The British Institute of
HUMAN RIGHTS

DH Department of Health

Human Rights in Healthcare – A Framework for Local Action

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Contact details	Mark Joannides Equality and Human Rights Group Skipton House London SE1 6LH 020 7972 1803 www.dh.gov.uk/equalityandhumanrights
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Human Rights in Healthcare – A Framework for Local Action

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Foreword

We are currently undergoing a fundamental reform of the whole system of health and social care. This reform will move towards services that are patient and service user led. During this period of change, it is vital to remember the principles that underlie this reform, which can be expressed as Fairness, Respect, Equality, Dignity and Autonomy for all. The Human Rights Act supports the incorporation of these principles into our law, in order to embed them into all public services. These principles are as relevant now as they were over 50 years ago when UK public servants helped draft the European Convention on Human Rights.

However, too often human rights are seen as an issue for other countries or a relic of the past century and not something we need to be concerned with in health and social care. This is not the case. Quite simply we cannot hope to improve people's health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an opportunity to make real improvements to people's lives. Human rights can provide a practical way of making the common sense principles that we have as a society a reality.

Traditionally, human rights in public services have been perceived as a legal issue and have remained in the domain of lawyers. Indeed when the Department of Health first began working with the British Institute of Human Rights in 2006 it was found that human rights materials were mostly focused on how to keep organisations out of court. This document: Human Rights in Healthcare – A Framework for Local Action aims to show the practical value of human rights for the whole organisation and demonstrate how human rights can be made real not just in terms of protecting rights but promoting them as well.

I would like to thank the five Trusts who have worked on developing this framework, showing how using a human rights based approach to embed human rights in the design and delivery of services can make a real difference in people's lives: Surrey and Borders Partnership Trust, Southwark Health and Social Care, Heart of Birmingham Teaching PCT, Mersey Care NHS Trust and Tees, Esk and Wear Valleys NHS Trust. In addition, I would like to thank the British Institute of Human Rights and ROI Operations for their support in helping the Equality and Human Rights Group in the Department of Health deliver this framework. I hope that this great work continues in these Trusts and inspires others to find out how a human rights based approach can make a positive difference in their organisations.

Rosie Winterton

ROSIE WINTERTON
MINISTER OF STATE FOR HEALTH SERVICES

Executive Summary

Neglecting people's human rights is bad for their health. In contrast, the protection and promotion of their human rights is not only good for individuals' health; it makes for better services for everyone. In this context the Department of Health, the British Institute of Human Rights and five NHS Trusts have worked in conjunction to produce this framework to assist NHS trusts to develop and apply human rights based approaches (HRBAs) in their organisations.

Framework Overview

Section 1: WHY?
Introducing human rights & human rights based approaches (HRBA) and why they are beneficial to NHS Trusts.

Human rights are based on principles of Fairness, Respect, Equality, Dignity and Autonomy.

Human rights based approaches are about putting human rights at the heart of policy and planning, ensuring accountability, empowering and involving people, and non-discrimination.

Using a HRBA can improve the quality of services, patient experience and also reduces risk of complaints and litigation.

Section 2: WHAT?
What the UK Human Rights Act and particular human rights can mean in day to day Healthcare situations.

About the rights in the Human Rights Act e.g. right to life, freedom from inhuman or degrading treatment, right to liberty and right to respect for family life.

Some human rights issues in reality e.g. do not resuscitate orders, unsanitary conditions, excessive force in restraint, patient dignity, privacy and family visits.

Section 3: HOW?
Examples and case studies of NHS Trusts using a HRBA at all organisational levels.

For example:
In leadership and governance – vision and values reflecting human rights principles.

In strategy and policy – assessing impact of policies on people's human rights.

In processes and procedures – ensuring staff have guidance and training on human rights in their role and that patients and service users can raise rights issues.

Case Studies

A Merseycare NHS Trust – Developing a human rights based decision making process at Learning Disabilities Directorate.

B Southwark Health & Social Care – Using a human rights based approach to commissioning of fertility based services.

C Surrey & Borders Partnership NHS Trust – Embedding human rights in the Equalities and Diversity Strategy.

D Birmingham Teaching PCT – Producing an action plan for creating a human rights based culture across the organisation.

E Tees, Esk and Wear NHS Trust – Developing a human rights based approach to the Trust service charter and care planning.

In essence this framework will assist NHS Trusts to put human rights principles, such as Fairness, Respect, Equality, Dignity and Autonomy, into practice. It is not a source of legal advice **but a starting point for Trusts planning to improve their practice**.

Introduction – About this framework

Summary of key points

Purpose: To assist NHS Trusts to use a *human rights based approach* (HRBA) to place human rights at the heart of healthcare.

Need: Lack of respect for people's human rights is bad for their health. Using a HRBA can improve health outcomes and deliver better quality "person centred" healthcare.

Scope: This framework is a starting point for Trusts on the principles, duties and practice of human rights. It is NOT legal advice. If Trusts are unsure they should seek legal advice.

Origin: It is the result of a collaboration between the Department of Health (DH), the British Institute of Human Rights (BIHR) and five NHS Trusts who are currently piloting HRBA in their work.

0.1 What is the purpose of this framework?

The purpose of this framework is to assist NHS Trusts to develop and use a **human rights based approach (HRBA)** to support their core business of planning and delivering high quality and accessible health services for all. As such, it is a starting point for Trusts seeking to:

- Put principles such as dignity, respect and equality into practice
- Shape services and procedures that put the 'human' at the heart of healthcare
- Effectively support their staff and commissioned providers to fulfil their specific duties under the Human Rights Act 1998, as well as progressing Healthcare Commission standards on human rights and patient treatment[i]
- Support and add value to their work on related duties and priorities such as
    - Equality
    - Health Inequalities
    - Dignity in Care[ii]
    - Commissioning a Patient-Led NHS[iii]

- ○ Delivering patient choice[iv]
- ○ Providing more personalised services and ensuring that people have a stronger voice[v]
- ○ Protecting the most vulnerable people

What is meant by a human rights based approach?

In essence a human rights based approach is the process by which human rights are put into practice. It has five key principles:

- **Putting human rights principles and standards at the heart of policy and planning**
- **Empowering** staff and patients with knowledge, skills and organisational leadership and commitment to achieve human rights based approaches.
- Enabling meaningful **involvement and participation** of all key stakeholders
- Ensuring clear **accountability** throughout the organisation
- **Non discrimination** and attention to **vulnerable groups**

0.2 Why is it needed?

Put simply, a lack of understanding and respect for people's human rights is bad for their health. On the flip side, the use of a human rights based approach by NHS Trusts can significantly improve people's health outcomes by directly supporting the delivery of more effective, better quality, 'person-centred' health care. Moreover, as public service providers, NHS Trusts have a legal duty to take steps to protect human rights. This is reflected in increased monitoring of human rights policy and practice by existing bodies such as the Healthcare Commission, and emerging bodies such as the Commission for Equality and Human Rights. Such monitoring helps to ensure that individuals get fair, dignified and equitable treatment within our healthcare system and that Trusts contribute to building a wider culture of respect for human rights here in the UK. Both of these objectives are ones that NHS staff, who have contributed to this framework, welcome and support when they have leadership, awareness of how human rights are relevant in their day to day experiences and practical support to apply them. This is particularly the case when people are looking to use human rights to support and add value to existing equalities work.

> *'Research has shown that the application of human rights principles, for example dignity and respect can help to improve a patient's experience and quality of care and will inevitably lead to improved outcomes.'*
>
> **Audit Commission**[vi]

However, media debates on human rights, where many NHS staff and stakeholders get their only information on this issue, have dealt with human rights in a very narrow, and sometimes misinformed way. This tends to miss the link between core human rights principles, such as fairness, dignity and respect, and good quality and efficient healthcare. This is coupled with a glaring 'gap' in practical human rights guidance for Trusts. What guidance there is tends to be legal or compliance centred – focusing on what should be achieved, but not why it is relevant to health or how to make it a reality.

In this context the framework starts to fill this gap, based on what NHS professionals have asked for (see 'How has it been produced?', page 9). The framework explains the principles behind human rights, their relevance to NHS Trusts and some of the practical benefits they can bring for patients and staff when they are put into practice.

0.3 Scope – what it does and does not cover

The framework is an introduction to human rights and HRBAs, rather than a detailed guide or a toolkit. It is designed to be used as a starting point for NHS Trusts who are considering why and how to develop work in this area.

It gives an **introduction** to the key principles and features of human rights and HRBAs, and how they are relevant to and support better general health outcomes and NHS priorities.

In terms of NHS Trusts' legal duties, it looks at how the Human Rights Act works. This includes the everyday implications of, and uses for, the specific human rights and principles the Human Rights Act brings into UK law. It also gives initial **guidance** on these.

It also gives some **practical examples** and **indicators** of what HRBAs can look like in action. These are in the areas of leadership and governance, strategy and policy and everyday processes and procedures. They are supported by case studies drawn from pilot projects at five NHS Trusts.[vii] These **case studies** give a flavour of the tangible benefits that HRBAs can bring in real terms.

Nothing in this framework constitutes legal advice. However, it may help NHS Trusts to identify where they need further guidance or support including legal advice. Sources of further information are provided on pages 73–75.

First and foremost the framework should be used as a 'first generation' guide and a launch pad for Trusts and others to kick-start more of this critical work and develop further NHS-led good practice in this area.

0.4 Target group – who is it for?

The framework is aimed at the broad range of people who make up NHS Trusts. The target group includes those engaged in formulating strategy at board and senior management levels, people who develop policies, and those undertaking planning or who deliver services directly to the public. It will also be of interest to a number of key stakeholders such as the voluntary and community sector or private organisations who are commissioned by Trusts to provide services, and patient advocacy groups. Although nothing in the framework constitutes legal advice, it may provide useful background for Trust lawyers. The framework is not designed to advise patients or their families in relation to specific human rights issues. The further information section on pages 73–75 provides a range of additional resources.

0.5 How has it been produced?

The framework has been produced by drawing on the experience of people and organisations with expertise in both human rights and the healthcare sector. It is a result of a collaboration between the Department of Health (DH), the British Institute of Human Rights (BIHR) and five pilot NHS Trusts.

The process included a scoping exercise which looked at existing guidance and frameworks available to healthcare providers and researched the need for a framework. Following this exercise, a first draft of the framework was produced and discussed with key stakeholders, including the pilot Trusts. The five Trusts are currently undertaking pilot projects looking at human rights in different aspects of their work, with support from DH (including consultants ROI Operations) and BIHR. Snapshot case studies of where these pilot projects are at now are included in the framework. These case studies are not intended to evidence impact, but to show what opportunities and challenges are being met by Trusts and how they have taken their projects forward.

Following this initial period of developing HRBAs in their work, the pilot Trusts have fed in suggestions and ideas to inform this framework. Both BIHR and DH are committed to updating and further developing this initial tool as additional practice and learning emerges from the pilot Trusts and elsewhere.

0.6 How to use it

In addition to this introduction, the framework consists of three main sections. The first section looks at human rights principles and features, and introduces HRBAs. This is followed by a focused look at the Human Rights Act and particular human rights as they relate to the day to day work of NHS Trusts. The final section contains some examples or features of HRBAs in action coupled with case studies from the five pilot Trusts who are currently developing HRBAs in their work.

The framework is designed to act as a key initial human rights planning or project tool, but also contains further sources of information for exploring particular areas in more depth.

Section 1:

Introducing human rights, their key principles and links to healthcare

1.1 What are human rights and where do they come from?

Key things for NHS Trusts to know about human rights

- They are part of what it means to be a human being
- They belong to everyone, all of the time – not only certain groups at certain times
- They cannot be ‘given’ to us, only claimed or fulfilled
- They cannot be 'taken away‘ from us, only limited or restricted in some circumstances (see pages 32–34)
- They are about how public authorities, such as NHS Trusts, must treat everyone as human beings
- Sometimes they require NHS Trusts to take steps to protect human rights when they are put at risk by organisations or other individuals
- They give expression to a set of core principles including **dignity, equality, respect, fairness and autonomy**
- They exist as a way of making these core principles real and meaningful in our lives, public services and in society generally

Human rights are about our basic needs as human beings. They capture the core rights we are all entitled to so that we may develop our potential and live our lives in dignity and respect.

Human rights are…

'basic rights to humane dignified treatment and things I should have access to simply because of the fact I am a human being'

(Mental health service user)[viii]

Human rights act as a set of minimum standards that need to be met if we are to build communities and a wider society based on fairness and respect.

They were first defined by the international community in the Universal Declaration of Human Rights[ix] adopted in 1948 as a response to the events of the Second World War, including the Holocaust. These events were a stark reminder of what may happen when states treat, or allow others to treat, some people as *less human than others*.

There are many different human rights reflecting our basic needs across different areas of our lives. For example our need for *physical and mental* well-being is reflected in our right to life, our right not to be tortured or degraded, and our rights to food and shelter. Our need for *social* well-being in our families, communities and wider society is reflected in our right to respect for private and family life, our right to hold and express our beliefs, and our right to participate in the cultural life of the community.

