

A GUIDE TO EVALUATING HUMAN RIGHTS-BASED INTERVENTIONS IN HEALTH AND SOCIAL CARE

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ABBREVIATIONS

BIHR	British Institute of Human Rights
BILD	British Institute of Learning Disability
CLDT	Community learning disability team
HRA	Human Rights Act 1998
HRBA	Human rights-based approach
HRBT	Human Rights Benchmarking Tool
HR-JRAMP	Human Rights Joint Risk Assessment and Management Plan
REC	Research Ethics Committee
SHRC	Scottish Human Rights Commission

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INTRODUCTION

Where this guide came from

For the past five years, the Department of Health, the British Institute of Human Rights (BIHR) and a number of NHS Trusts have been working together within the Human Rights in Healthcare Programme (www.humanrightsinhealthcare.nhs.uk). The programme assists NHS trusts to put human rights into practice in different areas of their work. The trusts involved in the programme during 2011-12 have developed and 'road tested' a range of practical human rights-based tools which:

- put human rights at the heart of health and social care
- provide staff with a framework of common values
- engage and empower service users
- improve the quality of care for patients, and
- support existing national health care 'drivers'; for example, personalisation and dignity in care.

It was also decided to develop this guide to evaluating human rights-based interventions in health and social care in order to:

- ensure that evaluation of a human rights-based intervention is built in from the earliest possible stage
- encourage a realistic and proportionate approach to evaluation, and
- embed evaluation of human rights developments into the culture of NHS organisations.

Aims of this guide

This guide provides a starting point for health and social care organisations that wish to evaluate the impact of human rights-based interventions. It does not suggest a single or 'right' way of approaching your evaluation. Rather, it examines a wide variety of methods that have been used in previous evaluations of human rights-based projects.

Nor is it a comprehensive guide to monitoring and evaluation in general; see the [Resources](#) section for some generic step-by-step guides to monitoring and evaluation that have been developed for public and voluntary sector organisations.

This guide focuses on particular aspects of evaluation that are relevant to human rights-based projects. Underpinning the guide is a set of human rights principles that provide a foundation for both your human rights-based intervention and your evaluation. These are explained in more detail in [Chapter 2](#).

Using this guide

Chapter 1 discusses why evaluation matters. **Chapter 2** draws on the evidence of previous evaluations to outline the common elements of a human rights-based approach to health and social care.

Chapters 3-9 will assist you to plan and design your evaluation by identifying key areas that you need to think about. These chapters will also help to ensure that your evaluation conforms to human rights principles.

Chapter 10 consists of nine case studies of previous evaluations of human rights-based interventions.

At the end of this guide you will find:

- a **checklist** of key things to consider in designing your evaluation
- a **glossary** of commonly-used terms
- a reminder of the **PANEL principles** (explained in detail in **Chapter 2**), and
- a **Resources** section, which contains publications and websites related to human rights-based approaches to health and social care and to evaluation.

Throughout this guide, you will see references to various **Annexes**. These are examples of road-tested evaluation tools that you may wish to adopt – or adapt – for your evaluation. For ease of downloading and printing, these are contained in a separate document, *A guide to evaluating human rights-based interventions in health and social care: Annexes*. This is available at: <http://www.humanrightsinhealthcare.nhs.uk>.

Who is this guide aimed at?

This guide is aimed at all those within NHS organisations who are involved in human rights-based interventions or who are interested to develop such interventions.

It is of particular interest to: the Department of Health; commissioners of health and social care; NHS Trusts; independent sector providers; professional associations; inspection and regulatory bodies; and advocacy organisations.

1. WHY EVALUATION MATTERS

The chapter addresses the question, ‘**why** should I evaluate?’.

Under the Human Rights Act (HRA) 1998, public authorities – including NHS organisations - have a legal obligation to respect and protect human rights. This requires them not only to refrain from breaching human rights (‘negative’ obligations) but also, in some circumstances, to take proactive steps to protect people from human rights abuses - even if the harm is caused by private individuals rather than directly by the authority (‘positive’ obligations). For example, if there is evidence that a patient is being abused by relatives, NHS organisations have a positive obligation to investigate this and, where necessary, take steps to prevent it.

How public authorities meet these obligations is likely to vary between institutions and professions with, for example, different targets, statutory and regulatory regimes, codes of ethics, and so on.

Some public authorities have chosen to adopt what is known as a human rights-based approach (HRBA). This approach views human rights as **both**:

- a set of legal standards and obligations, and
- a source of principles and practical methods which determine **how** those standards and obligations are achieved.

The Human Rights Act 1998

The Human Rights Act gives further effect in UK law to the fundamental rights and freedoms in the European Convention on Human Rights. Section 6 of the HRA requires all public authorities to act in a way which is compatible with the Convention rights (unless primary legislation requires them to act otherwise).

In other words, human rights are both an end and a means. Both aspects are important but we need to keep the distinction between the two clear in order to identify the added value of using human rights as a practical, everyday tool (the ‘how’ question).

Interventions which choose explicitly to use human rights in preference to, or in combination with, other approaches to policy and practice need to be backed up in terms of evidence and effectiveness. The question needs to be answered: is an intervention based upon human rights principles preferable to an alternative that could be pursued with comparable resources and which at least aims to produce similar – human rights compliant - outcomes? If so, in what ways is it preferable?

One evident benefit of ‘using human rights to achieve human rights’ is that it helps to ensure that human rights are respected and promoted at each stage of a process or activity. [Chapter 2](#) examines what it means in practical terms to embrace human rights as a framework for organisational change – to use human rights ‘along the journey’ as well as viewing human rights as the goal to be achieved.

However, the answer to our question will also involve identifying desired outcomes: using a human rights-based approach is not an end in itself but a means to achieving beneficial change for service users, carers and staff (and relationships between all these), as well as for the organisation as a whole (see [Chapter 5](#)). This, in turn, will entail – but not be limited to – consideration of the best use of resources to achieve the desired outcomes. This is sometimes described as making the ‘business case’ for human rights-based interventions. The business case involves not only the financial ‘bottom line’ but also, for example, the use of human rights as a tool of risk management (see [Case Studies B and C](#)). Indeed, making the business case may involve challenging and redefining - from a human rights perspective - prevalent notions such as ‘efficiency’ and ‘value for money’.

