally intended. This has led to some criticism that the system is concerned less with protecting patients than it is protecting the status quo relationship between the health service and its consumers.

This state of affairs has become significantly less acceptable over the last two years. Generally this shift in opinion is explained in terms of a particular reading of consumer relationships – people are more demanding, people are less willing to accept what is put in front of them, people are less deferential and people demand choice. This is an easily recognised analysis, and does in fact have some real purchase as an explanation. But it is clearly not the whole story. Continuing problems with access for those with the greatest need and with late presentation and consequent poor outcomes are not well explained by the ‘demanding consumer’ theory.

Arguably a more credible explanation of shifting attitudes to the NHS would be the impact of three key issues:

### *The normalcy of poor experience*

Many health and social care professionals will be familiar with the dreadful experiences of failure to feed that led to the deaths of six people with Learning Disabilities in 2008 – the general public less so. However talking to people with recent experience of care for their elderly relatives/partners, not being fed is in fact a denominator event. Not eating being explained as a behavioural problem on the part of the patient is not uncommon (the evidence underpinning the application of the Anticipatory Care Calendar in Merseyside and Cheshire attests to this). Instances of hospital accidents leading to deterioration and death are common. It is tempting to view the descriptions in the Patients Association Report, “Patients not Numbers, People not

Statistics”,<sup>15</sup> as emotional and unreasonable responses to what are inevitable events. However three things are striking in this report:

- The restraint with which family and carers describe events – events that could readily justify intense hurt and anger.
- The fact that many instances of harm and death do not appear to be inevitable.
- Failures to communicate that border on misinformation and dishonesty.

#### *Repeat instances of large-scale fallibility*

There are a number of instances that could be cited here, but the two most striking are:

- MRSA and the general and uncontrollable despair generated by the idea of the hospital as an ‘agent’ of death.
- Mid Staffordshire NHS Foundation Trust: the report from the Healthcare Commission depicted an institution out of control – not a specialism, not a particular type of doctor or nurse, but an entire system disinvesting in the core philosophical, ethical and service values in which they had continued to expect the public to invest.

#### *Increased willingness to challenge bad behaviour*

Choice, as an idea, has had a bad press, both generally and in the professional journals. Talking to people with recent experience of the healthcare system, what “I want” continues to lack propriety for many. People find it easier (and in some respects more acceptable) to say what they *don’t want*, or wouldn’t choose. This relates to people being increasingly able and willing to evidence bad behaviour and to know that they are voicing an experience based on shared evidence rather than as a function of a formally constituted involvement/engagement exercise. Such instances are **behavioural**, they are evidenced, and they are common.

The growing focus on patient experience may best be seen as a response to these factors. The limitations of patient involvement processes are such that they have little impact on the behaviour of the ‘system’ in ways that address these three issues above. The search for true ‘representativeness’, for finding the right combination of patient voice – while important – is something of a red herring in this sense. *A more pressing goal will be developing patient involvement processes that have a fighting chance of critiquing and changing systems of care.*

It is in this context that human rights principles have an appeal as an organising framework for the delivery of care – to the extent that they can

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<sup>15</sup> Patients Association, *Patients not Numbers, People not Statistics* (August 2009).

generalise and codify a view of what is ‘proper’ to the workplace and of what is critical to the organisation if it is to ‘trade’ more effectively and with greater mutual confidence with its consumers and the wider community.

## 2.5 Measurement, Metrics & Performance

### *Behavioural metrics*

While patients may not be able to define ‘dignity’ or ‘respect’, it is nonetheless increasingly evident that they are acutely aware of **behaviours** which signify their opposite.

The wider health policy environment, up to and including the Operational Framework 2010-2011, also reflects an increasingly **behavioural** approach, focusing less on principle and what organisations ‘know’ about their patients and the wider community and more on what organisations *do* or *fail to do*.

Market levers too are beginning to focus on ‘patient experience’ – with an emphasis on the **behaviours** of staff and the perceived organisational permissions given to particular staff **behaviours**, rather than simply whether or not treatment was successful.

In discussions with the pilot sites and with the wider constituency, approaches which focus on **actions** rather than intentions generate the greatest clarity regarding possible metrics that would make sense to patients, carers and staff. An additional benefit is that measuring **behaviour** can be both a formal and informal activity – and one in which patients and carers can participate.

### *The ‘personal’ metric*

During the course of the project, and in particular in our practical work with test sites, the idea of a ‘personal metric’ has gradually emerged – a means whereby staff can interrogate their own behaviour using a value-system that reflects a commitment to human rights and vocational ethics. At present this is an unevidenced idea but we have attempted to test it during the course of Stage 1 and in discussing it with staff we have found it resonates strongly with them. Indeed, on many occasions it seemed to create ‘eureka’ moments for staff and they articulated (often passionately) the convergence which exists between their vocational ethics and values, and the needs of patients.

This is explained in more detail in section 5.3.2.

### *Other metrics*

It became clear to us during the course of the project that other aspects of activity would need to be monitored alongside a ‘personal’ and ‘behavioural’ metric. These may already be measured through existing regulatory processes (for example, assessment of particular organisational procedures or policies). In other cases, there may be forthcoming measurement processes that would complement the framework.

A particular example of the latter is the ‘equality measurement framework’ currently being developed by the Centre for Analysis of Social Exclusion (at the London School of Economics) and Oxford University, with the backing of the Government Equalities Office and the Equality & Human Rights Commission. This involves measuring the ‘equality of autonomy’.<sup>16</sup> Autonomy will be an important component of any human rights framework that is driven – and shared – by staff, patients and carers.

The research identifies the need for further methodological development in measuring this type of equality and difficulties associated with this. It clearly states the need to see past models that over-emphasise the role of service users as entirely free and ‘active consumers’, to more nuanced models that recognise that service users’ choice and autonomy may be constrained by a whole host of factors, including perceptions, expectations, entrenched behavioural patterns, coercion and oppression by others:

“Moving away from the conventional ‘revealed preferences’ approach in welfare economics, where actual choices are taken as a guide to underlying preferences and goals, towards an approach that takes account of reasons and motivations underlying choice, the menu of options available, and the nature of underlying barriers and constraints”<sup>17</sup>

The research recommends potential methods for understanding equality of autonomy that begin to unpick these more complex barriers to choice and autonomy faced by people in a public service provision context. These methods could be very helpful in informing the development of the human rights framework in this project. For example, by assessing autonomy in this level of detail, it will help institutions to understand the limitations of personal choice and the contribution ‘choice’ may make to poor outcomes. It will also improve analysis of 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. These are issues that merit further scrutiny during Phase 2 of this project.

## **2.6 Wider Policy Ideas & New Thinking**

Again, this section is not comprehensive but focuses on areas of policy and new thinking in public policy that may have implications for a human rights-based approach.

### **(i) EBD – NHS Institute for Innovation and Improvement**

Experience Based Design (EBD) elucidates a process for bringing together the stories of patients and front line staff in order to identify mutually

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<sup>16</sup> Burchardt, T., Evans, M., Holder, H., *Measuring Inequality: Autonomy – the degree of empowerment in decisions about one’s own life*, CASE/Oxford University (November 2009).

<sup>17</sup> Ibid.

agreeable outcomes and a shared view on the best process for delivering those outcomes. The impact of EBD could be seen in co-production, which also opens the door to human rights-based approaches.

**(ii) *The Spirit Level – Why More Equal Societies Almost Always Do Better – Richard Wilkinson and Kate Pickett, 2009***

There is a growing recognition too that inequality is not just a ‘minority issue’ but exacts a price right across society. Two British academics, Richard Wilkinson and Kate Pickett, have demonstrated this in their book *The Spirit Level*, which shows that the more unequal a society, the more pronounced its social problems are *at every level*: inequality introduces society-wide (or system-wide) dysfunctions.

**(iii) *Michael Marmot – Strategic Review of Health Inequalities in England post-2010***

The review has taken a similar approach to *The Spirit Level*, focusing most particularly on “...the unequal distribution of health damaging experiences...” There is also specific reference to the impact of ‘power relations’.

A recent article in the Health Service Journal discussed the concept of ‘tolerated risks’ noting that, “Other factors such as ethnicity, gender and disability also impact on how our society shapes individual health outcomes.”<sup>18</sup>

**(iv) *Nudge: Improving Decisions about Health, Wealth & Happiness, Richard H. Thaler and Cass R. Sunstein (2009)***

Over the past year this book has become influential both in popular economics and amongst policy-makers. Some of its basic propositions are helpful in providing a reading of the impact that behavioural and ‘environmental’ factors have on choice. *Nudge* explores how complex systems, such as health care, can improve human decision-making by modifying the “architecture of choice” – providing ‘nudges’ (help), guidance and ‘real-time’ feedback which recognises that navigating complex choices is a shared activity that requires the collaboration of all the parties to that decision:

“...people will need nudges [help] for decisions that are difficult and rare, for which they do not get prompt feedback, and when they have trouble translating aspects of the situation into terms that they can easily understand.”