The more our human rights are respected, protected and fulfilled, the more of our humanity or 'what makes us human' is fulfilled. On the flipside, the less they are respected, protected or fulfilled, the more difficult it is for us to develop our personalities and contribute meaningfully to society.

Human rights are **not** only about the protection of particular groups and individuals in society. They are about providing a practical framework to protect the rights of **everyone**.

1.2 Human rights – the core principles

A good way to understand human rights is to see them as a vehicle for making principles such as dignity, equality, respect, fairness and autonomy central to our lived experience as human beings. These core principles are brought to life by a range of different human rights that make them real. For example, the principle of dignity is what lies beneath the right not to be tortured or treated in an inhuman or degrading way, while the principle of autonomy informs the right to respect for private and family life.

This means that obligations placed on Trusts and other public bodies to respect human rights can give these principles real meaning in people's lives.

This is illustrated by the following diagram which shows how changing a policy or practice to respect, protect or fulfil a particular human right also supports a broader principle.

'Human rights are a set of recognisable principles on which Trusts can base their everyday work'

(legal advisor, NHS Trust)

PRINCIPLE	HUMAN RIGHT	EXAMPLE POLICY OR PRACTICE CHANGE
Dignity	Right not to be tortured or treated in an inhuman or degrading way.	Ensuring there are sufficient staff to promptly change wet sheets to reduce the risk of people suffering degrading treatment.
Equality	Right not to be discriminated against in the enjoyment of other human rights.	Commiting to improving mental health services for people from black and minority ethnic groups. Ensuring that people are not denied treatment solely on the basis of their age.
Respect	Right to respect for family and private life.	Respecting all diverse families e.g. same sex couples with children. Not denying those detained or in residential care access to family without good reason.
Fairness	Right to a fair trial.	Ensuring that there is a robust and fair process for removing a doctor or dentist from the Performers List.
Autonomy	Right to respect for private life.	Involving people in decisions made about their treatment and care.

These core human rights principles are simple and resonate strongly with the personal values of both providers and users of public services. They are also of enormous practical use, for example as ‘flags’ that help people to identify when human rights may have been violated or as ‘prompts’ when solutions to human rights issues are being sought, whether in an individual case or at the policy level.

1.3 The full range of human rights and where to find them

As noted above, human rights reflect our basic needs in a wide range of areas. The main areas covered by human rights are reflected in the main categories of rights – civil, political, economic, social, cultural and environmental rights.

These rights can be found in and are defined by law at three different levels – international, European, and domestic – **all of which impact on NHS Trusts in different ways as outlined below**.

a) International law

The international community has agreed a range of human rights treaties (also known as conventions and covenants) that cover the full spectrum of **civil and political rights** and **economic, social, cultural and environmental rights**. Civil and political rights include the right to liberty and the right to free elections, while economic, social and cultural rights include the right to food, the right to social security, ***and the right to the highest attainable standard of health***.[x]

Specific international treaties have also been created to protect the human rights of diverse groups including women, children and migrant workers.[xi] A treaty on the human rights of disabled people has been adopted by the United Nations, but has not yet come into force. The existence of these treaties recognises the particular discrimination some groups face in having their human rights respected and protected and reflects a central role for human rights in tackling inequality.

✓ **Trust Check Point**

The responsibility to comply with these treaties lies with the UK Government not with individual NHS organisations.

However, the rights set out in these treaties can be used by NHS Trusts to define and achieve good practice and contribute to the achievement of Better Standards for Health. They are also a useful point of reference when contributing to government health policy and programmes which are monitored by the United Nations.

b) The European Convention on Human Rights

The European Convention on Human Rights[xii] (the 'European Convention') was adopted by the Council of Europe (not to be confused with the European Union) in 1950. It is the main source of our legal human rights protection here in the UK. The European Convention focuses on civil and political rights. However the broad ways in which these rights have been defined mean it is still of immense importance in the health context (see pages 27–41).

✓ **Trust Check Point**

Trusts have a legal obligation to respect the rights in the European Convention in all that they do (see page 27 for a list of these rights). This is because, unlike the international human rights treaties discussed above, the UK has taken steps to incorporate most of the human rights that it contains into domestic law through the Human Rights Act (see 'The Human Rights Act' below and Section 2 on pages 27–41).

c) The Human Rights Act

The UK has incorporated into law most of the rights defined in the European Convention through the Human Rights Act 1998 (for more detail see pages 27–41).

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The Human Rights Act imposes a *direct legal obligation* on NHS Trusts to ensure they respect European Convention rights in all that they do (see page 27 for a list of these rights). This means that Trusts need to consider the human rights implications of all of their policies and practices. Any person who feels that an NHS Trust has breached their human rights may be able to take the Trust to court or use human rights arguments in other processes. See pages 27–41 for more detail on the Human Rights Act.

1.4 How are rights made real?

There are two main ways in which human rights are made real in people's lives:

a) The state respecting, protecting and fulfilling human rights

The state is the core 'duty bearer' in relation to human rights. It has duties to respect, protect and fulfil the human rights of all those within its jurisdiction.

This means that state bodies, such as NHS Trusts, must respect people's human rights, and refrain from interfering with them without good reason. For example, a person's right to freedom of speech may be interfered with where this is necessary to protect the rights of others or the interests of the wider community. However this needs to be properly justified. The circumstances in which human rights can be 'balanced' in this way are discussed on pages 32–34.

Public authorities must also take proactive steps to protect and fulfil people's human rights. Systems must exist to protect people from human rights breaches caused by other individuals or groups. For example, we have criminal justice and child protection systems in place for this reason, and authorities must respond when they have reason to believe that a person's human rights may be at risk.

✓ **Trust Check Point**

Trusts have a role as 'duty bearers' under the Human Rights Act 1998. They need to work out which rights their services impact on, whose rights these are and how they should be responding or delivering a service in this context. More information on how to approach this can be found on pages 32–41.

b) People claiming or raising their human rights

Human rights belong to all of us all of the time, regardless of whether we are aware of our rights and regardless of whether we are actively invoking or claiming them. In other words, we are all 'rights holders'.

> *'The Human Rights Act and the European Convention don't grant rights to anyone. They protect rights we all have simply by virtue of being human'.*
>
> **Secretary of State for Constitutional Affairs and Lord Chancellor**[xiii]

In this way, at the minimum, human rights serve as a safety net for us all. When they are not being respected, protected or fulfilled, we should be able to activate or claim them. For example, we all have the right not to be treated in an inhuman and degrading way, but for most of us, most of the time, we do not need to raise this. However, at some stage in our life we may become more dependent on the actions or care of others, for example staff in hospital or carers at home.

✓ Trust Check Point

Human rights are not given or awarded on the basis of need. Each person involved in an NHS Trust is a permanent 'rights holder' capable of claiming their human rights. This includes staff as well as service users, their carers or families.

It is important to remember that people most at risk of human rights abuses, for example because they are socially excluded, are less likely to have access to information and resources about their human rights, and therefore are less likely to claim or raise their rights. Trusts, with assistance from voluntary and community organisations, should take active steps to support and facilitate those in need to claim or raise their human rights.

See case studies A & E for an exploration of service user and care involvement in practice.

1.5 How do human rights relate to NHS Trusts' core functions of preventing and treating poor health?

Human rights relate to the core functions of NHS Trusts and how they perform them in three main ways:

- ***Abuse and/or lack of respect or protection of human rights can actually cause or worsen poor health*** – in particular for those already more vulnerable due to poverty, inequality or social exclusion.

For example, violence and/or abuse of adults and children in their own homes, in hospitals or in residential care may violate their human right to be free from inhuman or degrading treatment. This can and does have a serious impact on a victim's physical and mental health. The World Health Organization[xiv] and others have identified a number of human rights issues or breaches that can detrimentally impact on health in this way such as sub-standard conditions in care homes because of inadequate procedures and training of staff

This reflects the existing recognition by the World Health Organization and in UK government health policy that 'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.'[xv]

- ***The way that Trusts and other NHS bodies deliver healthcare services to those in poor health can impact both positively and negatively on people's human rights.***

Trusts that respect, protect and fulfil human rights will support better health outcomes than those who do not. Trusts that do not can actually add to or worsen poor health outcomes.

- ***Bodies undertaking 'public functions', such as NHS Trusts, have a key role in respecting, protecting and fulfilling human rights.***

How Trusts undertake this work has a direct impact not only on the individuals that NHS Trusts are dealing with on a day to day basis, but also on the UK's wider culture and values. This is reflected in the Human Rights Act, which gives all bodies undertaking 'functions of a public nature' a legal duty to *respect human rights in all that they do*. More details can be found in Section 2 on pages 29–30.

1.6 What is meant by a human rights based approach, and how does it benefit NHS Trusts and their patients?

A human rights based approach (HRBA) is based on five key principles. Combined together, these principles support a wide range of benefits for NHS staff and patients and carers.

The 5 key HRBA Principles

- **PRINCIPLE 1: Putting human rights principles and standards at the heart of policy and planning**
- **PRINCIPLE 2: Ensuring accountability**
- **PRINCIPLE 3: Empowerment**
- **PRINCIPLE 4: Participation and involvement**
- **PRINCIPLE 5: Non-discrimination and attention to vulnerable groups**

Many NHS Trusts may already have a number of processes in place that support these principles. Using a HRBA does not automatically mean that lots of new processes are required – often its about improving what is already in place. See below for a further exploration of these principles and what they can mean for processes in Trusts.

PRINCIPLE 1: Putting human rights principles and standards at the heart of policy and planning (in other words looking at issues, decisions and practice through a "human rights lens")

NHS Trusts and staff deal in both policy and practice areas that engage people's human rights. In this context, it is important that this work is seen in terms of either its positive or negative impact on human rights principles. This means ensuring that in planning, policy and delivery there has been an analysis of which human rights are relevant, who the rights holders are and who is responsible for ensuring that rights are protected, promoted or fulfilled. Using human rights principles of dignity, equality, respect, fairness and autonomy as flags or areas to consider is often useful in identifying whether human rights are a concern. It also means ensuring goals and plans are expressly linked to and compatible with NHS Trusts' obligations as set out in human rights law and that those with decision making and delivery responsibility have the capacity to apply human rights principles in their work.

> *'Identify which rights fit into your strategy. You have to be able to name the rights you're working with, get the board to sign up to this, and link this to performance'*
>
> ***Senior Manager, NHS Trust***

✓ **Trust Check Point**

To apply this first principle in practice NHS Trusts need to know about the key provisions of the Human Rights Act. Section 2 looks at the Human Rights Act in more detail.

PRINCIPLE 2: Ensuring accountability

Once an NHS Trust is clear which principles and articles it is seeking to adhere to in its work it must ensure that there is proper accountability for meeting these. This involves:

- Clearly identifying who are ‘claim holders’ and the corresponding ‘duty bearers’ in the work of the Trust.
- Identifying which human rights patients and staff may claim or require protection for.
- Ensuring that Trust plans, policies and procedures have been assessed in terms of human rights impact.
- Identifying whether the Trust has any positive obligations (to protect and/or fulfil rights) or negative obligations (to abstain from breaching rights).
- Ensuring that there are appropriate mechanisms and procedures of complaint or redress in place to ensure accountability.

> *‘We need to visibly identify, for a range of our services, the rights holders, the human rights involved and how our staff impact on these with their actions.’*
>
> ***Head of Inclusion and Diversity, Primary Care Trust***

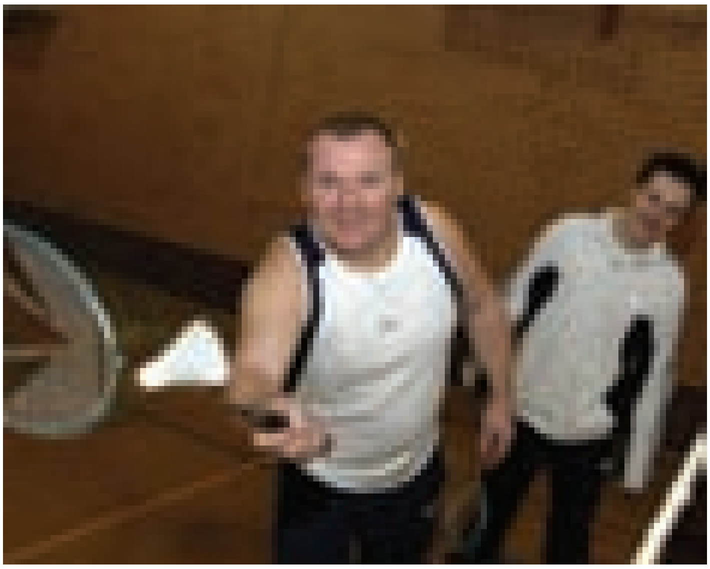
PRINCIPLE 3: Empowerment

Having clarity on what principles an NHS Trust is adhering to and accountability for ensuring this is not enough on its own. Trusts must also ask:

- Do rights holders (e.g. patients) and duty bearers (e.g. Trusts and their staff) share a common understanding of human rights goals and how to respect, protect and fulfil these?
- Are systems in place to educate and raise awareness of all relevant stakeholders? This includes not only ensuring that staff have skills and capacity in human rights, but also ensuring that patients and communities have the power, capacity and access to influence their own situations through participation and involvement.