At the level of a specific NHS organisation, evaluation matters because it is a means of establishing ‘what works’. Setting clear objectives - and monitoring progress towards those objectives on the basis of evidence - will enable health bodies to get the biggest impact for their human rights ‘investment’. Also, the ability to identify progress at different stages of the intervention enables staff to identify and celebrate achievements. This may increase motivation and make the HRBA more sustainable.

In a larger sense, evaluations – and especially those that take place over the longer term - are a means of creating an evidence base for the value of human rights-based interventions in health and social care. Without such an evidence base, we are left only with unsubstantiated claims or moral exhortations that are unlikely to be persuasive to decision-makers.

Key messages

- Under the Human Rights Act, public authorities – including NHS organisations - have a legal obligation to respect and protect human rights.
- Human rights are both (i) a set of legal standards, and (ii) a set of principles and practical approaches that determine **how** those standards are achieved.
- Evaluation will help you to establish ‘what works’ – to identify your achievements and improve your practice. More broadly, evaluations of specific projects will help to build an evidence base for the value of applying human rights in health and social care.

2. WHAT DOES A HUMAN RIGHTS-BASED APPROACH TO HEALTH AND SOCIAL CARE LOOK LIKE?

Before we turn to the design of your evaluation, it may be helpful to outline the common elements of a HRBA. It should be emphasised that there is no fixed template for how to embed human rights thinking and practice into an organisation, service or team. The process is a creative rather than prescriptive one. For example, it has been likened to a ‘magnet’ pulling policy, practice and organisational culture in a certain direction.

However, some common elements can be identified. We can divide these into:

- (i) the **principles** that underpin human rights-based interventions, and
- (ii) the **organisational dimension**: the type of activity - made visible in structure and process - that needs to happen to make those principles meaningful.

2.1 Principles

There are five broad principles which are widely recognised as core elements of a HRBA. These are known as the PANEL principles. They provide a useful foundation not only for human-rights based interventions but also for evaluations of such interventions.

Participation

People have a right to participate in decisions that affect their lives. Moreover, a process of change is more likely to be effective if all the communities of interest concerned participate in it systematically – especially those whom it is meant to benefit. This principle underpins an important aspect of a HRBA, which is to identify and, where necessary, change structures which determine who makes decisions and whose voice is heard and acted upon.

Accountability

Once goals for respecting, protecting and fulfilling rights are set, clear mechanisms need to be created that allow people to hold to account those with responsibility for ensuring these goals are met.

The PANEL principles

Participation in one’s own development

Accountability of duty-bearers to rights-holders

Non-discrimination and prioritisation of vulnerable groups

Empowerment of rights-holders

Legality: the express application of a human rights framework

Non-discrimination

The principle of non-discrimination recognises that some people and groups in society, at different times and in different circumstances, face discrimination in the enjoyment of their human rights. Targeted action is needed to address these inequities. Underpinning this principle is the idea that human rights are universal: everyone has rights regardless of their identity or background and rights are not privileges to be 'earned' or a matter of discretion.

Empowerment

Human rights provide a framework within which to challenge unequal power relationships and recast relationships between groups with differential power. In a health or social care setting, this might mean identifying and addressing power imbalances between service users and providers. The principle of empowerment recognises that human rights are largely meaningless if we are not aware that we have them or lack the ability or means to claim them. Similarly, those with a responsibility to prevent or respond to human rights breaches (such as public servants) cannot reasonably be expected to undertake this role if they are not supported to embrace it.

Legality

This principle refers to the express application of human rights standards in policy and practice. These standards are not limited to those contained in the Human Rights Act, but also include those in international human rights treaties which the UK has ratified (see [Annex 9](#)). The application of human rights standards can be described as using a human rights 'lens' to view and reframe particular problems, experiences and relationships. For example, bathing a person or assisting them to the toilet without regard to their privacy or dignity may in some circumstances amount to a breach of their right to respect for private life. Using excessive force to restrain someone may in some circumstances amount to a breach of their right not to be subject to inhuman or degrading treatment.

Viewing what has happened through a human rights lens involves identifying:

- which human right/s is/are relevant
- who they belong to (who is the 'rights-holder') and
- who is responsible for protecting those right/s (who is the 'duty-bearer').

It is important to remember that members of staff are not only duty-bearers but also rights-holders.

Balancing rights

In a specific situation, the explicit use of the human rights framework permits professionals to balance different people's rights and to know when one person's rights can be restricted to protect those of others, e.g. other service users, staff or the wider community. Central to this balancing act is the principle of proportionality.

Proportionality can be summarised as 'not using a sledgehammer to crack a nut'. It ensures that any restriction of a person's human rights is kept to a minimum.

The prior question to be asked is 'does the nut really need to be cracked?'. In other words, is the proposed restriction on the rights of a person a matter of **necessity**, to protect the rights of others? This question matters because any restriction of a person's right must be explicitly and transparently justified. If the answer to the question is 'yes', then to decide whether restrictions on a right are proportionate, three further questions need to be asked:

- Are there reasons for the restriction?
- Is there a less restrictive alternative that could apply?
- Have I considered the rights of all those affected?

2.2 Organisational dimension

We noted above that there is no single blueprint for implementing human rights principles in an organisation, department or team. However, previous evaluations of HRBAs in public service settings identify a number of broad lessons in relation to implementation. These include lessons that relate to policies and procedures, as well as steps that aim to bring about changes in behaviour and organisational culture. These lessons are not necessarily unique to the implementation of human rights – they may apply equally to other processes of concerted institutional change.

Generally, evaluations of HRBAs in different settings suggest that common elements are:

Leadership

Visible support from chief executives, board members and senior staff and clear executive leadership is vital for the process of implementation. For example, it is important that leaders publicly demonstrate how human rights fit with and reinforce other organisational priorities and values – 'articulating what their particular organisation might look like and how it might operate if human rights were embedded into every aspect of its work' (Office of Public Management, 2009: 9).