**(v) *The Idea of Justice, Amartya Sen (2009)***

Sen’s work as an economist and philosopher is groundbreaking and complex, but some of his ideas regarding social justice can be readily applied in

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<sup>18</sup> ‘Michael Marmot on why health inequalities matter’, HSJ, 16th April 2009.

healthcare settings. The ‘capabilities approach’ for example, that has its origins in Sen’s work, has direct application. The core idea of the capabilities approach is that the aim of development should be wellbeing in the widest sense – physical, mental, emotional, economic and social – rather than merely economic objectives. The notion of ‘capabilities’ refers to the freedoms that people need in order to realise their full potential and flourish. This approach suggests that people require more of a say in how they define the opportunities and freedoms that they should be afforded. Freedom *and* social choice are central to the capabilities approach, but so too is the notion that how we exercise our personal freedom is contingent on the effect this has on the freedoms of others.

There are two important principles from this approach that are potentially relevant for this project. Firstly, that the wider social, economic and political circumstances of people’s lives affect their ability to both define and exercise particular freedoms. Secondly, that there is a need to create a ‘space’ within society (or within systems or institutions) where people feel they can have a say in identifying what they need in order to do or be what they most value.

**(vi) *Free: The Future of a Radical Price, Chris Anderson (2009)***

This is a wide-ranging discussion and argument in favour of creating markets and value by giving services or products away for free. The author takes the view that in the future the two primary market dominant factors will be:

- Ease of use
- Reputation

Anderson suggests that gaining ‘reputation’ can be every bit as motivating as making ‘money’. Measured by the amount of attention a product attracts, reputation can be converted into other things of value such as tenure, audiences, and lucrative offers of other sorts.

The iPhone is perhaps a good example of this. But this has implications for the public sector too. There are opportunities to develop new ‘trading currencies’ in this ‘reputation economy’. Could public services ‘give away’ a guarantee of protecting human rights in order to generate increased tenure and new audiences and to improve take up of other services? Generating reputation, creating new markets and ‘trading’ as a ‘human rights organisation’ holds a certain allure and currency in this regard.

In order for this to happen it would probably require a more active role of public authorities as ‘market-makers’. In the current NHS model for example, this is seen to be the strategic province of commissioners – though it is a subject of discussion and specification with providers. But the creation of new markets or products is not often done through the route of ‘commissioning’ in the private sector – nobody commissioned the razor blade or Google for example. Shaping products and creating markets is arguably more a function of ‘willing providers’ than of willing commissioners and there is potential to

explore the role of both in creating new markets related to human rights in the future.

**(vii) *The Management Agenda 2010***

This is an annual report that reviews key strategic and tactical issues for managers across the private and public sectors. In the latest report 46% of public sector managers described the reputation of their senior board as positive or very positive, and 47% believed their leaders put the values of their organisation into practice. This, however, compared to two-thirds of managers in the private sector responding positively to these same two questions.

If managers and other staff across an organisation do not see their top team behaving in a way that reflects the wider expectations of themselves and the organisation then what might 'cultural/behavioural change' mean? As creators and managers of 'place', leadership must encompass behaviours that demonstrate the coherence of the organisation for staff, if that is to have any 'transferability' to consumers.

**(viii) *Institute for Health Improvement – Rasmussen's drift to danger model – Rasmussen and Svedung, 2000***

IHI has done a wide range of work scoping systems risk and effective risk management.

The following idea is highly relevant to the Macmillan enquiry: that the more a system is hedged around with procedural requirements, the more likely it is that this will promote higher risk behaviours to offset what are seen to be additional requirements that produce no benefit. Getting the job 'done' will achieve a higher priority than getting the job done properly.

This suggests that in devising any performance management tool/system, institutions should:

- Not create new and unnecessary systems.
- Not generate different rules for different actors in the system.
- Ensure that any and all actions to achieve desired outcomes should be visible to actors in the system – 'transgression' should be readily identifiable and reportable.
- Secure and test shared investment in compliance.
- Use 'permissive' systems where there is less risk or no additional risk when compared to the use of 'punitive' systems.

**(ix) *Risk Management – Identifying the Right Question***

Three recent articles have usefully investigated the relationship between risk, organisational cultures, leadership and risk management:

- Beyond the Blame Culture – Eileen Munro, The Guardian, 3rd November 2009.

- Sometimes it's the Workplace that's Stupid, Not the Staff, William Tate, The Guardian, 11th November 2009
- Can the NHS do more to catch local 'failures'? – Nigel Edwards, HSJ, 12th November 2009

The first two are concerned with the behaviours of social work organisations in the context of the Baby P case, the last takes as its starting point the Goodwin Report investigating accusations of bullying at the East Midlands SHA.

Making the presumption of good faith, Eileen Munro in the first article argues that "...we might consider if there is any point in asking why staff do not follow procedures, and ask instead what hampers them from doing so", and proposes "a systems approach – a recognition that performance is a blend of a worker's skill, experience and dedication with the design and organisation of their workplace." Such an approach "...gives us a way of adjusting the system so that it makes it easier for people to do the right thing and harder to make mistakes."

In his response piece, William Tate in the second article goes further, identifying "the system" as more than merely "an obstacle" but also "an actor". He likens the workplace to a fish tank in which "it is the quality of the water in the fish tank that determines the lustre of the fish". He continues: "It is what people are surrounded by that shapes their work behaviour. Yet most onlookers see only the fish, and then blame them."

Nigel Edwards makes a series of wider but related points about the complexity of NHS organisations, the creativity that they are able to bring to failure, the management of the 'rules' that are intended to constrain failure, and the reluctance to recognise and tackle problems in relation to wider systems. He is particularly critical of approaches to measurement that "...add complexity and work but may do little more than create the illusion of assurance."

Taken together these articles suggest that any approach to measurement of success and/or failure should seek to:

- Presume good faith – based at least on a reasonable assumption of an ethical aversion to incompetence.
- Recognise the active contribution of 'procedural' approaches to creating 'sins of commission' (again, doing what will get the job done irrespective of the 'rules') and promoting 'sins of omission' (feeling and/or being unable to complete tasks in the proscribed way or to the proscribed extent).
- Take a permissive approach to developing quality in systems, but police what needs to be policed – for example, the explicit and/or aggravated expression of prejudice and discrimination.
- People-focused metrics should be small in number and simple to enact.
- In a choice between blame and explain, 'explain' is most likely to produce changed behaviour, 'blame' most likely to achieve change in personnel.

### 3.0 ABOUT THE PROJECT: WHAT WE DID

In devising this project, Macmillan Cancer Support identified three test sites which would enable the practical application of a human rights framework to be tested in ways which reflect the experiences of three cancer settings:

- **Commissioning:** In Bury NHS, in the context of PRIDE, an existing research and consultation initiative seeking to develop an evidence-base that maps current cancer end-of-life care pathways as seen by patients, carers and staff, using this to improve service commissioning specifications.
- **Assessment:** In the South East London Cancer Network, which is developing a Common Assessment Framework that takes account of patient, carer and staff voices and is intended to manage and improve performance and quality at key points across the care pathways.
- **Provider Services:** In Merseyside & Cheshire Cancer Network, which is well advanced in its application of an Anticipatory Care Calendar as a means of improving the quality of early intervention for high risk groups – especially adults with learning difficulties.

This section offers a short summary report for each of the test sites.

#### 3.1 BURY NHS

##### **Context**

Bury NHS has developed the **PRIDE** project – an acronym for **P**ersonal, **R**espect, **I**nclusion, **D**ignity & **E**xperience – as its process for delivering the patient experience agenda, based upon an initial in-depth information-gathering exercise with patients, survivors, carers, families and staff. The project is intended to drive service transformation, shape commissioning strategies, improve standards and change behaviour.

Our initial review identified two ways that the PRIDE project could contribute to the human rights framework. First, the key messages from staff, patients, survivors and their carers seemed an obvious resource for exploring the extent to which equalities issues had arisen. Second, the PRIDE principles offered a platform to examine the application of human rights in the context of a “good” cancer end-of-life pathway experience. We worked closely with a core consultative group from the PRIDE project in these areas.

##### **Learning**

The value of the data emerging from the participants’ voices lay firstly in its “ownership” and acceptance by those who heard it, regardless of whether it was a hymn of praise or a lament. Whenever and wherever the things people had said were presented, they rung true for those listening, evidenced by the nodding of heads and the sharing of additional, supportive examples.

Secondly, it illustrated a convergence between what patients *want* and what staff would like *to be able to do*. And thirdly, there was a recognition that the kind of behavioural and performance change the human rights framework seeks would be welcomed by staff and would not necessarily require additional resources. As one clinician put it: “We don’t need to incentivise because doing these things (the metrics) will make staff feel good about themselves and the job they’ve done that day.”

Using the examples drawn from listening to patients, carers and staff definitely helped to illuminate the idea and application of human rights and a human rights framework, which might otherwise have been perceived as a complex and overly theoretical concept by many people. People found it relatively easy to identify simple **behavioural changes** that would not only increase staff satisfaction, but also crucially improve the patient experience.