'It is very important for staff to identify themselves how human rights can be used in their work.'

(Project lead, NHS Trust)



PRINCIPLE 4: Participation and involvement

People have a right to participate in decisions that directly affect their lives. Moreover, it is common sense, and an accepted aspiration within the NHS, that many services, policies and programmes will be more effective if the people and communities they are meant to benefit are involved in the design and, where appropriate delivery of these. In this context, people who are vulnerable to discrimination or marginalised because of location, lifestyle or group should be involved in an active, free and meaningful way. This could mean engaging with a geographical catchment area or a specific community of interest such as those on low incomes or faith groups to identify human rights issues for them.

'[What has worked well is…] contacting people who are members of socially excluded groups and getting them on board. If we hadn't gone out it wouldn't have happened. It means that when we go for Foundation status, we have a broader base of people with a more positive view of the organisation. It's a win-win for us as an organisation and a win for service users and carers from socially excluded groups.'

(Staff member, NHS Trust)

PRINCIPLE 5: Non-discrimination and attention to vulnerable groups

Using a HRBA recognises that some groups and people in society, at different times and circumstances, are more vulnerable to abuses or poor protection of their human rights. This applies in particular to those who are already facing discrimination or social exclusion. In this context, a HRBA prioritises looking at:

- whether people or groups vulnerable to human rights infringements have been identified;
- the impact of policies and practice on these people or groups; and
- whether actual or potential discrimination has been addressed.

> *'By linking the human rights framework to other local equality and diversity strategies we hope to tackle some of the key health inequalities.'*
>
> ***Equality and Diversity Manager, Primary Care Trust***

Using these five core HRBA principles can bring a range of benefits and improved outcomes for NHS Trusts and their patients.

Key Benefits of a HRBA to Healthcare

- ✓ **Improved quality of health services,** with patient experience reflecting the principles of **dignity, equality, respect, fairness and autonomy**
- ✓ Design and delivery of health services in a **person-centred** way
- ✓ **Human rights used proactively as a common sense tool for better practice**
- ✓ **Reduced risk of complaints and litigation** under the Human Rights Act and equalities legislation
- ✓ **Improved decision-making overall** – better reasoned and properly recorded decisions that can be presented to service users and those involved in internal and external scrutiny
- ✓ **Uncomfortable or complex issues** involving people's rights are handled more effectively and with greater patient satisfaction
- ✓ Broader range of **marginalised and disadvantaged people and groups are involved** and considered in the design and delivery of health services
- ✓ **More meaningful engagement** of patients and their carers and families in the development of policy and practice
- ✓ **A tool for pioneering good practice** particularly in new areas where guidance does not yet exist
- ✓ Underpinning work to meet indicators in the **Equality and Human Rights** agenda such as Health Care Commission Core Standards as well as guidelines set out by the National Institute of Health and Clinical Excellence.

> *'We expect [by using human rights based approaches] that our users and their carers will notice a positive change in the way services are delivered'*
>
> ***Director, Primary Care Trust***

Section 2:

Bringing rights home – the Human Rights Act 1998

2.1 Introduction

As discussed in section one, the starting principle of using a human rights based approach is to actively apply key human rights principles in policy, practice and service delivery. In this context this section focuses on a key source of these principles for NHS Trusts – the Human Rights Act. It looks at the direct duties and accountabilities the Act places on Trusts. It also shows how the framework of the Human Rights Act itself can be very useful for decision making at policy and day to day levels by staff.

The rights contained in the Human Rights Act are:

- The right to life
- The right not to be tortured or treated in an inhuman or degrading way
- The right to be free from slavery or forced labour
- The right to liberty
- The right to a fair trial
- The right to no punishment without law
- The right to respect for private and family life, home and correspondence
- The right to freedom of thought, conscience and religion
- The right to freedom of expression
- The right to freedom of assembly and association
- The right to marry and found a family
- The right not to be discriminated against in relation to any of the rights contained in the European Convention
- The right to peaceful enjoyment of possessions
- The right to education
- The right to free elections

2.2 What is the Human Rights Act trying to achieve?

The Human Rights Act came into force in the UK in October 2000. The Act has two main aims:

- **To bring most of the human rights contained in the European Convention on Human Rights into UK law**. In other words, to make it possible for people to raise or claim their human rights within complaints and legal systems here in the UK.
- **To bring about a new culture of respect for human rights in the UK**. The Human Rights Act is about much more than compliance with the law by public authorities. The Act was intended to place human rights at the heart of public service delivery, and through this to make rights a reality for all people in the UK.

> *[A culture of respect for human rights would exist when]'…there is a widely-shared sense of entitlement to these rights, of personal responsibility and of respect for the rights of others, and when this influence[s] all our institutional policies and practices'.*
>
> ***Joint Committee on Human Rights***

> *'We decided that to ensure we valued the principles of human rights as an organisation we needed to demonstrate our intentions …by including references to human rights in our service contracts and commissioning process.'*
>
> ***Senior Manager ,***
> ***Primary Care Trust***

2.3 What does the Human Rights Act mean in practice?

To achieve its aims, the Human Rights Act impacts on practice in four main ways:

a) ***All 'public authorities' in the UK must respect the rights contained in the Human Rights Act in everything that they do.*** This is explored in more detail later in this section by looking at the practical impact of human rights on the work of NHS Trusts.

What is meant by a public authority?

The term ‘public authority’ is not fully defined in the Human Rights Act, but it should be interpreted broadly. It includes any person or organisation ‘whose functions are of a public nature’ such as NHS Trusts, Primary Care Trusts and other statutory bodies.

The term can also cover private organisations such as companies or charities, but only when carrying out a public function. Whether a body that a trust commissions exercises a public function needs to be assessed on a case by case basis. There is currently a lack of clarity over whether, for example, care homes run by private companies or voluntary organisations, are considered to be public authorities. For more information see governmental guidance on this issue, listed in the further resources section on page 74.

✓ Trust Check Point

- As public authorities, NHS Trusts need to ensure that they respect the human rights in the Human Rights Act in everything that they do. This includes throughout planning, reporting, policy, day to day decision making and practice. It is the Trust itself, not individual staff members, that will be held to account for human rights breaches. This is the case regardless of whether or not the Trust is aware of potential or actual breaches by its staff or commissioned providers.

- When commissioning services, NHS Trusts should write terms of compliance with human rights into their contracts. This will help to ensure that human rights remain an identified priority for service providers. Please see Case Study B, Southwark Health & Social Care.

b) ***Anyone who is a ‘victim’ under the Human Rights Act can bring a claim against a public authority.*** This can be in the ordinary UK Courts, and in a range of other systems and processes including tribunals, hearings and complaints procedures. To be a victim a person must be directly affected by the Human Rights Act. Anyone in the UK can be a victim – the Act is not limited to UK citizens.

✓ Trust Check Point

- 'Victims' under the Human Rights Act could include patients, carers or staff. They can bring a human rights claim against an NHS Trust through the courts. Relatives can also make a claim on behalf of a victim if the victim has died, or if the victim lacks the capacity to bring the claim in their own name (for example a child).

c) ***Wherever possible, existing laws that many public authorities deal with on a day to day basis must be interpreted and applied in a way that fits with the human rights in the Human Rights Act.*** All other laws should be compatible with the Act. If it is impossible to interpret an existing law in this way, the courts will issue what is known as a 'declaration of incompatibility'. This sends a clear message to legislators that they should change the law to make it fit with human rights

For example, prior to 2001, if a mental health patient was detained under the Mental Health Act and wanted to be discharged, the patient used to have to prove that they were no longer suffering from a mental health problem that required further detention. In 2001 the UK Court of Appeal said that this did not fit with the human right to liberty and made a 'declaration of incompatibility'. The UK government then amended the law so that now it is the hospital which has to prove that a patient should remain in detention. If they cannot do this then the Mental Health Review Tribunal will release the patient.[xvii]

✓ Trust Check Point

Trusts need to be aware that when applying legislation such as the Mental Health Act, they should interpret it in a way that is compatible with the Human Rights Act as far as possible.

d) ***For all new laws, the Minister responsible for the Bill must make a statement confirming that it is compatible with the Human Rights Act*** (or explain clearly why it is not).

✓ **Trust Check Point**

- Remember that the government attempts to ensure that new legislation is compatible with human rights. This is a useful tool for Trusts when engaging in the development of new policy. For example, many of the provisions in new proposals for mental health legislation are being looked at again by the government after human rights concerns were raised.

2.4 More about human rights duties and obligations for NHS Trusts

NHS Trusts have to respect the different rights in the Human Rights Act, but what does this mean in practice? When answering this question there are three key things to remember:

- Not all human rights are of the same type
- Different rights need to be applied in different ways
- You need to understand what each right actually means or entitles someone to

Introducing different types of rights

It is very important to realise that not all of these rights are of the same type. Some rights are absolute rights, which means they can never be interfered with. However, some rights are non-absolute – they can be interfered with in certain circumstances. This has very important implications for the work of Trusts, as is shown below.

There are three main types of rights:

- **Absolute rights** cannot be limited or interfered with in any way, by NHS Trusts or any other public authorities. An example of an absolute right that may be engaged in a healthcare setting is the right not to be tortured or treated in an inhuman or degrading way. This is looked at further on page 37.
- **Limited rights** can be limited in specific and finite circumstances. These circumstances are set out in full in the Human Rights Act. An example of a limited right is the right to liberty, often of relevance in mental health or residential care facilities. This is looked at further on page 37. One of the circumstances where the right to liberty can be limited is the legal detention of someone with mental health problems.

> *'One of the benefits of absolute rights is that we don't have to have a moral debate about whether to act or not when there is an emergency'*
>
> ***(Mental health service provider)***

- The majority of the rights in the Human Rights Act are **qualified rights**. NHS Trusts can take action that interferes with these rights when a number of conditions are met. Any interference with a qualified right must be:
    - in pursuit of a legitimate aim, e.g. to protect the rights of others or for the wider good;
    - lawful i.e. be allowed within existing legislation;
    - necessary; and
    - **proportionate**.

An example of a **qualified right** that NHS Trusts will commonly need to consider is the right to respect for private and family life, home and correspondence – see page 39.

What is meant by a *proportionate* action?

In short, a proportionate response to a problem is one that is **appropriate and not excessive** in the circumstances.

Applying the principle of proportionality is central to considering and respecting human rights in the day to day work of NHS Trusts. It provides a very important mechanism to ensure the infringement of rights is kept to a minimum and is always reasonable. Proportionality also allows NHS Trusts to balance competing interests, e.g. the rights of individuals with the rights or needs of others (such as patients, staff or the wider community).

Certain questions can be asked to help decide if an action is proportionate, such as:

- What is left of the person's rights if we take this action or adopt this policy?
- Is there an alternative approach to the problem that is less drastic?

A straightforward way of thinking about proportionality is you must not use a sledgehammer to crack a nut.

Explaining proportionality – a scenario

A care home takes a decision to have a blanket policy of placing CCTV in the bedrooms of all residents, for safety reasons.

Outcome
This interferes with the right to respect for private life of all residents.

Alternative
A decision is made that only residents who pose a risk to themselves and/or others will have CCTV placed in their rooms. This decision will be made on a case by case basis.

Outcome
Some residents have their right to respect for private life interfered with for their own safety or the safety of others; other residents do not have their right to respect for private life interfered with.

✓ Trust Check Point

Proportionality is a key consideration for NHS Trusts when making decisions that may have an impact on people's rights. By following this principle, Trusts will ensure that their decisions and actions follow a straightforward, common sense approach that staff and patients can understand, and that complies with the Human Rights Act.

What positive duties or obligations do NHS Trusts have to protect people's rights?

NHS Trusts are not just under a duty to refrain from committing human rights abuses. In some situations, Trusts have a duty – known as a **'positive obligation'** – to take proactive steps in order to ensure that human rights are respected, protected and fulfilled.

Positive obligations are triggered when a public authority is aware, or ought to be aware, that someone is at risk. They may require public authorities to protect people from human rights abuses even if the harm is caused by private individuals rather than directly by the public authority, e.g. in child protection cases or domestic violence.

Some examples of what this may require in practice are outlined below:

ACTION	EXAMPLE
Building a system to protect rights	NHS Trusts should make sure there is a framework in place to protect patients and staff from abuse. They should have procedures to respond effectively when abuse does occur.
Informing people of dangers that may lead to the loss of their life or future ability to consent.	NHS Trusts should ensure that patients are informed of possible harmful side effects that might result from certain medication.
Responding to breaches of human rights	If someone dies in a hospital in suspicious circumstances, NHS Trusts should ensure that a thorough investigation is carried out.
Taking action to prevent breaches of rights	If there is evidence that a patient is being abused by relatives, NHS Trusts should investigate this and where necessary take steps to prevent it. Providing staff with training and information to undertake this role is also important.

As this table suggests, many NHS Trusts will already have a number of existing systems in place that support positive obligations. However, this does not mean that additional actions are not required.