Participation of service users and carers

A common feature of human rights-based projects is the systematic participation of serviced users and carers in decisions that affect them; for example, decisions about care and treatment; the monitoring of service delivery and the planning of service improvement. Mersey Care NHS Trust (see [Case Studies B-G](#)) has promoted the systematic participation of service users and carers in:

- recruiting and training staff
- research, audit and evaluation of services
- serious incident reviews, and
- the development of an information and communications strategy to enable service users and carers to make informed decisions.

Evaluations of this experience (Dyer, 2010; Mersey Care NHS Trust, 2011) suggest that service user and carer involvement has:

- challenged entrenched and often prejudicial attitudes to service users as passive recipients of care or services, rather than as active participants in shaping and evaluating those services
- made services more responsive to the people that use them
- improved relationships between service users and staff and made them partners in finding shared solutions to problems, and
- eroded stigma and mistrust between service users and professionals.

Creating 'champions'

The success of a HRBA can be enhanced by the creation of a network of committed 'champions' at different levels of seniority who can advocate for human rights among staff and stimulate interest. The intention is to create a continuous cycle of reinforcement of the HRBA from the top to the bottom of an organisation. For example, NHS trusts in the Human Rights in Healthcare programme whose projects focused on care homes involved housekeeping and kitchen staff, as well as nursing and care staff, in human rights training (Ipsos MORI, 2010: 90).

Changing everyday behaviour

Some evaluations place emphasis on the imperative to achieve behavioural change in the workplace at the level of everyday practice, as well as on more strategic issues like leadership, policies and procedures. A report on the development of a HRBA to cancer care notes that a focus on behaviour 'encourages self-reflection and self-regulation on the part of staff ... Organisational culture change **is** behaviour change' (brap, 2010: 35).

Training

Training in human rights principles and standards is almost invariably an element of a HRBA. Evaluations (ekosgen, 2011; Ipsos MORI, 2010: 93; Redman et al, 2012) suggest that successful human rights training is that which:

- has the active endorsement of senior managers
- is tailored to the organisation and developed in partnership with staff
- gives immediate opportunities to participants to put their learning into practice
- is spaced over time to permit reflection and consolidation between sessions, and
- is integrated into core training programmes rather than being a 'one-off'.

Integrating human rights into existing policies and practices

Organisations that have sought to embed a HRBA have commonly integrated human rights into existing equality and diversity mechanisms or care planning processes, rather than viewing human rights as a 'bolt on'. Organisations have used human rights as a basis for embracing new policy imperatives - such as commissioning, partnership working, user choice and personalisation. In this sense, human rights can provide an overarching framework over the longer term, as other policy agendas come and go. Human rights are described by clinicians at Mersey Care NHS Trust as providing an 'elegant, unifying conceptual framework drawing together disparate strands of current best practice and making these real in the lives of the people who use our service' (Roberts et al, 2010a: 9).

Informing people about their rights

It is possible to build momentum for change by:

- informing service users and carers about their rights in accessible language, and
- strengthening advocacy arrangements which help them to articulate their views and experiences in human rights terms.

Regular reviews of policies and procedures

Organisations that wish to embed human rights in their decision-making are likely to review their policies and procedures for human rights compliance. This may take the form of a human rights 'audit', involving staff and other interested parties (see, for example, [Case Study I](#)). A commonly-used device is a 'traffic light' system where red signals non-compliance with human rights and amber a risk of non-compliance.

Use of external human rights expertise

Some human rights-based interventions have brought in external specialists at the outset; for example, the British Institute of Human Rights has advised the Human Rights in Healthcare programme and The State Hospital ([Case Study I](#)) involved external experts in its human rights audit. The need for external expertise will vary between projects and it may change or diminish over time.

Public commitment to human rights

Organisations that have adopted a HRBA commonly 'broadcast' their commitment to human rights to staff, service users, carers and the wider public; for example, by including human rights principles and language in public communications; producing best practice guides and codes of ethics; or developing a 'human rights charter'.

Focusing on the rights of everyone affected

An important attribute of human rights in a public service context is that they provide a framework for decision-making which balances in an explicit and transparent way the rights of all those involved - staff, service users, carers and, where appropriate, the wider community, since all are 'rights-holders'.

Key messages

- There is no single blueprint for how to embed human rights thinking and practice into an organisation, service or team: the process is creative rather than prescriptive.
- However, human rights-based interventions share common **principles** and **organisational dimensions**: the type of activity - made visible in structure and process - that needs to happen to make those principles meaningful.
- The guiding principles can be summarised as PANEL: participation, accountability, non-discrimination, empowerment and legality.

3. DECIDING WHO TAKES PART IN YOUR EVALUATION

This chapter addresses the question, ‘**who** should take part in my evaluation?’. It examines the issue of how service users and their carers can participate in your evaluation. It also discusses the pros and cons of keeping your evaluation purely internal to your organisation as opposed to involving external actors.

3.1 Service users’ and carers’ participation in your evaluation

As we saw in [Chapter 2](#), the participation of service users and carers in decisions that affect them - the first of the ‘PANEL’ principles - is an integral part of many human rights-based projects. According to Roberts et al (2011: 2) involving service users and carers in all aspects of service design and delivery is no longer a mere ‘optional extra’, but has a moral, policy and legislative backbone: ‘Where once tokenistic gestures of engagement were seen by many in services as “adequate”, political drivers have rendered service user and carer involvement essential’. Clinicians at Mersey Care (drawing on the work of Boyle and Harris, 2009) have attempted to produce a shift towards ‘co-produced’ public services, defined by reciprocal relationships and a more balanced distribution of power between professionals and people who use services and their carers.

It follows that if service users and carers participate in the design and delivery of your human rights-based activity, then they should also participate in the evaluation of the activity. This has been attempted to varying degrees in the case studies reviewed in this guide.