It appears less easy, however, to ‘mesh’ the human rights framework with the arm’s length nature of the commissioning process.

## 3.2 South East London Cancer Network

### **Context**

South East London Cancer Network was selected as a pilot site based on their work to develop a Common Assessment Framework (CAF) for cancer care pathways. The intention has been to ensure that the assessment is fit for purpose for health and social care professionals – combining CAF and Holistic Assessment requirements. The Common Assessment Framework has been through a rigorous process of development – based on best practice, a review of the literature, consultation and multi-disciplinary groups with accountability for the content of each of the assessment domains.

While the Common Assessment Framework will begin as a paper-based tool, the aspiration is that it should be developed in an electronic format to ease use and support effective information sharing.

In working with South East London Cancer Network we reviewed the planning and guidance documents relating to the development of the Common Assessment Framework, provided written feedback on content from a human rights perspective – this has applied aspects of the emerging model, and held discussion groups with SEL principals to explore the relationship between their work, the application of human rights and their initial views regarding some of the key ideas in the emerging human rights framework.

### **Learning**

The Common Assessment Framework has the potential to be an effective learning tool in its own right for staff – setting the bar for the delivery of a rights-based approach and for the exercise of rights by service users.

It also provides a platform for extending engagement with the wider participants in health and social care interventions – e.g. supporting the development of FREMS or CREMS (Family and/or Carer Reported Experience Measures).

A critical issue across all sites has been the issue of ‘deception’, the extent to which service users are ‘managed’ in relation to prompt and accurate information – the Common Assessment Framework provides a platform for accountability in the same manner as the Anticipatory Care Calendar. It also begins to codify key human rights behaviours – such as the direct and immediate relationship between dignity, respect and the privacy of disclosure.

### **3.3. Merseyside and Cheshire Cancer Network**

#### ***Context***

Merseyside and Cheshire Cancer Network was selected as a test site based on the work it is doing to develop an Anticipatory Care Calendar. The Anticipatory Care Calendar seeks to address failures in identifying symptoms, misidentification of symptoms, and tendencies to misinterpret symptoms as behaviours (thus shifting the emphasis from perceived ‘disruption’ caused by the service user, to the validity of service users’ experience).

The Anticipatory Care Calendar approach has been tested in caring for adults with Learning Disabilities, recently expanded to include older people with dementia and in future may also be used with sight-impaired people with Learning Disabilities and offenders.

In working with Merseyside & Cheshire Cancer Network we provided written feedback on the patient survey from a human rights perspective; delivered a workshop on human rights and metrics; took part in a review of the application of the Anticipatory Care Calendar; and facilitated discussions with staff to explore the relationship between their work and the application of human rights principles.

#### ***Learning***

Initial assessment suggests that the application of the Anticipatory Care Calendar has the potential to redistribute power within the system. Care home staff with the lowest ‘system status’, for example, saw that they could use their more detailed knowledge of the patients in their care to intervene more effectively with powerful clinical staff. The Anticipatory Care Calendar is a powerful tool for promoting accountability.

The ‘journey’ that staff make in understanding the application of the Anticipatory Care Calendar can be mapped and could provide further opportunities to develop the tactical application of a human rights framework – in particular the selection of effective metrics in different health and care environments. We also found that the idea of a personal behavioural metric

resonated strongly with staff as a means of protecting the individual and the system from behaviours that were seen to have normalised bad practice.

The work with Merseyside & Cheshire Cancer Network indicates that staff can be engaged by a human rights approach when they see its potential to support patients while also reasserting their own professional aspirations and public service values.

### 3.4 Evaluation

As part of the conclusion to stage one of the Macmillan pilot, we asked the sites to evaluate:

- the process of working with brap
- their interaction with human rights (in terms of their own learning and applicability to issues of equality within their respective settings)
- ideas that they may have for implementing human rights in the future

#### ***About brap***

We received very positive feedback on the relationships that have been developed between the test sites and the brap team. Respondents commented on the quality of this interaction, the creativity of ideas and the practical help and guidance.

#### ***About human rights***

All feedback suggested that individuals had found the concept of human rights easy to understand and that it made sense in relation to 'the everyday considerations of what we do'. Staff who participated in the workshops found the sessions enjoyable and more importantly were 'enthused' by the potential application of human rights within their work.

#### ***About human rights and equalities***

Feedback was overwhelmingly positive in relation to how human rights could make an impact on the lives of patients. Staff in particular grasped the notion of having a set of 'negotiated behavioural' rights which guaranteed the quality of service provision.

#### ***Are there any barriers to the implementation of Human Rights?***

The barriers described were logistical in nature – having enough time, competing priorities and changing longstanding practices and ideologies. Money was specifically identified ***as not being a*** barrier to progressing this work.

#### **Opportunities and levers for implementation?**

Sites were quick to see the applicability of a human rights model outside of realm of cancer care and saw linkages between the aspirations of this work into WCC, QUIP and other policy levers

## 4.0 USING A HUMAN RIGHTS FRAMEWORK IN CANCER CARE

### 4.1 Human Rights Based Approaches: An Introduction

The conclusion reached by the EHRC's recent human rights inquiry<sup>19</sup> was that public bodies could be doing much more to use a human rights approach to improve service delivery – but “a true understanding of human rights as a tool to improving people's lives,” the report concludes, “is not widespread.”

A number of factors have prevented a proper, constructive debate regarding human rights and this has also impeded progress in their practical application – perhaps especially in the context of public service provision. For instance:

- In the media, human rights issues are often reported in relation to the ‘other’ (criminals, terrorists, foreign countries, asylum seekers). This does not encourage all people to take ownership of human rights. ‘What about my rights?’ is a common response to stories about the protection of people's human rights.
- Lacking a strong human rights culture in the UK has meant that human rights issues are often associated with ‘lefty activists’.
- Human rights tend to be seen as being very legalistic. The language used to describe human rights, especially case law, can be impenetrable and jargonistic. The legal side of human rights also isn't accessible to everybody because people can experience inequality in access to support to take civil action against public institutions (perhaps for financial reasons or lack of information). In some cases, traditionally excluded groups are less likely to seek assistance for their problems and do not really view their deprivation in terms of legal remedies.
- There is a fear amongst equality lobby groups and within the public sector that human rights based approaches will ‘dilute’ work carried out already for particular protected equality groups. There is a general lack of understanding about the relationship between ‘equality’ and human rights.

There is still widespread public confusion, then, regarding the practical application of human rights principles. In our practical work with test sites, we found staff shared this but in addition had understandable concerns regarding the use of human rights principles in a cancer care context. These discussions also highlighted opportunities and a positive desire to use human rights as an additional ‘equality tool’, however. Key issues discussed included:

- How to define ‘rights’: what are human rights, what role should staff, patients or carers play in defining what those rights are? What types of

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<sup>19</sup> *Public Perceptions of Human Rights*, IPSOS Mori for the Equality & Human Rights Commission (June 2009). <http://www.equalityhumanrights.com/human-rights/human-rights-inquiry/>

engagement processes help people to define those rights? What role does informed consent play in defining 'rights'?

- How should the 'rights' of different groups or individuals be balanced and the protection of particular rights be prioritised in terms of state intervention? How do we move to a situation in which groups understand the mutual and interdependent nature of society? What happens when protecting or upholding the 'rights' of one particular group or individual impinges on the rights of another?
- How do we ensure that people benefit from the same level of protection or promotion of their rights, irrespective of their background or identity?
- How can human rights based approaches help us overcome what is seen by some as a 'hierarchy' of protection for particular equality groups (e.g. race, gender and disability groups have enjoyed protection for a longer period than 'newer' protected groups – e.g. sexual orientation and age)?
- Previously, public service providers have tended to rely on consulting with representatives of specific excluded groups in order to identify their needs. Does a human rights based approach differ from this?
- How do public service providers ensure consistency in the protection of people's rights (e.g. at different parts of the care pathway)?
- How do staff measure and performance-manage protection of people's rights?
- What will be the fallout of adopting a human rights based approach? Will it address inequalities?

But perhaps the biggest obstacle to using human rights to improve public service delivery is the relative lack of real-life examples of how this might be done in a UK context. A study conducted by the Audit Commission in 2003 revealed that 58% of public bodies surveyed had no clear corporate approach to protecting and promoting human rights. And 61% of public bodies did not have arrangements to ensure human rights are protected through procured services (from the private and voluntary sector).

The EHRC's more recent human rights inquiry did cite a number of examples of improvement in this regard, where public authorities have been able to use human rights based approaches to improve policies and practice. However, the inquiry also says there is still a lot of work to do specifically on issues such as:

- Leadership on human rights.
- Developing knowledge and understanding of what human rights based approaches mean in practice.

- Addressing negative perceptions about human rights.
- Building capacity and confidence to use human rights based approaches.
- Addressing barriers posed by organisational culture and structure.
- Operating human rights based approaches in an environment of scarce and limited resources.
- Improving access to advice, guidance, training and information about human rights.

The kind of *practice-based* human rights framework proposed in this report and the subsequent work it is hoped will flow from this has the potential to address these issues.