2.5 Rights in reality – some key rights to consider for NHS Trusts everyday work

The Human Rights Act contains fifteen rights, all of which NHS Trusts have a duty to respect, protect and sometimes fulfil. However, some of these rights are particularly relevant to the day to day work of Trusts. Here we introduce six rights that raise a number of important issues for Trusts. For a fuller explanation of the content of these rights and the other rights in the Human Rights Act, please refer to the sources in the Further Information section on pages 73 – 75.

HUMAN RIGHT	SOME RELEVANT ISSUES IN HEALTHCARE	AN EXAMPLE ...
The right to life Public authorities must: – not take away a person's life, except in a few very specific and limited circumstances, such as lawfully defending someone from violence. – take reasonable steps to protect a person's life in nearly all circumstances. Although the right to life is fundamental, there is no corresponding right to medical treatment in all circumstances	• Do Not Resuscitate orders • Refusal of life saving medical treatment • Active or passive euthanasia • Advance directives • Deaths through negligence • Investigations including inquests where a death is suspicious	A disabled woman was admitted to hospital with a chest infection. Whilst there she discovered that a 'Do Not Resuscitate' order had been placed on her file, because medical staff considered that she had a low quality of life which should not be prolonged. This kind of situation could be a breach of the right to life.

HUMAN RIGHT	SOME RELEVANT ISSUES IN HEALTHCARE	AN EXAMPLE ...
The right not to be tortured or treated in an inhuman or degrading way – Inhuman treatment means treatment causing severe mental or physical harm – Degrading treatment means treatment that is grossly humiliating and undignified Inhuman or degrading treatment does not have to be deliberate	• Physical or mental abuse • Unchanged sheets • Leaving trays of food without helping patients to eat, when they are too frail to feed themselves • Excessive force used to restrain patients • Washing or dressing without regard to dignity • Staff not being protected from violent or abusive patients	A man with learning disabilities was living in a residential care home. He was regularly tied to a bed or his wheelchair for 16 hours at a time, to prevent him from hitting his head and face. This kind of situation could breach the right not to be treated in an inhuman or degrading way.
The right to liberty The right to liberty is not a right to be free to do whatever you want. The right to liberty is a right not to be locked in a cell or a room, or have any other extreme restriction placed on movement. The right to liberty is a limited right. It can be limited in a number of specific circumstances, for example the lawful detention of someone who has mental health issues.	• Informal detention of patients who do not have the capacity to decide whether they would like to be admitted into hospital e.g. learning disabled or older patients • Delays in reviewing whether mental health patients who are detained under the Mental Health Act should still be detained • Excessive restraint of patients e.g. tying them to their beds or chairs for long periods	A large number of patients throughout the UK who do not have capacity to make their own decisions are informally admitted into hospital. This kind of admission has been ruled to breach the right to liberty, as there are no clear rules about who decides that someone should be detained, and for what reasons. The government is currently exploring ways of protecting people who are admitted informally in this way, to make sure that their right to liberty is not breached.[xviii]

HUMAN RIGHT	SOME RELEVANT ISSUES IN HEALTHCARE	AN EXAMPLE ...
The right to a fair trial The right to a fair trial contains a number of principles that need to be considered at *some stage* during the decision making process. The person whose rights will be affected has the right to: – an independent and impartial tribunal; – be present at some stage during the decision making process; – a reasonable opportunity to present their case before the decision is made; – an adversarial hearing; – disclosure of all relevant documents; – have their hearing take place within a reasonable time; and – be given reasons to enable them to understand the decision that has been made.	• Staff disciplinary proceedings • Compensation claims • Independence of Tribunals e.g. the Mental Health Review Tribunal	Ensure that there is a robust and fair process for removing a doctor or dentist from the Performers List.

HUMAN RIGHT	SOME RELEVANT ISSUES IN HEALTHCARE	AN EXAMPLE ...
The right to respect for private and family life, home and correspondence This right is a very wide ranging right. It protects four interests: – Family life is interpreted broadly. It does not just cover blood relatives. – Private life is also interpreted broadly. It covers more than just privacy, including issues such as personal choices, relationships, physical and mental well-being, access to personal information and participation in community life. – The right to respect for home is not a right to housing, but a right to respect for the home someone already has – Correspondence covers all forms of communication including phone calls, letters, faxes, emails etc. This right is a qualified right and may be interfered with in order to take account of the rights of other individuals and/or the wider community.	• Privacy on wards and in care homes • Family visits • Sexual and other relationships • Participation in social and recreational activities • Personal records – including medical, financial • Independent living • Closure of residential care homes or hospitals • Separation of families due to residential care placements	A hospital had a mixed ward and promised to re-order it so that men were at one end, with women at the other. It did not do this, and an orthodox Jewish woman was highly distressed about sharing a ward with men. This kind of situation could be a breach of the right to respect for private life.

HUMAN RIGHT	SOME RELEVANT ISSUES IN HEALTHCARE	AN EXAMPLE ...
The right not to be discriminated against This right is a right not to be discriminated against in relation to the other human rights contained in the Human Rights Act. Discrimination takes place when someone is treated in a different way compared to someone else in a similar situation, or where people in very different situations are treated the same. However, an action or decision will only be considered discriminatory if it cannot be reasonably and objectively justified.	• Refusal of medical treatment to an older person solely because of their age • Non-English speakers being presented with health options without the use of an interpreter • Discrimination against NHS Trust staff on the basis of their caring responsibilities at home	A hospital had a practice of sectioning asylum seekers with little or no English without the use of an interpreter. This practice could breach the right not to be discriminated against (on the basis of language or race) in conjunction with the right to liberty.

✓ Trust Check Point

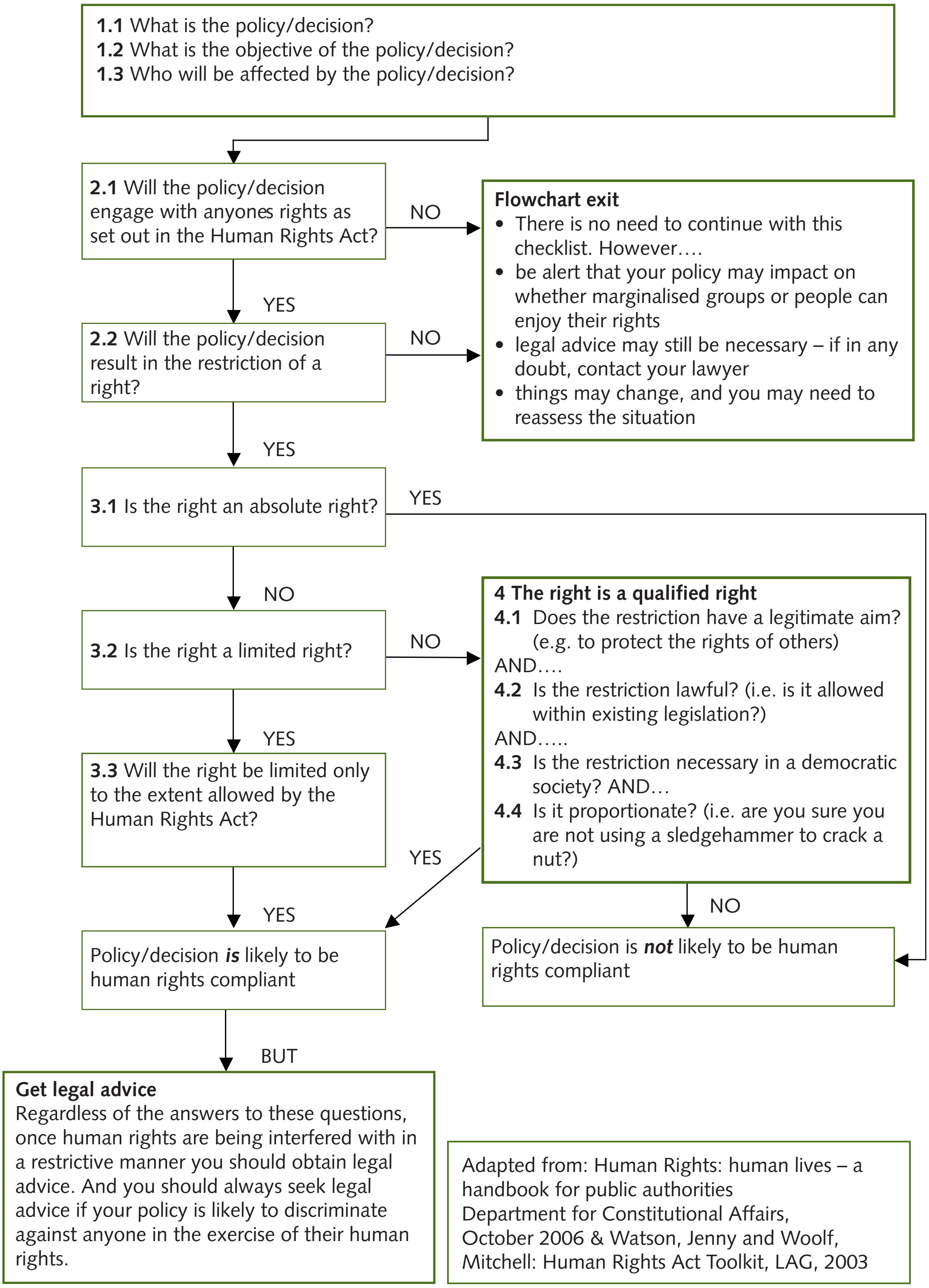
The right not to be discriminated against

The human rights definition of discrimination allows for circumstances when it is actually appropriate or will lessen inequality to treat people differently e.g. a targeted leadership scheme for employees with a disability to improve representation of this group at a senior level. But if people with very different needs are treated in the same way that would be discriminatory.

This kind of discrimination is prohibited on a *non-exhaustive list of grounds*, including but not limited to ‘sex, race, colour, language, religion, political or other opinion, national or social origin, association with a national minority, property, birth or other status’. ‘Other status’ has been interpreted very broadly to include grounds such as disability, sexual orientation and caring status.

The following flowchart brings together a number of the key considerations and questions discussed and is a good starting point for Trusts thinking about the likely impact of a policy or decision on people's human rights.

Human rights in policy and decision making – some key questions



1.1 What is the policy/decision?
1.2 What is the objective of the policy/decision?
1.3 Who will be affected by the policy/decision?

2.1 Will the policy/decision engage with anyones rights as set out in the Human Rights Act?

2.2 Will the policy/decision result in the restriction of a right?

Flowchart exit

- There is no need to continue with this checklist. However….
- be alert that your policy may impact on whether marginalised groups or people can enjoy their rights
- legal advice may still be necessary – if in any doubt, contact your lawyer
- things may change, and you may need to reassess the situation

3.1 Is the right an absolute right?

3.2 Is the right a limited right?

3.3 Will the right be limited only to the extent allowed by the Human Rights Act?

4 The right is a qualified right
4.1 Does the restriction have a legitimate aim? (e.g. to protect the rights of others)
AND….
4.2 Is the restriction lawful? (i.e. is it allowed within existing legislation?)
AND…..
4.3 Is the restriction necessary in a democratic society? AND…
4.4 Is it proportionate? (i.e. are you sure you are not using a sledgehammer to crack a nut?)

Policy/decision ***is*** likely to be human rights compliant

Policy/decision is ***not*** likely to be human rights compliant

Get legal advice
Regardless of the answers to these questions, once human rights are being interfered with in a restrictive manner you should obtain legal advice. And you should always seek legal advice if your policy is likely to discriminate against anyone in the exercise of their human rights.

Adapted from: Human Rights: human lives – a handbook for public authorities
Department for Constitutional Affairs, October 2006 & Watson, Jenny and Woolf, Mitchell: Human Rights Act Toolkit, LAG, 2003

Section 3:

From principles to practice – human rights based approaches in action

3.1 Introduction

Sections 1 & 2 have given an outline of how NHS Trusts can start to answer the questions that need addressing in order to put in place the first key principle of using a human rights based approach (HRBA). This principle is to put human rights at heart of policy and planning. Questions need to be asked such as:

- What are the human rights principles that we want to promote?
- What human rights are relevant to our service design and delivery? Whose rights are they?

As outlined in Section 1 (pages 20–25), using a HRBA involves another four principles that focus on ***how*** trusts should be working towards human rights principles if they are to be successful. These principles come with their own key questions such as:

- How are we ensuring accountability?
- Do all relevant stakeholders, e.g. staff, patients, carers and families understand enough about human rights? Are they empowered to put them into practice or claim them?
- How will we ensure meaningful participation?
- Are there any groups or people being discriminated against in terms of their rights and what targeted action can we take?

Addressing and taking action on these questions is what will move NHS Trusts forward in putting the key principles of a HRBA into practice.

3.2 Examples or indicators of a human rights based approach

Some examples of actions that can be taken forward to make this move are outlined in the table below. The table includes links to case studies of NHS Trusts who are undertaking this work, and/or links to the relevant guidance in this framework.