It is important to note that the priorities of service users and carers may differ from those of the professional. For example, there may be a tension between:

- identifying outcomes that make sense to the life of a person using a service (who might ask, ‘what will change for the better in my life?’), and
- identifying outcomes that make sense to the professional (who might ask, ‘what are the targets and indicators that I am obliged to report against?’ or ‘what are my priorities as a clinician?’).

Case Study D is a good example of the potentially transformational impact of the participation of service users in defining what ‘success’ would look like for the project. In this example (the evaluation of the ‘Standing up for my human rights group’ at Mersey Care NHS Trust), service users redefined the objectives of the activity – and therefore of the evaluation - after the project got underway. The group thereby achieved beneficial outcomes that were not originally foreseen by the professionals involved. The evaluators recommend that in the future, service users

should participate in decisions about the format of the evaluation and should work with staff to set up, run and evaluate the activity as 'service user facilitators'.

3.2 In-house or external evaluation

A decision to be made early on is whether your evaluation will be conducted in-house or by an external, independent evaluator - or a mixture of the two. The case studies in this guide have used a combination of approaches, from wholly in-house to wholly external, with some bringing in outside specialists on specific areas. For in-house evaluations, it is useful to distinguish between staff or service users who are directly involved in the project, and staff or service users from other parts of the organisation who are not directly involved in the project.

There are pros and cons to each approach, depending on the circumstances. An in-house evaluation benefits from the detailed knowledge that you and your team have about your activity. Keeping the process in-house might also make it easier to manage the evaluation and ensure that it stays within available resources.

On the other hand, you may feel that your team is ill-equipped to undertake its own evaluation and needs to bring in an outsider with specialist skills or knowledge, either from another team or department within your organisation or from an external organisation. In some cases, e.g. where an activity is particularly ambitious or high-profile, it may be necessary to involve external evaluators to ensure that the process is seen to be unbiased. You should also consider whether, if you conduct the evaluation yourself, participants will be open and honest; for example, if they know you, they may express more favourable responses than they really feel in order to avoid offending you or because they fear negative repercussions.

If your evaluation does involve people external to your team or organisation, it is even more important to be clear about the objectives of both the activity and the evaluation – otherwise there is a risk that the values and purpose of the project become overtaken by those of the external evaluator.

Key messages

- The participation of service users and carers in decisions that affect them is an integral part of many human rights-based projects: it follows that service users and carers should also participate in evaluating projects.
- Such participation is potentially transformational, since service users or carers may have very different priorities from those of the professional.
- Your evaluation can be conducted in-house or by external specialists - or by a mixture of the two.

4. THE DIFFERENT STAGES OF EVALUATION

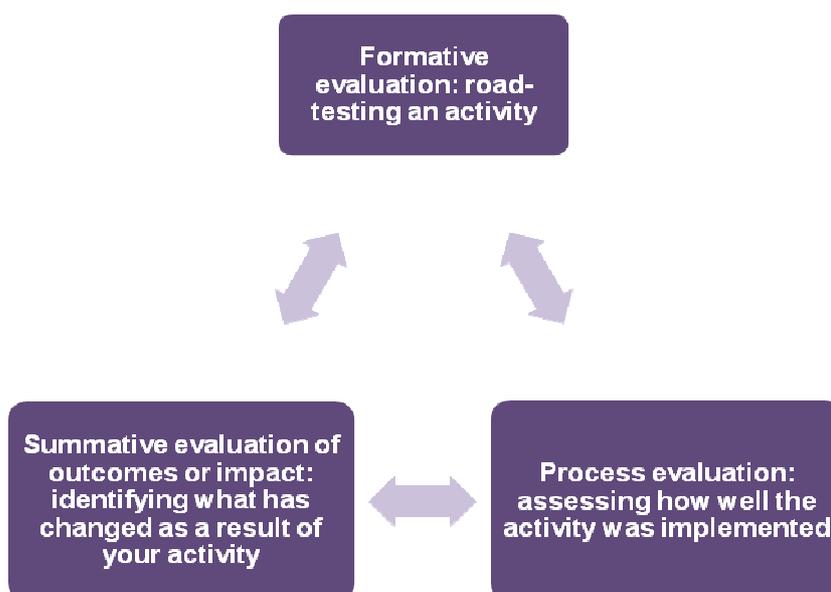
This chapter addresses the question, ‘**when** should I evaluate?’. It examines the stages at which evaluation may take place during your human rights-based intervention. It also discusses what sorts of questions might be asked at different stages, recognising that different types of change are likely to occur over different timescales. For example, changes to an organisation’s culture are unlikely to be rapid and therefore an evaluation which seeks evidence of such change at an early stage is likely to be disappointing.

The chapter introduces the following broad stages of evaluation:

- formative evaluation
- evaluation of process
- summative evaluation of outcomes
- summative evaluation of impact.

Evaluation is not necessarily a linear process – indeed for longer-term or multi-stage projects, it may be more cyclical or iterative, as shown in Figure 1. Nor will you necessarily undertake an evaluation at each of these stages; for example, you may not need to do a formative evaluation, or it may be premature for you to do a summative evaluation of outcomes or impact. However, it might be useful for you to think about your evaluation in relation to the broad stages outlined in this chapter.

Figure 1: The stages of evaluation



Monitoring

At this stage, we should also introduce the idea of monitoring. Monitoring is about counting things (such as the number of participants in training sessions) in order to ensure that your activity is on track as you go along. The same basic tools for gathering and analysing data can be used for both evaluation and monitoring (see [Chapter 5](#)).

4.1 Formative evaluation

A formative evaluation is one which takes place during the development of an activity in order to 'road-test' elements of it with a sample of your target group. For example, you may want to try out all or part of a training activity in order that you can make immediate improvements to it and better meet your objectives. At this stage, you are likely to use discussion-based tools (qualitative research) (see [Chapter 5](#)) that will give you a detailed understanding of your target group and the best way of attracting their interest and influencing them.

At this stage, you might ask questions such as:

- Does the group like the activity – does it engage their interest and do they think it is relevant to them?
- If not, why not?
- Do I need to adapt or refine my activity so it is more likely to help me meet my objectives?