### ***'FREDA' as way to describe human rights***

In the recent past FREDA principles – **F**airness, **R**espect, **E**quality, **D**ignity, **A**utonomy – have been used as an aid to explain human rights in a public services context, but we have found there to be limitations to people's understanding of this term. Although it is an easy to understand acronym, and has been used in some instances as a kind of 'short-hand explanation' of what human rights stand for, the ideas underlying it are seen as quite complex and at times murky by people working on the ground.

A good example of this complexity is the difficulty health care agencies have experienced in trying to define what 'dignity' or 'respect' mean in different circumstances and for different people. Effective processes for identifying and balancing sometimes 'competing' views about what 'dignity' or 'respect' mean from different 'equality groups' have not yet been developed. More sophisticated methods of participation and negotiation between staff, patients and carers are potentially required.

FREDA has clearly offered a 'way in' that helps people begin to conceptualise human rights, but has been of only limited use in making it possible to translate human rights principles into consistent, practical action.

### ***Confusion about the relationship between equality and human rights***

Although equality is included as one of the elements of FREDA, there is still confusion regarding the relationship between equality and human rights. In particular, staff asked us what the exact relationship is between what they are already doing to promote equality – equality monitoring, equality schemes, equality impact assessments, targeted interventions for specific excluded groups etc – and human rights? We were also asked whether a focus on human rights would 'take the wind out of the sails' of previous work done on equality.

It became evident that a clearer way of describing human rights is required – one that emphasises their true potential for re-energising and improving approaches to equality. This is one of the greatest strengths of human rights principles. It also needs to be made clearly understandable that human rights

approaches are not a 'replacement' for existing equality measures but a reinforcement, an aid to making equality work well *for everyone*. In other words, a better conceptual description of the inter-dependency – the 'co-existence' – of human rights and equality is required.

Our practical work with staff at the test sites has been instrumental in informing the design of a new way of describing human rights principles that helps to address some of these challenges. These principles have direct resonance with the framework we recommend to Macmillan later in the paper.

They are:

- **Participative:** I have a say in determining what my rights are and how they should be protected and promoted.
- **Balanced:** Others have a say too. What I do and the way in which I would like my rights to be protected might have an impact on others. The protection of rights needs to be reasonable and proportionate.
- **Universal:** I have the same entitlements to rights as everybody else, it doesn't matter what my background is or my identity.
- **Not 'earned':** We are born with human rights. I don't have to ask or lobby for rights or belong to a particular excluded group in order to enjoy these rights. I should get them because I'm entitled to them.
- **Guaranteed:** My rights can't be taken away unless I consent to this. In very specific circumstances I may choose to 'waive' a particular right. For example, if a doctor asks me if I mind whether my diagnosis and treatment options are discussed in a crowded room, I may consent to this, in which case I have waived my right to privacy. But this doesn't mean I always waive the right to privacy. I should be asked. If at a future appointment I insist on the right to privacy, then the doctor must try to find a private space so that my right to privacy and family life are respected – assuming it is within her power to do this and doesn't have a disproportionate effect on the rights of others.
- **Improving quality:** A human rights based approach involves identifying a set of benchmarks or expectations about the standards of service provision that we all can and should receive. A human rights offer should raise organisational standards through a change in the relationship between staff and service users. This behavioural change should protect the rights of service users and raise the quality of care resulting in improved satisfaction and outcomes. After all there is a difference between 'feeling good' about a service and 'being well'.

## 4.2 Developing the Macmillan Human Rights Framework

The exact nature of the framework to be developed through this project was not prescribed by Macmillan. Rather it was indicated that that the framework

should reflect our practical work with the three test sites and that ultimately what was developed should have the capacity to:

- Equip health & social care professionals with the skills and experience to competently and confidently respond to existing service inequalities.
- Encourage health and social care services to treat patients as individuals, catering for all their equality needs rather than simply viewing them as part of one equality group.
- Empower service users to work in partnership with professionals, contributing their ideas and experiences to efforts to improve cancer services.

Macmillan were also keen that the framework should complement other broad objectives such as the need to:

- Generate a nationally recognised Human Rights standard that indicates a beacon of excellence in providing quality care to people living with cancer.
- Develop a patient experience and workforce development learning programme linked to service development that aims to reduce cancer inequalities.
- Develop a patient empowerment programme to ensure that service users have better access to services that promote and uphold key human rights principles.

### **4.3 The Proposed Human Rights Framework**

Our research has informed the seven principles behind the framework that we are proposing. The feasibility of these have been discussed with the test sites and with members of the stakeholders group and in both cases met with a broadly positive response.

These seven principles are:

- (a) No more punishment
- (b) Let's behave
- (c) Let's reinvigorate
- (d) Win-win
- (e) No going back
- (f) Measuring progress
- (g) Personal metric

In the sub-sections (a)-(g) below we explain the role these principles would play in developing fully operable behavioural standards within an organisation (or network).

**(a) No more punishment!**

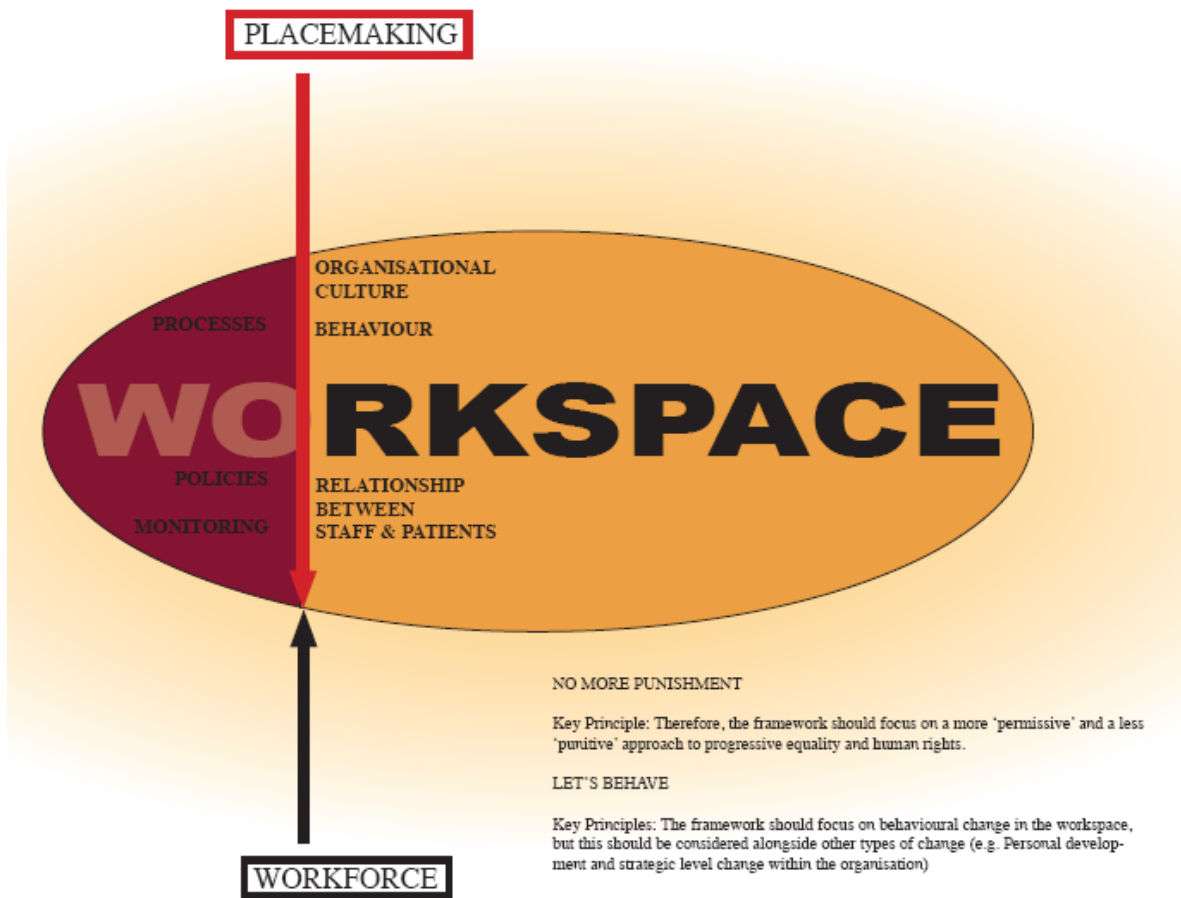
The implementation of equality within public authorities has tended to be 'punitive' – that is, prohibitive rather than empowering. Legal and procedural requirements placed upon public authorities have not had the 'Heineken effect'. In other words they have not always had the 'reach' that they need. They have not enabled staff to understand what they need to do differently and have emphasised the sorts of things they *shouldn't* be doing rather than those things they *should* be doing. Previous equality training has been confusing and can lead, albeit inadvertently in many cases, to a kind of 'professional paralysis' where staff become so concerned that they will do the 'wrong thing' that a safer response seems to be to do nothing at all.