Key to Case Studies

A Case Study A – Mersey Care NHS Trust
B Case Study B – Southwark Health and Social Care
C Case Study C – Surrey & Borders Partnership NHS Trust
D Case Study D – Heart of Birmingham tPCT
E Case Study E – Tees, Esk & Wear Valleys NHS Trust

Some good practice actions and indicators

HRBA PRINCIPLE	LEADERSHIP AND GOVERNANCE	STRATEGY AND POLICY	PROCESSES AND PRACTICE
Putting human rights at the heart of policy and planning	C Trust vision and values explicitly reflect core human rights principles and outcomes Define Trust's key goals or objectives in terms of relevant human rights commitments Key human rights communication messages agreed and promoted internally and externally D Dedicated Strategic Level Team	D Mainstream human rights into new policy development via a Human Rights Strategy B Audit existing strategies, policies, budgets and programmes in terms of human rights impact Use a human rights proofing process or checklist (similar to the flowchart on page 31) for all new policies A Ensure 'human rights relevant' baseline data is gathered to inform policy and strategy and to monitor impact	Ensure complaints are recorded and responded to B Incorporate human rights based quality indicators into Trust's services and commissioned services Use human rights based decision making checklists (see p 41) and keep systematic records of potential human rights issues and related actions
Ensuring accountability	D Executive and Non Executive board lead or champion on human rights Board sub-committees such as Clinical Governance, ethics, risk assessment, given clear human rights remit Identify Trust's key required actions and positive obligations (see pages 34–35) and ensure reporting to the Board as part of regular cycles	Human rights policy and strategy leads assigned Clear goals (related to above principles) are set and monitored across different departments/policy areas B Commissioning policy explicitly requires human rights accountability from providers and sets out what this means	Job descriptions clarify relevant human rights responsibility Staff supervision/ management performance to include human rights monitoring D Appoint dedicated human rights post

HRBA PRINCIPLE	LEADERSHIP AND GOVERNANCE	STRATEGY AND POLICY	PROCESSES AND PRACTICE
Empowerment – staff, patients, carers and other key stakeholders are aware of and share common understanding of duties, rights and responsibilities	Skills audit and ensure human rights training provision to Board, Senior Team and key advisory sub-groups. Provide access to internal and external specialist advice	C Include human rights as a mandatory competency in Trust's key learning and skills frameworks B C D Train those with policy making role to human rights 'proof' or impact assess B Give guidance to commissioned organisations D Resource allocation in overall staff and organisational development budget	C Provide job specific human rights training and related guidance and information D Access to human rights advice for staff and patients E Patients and service user groups given human rights information, and routinely given a chance to raise issues
Participation – all relevant stakeholders are enabled to participate in an active and meaningful way	E Existing participation initiatives to incorporate human rights as appropriate E Resource and provide staff support to independent and internal mechanisms that support patient and stakeholder participation e.g. service user-led projects	A Involvement of patients in assessment of policies C Ensure all policy staff have awareness (not just equalities and human rights leads) of human rights Timely and transparent proposals given out for consultation with clear information on human rights impact	Human rights part of patient discussion in routine processes e.g. one-to-one care planning or patient forums Space given in staff meetings and separately for staff to discuss human rights issues and feedback E Engage with the Voluntary and Community Sector, particularly service user led groups

HRBA PRINCIPLE	LEADERSHIP AND GOVERNANCE	STRATEGY AND POLICY	PROCESSES AND PRACTICE
Non discrimination and attention to vulnerable groups – those most vulnerable to human rights breaches are identified and targeted, and measures are in place to address and prevent this	C Include clear commitments and goals for tackling discrimination in all Trust policy and planning and link this directly to human rights principles Initiate and support 'cross interest' human rights projects or initiatives that engage a range of groups vulnerable to discrimination	B C D Integrate human rights into Equality Strategies and impact assessment processes Ensure baseline data is disaggregated by categories where there are human rights concerns e.g. disability, gender, race, age, sexuality, religion, caring status	Issue staff and patients with clear guidance/ check lists on when differential treatment can be discriminatory Support and resource patient advocates for vulnerable groups

3.3 Case studies

Introduction

These case studies aim to provide a picture of how five NHS Trusts, acting as pilots in the human rights in healthcare project, are developing and using human rights based approaches (HRBAs) in their work. They bring together the learning so far from projects that the five Trusts have been developing. They have helped to shape the framework overall and provide illustrative examples to other Trusts interested in developing HRBAs.

These case studies are not the 'full story', but a first step on a longer journey. They are not designed to evidence impact. Rather they provide an initial snapshot of how the pilot Trusts have taken HRBAs forward in their work so far, and what kinds of resources and information are needed to kick-start this process. They will be revisited and updated as additional practice and learning emerge.

Overview

a. **Merseycare NHS trust** – Developing a human rights based decision-making process at the Trust's Learning Disabilities Directorate

b. **Southwark Health & Social Care** – A human rights based approach to the commissioning and delivery of Fertility Services in Southwark

c. **Surrey & Borders Partnership NHS trust** – Embedding human rights in the Trust's Equality & Diversity strategy

d. Heart of **Birmingham Teaching Primary Care Trust** – Producing an action plan for creating a human rights based culture across the organisation

e. **Tees, Esk and Wear Valleys NHS trust** – Developing a human rights based approach to the design and production of the Trust's Service User and Carer Charter and Care Programme Approach

A summary of learning from NHS Trust's pilot work to date

The pilot Trusts felt that the following learning points were vital in the *process* of developing and using HRBAs in their work:

Getting started

- Before getting started, Trusts needed to 'make the case' for themselves and colleagues, by challenging common myths like rights being a hindrance for staff or human rights not being an issue for people in the UK.
- Commitment from leaders at the top of the organisation was crucial, but it was equally important to involve staff from all levels of the organisation. Trusts found real appetite and motivation among staff once they could see the benefits of putting human rights principles into practice.
- A basic understanding of human rights ideas, the legal framework, implications for practice and specifically for healthcare was essential to progress the work. Otherwise project planning would be based on a limited or flawed understanding of rights.
- Trusts found human rights to be a way to support existing work rather than being an 'add on'. For example human rights should centrally underpin work like Equality and Diversity policy and practice or patient choice initiatives. They provide an additional tool for working more effectively in these areas as well as filling gaps – see case studies B, C & D.
- Linked with this, the project needed strong foundations across the Trust, e.g. embedded in strategic plan and communications strategy and given sufficient allocation of resources and management support.

Project planning and development

- Taking forward a HRBA within a project environment that has a designated person with responsibility for delivery, clear timescales for actions and senior management oversight can help to ensure the successful implementation of a HRBA.
- Whilst the five core principles of a generic HRBA are key, there is no one 'correct' human rights based approach. Trusts need to develop something that reflects the nature and context of their organisation.

- Participation and consultation is absolutely vital and this must involve the engagement of service users and carers as well as staff. Voluntary and community sector organisations can be a key partner in supporting participation. They have a great deal of expertise and are a very useful resource on the needs of particular groups.
- It is important to share learning and communicate with other Trusts as well as with other NHS or public sector organisations undertaking similar work.
- Service users, carers and families need awareness of what their human rights are and how they relate to their healthcare in order for good practice to be developed.
- Staff need to be aware that they have human rights themselves; human rights are not just about how they are treating others.
- It is important not to be overambitious and to keep the project simple to start with. It is then possible to see how a HRBA fits a particular area and later on to apply the learning more broadly.
- An evaluation and monitoring framework must be built in from the start of the project. It must show how the project will support existing targets. Overall, the project must focus on the practical ways in which human rights can make a difference.

Case Study A:

Mersey Care NHS Trust

1. WHO – Overview of Trust

Mersey Care NHS Trust was established on 1 April 2001 to provide specialist mental health and learning disability services for the people of Sefton, Liverpool and Kirkby. The Trust serves a local population of 763,000 including areas of high deprivation and high levels of mental health need. Overall 96.4% of the North Mersey population is white. In the Liverpool area this figure is 91.8%.

Mersey Care is one of only three Trusts providing the entire range of mental health services and provides medium secure services to Merseyside and high secure services for the North West, Midlands and Wales. The Trust currently employs a total of 4,682 staff and has an annual budget of £185.1m.

Mersey Care takes a rights based approach and has invested in leadership to ensure that service users and carers have the right to be involved in decisions which affect their lives and that equality and human rights are promoted throughout the Trust.

2. WHY – Reason for involvement

Mersey Care was keen to get involved in this project as we believe in a human rights approach to the provision of mental health and learning disability services. The Trust has a national reputation for its work on involving service users and carers and the learning disability service has created a wide range of innovative opportunities for clients to be involved in decision making.

The Trust sees this project as a great opportunity to learn more about human rights and how they can be applied in healthcare. The Trust hopes to link its existing work on involvement and diversity and equality into a wider human rights framework. The Trust wanted to see if it could apply a "bottom up" approach – to explore human rights issues in the context of learning disability inpatient services and to then take that learning into the whole organisation.

It was also a great chance to work with the Department of Health on a pioneering initiative and to learn from the British Institute of Human Rights and other like-minded NHS organisations.

3. HOW – Approach

We decided to focus on the experiences of inpatients in learning disability services. We decided to do this by:

- identifying the human rights issues that were relevant to the inpatient experience;
- testing out patients' experiences in relation to human rights; and

- taking the learning from peoples' experiences and applying it to Trust strategy, policy and decision making.

We wanted the pilot project to help to develop a "human rights" way of thinking within the Learning Disabilities Directorate. We wanted our human rights related policies to be clearly informed by user experiences, and to be expressed in simple language accessible to all.

We decided to move forward by interviewing 6 people with learning disabilities who have been admitted as inpatients to Wavertree Lodge in the last two years. We wanted, through a snapshot, to capture their experiences of the inpatient service specifically in relation to human rights issues. We designed a questionnaire with support from BIHR. Once interviews are complete, the findings will be used to review strategies, policies and decision making processes both in the Learning Disabilities Directorate and across the Trust.

4. WHAT – Issues identified by the Trust in taking forward the project and how these were addressed

There was widespread enthusiasm for the project and the induction day for managers and staff was well attended. A number of human rights related issues were considered to be particularly important in the context of learning disability services. These included the religious needs of service users, accessibility of services for people with physical disabilities, accessible information, issues about informed consent, and issues about care and treatment including privacy, dignity, gender sensitivity, restraint and seclusion. These issues helped guide the development of the human rights questionnaire and to keep it rooted in everyday experiences and concerns.

The questionnaire itself took both time and patience to construct. The project team took very seriously the challenge of applying human rights articles and principles to the reality of the inpatient experience and developing a tool that can be used with people with learning disabilities. The questionnaire went through several versions to hone it as near as possible to perfection. Expert advice from the British Institute of Human Rights was invaluable and their feedback impeccable. If we were doing it again we would have arranged for more direct support from BIHR earlier in the project. The task was made easier because the person leading the design of the questionnaire was a member of Trust staff with experience of "easy read" and making information accessible for people with learning disabilities. We have decided that the questionnaires will be administered by one person to ensure a consistent approach and this is currently in process.

The next challenge will be identifying the learning in a very specific human rights way and applying it in both the Learning Disabilities Directorate and across the Trust. We are especially keen to find ways of reaching people with learning disabilities who, because of the nature of their disability, could not participate in this project. As we have seen recently in Cornwall and in Sutton and Merton, the most vulnerable are most at risk of abuse of their human rights.

5. Progress to date and next steps

The Trust has engaged widespread interest and commitment to the human rights project. A new and innovative human rights tool has been developed for use with people with learning disabilities and this is currently being "road tested".

The benefits have already been felt in that the Trust is now planning to make promoting human rights one of its key objectives.

The learning from the initial phase will inform the Trust-wide approach to promoting human rights and further human rights focused work within the Learning Disabilities Directorate.

Contacts:

Meryl Atkins, Equality and Human Rights Lead
Email: meryl.atkins@merseycare.nhs.uk

Lindsey Dyer, Director, Service Users and Carers
Email: lindsey.dyer@merseycare.nhs.uk

Case Study B:
Southwark Health & Social Care

1. WHO – Overview of Trust

Southwark Health & Social Care is an integrated structure between Southwark PCT (Health) and the London Borough of Southwark's Social Services department. Health & Social Care commissions and delivers services to residents in Southwark – one of the most ethnically and socially diverse populations in the country.

Southwark serves an area with a population of approximately 253,800. The population demonstrates a rich ethnic and cultural diversity with nearly 40% of the borough's population from a black or minority ethnic community. The population is also young, with 20% under 15 years old – and this figure is growing. From 1991-2001 there was a growth rate of 7% compared to the national average of 2.5%.

Southwark PCT currently employs 920 people with another 1100 employed by Social Care. In recent years, the Equality & Diversity team has made good progress in driving forward the equality agenda within Health & Social Care – Southwark's integrated services. Our vision of promoting and respecting human rights is shared by Southwark Council which has been at the forefront of promoting human rights in social care. In partnership with the Council and the new Children's Services, we have the capacity to embed a human rights framework throughout Health & Social Care. In addition, as part of our learning and development framework, we hope to ensure that all our Health & Social Care staff will receive human rights training in the near future.

2. WHY – Reason for involvement

Southwark Council as a whole has carried out significant previous work on human rights. Training has been rolled out across a number of departments of the Council since 2001, including Social Services, Housing and Education. We see this project as a further opportunity to embed human rights across the work of Southwark.