Example: A formative evaluation of a human rights board game

Mersey Care NHS Trust developed a 'human rights board game', in which players move around a board and pick up cards that prompt them to discuss their own human rights and those of others using different scenarios ([Case Study G](#)). Using the prototype, the game was evaluated as a tool to facilitate human rights education for people with learning disabilities, carers and professionals. Some players found the game too complicated. As a result, before the game went into production, it was revised to make it more accessible to people with more severe cognitive impairments or limited verbal and literacy skills.

4.2 Evaluation of process

A 'process evaluation' focuses on the **management and implementation** of your project. Conducting an evaluation at this stage will help you and others run the same (or a similar) activity later.

At this stage, you might ask questions such as:

- Have the activities that were part of the HRBA been delivered as planned?
- Have they reached the intended group/s?
- How many participants have received human rights training or other form of tailored human rights activity?
- Are participants satisfied with the training or other activity? Did they perceive it to be relevant to them and of high quality?
- Have participants been given opportunities to put the learning from the training or other activity into practice?

Your monitoring data will help you to answer these questions.

Example: A process evaluation of human rights awareness training

Mersey Care NHS Trust developed an evaluation questionnaire which participants filled in before and after human rights awareness training for staff within a learning disability service (**Case Study E**). One aim of the evaluation was to assess staff responses to the training in terms of its usefulness, pace, format and structure, and to elicit suggestions for how it could be improved.

4.3 Summative evaluation of outcomes

A summative evaluation is one which looks at the **results** of your activity over a period of time. Outcomes are described by Ipsos MORI (2010: 16) as short-term changes that occur as a result of the HRBA and changes that are anticipated to occur in the next 3-12 months.

At this stage, you might to ask questions such as:

- Have human rights have been integrated into core areas of policy and practice, as intended?
- How is this integration made visible, e.g. in written policies and procedures; care plans, or other documentation?
- To what extent has the human rights activity produced changes in knowledge, understanding, skills, behaviour and/or perspective after a period of, say, 12 months (see Figure 2 in **Chapter 5** for discussion of these types of change)?
- In what specific ways are human rights better respected, protected and promoted as a result of the activity?

Example: Summative evaluation of the outcomes of a project to embed a human rights-based approach to risk

Mersey Care NHS Trust evaluated how far a human rights-based approach to assessing and managing risk had been integrated into the work of three Community Learning Disability Teams. Mersey Care had developed three practical resources to support staff to use human rights principles to assess and manage risk in their everyday work. The Trust used various methods of evaluation to determine what impact these tools had made on staff knowledge, attitudes and behaviour after 12 months (see [Case Studies B and C](#)).

4.4 Summative evaluation of impact

Ipsos MORI (2010: 16) describes impact as 'the long term reason for the programme – what it is designed to bring about'. It notes that this includes measures put in place to ensure the sustainability of the HRBA. Human rights-based interventions are principally concerned with effecting long-term change. Yet without doubt, this is the most difficult stage to evaluate and compelling evidence of longer-term impact is therefore elusive.

Some of the methods employed to determine impact may be similar to those used to determine short- and medium-term outcomes, but employed over a longer time-scale. In this sense, 'outcomes' and 'impact' are best viewed as a continuum rather than as essentially different types of change (see [Chapter 5](#)).

Changes to organisational culture are likely to be more evident over the longer term than in the earlier stages. Similarly, tangible changes in the lives and experience of people using services may become evident only over a longer time period. Indeed, in their earlier stages, HRBAs may appear to produce negative outcomes. For example, a service user's subjective assessment of (say) their quality of life or self-esteem might become more negative because they may, as a result of thinking about their human rights, realise they have a problem and find a new language to articulate it. The HRBA might take months or even years to 'pay off' visibly for the individual. This observation again highlights the importance of setting clear objectives for different stages of your human rights-based intervention.

At this stage, you might to ask questions such as:

- Has the culture of my organisation changed?
- Have relationships between staff and people using services changed?
- Have longer-term clinical outcomes for service users changed?
- In what specific ways are human rights better respected, protected and promoted as a result of the activity?

Example: Summative evaluation of the impact of the HRBA at The State Hospital

In 2009, the Scottish Human Rights Commission evaluated the impact of the human rights-based approach to facilitating cultural change at The State Hospital, a high-security mental health hospital in Lanarkshire ([Case Study I](#)). The intention was to enable the SHRC to identify key lessons that could help the hospital further improve its policies and practices. More broadly, the SHRC aimed to help other organisations to facilitate cultural change and integrate human rights into their day-to-day operations, behaviour and policy development.

4.5 Setting the baseline

Don't forget that if you're trying to change something, then you need to know the state of affairs **before** people interacted with, or were affected by, your activity, in order that you can see if there has been a change afterwards. This is known as setting the 'baseline'.

This imperative applies both to the project as a whole and to its constituent parts. For example, human rights training should involve a 'pre' and 'post' assessment of knowledge, understanding and/or attitudes in order that the impact of the training can be identified (see [Case Study E](#)). Where you are assessing 'before' and 'after' changes, it is important to ensure consistency of data so that, as far as possible, you are comparing like with like at each stage.

Key messages

- Evaluation can take place at different stages of your project.
- A formative evaluation allows you to 'road-test' all or part of your activity in order to make immediate improvements to it.
- A process evaluation allows you to assess how well your project was run and managed.
- A summative evaluation allows you to identify the results of your activity either in the short- to medium-term or longer-term.
- Don't forget to take the baseline – that is, the state of affairs before your activity – in order that you can assess 'before' and 'after' changes.

5. SETTING YOUR AIMS AND OBJECTIVES

This chapter addresses the question, ‘**what** should I evaluate?’. It examines different kinds of change that human rights-based interventions seek to bring about. It discusses how you go about setting the aims and objectives of your human rights-based intervention – and the difference between the two. Deciding upon clear aims and objectives is vital for your evaluation: if you are not clear at the outset about what you are trying to achieve, then it will be difficult to identify what ‘success’ looks like – let alone measure it.

For tips on how to frame your aims and objectives, you may find it helpful to refer to the generic guides to evaluation contained in the [Resources](#) section.