The issue, of course, is not as simple as saying 'equality compliance bad–human rights good'. Human rights based approaches have the potential to accelerate people's understanding of how to deliver equality in practical terms. When we worked with staff to discuss human rights, we saw a number of people having 'light bulb moments'. They came to a realisation about how they could act in certain situations to improve the quality of patient care.

Fear of doing the wrong thing, a feeling that equality is being 'done to' staff, and a lack of certainty about what staff should be doing anyway has given equality a bad reputation. It is often seen as being 'punitive' rather than an enabling process to get the job done better. Diagram 1 (below) shows how leadership and performance management of equality have tended to prevent staff, patients and carers from sharing their views on what effective equality practice could look like. More 'permissive' approaches have the potential to allow staff, patients and carers more of a role in shaping what equality practice could and should look like in a workspace setting.

**Key principle: Therefore, the framework should focus on a more 'permissive' and a less 'punitive' approach to progressing equality and human rights.**

Diagram 1



### (b) Let's behave

Current equality processes have tended to impact on policies and procedures. But they haven't had the kind of impact (or rapidity of impact) on other areas of the workplace – organisational culture or staff behaviour, for example – that was originally intended. Diagram 1 shows this in pictorial form.

Through work on this project, we identified a number of convincing arguments for focusing on *behaviour* in the workplace at the level of everyday practice as opposed to more strategic issues like leadership, organisational policies and procedures. Behavioural change has the potential to be more rapid. It also focuses directly on the relationship between staff and patients.

While processes like equality monitoring or service user engagement have equipped staff with a wealth of information to understand patterns of inequality and user needs, a behavioural focus will support staff to take another important step in *acting* upon that information and modelling their behaviour with patients and carers on a day-to-day basis accordingly. A behavioural

focus relates to what staff members feel they are able to enact or do. **It was at the level of everyday practice that many project participants in the test sites felt most gains could be made in improving outcomes for service users and carers.** Many feel that it is often in relation to the 'little things' and specific details of everyday practice that patient and carer experience can be improved.

By focusing on behaviour the framework encourages self-reflection and self-regulation on the part of staff. It places clear responsibilities upon staff to behave in a particular way. It is also more measurable. It provides a clear set of behaviours that can be monitored and offers a clear focus for discussion with line managers (with a view to improving behaviour through learning and professional development if required). An additional reason for focusing on behaviour is that it also helps to shape organisational culture – organisational culture change *is* behaviour change. Behaviour change also has the potential to address other issues, such as institutional discrimination and apathy: some test site participants suggested that if more people start acting in a particular way, then others are likely to emulate them.

#### *How to influence behaviour?*

When discussing these issues with staff at the pilot sites, an approach which focuses on *actions not intentions* generates the greatest clarity in thinking about the kind of metrics or measurements that would make sense to patients, carers and staff. Measuring behaviour can be both a formal and informal activity – and one in which patients and carers can participate. We see this as something that can be measured at a 'personal' level by staff too, and at a workplace level by other staff and managers.

In order to influence behaviour there is a need to encourage greater 'agency' and autonomy on the part of staff – to improve the level of control they feel they have over their own behaviour *and the outcomes of that behaviour*. Also there is a need to generate more inclusive and universal standards of behaviour that all staff, patients and carers can sign up to. This will help to eliminate some of the confusion previous equality initiatives aimed at certain excluded groups have caused. That is not to say targeted initiatives for specific groups do not have a role to play, but alongside these a set of behavioural quality standards could help create consistency of outcomes for *all* staff, patients and carers.

Some of these changes in behaviours won't necessarily 'cost' anything. In enacting the framework, staff would need to be allowed to pilot and test new behaviours and processes in the workplace to improve protection of patients' rights. However, other improvements in behaviour and everyday practice would need to happen alongside other types of change (e.g. policy, process, resources) at a more strategic, organisational level. For this reason, despite being behaviour focused, the framework also indicates policy and resource issues that should be considered (Diagram 4). The human rights framework we propose does not favour a particular approach to implementing equality and human rights improvement. Personal development, behavioural change

of staff in the workplace, policy change, organisational change and broader societal change are parts of the same jigsaw. Instead, the framework proposes a clearer model for identifying which types of interventions will lead to particular types of change in relation to human rights at a Cancer Network or organisational level (e.g. when is a 'policy' intervention needed as opposed to a 'behaviour' intervention).

**Key principle: The framework should focus on behavioural change in the workplace, but this should be considered alongside other types of change (e.g. personal development and strategic level change within the organisation).**

### **(c) Let's reinvigorate!**

In our work with test sites a number of staff and patients reflected upon how they had felt equality initiatives had been 'done to them' rather than them having an opportunity to shape equality and make it work for themselves. Diagram 2 (below) shows how there has not really been an opportunity for staff and patients to debate, discuss and reconcile differing expectations or views about fairness and equality in a workplace setting.

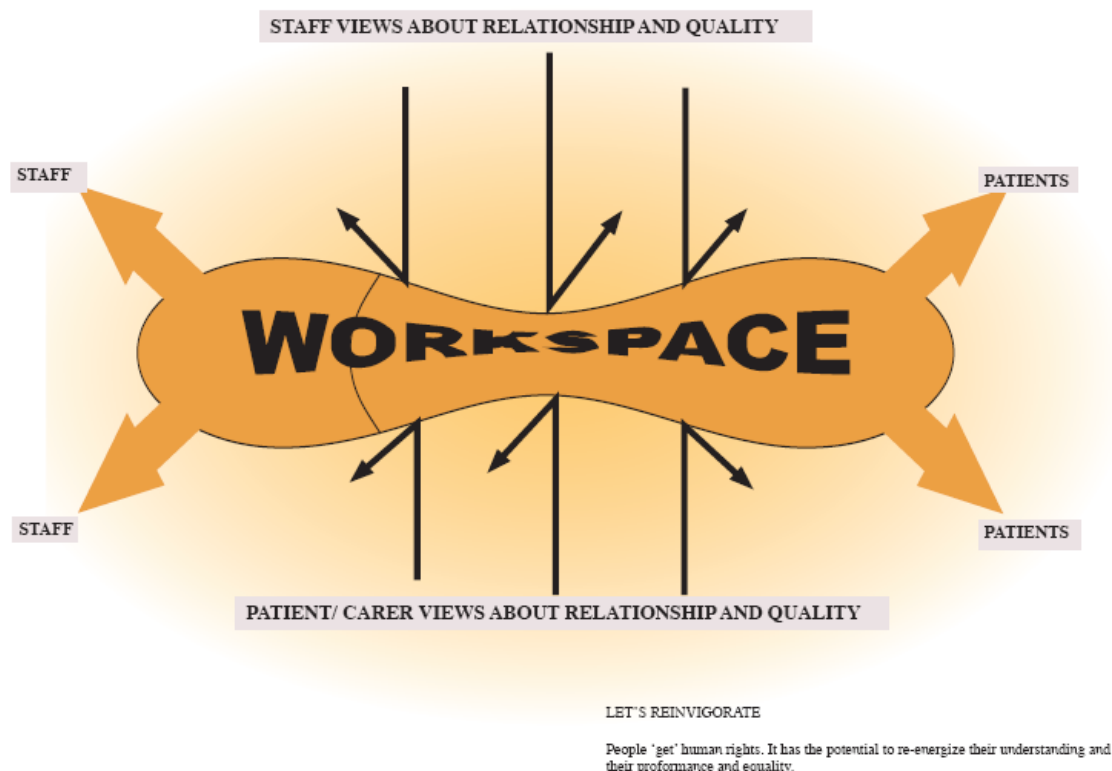
This has had the effect of squeezing both staff and patients out of the system as they feel they have less control over defining what fair equality outcomes should look like. There is a need for an approach which brings this debate and engagement on equality and human rights *into* a workplace setting. This will help to generate more harmonisation between what staff, patients and carers view to be important in terms of behaviour and fairer outcomes. It will also improve the level of control staff, patients and carers have over their own behaviour in a workplace setting.

Fundamentally, we believe that there is a real opportunity to reinvigorate people's belief in equality making an impact through the vehicle of human rights. This approach has received outstanding feedback from staff in phase 1 of the project.

A human rights-based approach enables staff to consider and respond to the needs and entitlements of *all* patients, rather than responding primarily to the perceived needs of patients as determined or suggested by their different 'cultural identities'. Asking a set of clear questions to help inform patient entitlement and respond to these concerns is far clearer to staff than figuring out what may be required as a consequence of previous equality training or by finding out more about somebody's culture or their religion, for example.

Staff that we spoke with had a real desire to understand what they need to know in order to get more out of their engagement with patients and carers. They would like to know what actions they need to take and how this will make a difference to people's lives. A much clearer link will need to be made between improving these aspects of practice within organisations and seeing discernible improvements in service provision. After all these are the things that matter most to patients and staff alike.