We see human rights as being very much linked to work we are doing already. The project provides a good opportunity to link existing equality and diversity work in Southwark with human rights. We also see the project as an opportunity to keep pace with national developments in equalities and human rights, for example the new Commission for Equality and Human Rights and the PCT Commissioning Framework.

Southwark's rich and diverse population encompasses over 100 spoken languages. Ensuring positive health outcomes for this diverse population, and their challenging health needs, presents Health & Social Care with a huge challenge. We consider our human rights work as one of the key drivers to help meet this challenge. By linking the human rights framework to other local equality and diversity strategies we hope to tackle some of the key health inequalities in Southwark.

We hope that this project will create a framework that assists NHS Trusts, their staff and their commissioned partners to respect and promote specific human rights and human rights principles as part of their daily work of planning and delivering quality health services.

3. HOW – Approach

We decided to focus on contract commissioning for our project. This was partly to help ensure that the commissioning and procurement processes undergo an equality impact assessment. Following an induction day with the British Institute of Human Rights (BIHR) we realised that this was a very broad and possibly complex area, particularly due to the current lack of clarity regarding the status of commissioned bodies under the Human Rights Act 1998. This was a key learning point from the induction day. Even though commissioned bodies may not be directly accountable under the Act, Southwark is and will be held to account ultimately for any human rights breaches that occur in the course of commissioned services. Therefore we decided to focus initially on one specific contract – our contract for fertility services – rather than commissioning as a whole.

Our key objectives for the pilot are to:

- Develop a ‘human rights mindset’ to the commissioning, service provision and delivery of fertility services in Southwark.
- Make a ‘first step’ towards ensuring that the protection of human rights becomes part of organisational thinking from the way we commission, deliver and monitor the quality of services across the whole of Health & Social Care.
- Develop a ‘test’ performance management framework to expand and include other projects, linking the project’s goal with critical success factors and these to key performance indicators.

4. WHAT – Issues identified by the Trust in taking forward the project and how these were addressed

Fertility services were chosen because the commissioning processes are currently being reviewed to provide clarity to GPs, service providers and patients around the eligibility criteria. This is also a challenging and controversial service area with ethical issues and competing individual human rights. In this respect, the core human rights principles of fairness, respect, equality, dignity and autonomy are relevant not only to the eligibility criteria but also to the principles behind the referral system, NHS funded IVF cycles, the number of cycles a services user is permitted, waiting times for NHS funded clients as compared with self-funded patients, the issue of fresh embryos/frozen embryos and other matters.

The key stakeholders are the commissioners (Southwark PCT) and the service providers (King's College Hospital (KCH) and Guy's & St Thomas). Southwark PCT, under the new London arrangements, will also handle complaints process regarding fertility services in relation to KCH on a London-wide basis.

To take this work forward we are looking at real-life based case studies that will monitor whether human rights have been respected from initial referral to service outcome (irrespective of conception success or failure). The key stakeholders will be involved in defining and agreeing the projected outcomes. The project will link with existing equality and diversity strategies/legislation and National Institute for Clinical Excellence (NICE) guidelines. To ensure the project remains focused on its objectives, a performance management framework specifying goals, success factors and indicators will be developed from the early stages of the project. The work will include human rights training for stakeholders, and the development of human rights good decision-making guidance.

5. Progress to date and next steps

Within Health and Social Care, a new equality and human rights framework will come into existence in April 2007. This human rights project has enabled this to gain momentum. We have held exploratory meetings with stakeholders to define the project and agree a timeframe. Work is in progress on producing a position/options paper redefining the fertility service using a human rights framework. This is due to be completed by the end of March. In the next phase of work, we intend to evaluate the position/options paper with the support of BIHR to help produce a human rights framework that can be initially applied to the fertility service. If successful, the framework will be developed further so that it can be applied to wider commissioning areas.

We also want to develop an equality and human rights performance framework so that equality and protection of human rights becomes part of organisational thinking from the way we commission, deliver and monitor the quality of services across the whole of Health & Social Care. As part of this, we intend to ensure that our Health & Social Care staff receive human rights training in the near future.

Contacts:

Tod Heyda, Equality and Diversity Project Manager
Email: Tod.heyda@southwark.gov.uk

Harjinder Bahra, Equality and Diversity Project Officer
Email: harjinder.bahra@southwarkpct.nhs.uk

Case Study C:
Surrey & Borders Partnership NHS Trust

1. WHO – Overview of Trust

Surrey and Borders Partnership NHS Trust is a specialist Trust providing mental health services to the people of Surrey, Croydon and North East Hampshire. Services include drug and alcohol, child and adolescent mental health and specialist learning disabilities. The Trust was formed on the 1st of April 2005 after a merger between Surrey Hampshire Borders NHS Trust, Surrey Oaklands NHS Trust and North West Surrey Partnership NHS Trust. The Trust currently employs in excess of 4000 staff.

The Trust covers an approximate population of 1.3 million, and is the largest provider of services to a mix of urban and rural areas. There are high levels of affluence, especially in Surrey, resulting in a significant inequality gap between pockets of deprivation and areas of affluence. Surrey is amongst the ten local authorities with the highest levels of health in the country.

Following the formation of the Trust, the organisation defined a 'Diversity – Yes, Stigma – No' Equality and Human Rights Strategy. This strategy is a key part of the organisation's five year strategic direction and aims to place human rights principles at the heart of its business. As part of this strategy, the organisation has defined an action plan that addresses six key priorities:

1) Ensure that services are accessible, appropriate, inclusive and responsive to people who use services, their families and carers, taking into account equitable spread across all groups and all backgrounds

2) Ensure that the Trust is responsive and pro-active in meeting current and emerging legislative duties between now and 2012

3) Ensure that the Trust develops its staff to deliver the Trust's vision and values

4) Achieve a Trust that reflects the diversity of its local population in its composition and leadership group

5) Ensure that the Trust is effective in communicating and working in partnership with local community groups, significant individuals and marginalised or disengaged groups

6) Ensure that the Trust sends out a clear message of its determination to identify and work pro-actively towards reducing and eliminating stigma associated with mental health and learning disability through practical and measurable activities

Our organisation has already taken forward work addressing our key priorities through our involvement in the Human Rights in Healthcare Framework project and other work on equality, diversity and human rights. We hope that our commitment to this project and the development of a human rights based approach to our work will result in significant improvements to the way we operate in the short, medium and long-term.

2. WHY – Reason for involvement

We decided to participate in the Human Rights in Healthcare Framework project for three key reasons. Firstly, our high proportion of affluent residents is combined with pockets of significant deprivation. The social difference between residents in these areas results in a significant inequality gap. To ensure that our services are provided in a fair and equal manner to all, we decided to base our service design and service provision on the human rights principles of fairness, respect, equality, dignity and autonomy. As a result, we saw that early involvement in this human rights project would allow us to better understand the meaning and application of these principles in our work. The support in terms of human rights expertise provided by BIHR and project management expertise offered by the Department of Health also contributed to our decision to get involved.

Secondly, at the start of the Human Rights in Healthcare Framework project, we were already in the process of finalising our Equality & Diversity strategy. The project provided us with an opportunity to gain and contribute towards a better understanding of how current work on equality, diversity and human rights based approaches can be integrated. As a result, we revised our existing strategy and obtained approval for a revised strategic plan that addressed equality and diversity in the context of human rights principles.

Finally, we saw that joint work with the other four NHS trusts, the Department of Health and BIHR would allow us to better understand the processes involved in embedding human rights in our work. This collaboration also enabled us to draw on our project partners' learning and hence reduce duplication and associated risks.

3. HOW – Approach

From the beginning we decided to look at the inclusion of human rights in our mission, values and five year strategic plan. During the first 12 weeks of the project, we looked at the link between our current work on equality & diversity and human rights and started the implementation of our five-year strategic plan.

In these first weeks we completed the following activities to help us achieve our project objectives:

1) A human rights induction day was delivered by BIHR to a group of staff and users'/carers' representatives

2) We revised our equality, diversity and human rights strategy to include specific references to human rights principles

3) We amended our five-year strategic plan to incorporate activities promoting human rights based thinking

4) We defined human rights training/organisational development requirements for our staff and designed a 'train the trainer' module

5) We established a project governance team that demonstrates carer, user and staff involvement from the early stages of the project (involvement from Trade Unions, carer representatives, user representatives)

6) We are running a workshop for staff to further define our human rights training. This aim is to develop a clear framework to implement our 'train the trainer' programme.

This approach was designed to address the human rights issues we identified during the human rights induction day. These issues are listed in the paragraph below.

4. WHAT – Issues identified by the Trust in taking forward the project and how these were addressed

During our induction day with BIHR we identified human rights issues that were specific to our work and that we wanted to explore further as part of this project. These were:

1) We would like to explore the links between equality, diversity and human rights, recognising that equality is a human rights principle and a fundamental human right

2) We agreed that to promote human rights, the wards and the institutions within which many of our patients reside should be seen as their 'home'

3) We would like to further promote human rights based approaches in our service provision for older people

4) We would like to assess the impact of our Trust-wide policies on vulnerable groups

5) We intend to make available information about human rights to non-English speakers

6) We recognise that human rights are an area for further organisational development and intend to define training requirements and design the best possible training package.

7) We need to visibly identify, for a range of our services, the rights holders, the human rights involved and how our staff impact on these with their actions.

To address the above issues, we decided to first revise our 5-year strategic plan and secondly, to educate all our staff about human rights. Although the strategy was amended in a short-timescale, we recognised that the task of educating all our staff on how human rights affect their work and those they care for would be a lengthy one. As a result, the Director for Equality & Diversity assumed ownership of the project, incorporated organisational development and other capacity building tasks into our 5-year strategic plan and received approval for the proposal from the Trust's board of directors. This enabled us to define what we could do in the short term (e.g. train the trainers) and in parallel, start the delivery of our strategic plan.

We see the first stage of this project as having been very successful. In less than 12 weeks we have achieved our objectives and have been able to start implementation of our strategic plan. However, the time required by our staff to deliver our first outcomes was greater than anticipated. If the project was to be launched again, we would dedicate specific project support resources to take this forward. From our perspective, the definition of human rights issues at the induction day was a good starting point as it defined what should be addressed before the 'when' and 'how'. Although our thinking and discussions prior to the induction day enabled us to define our broad areas of interest and involve key stakeholders, we found that only after the induction day were we able to plan and deliver outcomes.

5. Progress to date and next steps

Since the project started at the end of November 2006 we have managed to complete the following:

a) Human rights induction day for Human Resources, Equality & Diversity stakeholders and carers' representatives. The day was facilitated and led by the British Institute of Human Rights and introduced key stakeholders to human rights principles and approaches. As part of the day, stakeholders from our organisation planned next steps for our project

b) Following the completion of the induction day, we revised our Equality & Diversity strategy and our 5-year strategic plan to incorporate activities needed for the development of a human rights based approach to our work. Both the strategy and the action plan were presented to the organisation's leaders in December 2006 and circulated to the public for review, through the Trust's website.

c) Following the revision of our strategy, we have agreed to define our human rights training requirements and deliver a training module to all our staff.

With our 5-year strategic plan approved, we now have a clear direction as to how we will embed human rights across the Trust. We expect that our users and their carers will notice a positive change in the way services are delivered over the next five years.

Contact:

Diane Baderin, Director of Diversity and Inclusion
Email: Diane.Baderin@sabp.nhs.uk

Case Study D:
Heart of Birmingham PCT

1. WHO – Overview of Trust

Heart of Birmingham PCT serves one of the most deprived and culturally diverse communities at the heart of the inner city, in Birmingham. The teaching Primary Care Trust (‘tPCT’) has a budget of approximately £360 million. It operates 20 health centres and commissions services from more than 150 GPs based in nearly 80 practices. Over 70% of these are single handed practices providing services to one of the most challenging areas of the country.

The Trust covers a population of approximately 310,000. There are high levels of deprivation across the majority of communities combined with high levels of affluence in the City Centre. Approximately 70% of the population are Black or Asian. There are high rates of poor health, premature death, long-term chronic illness and disability.

The number of staff employed by the Trust at the end of January 2007 is 1,140. It is a very diverse workforce, with BME representatives populating up to 49% of staff posts. The diversity of the patient population and the current workforce makes work on human rights and equalities a very high priority for the tPCT. There is a high incidence of health inequality and deprivation in the area that the tPCT provides services to. Human rights and equalities are therefore seen as essential to providing better quality services.

2. WHY – Reason for involvement

From the outset there has been strong support from organisational leaders for the project. The Chairman and Chief Executive have a personal interest in human rights which has been a key driver for the launch of the project. There is also strong support from both Executive and Non-Executive directors.

We are keen for human rights to provide support for existing initiatives, and intend to embed human rights in the work of the reformed Chief Executives Reference Group (based on the work previously undertaken by the tPCT’s Equalities Board). The project also provides an opportunity to engage with commissioning partners and set human rights values across commissioning and service delivery.

The tPCT engaged in this project with the intention that it would take a ‘small steps’ approach. By using a gradual introduction of new human rights ideas, we hoped that we could ensure the learning would grow to become a core part of our overall strategy. This would ensure that basic human rights principles would not be lost through poor planning and would remain an essential ingredient in our planning at all levels.