5.1 Setting your aims

The first step is to set your aim/s; that is, the longer term change/s the project seeks to bring about. You can think of these as ‘big picture’ goals: they are an expression of why your team or organisation exists and its broader purpose and vision. Generally, your aim/s should be able to be expressed in one or two sentences. Your aims will be geared towards producing changes or benefits for particular groups of people: these are commonly referred to as **impacts**. These impacts may be cumulative and may, over time, affect a wider group of people than the original ‘target’ group.

5.2 Setting your objectives

Objectives are the methods or concrete activities by which you will achieve your aim/s. The process of setting objectives will help you think through not only your evaluation strategy, but also the whole process of running your human rights-based intervention. Generally, the simpler an objective, the better: each objective is designed to achieve a single identifiable result which will show whether your intervention has succeeded. Such results are commonly referred to as outcomes; i.e. the short- and medium-term results of your activity. At this stage, you may also identify some specific outputs; i.e., tangible things that you will produce, e.g. a toolkit, DVD or website.

SMART objectives

An acronym often used to help set objectives is SMART.

Specific: What exactly will you do - and with or for whom?

Measurable: Will you be able to measure whether or not you are achieving, or have achieved, the objective?

Achievable: Can you achieve the objective within the time, skills and budget available?

Relevant: Will achieving the objective contribute directly to the achievement of your overall aim?

Time-bound: By when do you want to achieve this objective – and have you allowed enough time to get it done?

Example: Setting aims and objectives (see also [Case Study A](#))**Betsi Cadwaladr University Health Board: Putting human rights at the heart of hydration and nutrition: a toolkit for ward sisters and charge nurses**

The **aims** were to:

- adopt a human rights approach to hydration and nutrition as an innovative way of delivering excellence in nutrition and hydration by firmly placing the patient at the centre of care.
- promote high quality hydration and nutritional care standards, and
- embed dignity and respect and promote human rights with respect to hydration and nutrition within the everyday ward routine to ensure that it becomes a fundamental aspect of care.

The **objectives** were to:

- over 12 months, produce a human rights-based toolkit which would enable ward managers and multidisciplinary teams to apply a human rights-based approach to hydration and nutrition in their everyday practice, and
- over 12 months, undertake training and awareness-raising activity about human rights among multi-disciplinary teams, service users and six pilot wards (see [Case Study A](#) for details of who was involved).

The **output** was a practical toolkit which draws upon a number of defining principles and identifies six key components: Safety, Environment, Audit, Meal times, Choice and Empowerment. The six key areas are underpinned by a range of related practical interventions.

The desired (short-and medium-term) **outcomes** were to:

- increase knowledge and awareness of human rights in relation to hydration and nutrition for key staff (identified in [Case Study A](#)), and
- provide a practical human rights-based tool which other health organisations may wish to adopt.

The desired (longer-term) **impact** was to:

- achieve sustainable increases in hydration and nutritional standards of care
- influence patient clinical outcomes, and
- increase patient and carer satisfaction with the quality of care provided and hospital stay overall.

5.3 Setting aims and objectives for the evaluation

So far we have talked about setting aims and objectives for your wider project or activity. It is also good practice to set aims and objectives for the evaluation itself. These will be integrally linked to the aims and objectives of your wider project or activity.

For example, if one objective of your activity was to increase service users' knowledge of human rights (as in [Case Study D](#)), then one objective of your evaluation would be to find out whether, and by how much, service users' knowledge of human rights had, in fact, increased.

5.4 What sorts of change do human rights-based interventions seek to bring about?

In this section, we examine some specific types of change that human rights-based interventions might seek to bring about.

A HRBA may seek to effect change in a variety of ways. The emphasis and ambition of a project will vary between different initiatives in different contexts over different timescales and with varying levels of resources.

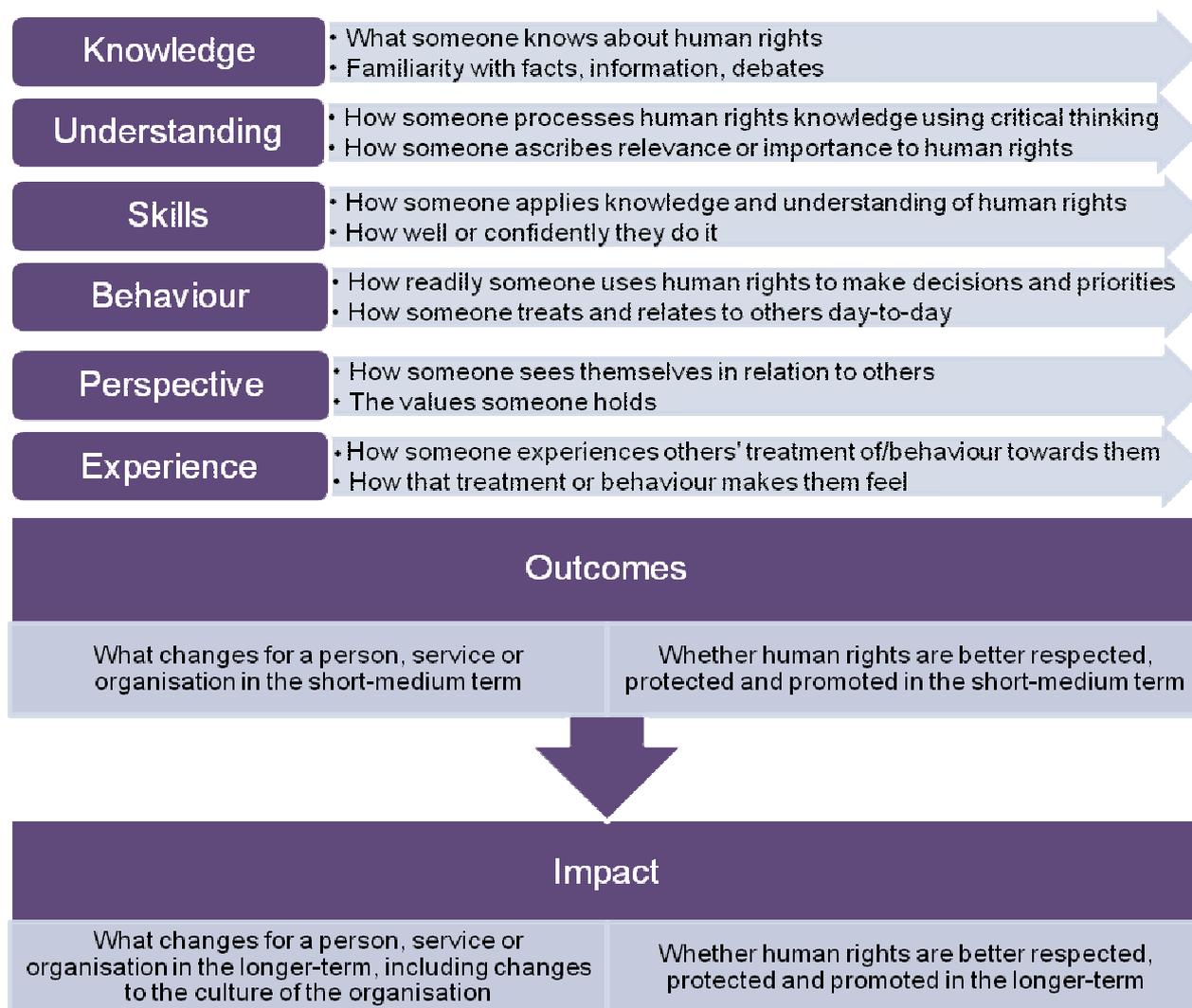
As a starting point, we can think of change in relation to:

- **what** you want to change, and
- **who** is involved in, and/or affected by, the change.

What to change

Figure 2 below shows some different types of change and gives examples of each. These types of change are not discrete and nor is the process of change necessarily a linear or straightforward one. For example, it might be that expanding someone's knowledge of human rights changes their behaviour and perspective; however, this will depend on the nature and extent of the knowledge imparted and the person's understanding of **why** human rights are relevant to their everyday life and work. In this sense, interventions specifically aimed at changing people's behaviour and perspective may need to go hand-in-hand with the transfer of knowledge and understanding.

It is useful for you to be aware of these different types of change in order that you can identify the specific types of change that you want to result from your project and the relationship, if any, between those types of change. Your awareness of the (often subtle) differences and relationships between types of change will also help you to identify **when** to look for evidence of change – as discussed in [Chapter 4](#).

Figure 2: Identifying types of change in relation to human rights**Who is involved in or affected by the change**

As well as thinking about the type of change, you will want to think about who will participate in creating the change and/or benefit from it. Figure 3 below shows the groups that might form part of a human rights-based intervention – as ‘makers’ and/or beneficiaries of change. Of course, within a specific project, these groups might be further subdivided; for example, on the basis of where they are based; what service they have contact with; their personal or professional experience, and so on.

Your project may focus on only one of these groups – or it may focus on two or more groups, and on the relationship between them. Depending on the scale of your project, it may also seek to bring about changes in the design and delivery of a service at the level of a team, multiple teams or the organisation as a whole.

Figure 3: Identifying makers and/or beneficiaries of change



In [section 5.2](#), we presented as an example the way in which Betsi Cadwaladr University Health Board set its aims and objectives in a project to put human rights at the heart of hydration and nutrition on hospital wards.

In Figure 4 below, we present the same information - but this time it is set out according to the **type of change** desired and **who is involved**, i.e. the makers and/or beneficiaries of that change.

Figure 4: Designing a process of change: what changes and who is involved?

Betsi Cadwaladr University Health Board - Putting human rights at the heart of hydration and nutrition: a toolkit for ward sisters and charge nurses (see also Case Study A)			
	Service users & carers	Staff	Service
Knowledge	Provide information to patients/carers about what they can expect in relation to hydration and nutrition on wards	By means of a human rights-based toolkit and associated measures, increase knowledge and awareness of human rights in relation to hydration and nutrition among key staff	
Understanding		Increase understanding of the importance of human rights in relation to hydration and nutrition among key staff, including as a right to life issue.	
Skills		Undertake training and awareness activity to enable key staff to apply a HRBA to hydration and nutrition and to the planning and delivery of care.	
Behaviour		Ensure that the HRBA becomes embedded in day-to-day practice and decision-making through a range of routine, practical interventions and auditing mechanisms.	Promote high quality hydration and nutritional care standards across the service.
Perspective		Embed a human rights-based approach among key staff, in which service users' right to receive adequate hydration and nutrition is explicitly recognised.	Develop a culture of transparency and improvement, based on regular audits and learning from concerns.
Experience	Improve patient and carer experience in relation to hydration and nutrition.		
Outcomes (short-medium term)	<ul style="list-style-type: none"> • Increase knowledge and understanding of human rights in relation to hydration and nutrition for key staff, and • provide a practical human rights-based tool which other health organisations can adopt. 		
Impact (longer term)	<ul style="list-style-type: none"> • Achieve sustainable increases in hydration and nutritional standards of care • influence patient clinical outcomes • increase patient and carer satisfaction with the quality of care provided and hospital stay overall, and • reduce complaints/litigation. 		

5.5 Changing organisational culture

Previous human rights-based interventions have sought to (among other things) change the 'culture' of a service or organisation (for example, see [Case Study I](#)). What do we mean by changing an organisation's culture - and how do we know when a culture has changed?

Researchers at Mersey Care NHS Trust identify an organisation's culture as the beliefs, values, attitudes and norms of behaviour which form the shared understanding that underpins working life and routine practices (Roberts et al, 2010a : 23). Changing a culture is therefore about shifting and moulding these shared beliefs, values, attitudes and behavioural norms in a particular direction.

Where beliefs and values are both strongly held and widely shared in an organisation, it may be said to have a 'strong' culture. Thus, a strong human rights culture is one in which there is a high level of uniformity between (i) the personal beliefs and behaviour of individuals at different levels of the organisation and (ii) human rights principles.