Diagram 2



#### (d) Win-Win!

In relation to the empowerment of staff, service users and carers, we identified a clear *and common* desire amongst *all* of these groups for more control over particular aspects of everyday practice and behaviour. Finlay in a recent study found that in a health care and social setting there was a tendency to focus attention on the larger decisions in people's lives when in fact empowerment could more quickly and effectively be promoted at the level of everyday practice<sup>20</sup>. In Merseyside and Cheshire staff felt empowered and able to question and challenge the views of other (sometimes more senior) staff by using an Anticipatory Care Calendar to map and understand the specific needs and care journey of patients. In Bury, patients and carers felt empowered through the PRIDE project to map those stages of the care pathway where patients were most at risk, or where particular interventions were required to protect their rights.

This human rights framework builds on this idea and requires staff, service users and carers to actively involve themselves in defining which behaviours and aspects of everyday practice along the care pathway are most feasible and most important in protecting and promoting human rights.

<sup>20</sup> Finlay, W. *Promoting choice and control in residential services for people with learning disabilities*, in *Disability & society* 23 (4), p. 349.

The focus here is placed on balancing the views of staff, patients and carers. We see these as issues that will need to be tested in more detail in Phase 2 of the work. However, as Diagram 3 (below) shows, an environment would need to be created within the workspace in which:

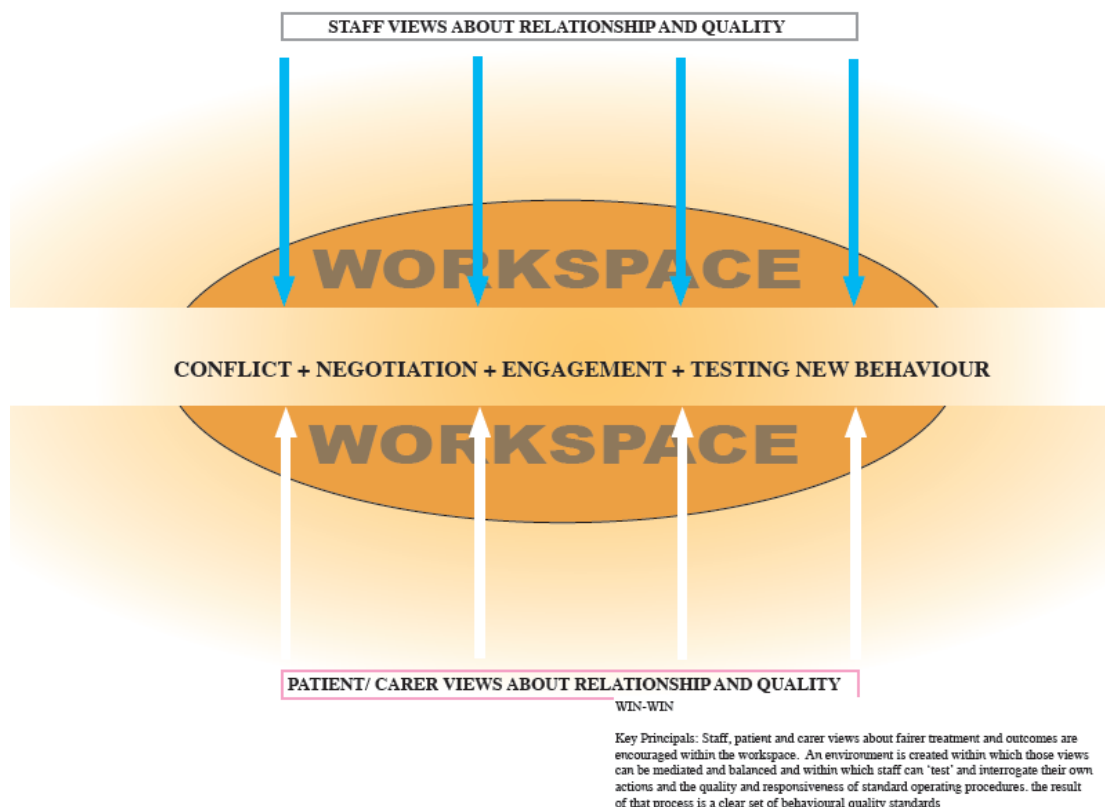
- Engagement of staff, patients and carers and an exchange of views can happen.
- Conflict and differing 'equality claims' (from particular individuals or groups) can be mediated, negotiated and balanced; and
- New ideas for changing staff, patient and carer behaviour can be tested.

We see this as a 'win-win' situation in that it has the potential to allow staff, patients and carers to feel they have more control over their own behaviour and the behaviour of others along the care pathway. It also provides a space in which decisions to use resources in a particular way, or for staff to act in a particular way can be more clearly explained.

After going through this process, we envisage that the result will be a set of **negotiated, behavioural quality standards** that protect the human rights of all staff, patients and carers at all stages of the care pathway. This is not dissimilar to the approach adopted by the Equalities Review Team in developing an 'equality scorecard' of freedoms or domains where people's rights should be protected, based on the use of existing human rights, legal instruments and a process of deliberative engagement with the public.

**Key principle: Staff, patient and carer views about fairer treatment and outcomes are encouraged within the workspace. An environment is created within which those views can be mediated and balanced and within which staff can 'test' and interrogate their own actions and the quality and responsiveness of standard operating procedures. The result of that process is a clear set of behavioural quality standards.**

Diagram 3



### (e) No Going Back

Rather than focusing on a particular aspect of cancer care services, it makes sense to understand particular cancer care pathways in their entirety. Behavioural standards are placed onto a care pathway at points where patients are most vulnerable in order to protect and promote their rights.

In Diagram 4 (below), the 'Key Rights' shown at various stages of the care pathway would refer to specific behaviours (or actions) that reflect – and protect and promote – specific human rights. Our discussions with staff at the test sites have already highlighted a number of practical examples of how these 'Key Rights' could be populated. For example:

#### Behaviour

Being called by the right (preferred) name

#### Corresponding human right

The right to a dignified life and freedom from torture or inhuman or degrading treatment.  
Freedom of expression.

Being able to discuss diagnosis and treatment options in private

The right to respect for private and family life, home and correspondence

Being able to choose where you want to die

The right to a dignified life and freedom from torture or inhuman or degrading treatment

It should also be noted – and again the examples above can be used to illustrate this – that some rights are ‘absolute’, while others are ‘qualified’ (and ‘interference’ with them can be negotiated). An example of this distinction would be the absolute right to freedom from torture and inhuman and degrading treatment: being able to choose where you die would be ‘non-negotiable’. The right to respect for private and family life, however, is qualified, and so the right to privacy in discussing one’s diagnosis or treatment options might be contingent on the organisation being able to provide a private space at that particular time and in the circumstances prevailing. (Conversely, in the spirit of this framework and the desire for service improvement that underpins it, if a provider found that they were consistently unable to uphold the right to privacy then some adjustments would be made to ensure that this shortcoming is addressed – the behavioural standard would need to change.)

Another compelling reason for focusing on key points or ‘moments’ along the care pathway relates to previous research on systems management. During the mid-1990s the Harvard Business Journal published a series of articles examining the relationship between quality, performance and systems of measurement. This work had two major strands focusing on what minimises *and* optimises the impact of quality assurance, and how to characterise the behaviour of systems that produce the greatest impact from their key resource – people.<sup>21</sup>

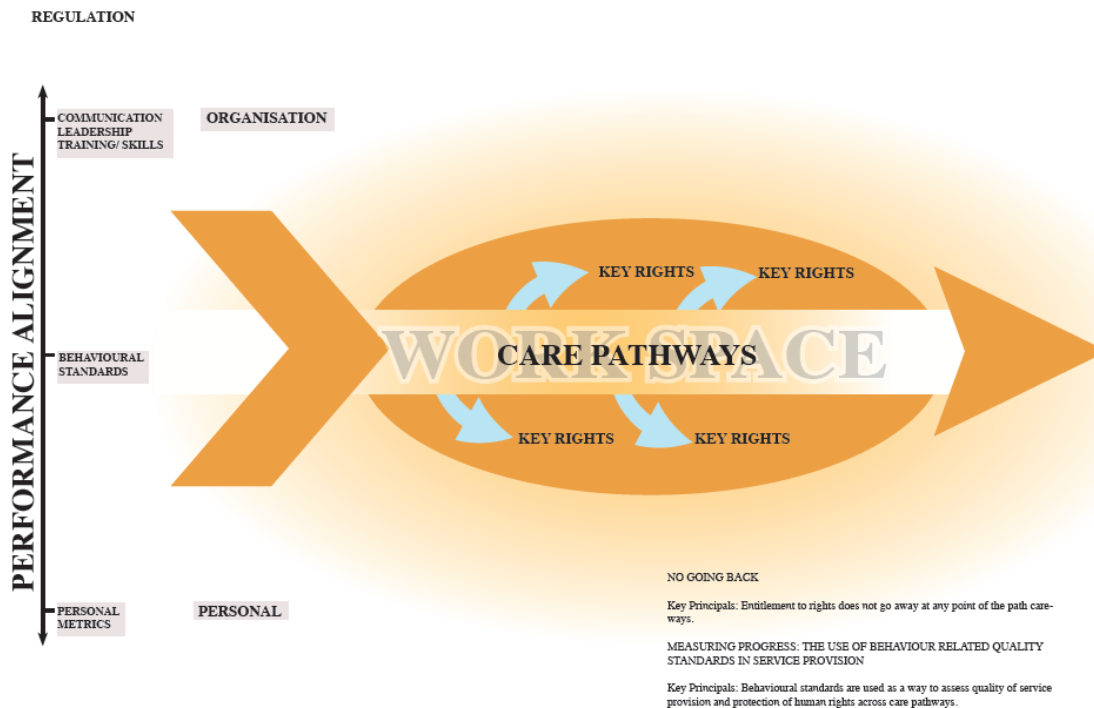
A key argument on systems management was the idea that any intervention to measure quality should be strategically limited and focused, on the grounds that this made the system tactically credible (plausible) both for the people being measured and for the people doing the measurement. If the correct measures could be negotiated and focused on key strategic moments (moments of difference) this could provide assurance across the system, because it made it easier for people to do the right thing and made doing the wrong thing more clearly counterproductive. This creates a shared sense of what is wrong with, and about, negative impacts on the system.