As a learning organisation, we want to ensure that our service delivery will be enhanced by a human rights based approach. We believe that this can only be achieved by embedding human rights at the core of our learning, with the express goal of integrating that learning into our service delivery. To achieve this we believe we need to learn from our front line staff and service users' experiences. This should enhance our service delivery and patient experience as stated in Government policy for the NHS and the tPCT's overall objectives.

3. HOW – Approach

With top level commitment, the tPCT decided to commence a long term process that will look at both the strategic/planning and operational levels of the organisation.

Our initial activities included:

- Definition of a statement of human rights principles to guide service commissioning and a human rights based mission statement
- Assessment of requirements for including human rights in service contracts with commissioned providers and the definition of an action plan at a PCT/providers roundtable
- Definition of performance indicators to measure progress on and impact of human rights, starting by undertaking a human rights impact assessment on Trust complaints reported through the PALS service

We decided that to ensure we valued the principles of human rights as an organisation we needed to demonstrate our intentions to our commissioned partners and services. By including references to human rights in our service contracts and commissioning process we feel that systems for raising awareness of our expectations and monitoring of that process can be developed. We believe this is essential to demonstrate our commitment to the project and ensure that progress is ongoing.

In accordance with a human rights based approach, the tPCT needs to take into account what the issues of the service users are currently. By using existing complaints through the PALS service, the tPCT can evaluate issues concerning human rights that have been reported. Using this information we intend to develop a strategy for monitoring progress against human rights using key performance indicators. We will use these to measure the impact of human rights complaints to the tPCT, and thereby monitor progress and improvements.

4. WHAT – Issues identified by the Trust in taking forward the project and how these were addressed

Human rights issues identified in the induction day provided by BIHR included:

- Low awareness of what human rights are and their relevance amongst PCT staff and commissioned partners (though many staff have good instincts about human rights issues and many know more than they realise)
- Service users and their representatives do not have knowledge of their human rights – it is critical that patients/service users/carers should be able to identify human rights issues as well as staff
- It is very important for staff to identify themselves how human rights can be used in their work
- Human rights need to be embedded in our working culture – they are not embedded currently
- There is a danger of human rights being seen as another 'add on' to existing work. Staff may be too busy delivering care to take this on and will ask why should we do things differently? However, human rights give us an opportunity to take a fresher and broader approach that may engage more staff and increase their ownership
- In much of our existing practices and procedures we are implicitly or indirectly supporting/tackling human rights issues but are not explicitly stating this or seeing things in human rights terms
- We are not currently looking at people as human beings first and foremost but by their label or group
- How genuinely informed is patient consent? e.g. patients relying on translators or those without them

The induction day was used to scope the challenge in introducing the human rights project with a selection of senior and middle managers. The challenges identified and confirmed during the induction day demonstrated the need for a learning approach. The tPCT is now reviewing the current learning on equality and diversity to ensure that human rights form a core theme. We hope that this will create a forum for organisational learning to progress the programme and create new ideas in integrating human rights at the core of the tPCT strategy.

In the early stages of the project we encountered problems with the resources required to undertake this programme. We realised that to ensure a high level of commitment to the project, designated resources needed to be made available. Time constraints in the first phase of the project also highlighted the difficulty in creating early ‘wins’. We decided that this could partly be achieved by creating a Chief Executives Reference Group to provide the necessary leadership for the project, and by providing the funding for a project managers post to manage the objectives. The Trust Board supported this initiative and approved the necessary resources.

The important and promising developments witnessed by the project so far are the full backing that the Trust Board has given to the project, and their expressed wish to be kept updated on the progress. This was further enhanced by the enthusiasm for the project demonstrated by the managers involved in the BIHR induction day. The tPCT believes that the commitment demonstrated so far has ensured that the project has the ability to be successful.

From this first phase of the project, we have learned that in order to be successful, Board level commitment is essential in the first instance. This was demonstrated by the Trust Board and has provided the foundations for the project. To ensure ongoing progress and to drive the project forward, the tPCT started working with bRAP, a voluntary organisation with expertise in the field of human rights. This has been a very valuable relationship. If we had begun working with them in the planning stages of the project we may have been able to achieve more in the time frame given for the first phase. The profile of the project and the magnitude of its importance does need to be emphasised to the whole organisation and its service users. This can only be achieved through a robust communications strategy. This has been identified as a major objective by the tPCT for the future planning of the project.

5. Progress to date and next steps

The tPCT has to date established the Chief Executives Reference Group and the terms of reference required to guide the principles of this forum. This group was initiated through a Trust Board paper delivered by the Chief Executive to the Board, which also informed the Board of the high profile of this project and the importance of the Human Rights and Equalities strategy to the tPCT. The paper also confirmed the resources required for the project manager’s post and the funding for the engagement of bRAP to consult on the project in the first instance. This has resulted in a 6 month secondment opportunity for a bRAP consultant prior to the project manager being appointed. The tPCT has also undertaken recruitment of staff in a voluntary capacity to be members of the Chief Executives Reference Group. This will engage front line staff in the development of our human rights and equalities strategy.

The bRAP consultant will engage the commissioning arm of the Trust to consider the use of human rights statements in existing commissioning contracts, designed with BIHR, including the national framework document. This also includes planning a facilitation event, which will include tPCT partners, to consult on commissioning processes for human rights inclusion. The consultant will also design tPCT human rights training programmes for all staff. Other areas for development include the key performance indicators and impact assessments to ensure evaluation and monitoring underpin the human rights project. Work with the PALS department is due to be undertaken shortly to assess the current human rights issues that are faced by the tPCT and its service users.

We have also written into the tPCT's governance strategy that a human rights statement, designed with BIHR, will inform any future personnel and service delivery policies of our commitment to human rights. We are also committed to reviewing all existing policies to ensure that human rights principles are an essential consideration.

The next steps for the project will include the ongoing work previously described and the development of a robust human rights communications strategy. The strategy will inform the organisation of the principles of human rights, the development of the project and the outcomes that are achieved. We plan to develop an intranet link for staff to communicate new ideas or experiences to assist in developing the human rights strategy. We also envisage that service users will be consulted through the communications strategy in order to gain their involvement on human rights and to add their experience during service redesign.

The eventual and obvious objective for this project is that service delivery will be enhanced for the patient population through proper consideration of their human rights. We believe that by initiating the strong foundations of this project and by using a robust communication policy the Trust will be able to achieve this objective. The major consideration in delivering this project is to be able to manage expectations. Communication is going to be the key to success.

Contact:

Peter Turner, Senior HR Manager
Email: peter.turner@hobtpct.nhs.uk

Case Study E:

Tees, Esk and Wear Valleys NHS Trust

1. WHO – Overview of Trust

Tees, Esk and Wear Valleys (TEWV) NHS Trust was formed on April 1st 2006, following the merger of County Durham & Darlington Priority Services NHS Trust and Tees and North East Yorkshire NHS Trust. The new Trust provides mental health and learning disabilities services as well as addictive behaviour services. It cares for a population of more than 1.4 million living across County Durham, the Tees, Esk and Wear Valleys and North East Yorkshire. TEWV NHS Trust employs approximately 5000 staff.

The Trust's Research and Development Department currently collaborates on the ARISE (Accessible Research Involvement for Service Evaluation) project. This is a service user and carer led research and personal/professional development programme to increase the diversity and involvement of people who have long term mental health needs and their carers in the research and evaluation process. The long term aims and objectives of this programme include increased engagement in the strategic and operational management of the organisation and the employment of service users and carers as paid members of the Trust.

Members of the ARISE Project devise their research questions directly from their lived experience, through their stories (narrative accounts) which are shared when they begin working on the project.

Their narrative accounts then lead to the formation of research questions that have direct relevance for project members. The implications of these for the organisation as a whole are far reaching and can often impact upon other services in social care, education, prisons and the voluntary and community sector.

Examples include:

- Domestic violence provision for members of the Lesbian, Gay, Bisexual and Transgendered Community in the North East of England.
- The implications and process of detention under the Mental Health Act from a human rights perspective.
- Assessment of capacity to parent when a parent has mental health needs.
- Same sex and mixed sex wards, choice and preference for people with mental health needs.

2. WHY – Reason for involvement

In 2006 Members of the ARISE Project contacted BIHR to request human rights training and we were informed of the possibility of participating on in the Human Rights in Healthcare Pilot Project. When this invitation was extended to the TEWV NHS Trust, members of the ARISE Project were extremely enthusiastic and approached the newly appointed Director for Public and Patient Involvement, Harry Cronin, to ascertain his willingness or otherwise to engage in the project.

Happily, following discussion with Board members, the TEWV NHS Trust formally signed up to this project. This came at an opportune time for the organisation given the recent merger and a commitment to work towards Foundation Trust status.

3. HOW – Approach

Following the first round table meeting hosted by the Department of Health, a meeting was arranged at the TEWV NHS Trust, to which service users, carers, service user involvement workers and other key staff members were invited. This meeting was attended by approx 15 people, the majority of whom had used services, or continued to use services, and their carers. This included a small number of service user staff members and staff from Clinical Governance and Public/Patient Involvement.

It was originally proposed that the soon to be implemented No Smoking policy would be an ideal focus for this project. However following on from the delivery of a human rights training day by BIHR to the group, discussions were held regarding other potential projects that had human rights implications and direct relevance for service users and carers. Two potential areas were put forward. These were the Service User and Carer Charter, of which there were two due to the amalgamation of both Trusts, and the Care Programme Approach.

We decided to review both Service User and Carer Charters from a human rights perspective, with service user and carer members effectively leading this work in accordance with a human rights based approach and its emphasis on participation.

The Care Programme Approach project will be undertaken following the completion of the Service User and Carer Charter project. Given that the Government and the Department of Health are currently in consultation nationally regarding this policy, it makes sense to await the outcomes of these consultations prior to starting this work. Service users, carers and staff members across the organisation are engaging in this consultation process.

The aim of the first part of the project was: To amalgamate into one document and update both Charters currently in existence drawn from the TNEY NHS Trust and CDDPS NHS Trust. This document will apply to the whole of Tees, Esk and Wear

Valleys NHS Trust and will highlight human rights as the fundamental guiding principles throughout.

The plan was to form an Action Group which would effectively take responsibility for rewriting the Charter, made up of members of the original group that had met and attended the human rights induction day delivered by BIHR. Some service users and carers from the Monitoring of Services Team (MOST) based in County Durham and Darlington were unable to attend this meeting. They will also be invited to participate as members of the Action Group, so that both sides of the geographical boundaries of the TEWV NHS Trust are represented in this process.

In order to undertake this work using a human rights based approach, it is also necessary for us to prioritise engagement with people who are members of socially excluded groups, and to involve them in this process. Therefore, as we would need to validate the Charter with ALL of the groups who potentially use or support someone to use the TEWV NHS Trust's services, it was decided to have Reference Groups covering each of the groups who are at risk of and often encounter social exclusion. These include:

- People who have a physical disability
- Women who have young children
- People who have mental health needs
- People who have a learning disability
- People who are members of Black and Ethnic Minority Groups
- People who are seeking asylum and/or are refugees
- People who are members of the Lesbian, Gay, Bisexual and Transgendered Community
- People who have experienced sexual abuse and/or violence
- People who have committed offences
- People who have spent time in prison
- People who have used illicit substances/drugs
- People who define themselves as Travellers/Gypsies
- Children and young people

We have already started to make contact with local voluntary and community groups who represent the interests of these diverse groups of people in order to find out their willingness or otherwise to be involved in this work. The response so far has been very positive, with groups feeding back their enthusiasm and interest for this work.

Members of the Reference Groups will also receive human rights training focusing on issues relevant to people who have mental health needs and/or a learning disability. They will review the work completed by the Action Group and feedback any concerns/recommendations directly to this group. This will ensure that the needs/wants of a broad range of people who are members of socially excluded groups are properly taken account of in the Service User and Carer Charter.

The training session will be delivered by service users who are members of the ARISE Project and will focus on the following areas:

- History of human rights – their development following World War II
- Human rights in relation to people with mental health needs and/or a learning disability
- Human rights protection under the law
- Key principles underpinning human rights
- Claiming your human rights
- Raising human rights concerns/issues in order to have these taken account of in your care or the care received by the persons you care for

The training will be both academic and experiential as this is enabling and empowering to learners. It is anticipated that following the delivery of this training to groups working in the voluntary and community sector, a greater number of people who use services and their carers will feel empowered to challenge and discuss human rights issues that may exist within their own care packages.

This process will also aid the TEWV NHS Trust in its formation as a Foundation Trust and ensure that the organisation has a large number of people active within the Third Sector (Voluntary and Community Sector Services) with whom it has engaged in a positive manner. Following on from this experience these individuals and groups may then be willing to become involved in the strategic and operational workings of the organisation.

4. WHAT – Issues identified by the Trust in taking forward the project and how these were addressed

Particular human rights identified as relevant by group members during the induction day delivered by BIHR include:

- The right to respect for family and private life
- The right to liberty

- The right not to be tortured or treated in an inhuman or degrading way
- The right to freedom of expression

All of the above are particularly pertinent to people with mental health needs and/or a learning disability and their carers.

One of the issues identified as a potential barrier to the work was lack of access to and awareness of information about human rights for service users and carers and staff members.

An example of this for service users and carers is outlined below:

Group members consulted with some service users and carers in a group already involved in evaluating services within the organisation in relation to their willingness to be involved in rewriting the service user and carer charters, one of which they had written. Their response was that this process would be 'unwieldy'. They were however willing to write an 'add on' document which could be provided in addition to the Charter.

These group members have not as yet received human rights training and had spent a lot of time and energy in writing the charter in the first place. It was therefore felt that to challenge this would be unfruitful and possibly even damaging at this point. Therefore we are hopeful that following delivery of human rights training, this group may well decide that they are willing to be involved in this work and see the usefulness of incorporating human rights into the service user and carer charter for themselves.

If the Trust was to undertake a project of this nature again we would want to deliver human rights training to as many individuals and groups across the organisation as possible. This would have given a greater number of service users, carers and staff the information with which to make a more informed decision about the area to be looked at. This would have potentially reduced the barriers to engagement which we may now face as a result of time constraints within the project. This would also have ensured that we had a broader range of people with whom to consult in relation to the area of work to be undertaken.

We would also prioritise engagement with people who are members of socially excluded groups. This would be appropriate to a Human Rights Based Approach and would ensure that the voices, thoughts and feelings of those people who suffer from the highest level of marginalisation were steering this work. Although members of the Steering Group are also members of socially excluded groups we are aware that we have not been able to include all of those people who suffer from social exclusion and are currently working to address this issue through the contacts we are making in the voluntary and community sector.

5. Progress to date and next steps

- What has been delivered so far?

The first draft of the human rights training has been commented on by BIHR and is in the process of being redrafted in light of the comments/recommendations made. We are hopeful that this will be ready to roll out by the end of March 2007. We are aiming to make this as experiential an exercise as possible to aid learning.

- What have been the benefits to the Trust and patients/service users so far?

Benefits for the Trust include the development of a systematic approach to consultation and engagement that takes account of the needs of those people most marginalised and socially excluded.

A further benefit to the Trust is the development of human rights training for service users, carers and staff members. This will ensure that human rights are not seen as an alien concept but a real, working set of principles that can be applied in the day-to-day work of the organisation. This will impact upon the care given by staff members and increase the capacity of service users and carers in asserting their rights and acting to have them met.

- What action is planned beyond this initial phase?

The next step is to develop a business case outlining the area of work, to include what, who, where, how, and importantly the costs/resources needed for this work. This will need to be approved at Board level. There is however already a willingness to carry this work forward across the organisation and we are hopeful there will be a favourable response to the business case we submit in relation to the Service User and Carer Charter.

Regarding the future work we hope to undertake in relation to the Care Programme Approach, we would include a period of consultation following on from the delivery of Human Rights Training. This would ensure that the areas of the Care Programme Approach on which we focus truly reflect the needs/wants of the people with whom we are engaging, namely those people who have mental health needs and/or a learning disability and their carers.

We would again present a business case to the Board for approval, although it makes sense to wait until the consultations at the Department of Health level have been completed and recommendations as to future directions have been decided prior to undertaking this work.

Contact:

Jacqui Lovell, R & D Manager
Email: jacqui.lovell@tney.northy.nhs.uk

Glossary

Human Rights Based Approach (HRBA)
A human rights based approach is one where the realisation of human rights principles are a central aim in policy and planning, where staff and patients are empowered and involved in achieving these, where accountability is clear and the most vulnerable are prioritised. It is the process by which human rights principles are put into practice.

European Convention on Human Rights
The European Convention on Human Rights is a regional human rights treaty made by the member states of the Council of Europe after the Second World War. The Convention established a European Court of Human Rights, based in Strasbourg, France. The UK signed up to the Convention in 1951.

Human Rights Act
The Human Rights Act became effective in the UK in October 2000. It brought most of the rights contained in the European Convention on Human Rights into UK law. The Act places a duty on all public authorities in the UK to act in accordance with the rights protected by the Convention.

Public authority
The term ‘public authority’ is not fully defined in the Human Rights Act, but it should be interpreted broadly. It includes any person or organisation ‘whose functions are of a public nature’. Health authorities, NHS Trusts, Primary Care Trusts are all included. The term covers private organisations such as companies or charities, but only when they are carrying out a public function.

Absolute rights
These rights may never be interfered with, not even in times of war or national emergency. Lack of resources is never an excuse for interfering with an absolute right. An example is Article 3 (the prohibition of torture, inhuman and degrading treatment).

Limited rights
These rights are not absolute. They may be limited in certain strictly defined circumstances. An example is Article 5 (the right to liberty and security). This right may be limited in circumstances including where someone has committed a crime or where someone is suffering from serious mental health problems.

Qualified rights
These rights are not absolute. They may be interfered with so long as the interference is (1) lawful, (2) for a legitimate purpose, (3) necessary and (4) proportionate (see ‘proportionality’ below). An example is Article 8 (the right to respect for private and family life, home and correspondence).

Proportionality
A proportionate response to a problem is one that is appropriate and not excessive in the circumstances. The expression commonly used to capture this meaning is *you should not use a sledgehammer to crack a nut.*

Positive obligations
These obligations require authorities to take proactive steps to protect human rights. Positive obligations are often contrasted with negative obligations which require authorities to refrain from action that may violate human rights.

Useful Websites

Audit Commission
www.audit-commission.gov.uk

British and Irish Legal Information Institute (useful source of case law)
www.bailii.org

British Institute of Human Rights
www.bihr.org.uk

Commission for Equality and Human Rights
www.cehr.org.uk

Department of Health
www.dh.gov.uk

European Court of Human Rights Home Page
www.echr.coe.int

Human Rights Division, Department for Constitutional Affairs
http://www.dca.gov.uk/peoples-rights/human-rights/index.htm

Joint Committee on Human Rights (Houses of Parliament)
www.parliament.uk/parliamentary_committees/joint_committee_on_human_rights.cfm

Justice
www.justice.org.uk

Liberty
www.liberty-human-rights.org.uk

Mental Health Act Commission
www.mhac.org.uk

NHS Litigation Authority
www.nhsla.com

Office of the UN High Commissioner for Human Rights
www.ohchr.org

United Nations Home Page
www.un.org

World Health Organization
www.who.int

Further Resources

Health-specific resources:

Croft, Jeremy: *Health and Human Rights – a guide to the Human Rights Act 1998*, The Nuffield Trust, 2003 (available from www.nuffieldtrust.org.uk)

Lilley, Lambden and Newdick: *Understanding the Human Rights Act – a toolkit for the health service*, Radcliffe Publishing, 2001

Mental Health Act Commission: *Making it real – a human rights case study*, January 2007 (available from www.mhac.org.uk)

NHS Litigation Authority Human Rights Information Service: www.nhsla.com/humanrights

Wilkinson and Caulfield: *The Human Rights Act – a practical guide for nurses*, Whurr Publishers, 2000

World Health Organization: *25 Questions and Answers on Health and Human Rights*, Health and Human Rights Publications Series, July 2002 (available from www.who.int)

Non health-specific resources:

Guides/toolkits

British Institute of Human Rights: *Your Human Rights Guides*, 2006 (available from www.bihr.org.uk)

Department for Constitutional Affairs: *A Guide to the Human Rights Act 1998* (3rd Edition), October 2006

Department for Constitutional Affairs: *Human rights: human lives – a handbook for public authorities* (available from http://www.dca.gov.uk/peoples-rights/human-rights/index.htm)

Office of the Deputy Prime Minister: *Guidance on contracting for services in the light of the Human Rights Act 1998*, 2005 (available from www.communities.gov.uk)

Watson, Jenny and Woolf, Mitchell: *Human Rights Act Toolkit*, LAG, 2003

Reports

Age Concern: Rights for Real – *Older People, Human Rights and the CEHR*, May 2006

Amnesty International Irish Section: *Our Rights, Our Future, Human Rights Based Approaches in Ireland: Principles, Policies and Practice* (available from www.amnesty.ie)

Audit Commission, *Human Rights: Improving Public Service Delivery*, September 2003 (available from www.audit-commission.gov.uk)

Butler, Frances: *Improving Public Services: Using a human rights approach*, IPPR, June 2005 (available from www.ippr.org)

Carers UK: *Whose rights are they anyway? – Carers and the Human Rights Act* (available from www.carersuk.org)

Daw, Rowena: *The Impact of the Human Rights Act on Disabled People*, Disability Rights Commission and the Royal National Institute for Deaf People, September 2000 (available from www.drc-gb.org)

Finnegan, Patricia and Clarke, Stephen: *One law for all? The impact of the Human Rights Act on People with Learning Difficulties*, VIA UK, August 2005

Help the Aged: *Rights at Risk: older people and human rights,* 2005 (available from www.helptheaged.org.uk)

Watson, Jenny: *Something for everyone: The Impact of the Human Rights Act and the Need for a Human Rights Commission*, The British Institute of Human Rights, December 2002 (available from www.bihr.org.uk)

Books

Clements, Luke (ed.): *Human Rights Act: A Success Story?*, Blackwell, 2005

Drabble, Maurici and Buley: *Local Authorities and Human Rights*, OUP, 2004

Harris, O'Boyle & Warwick: *Law of the European Convention on Human Rights*, Butterworths, 2003

Harvey, Colin (ed.): *Human Rights in the Community: Rights as agents for change*, Hart Publishing, 2005

Hoffman & Rowe: *Human Rights in the UK – an introduction to the Human Rights Act 1998*, Pearson Longman, 2006

Leach: *Taking a Case to the European Court of Human Rights* (2nd Edition), OUP, 2005

Lester & Pannick: *Human Rights Law and Practice*, Butterworths, 2004

Simor, Jessica and Emmerson, Ben QC: *Human Rights Practice*, Thomson, Sweet & Maxwell

Starmer: European Human Rights Law: *The Human Rights Act 1998 and the European Convention on Human Rights*, LAG, 1999

Wadham, Mountfield and Edmundson: *Blackstone's Guide to the Human Rights Act 1998*, OUP, 2003

Endnotes

i Targets include:

- Challenge discrimination, promote equality and respect human rights (C7)
- Have systems in place to ensure that staff treat patients, their relative and carers with dignity and respect (C13)

National Standards Local Action Framework – Health and Social Care Standards and Planning Framework 2005/6 – 2007/8 (available from www.dh.gov.uk)

ii Dignity in Care
http://www.dh.gov.uk/en/Policyandguidance/Healthandsocialcaretopics/Socialcare/Dignityincare/index.htm

iii Commissioning a Patient-Led NHS
http://www.dh.gov.uk/en/Policyandguidance/Organisationpolicy/Commissioning/Commissioningapatient-ledNHS/index.htm

iv Patient Choice
http://www.dh.gov.uk/en/Policyandguidance/PatientChoice/index.htm

v Our health, our care, our say: a new direction for community services – http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4127453

vi Audit Commission, *Human Rights: Improving Public Service Delivery*, September 2003

vii Participating Trusts are: Mersey Care NHS Trust, Surrey & Borders Partnership NHS Trust, Southwark Health & Social Care, Tees, Esk & Wear Valleys NHS Trust and Heart of Birmingham PCT

viii Through Mental Health Act Commission: *'Making it real – a human rights case study'* Project, 2007

ix www.udhr.org

x Article 12, International Covenant on Economic, Social and Cultural Rights. More about the right to the highest attainable standard of health can be found at http://www.who.int/hhr

xi Text of international human rights instruments can be found at www.ohchr.org/english/law/index.htm

xii Full text available from www.coe.int xiii Department for Constitutional Affairs Human Rights Conference 30 October 2006

xiv World Health Organization: *25 Questions and Answers on Health and Human Rights*, Health and Human Rights Publications Series, July 2002

xv Constitution of the World Health Organisation, www.who.int

xvi Joint Committee on Human Rights, 6th report, 'The Case for a Human Rights Commission', 12

xvii *R(H) v Mental Health Review Tribunal, North and East London Region* (2001).

xviii HL v the United Kingdom, 2005

Evaluation of this Framework

1. What do you believe is the value of the knowledge you have gained from reading this framework?

No value	Of some value	Lots of value
☐	☐	☐

2. How confident are you in your ability to interpret human rights in a Healthcare setting after reading this framework?

Not confident	Confident	Very confident
☐	☐	☐

3. How equipped do you feel to apply the knowledge you have gained from reading this framework to your work area?

Not equipped	Equipped to some extent	Fully equipped
☐	☐	☐

4. After reading the framework how confident are you that you will be able to engage the Trust in carrying out a human rights Based Approach to your work area?

Not confident	Confident	Very confident
☐	☐	☐

5. What do you intend to do now that you have read this framework?

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6. Was there anything within the framework that you would have liked further information on?

____

____

____

7. Was there something within the framework that you felt there was too much information on?

8. Any other comments?

Please email responses to mark.joannides@dh.gsi.gov.uk

Or alternatively send responses to:
Human Rights in Healthcare – A Framework for Local Action
Equality and Human Rights Group
Department of Health
Skipton House
80 London Road
London
SE1 6LH

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