This leads to the argument that a similar strategic investment in people is likely to be most ‘profitable’ – for them, for the system, for the market position of the ‘product’ and for the consumer.

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<sup>21</sup> See for example, Pfeffer., J, *The Human Equation: Building Profits By Putting People First* Boston, Harvard Business School 1998.

## Diagram 4



An important part of this model is that each stage of the process is cumulative. In other words the quality of experience of a patient improves exponentially after particular rights are protected along the care pathway.

For example, the experience of providing somebody with a private space to discuss their treatment and diagnosis *without* using the person's name properly in that discussion would not be as valuable to the patient as when their name was used properly as well. The end result in the latter situation would be greater than the sum of its parts. The overall experience of the patient would increase exponentially as different rights are protected simultaneously or concurrently along the pathway. Although the pathway represents a chronological series of events, this does not mean those events (and associated) can't be re-enacted again at later stages of the pathway. This helps to reinforce the importance of ensuring that once a patient or carer's rights are protected, they should not then be infringed later on in the care pathway. In other words there is 'no going back' in protecting rights along the care pathway journey.

Our thinking on this issue is informed by two human rights principles. Firstly, that all human beings have 'inalienable' rights that cannot be taken away, apart from in very particular circumstances (e.g. freedom of movement if in prison, or restriction of rights if they interfere in a disproportionate or unreasonable way with the rights of others in society). Once a particular right is protected along the care pathway, this right should be protected by all staff the patient or carer comes into contact with throughout the pathway. This is particularly significant in Cancer Networks which can be at times complicated structures for patients to navigate (with a number of different organisations and staff involved in delivering services). Staff need to be mindful that they

may not have been the first person to meet patients or carers on their journey through the care pathway. Another practical point in this regard is that once a patient or carer is made aware of their rights, it can be extremely de-motivating for that right to be taken away later on.

**Key principle: Entitlement to rights does not go away at any point of the care pathway.**

Secondly, human rights are ‘indivisible’ in the sense that somebody can have more than one right at the same time. Human rights are inherent to the dignity of all people, so all human rights have equal status and can’t be organised in a hierarchical order. Denying one right normally prevents people from enjoying other rights, so rights protected or promoted at particular stages of the care pathway are equally important in relation to one and other.

The process of defining rights and behaviours described above in the section ‘Win-Win’ also allows for a process of continuous service improvement. Those behavioural standards could potentially be revisited and refined on a periodic basis. We envisage that this will be necessary as staff behaviour improves at a particular point along the care pathway, or as the system becomes better at responding to particular inequalities or rights infringements. When this happens, or as patient needs change, staff, users and carers will be able to identify other aspects of behaviour that could be improved to protect human rights. These behavioural standards could be reviewed say every three years on this basis. In this way gains made through using the tool by staff, users and carers are cumulative over time and the framework can be used to ensure continuous service improvement.

**(f) Capturing Change: The use of behaviour-related quality standards in service provision**

We also began to consider how these behaviours could be monitored, measured and performance-managed across a care pathway in Cancer Networks. Our contact with test sites has led us to believe that staff do not really require a ‘carrot’ (incentive) for behaving in a particular way. There is a general awareness of the gains that can be made by treating patients fairly and developing a reputation for doing that. As one person put it, “We don’t need to incentivise because doing these things will make staff feel good about themselves and the job they’ve done that day”.

Neither do they require a ‘stick’ (punishment for non-compliance). Partners within Cancer Networks are already regulated for equality compliance by a range of bodies. Instead we were left with an overwhelming sense that **staff, patients and carers require a clearer process for sharing and acting upon their aspirations for improved behaviour**. They need support to take action rather than ‘walking on by’ (a default stance some staff feel is taken when it is not clear what they are ‘allowed’ to do to improve patient experience). The focus is on the quality of service provision that patients and carers can expect in their relationship with staff within a Cancer Network.

With this in mind, the framework is based on a more ‘permissive’ model of regulation and quality assurance that is driven by staff, users and carers. The model encourages the use of self-reflection and negotiation as a means for networks to develop their own indicators based on both staff and patient/carer experience. Specific behaviours are then used as a yardstick against which to assess protection and promotion of particular rights of staff, patients and carers (represented on Diagram 4 as ‘key rights’). It is also important to say that while monitoring these behaviours, the framework will need to complement existing processes for regulation. We would be particularly keen to explore the synergy with emerging work on CQUIN as a method of assuring quality.

**Key principle: Behavioural standards are used as a way to assess quality of service provision and protection of human rights across a care pathway.**

There are other more theoretical reasons for focusing on a set of common behavioural quality standards that can be monitored through a care pathway. These relate to problems with previous approaches to ‘thinking’ about and doing equality.

*Fairness & Freedom*, the final report of the independent Equalities Review Team, concluded that while the UK has amongst the most comprehensive and advanced equalities legislation in Europe, this has not ‘delivered’ equality. There are three key reasons for this. First, there is evidence that past approaches to promoting equality, introduced in a piecemeal fashion in response to the social pressures of the time, have run out of steam. Second, our aspirations for equality have become bogged-down in a complex framework of negative prohibitions – a focus on the kind of society we *don’t* want rather than that which we do want. And third, the old ‘identity-driven’ policies of the past two decades – what the Review Team characterised as “a top-down state pulling levers” to improve outcomes for particular groups – can no longer cope with either the increasingly global pressures we face, or accelerating demographic change in our own country.

The human rights framework we are proposing is based on the idea that human rights can be protected and promoted for all people irrespective of their identity through the process of ensuring core quality standards are met when services are provided. Two human rights principles in particular help to reinforce the fairness of this approach:

**Universality:** Firstly, the human rights principle of ‘universality’ states that all people have human rights irrespective of their identity. It suggests that the pursuit of common, mainstream quality service standards that protect fundamental freedoms for all people is worthwhile because many people require and value the same freedoms in life.<sup>22</sup> Where particular groups are

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<sup>22</sup> Although of course there has been a long standing debate about the degree to which ‘universal’ rights are relevant to all people. Some have argued that a more ‘culturally relative’ approach to defining rights would be more appropriate. These are relevant debates, but could be more easily applied to Phase 2

not receiving the same level of protection of those rights, this should be redressed. In this sense the process of supporting particular excluded groups and the process of adopting a more mainstreamed approach to equality protection are not mutually exclusive.

This helps to address the challenge highlighted in the Equality Review regarding the lack of progress made by 'identity driven' equality initiatives and policies. It also offers a more 'positive' approach to ensuring fair treatment. It advocates the development of a set of clear, universal standards of treatment that staff, patients and carers can expect – rather than a set of things staff shouldn't be doing in their relationships with patients and carers.

**Inherent:** The second principle is that human rights are 'inherent'. We are all born with human rights and they do not need to be 'earned'. By employing these principles in the human rights framework, there is an opportunity to address some of the damaging effects and pressures of a system that has relied on equality interest groups to drive change.

A natural consequence of previous approaches has been that a 'hierarchy' of protection has developed where individuals and groups have been able to lobby for and thus 'earn' improvements in treatment for others like them. This has resulted in a complex patchwork of laws, policies and equality initiatives where groups' rights are protected and promoted to a lesser or greater extent depending on their ability to influence change.

By offering a more universal set of service quality standards through a human rights framework (influenced by a wide range of people), this approach aims to eliminate the more damaging effects of previous 'hierarchies' of protection. As the system develops and rights infringements and associated priorities change, all people should have an opportunity to inform new service quality standards.

**Key principle: Opportunities to define quality standards should be open to all equally because human rights do not need to be 'earned'. All people, irrespective of their identity are entitled to equal protection of their rights. Equality and human rights go hand in hand. A common set of behavioural quality standards should be periodically revisited to ensure alignment with a 'universal' set of fundamental freedoms.**

### **(g) The Personal Metric: interrogating one's own behaviour**

Finally, there is a seventh principle which we have explored, but would need to test much further in Phase 2 of this work.

The beauty behind the idea of a 'personal metric' is that it puts professionals back in the driving seat. It is controversial because it is about the ability of staff to interrogate and question their own behaviour on a daily, even hourly

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work where patients and carers could have an opportunity to define their rights and what they have reason to value along the Cancer Care Pathway in more detail.

basis. It responds directly to the types of questions that patients ask when things go wrong. Questions like “how could they [staff] allow this to happen?”

The application of the personal metric is premised on staff being able and prepared to ask themselves **the hardest question they can** about their current practice and the impact of that practice on patients. And to be able and willing to do this in any circumstance in which they consider their behaviour, or a decision, or standard operating procedure requires interrogation.

Discussion with staff at the test sites indicates a high level of interest in the idea. Interestingly, the readiness with which many staff responded also indicates that the idea is more transparent to staff than its explanation might suggest. The application of a personal behavioural metric has some potentially transformative qualities because it helps staff to set themselves personal goals that challenge what they do on a day to day basis. It is an extreme version of reflective learning in this sense.

The personal metric, then, is an attempt to frame and enable a staff response to the challenges thrown up by the work to date using the same principle of autonomy that would be applied to the human rights of patients.

To that extent it tries to recognise the need for subsidiarity and personal autonomy – those areas where staff say they experience the least flexibility (and the greatest frustration) in their relationship with the care system.

It is intended to offer staff a ‘real time’ mechanism for testing behaviour and securing consistency between aspiration, activity and ‘achievement’.

The characteristics of the metric are:

- It ‘believes in’ staff – accepting that they have aspirations for the service that are convergent with those of patients and that they are the best judge of the extent to which those aspirations are being realised.
- It is personal – it is not shared, it is not discussed, it does not feed into formal systems of measurement, but it would be expected to significantly contribute to the wider achievement of quality and performance targets.
- Impact would be evident – different things would happen or things would happen in a different way. A weighting towards pro-patient activity in the system should emerge – something that the staff group could test for through observation.
- It is ‘extreme’ – the evidence of this project makes clear that staff at times feel that they are engaged in activity which fundamentally betrays their personal and professional ethic, contradicts the vocation that originally drove their choice of profession, and fails to meet their idea of the legitimate rights of patients and carers.

- It empowers staff by putting a health service metric directly in the hands of practitioners.
- It therefore realises, in a very practical way, a dynamic measure of personal values and personal value – the aggregate feeling of self-worth that many describe as absent and the most debilitating part of the day-to-day experience.

During the course of our work with the test sites we discussed a number of practical examples of personal metrics. Here is one.

*“Today I will not deceive anyone.”*

This can be translated in a number of different ways – we use it here to illustrate the kind of discussion these personal behavioural metrics prompted.

I will not tell little lies of convenience. (*‘Sister is just coming.’*)

I will not be dishonest in my dealings with patients and carers to make my life easier. (*‘There’s always hope...’ ‘The results are not back just yet...’*)

I will not excuse my own failure to act. (*‘Someone else will do it.’ ‘If someone else hasn’t done it, it probably doesn’t need doing.’*)

I will not make excuses for the failure of the environment to respond to patients needs. (*‘In these circumstances that would be impossible...’*)

I will not dissemble about what I do not know. (*‘I’m sure that will all be sorted out soon...’*)

## 5.0 CONCLUDING REMARKS & RECOMMENDATIONS FOR STAGE 2

### 5.1 Concluding Remarks

This project has demonstrated that there is a convergence between what patients *want* and what staff would like *to be able to do* but **behavioural change** throughout the system is required in order to capitalise on and realise this potential. It has also demonstrated that there is an appetite amongst staff for a human rights-based approach to addressing inequalities in cancer care – especially if this enables and strengthens personal empowerment, responsibility and autonomy.

The human rights framework, then, should be permissive (i.e. encourage personal responsibility and autonomy) rather than punitive (i.e. merely impose penalties for failure) and should display the following principles:

- **Participative:** I have a say in determining what my rights are and how they should be protected and promoted.
- **Balanced:** Others have a say too. What I do and the way in which I would like my rights to be protected might have an impact on others. The protection of rights needs to be reasonable and proportionate.
- **Universal:** I have the same entitlements to rights as everybody else, it doesn't matter what my background is or my identity.
- **Not 'earned':** We are born with human rights. I don't have to ask or lobby for rights or belong to a particular excluded group in order to enjoy these rights. I should get them because I'm entitled to them.
- **Guaranteed:** My rights can't be taken away unless I consent to this. In very specific circumstances I may choose to 'waive' a particular right.
- **Improving quality:** A human rights based approach involves identifying a set of benchmarks or common standards of service provision which all people can and should expect.

And it should have three dimensions:

- The development of a set of **behavioural standards** that apply across care pathways and which reflect and uphold specific human rights.
- Tools for developing the 'Human Rights Organisation' – an 'accountable body' for the space in which rights are negotiated, offered and realised.

- The adoption by all staff of a '**personal metric**' – a rigorous, challenging question or set of questions which enables individuals to interrogate and change their own behaviour – with a direct link to accepted good practice – reflective practice/learning.

All three of these areas of development have the potential to feed into existing performance management processes: formally, through inspection/scrutiny, and informally, through the application of higher level reflective practice.

Of these, the personal metric may well prove the most challenging idea – but at this stage we see it does have potential, as it offers a way of harnessing the values, commitment and vocational ethics of staff at all levels, promoting rather than 'prohibiting' personal responsibility.

## 5.2 Macmillan – Stage Two Recommendations

However, we also acknowledge that what is presented here is both challenging and experimental and currently exists as a *conceptualisation* of operating within a human rights framework. Much remains to be tested in practice.

The specific tasks and activities that make up Stage 2 of this work will require detailed discussion with Macmillan Cancer Support, but we anticipate that the following would need to form at least some part of the work programme:

- 1) **Behavioural quality standards:** Further work needs to be done to fully populate a set of behavioural quality standards capable of reflecting and upholding human rights principles at key points of intervention across care pathways. Rather than be prescriptive about which rights are used across a care pathway, we have recommended that sites negotiate a set of rights across a care pathway which reflects the experiences of patients and carers.
- 2) **Personal metric:** Further development and testing of the Personal Metric. The wider implications of this need fuller investigation. While we have predicated the Personal Metric on a basis of privacy and personal ownership, from a staff perspective we believe initially it probably lends itself to small, collaborative workshops in which people can develop and test their own Personal Metrics in discussion with their peers, formulating through discussion and exchange the kind of metrics that will work for them. Further work would also need to be done to see to what extent, **if any**, (where, when, by whom, how) personal behavioural change is 'observed' and assessed.
- 3) **Process for agreeing standards and balancing rights:** In order to achieve this aim, a 'space' will have to be constructed for this negotiation to take place. This would cover issues such as

- How are rights determined?
- Who is involved in the process (and how)?
- What the process might look like.
- What skills people would need to have in order to be involved.

This would probably need developing into a body of guidance.

- 4) **Resources and routines:** We are not complacent about the fact that some rights might require more than a behavioural adjustment in order to be protected or upheld. There may also be resource implications. The types of resource implications, which **might** arise from this process, will have to be explored. We are particularly keen to test out 'routines and rituals' – the ways that organisations do things, which help to maintain order and routine, but which frustrate/deny patients.
- 5) **Market Research:** Exploring the interface between the proposed human rights framework and different types of client group will be important to understand its applicability (e.g. high need groups such as prisoners).
- 6) **Chicken or egg:** Which came first human rights or equality? To what degree will human rights based approaches complement existing equality practices? We are aware that organisations have many other systems in place to address inequality. Both staff and patients hold expectations about what equality practice should look like. What would need to change if there is to be more synergy between human rights and equality practice? Who would need to be influenced? What kinds of skills and knowledge are required to generate more integration between equality and human rights practice? How can human rights be aligned with existing regulatory practices that currently reward staff?
- 7) **Regulation:** Regulators will need to feel confident that this approach is adequate. We would need to explore:
  - What is being quality assured?
  - What types of skills are required by assessors to capture progress?
  - How does a human rights quality standard in cancer care relate to existing regulatory practices more broadly?

We already believe there is synergy between this proposed framework and a number of existing regulatory practices but this would need to be explored in more detail.

- 8) **Universal rights vs. specific groups:** In the longer term, some examination will need to be made regarding whether a 'universal' human rights-based approach proves capable of improving outcomes and reducing inequalities for all groups in cancer care.

- 9) **Competence:** The application of a Human Rights Framework across the network of scrutiny functions and the change agenda this might set for the wider performance regime.

In particular this might focus on organisational priorities and strategies – e.g. it seems apparent that a ‘Communications Strategy’ might become a very different thing with a very different order of priority, for an organisation that wished/choose to use Human Rights as a key trading currency.

This has the potential to be applied to a ‘kite-marking’ regime.

What we have proposed in this report might appear controversial, but our brief was to look at something that would, in our opinion, get to the heart of the relationship between staff, patients and carers. Traditionally, quality standards have tended to attach themselves to systems and processes within an organisation and have attempted to drive change through a ‘top down’ approach. Leadership is entirely necessary to complement the behavioural standards we are proposing in this human rights framework. However the leadership we are recommending in the first instance is the type that can be driven by staff working on the ground.

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