It is important to distinguish between the corporate articulation of an organisation's culture (e.g. what appears in public statements and written policies) and the 'grassroots' or 'canteen' culture which will be visible in people's everyday practice. An evaluation which seeks to identify changes to culture will, as far as possible, need to examine changes to both the 'corporate' and 'grassroots' culture.

Key messages

- Identifying clear aims and objectives is vital for your evaluation: if you are not clear at the outset about what you are trying to achieve, then it will be difficult to identify what 'success' looks like – let alone measure it.
- Your aim encapsulates the longer-term change you wish your project to achieve. Objectives are the methods or concrete activities by which you will achieve your aim.
- When setting your aims and objectives, it is useful to think in terms of **what** you want to change and **who** will be involved in, and/or affected by, the change.

6. DESIGNING YOUR EVALUATION

This chapter addresses the question, ‘**how** shall I conduct my evaluation?’.

In [Chapter 5](#), we discussed the need to set clear objectives for your human rights-based project. The next stage is to consider how will demonstrate whether or not you have achieved each of your objectives; that is, the evidence (or ‘data’) that you need to collect and the tools with which you will collect it.

It is beyond the scope of this guide to describe all the available tools for collecting data and the methods of analysing that data. Some useful resources which explain these tools and methods of analysis – and their pros and cons – are listed in the [Resources](#) section of this guide.

In this chapter, we examine some of the tools and techniques that have been used in previous evaluations of human rights-based interventions.

First, let’s introduce some of the basic concepts associated with data collection. These are concepts which have been developed in the context of social and market research. We can distinguish between quantitative, qualitative and observational methods.

6.1 Quantitative methods

Quantitative methods are concerned with measurement. They are designed to answer questions about **how many** people did or thought something.

There are two underlying principles to quantitative research:

- each respondent is asked the same questions in the same way in order that their answers can be added together, and
- the respondents are representative of the wider group whose views or preferences are of interest to you.

Quantitative tools can include written questionnaires (on paper or online) or interviews. The common element is that the questions are highly structured so as to ensure consistency between respondents. These generally include:

- five-point ‘Likert scales’, which are commonly used to gauge attitudes and preferences. For example, they may present statements with which the respondent may choose to (i) agree strongly; (ii) agree; (iii) neither agree nor disagree; (iv) disagree, or (v) disagree strongly (or say they don’t know). See [Annex 3](#) for an example from [Case Study E](#).

- questions designed to assess knowledge, e.g. true/false options or multiple choice questions (see [Annex 4](#) for an example from [Case Study E](#)), or
- questions with a limited range of prescribed responses, e.g. 'yes', 'no', or 'don't know'.

For useful guidance on constructing a questionnaire, see Research Councils UK (2012), Annex 1.

Quantitative sampling

Sampling techniques are used in order to (i) avoid bias and (ii) ensure that your respondents are representative of the wider group whose views or preferences are of interest to you. Methods of sampling include the following:

- systematic sampling: for example, surveying every fifth person that completes your activity, and
- quota sampling: setting quotas so that your sample matches the wider group in relation to key characteristics.

Alternatively, you might adopt a 'census' approach, which means collecting information from everyone who engaged with your activity.

Analysing quantitative data

Analysing quantitative data is a specialist task. It involves coding the data you have gathered and entering it into a spreadsheet or specialist software package in order that you can add up the responses and analyse them against significant variables. If you think your evaluation requires a quantitative element, you should ensure that a member of the evaluation team is familiar with quantitative research methodology.

6.2 Qualitative methods

Qualitative methods enable you to address **why** people think or behave in a certain way or have certain preferences. Social and market researchers use the term qualitative research to refer to either:

- one-to-one interviews (known as 'semi-structured' or 'in-depth' interviews), or
- 'focus' groups (discussion groups of around 6-8 people), which are generally facilitated by someone who is involved in the evaluation and therefore understands the objectives of the activity.

Qualitative techniques offer a depth of insight which quantitative methods cannot provide. The researcher will generally use a 'topic guide' listing questions or issues of interest in the interview or focus group; this is also known as an 'interview schedule' (see [Annex 7](#) for an example from [Case Study C](#)). The techniques allow

the researcher to interact with participants to probe in detail their thoughts, feelings and preferences.

Qualitative sampling

Qualitative techniques are concerned with depth rather than breadth; therefore sample sizes tend to be small. Interviewees or focus group participants tend to be selected to give you a cross-section of your audience rather than a representative sample. Generally, you will draw up criteria for inclusion, rather than using the 'stricter' methods of sampling that are used in quantitative surveys. You will need to consider which criteria are relevant given the nature of your activity. Such criteria might include, for example, the seniority or professional background of participants, or their experience (or lack of experience) of a particular service.

In the case of focus groups, you may also want to consider the group dynamics: for example, is there a risk that your focus group will be dominated by more senior or articulate participants, or that men will dominate a mixed-gender discussion? Do you need to ensure that there is a mixture of staff and service users in the group?

The small size of your sample and the way in which it has been selected means that the results are not statistically representative of the wider group/s that are of interest to you.

Analysing qualitative data

Qualitative data is gathered by means of recording the interview or focus group, preferably either in video or audio rather than merely by taking notes. These recordings are then transcribed and analysed in detail in order to identify:

- themes and sub-themes
- groups/individuals that hold particular views or use particular language
- how and why views are formed and/or change
- the context in which a person's views are expressed, which may affect your interpretation of their responses
- illustrative quotations that you can use in your evaluation report or other contexts.

Qualitative data is analysed by plotting these different elements on a chart in order that you can build up a picture of who said what and identify themes or patterns in the data. Specialist software packages are available to support this 'charting' process; however, for smaller amounts of data it can also be done manually. As with quantitative analysis, analysing qualitative data is a specialist task and it is advisable to include in your evaluation someone skilled in this area.

6.3 Observational methods

Observational research is a qualitative approach which involves watching and recording people's behaviour in a real-life setting, e.g. as they engage with a particular activity. Observation allows evaluators to understand at first hand how individuals behave in the particular setting. It looks at what they actually do rather than what they say they do, thus eliminating some of the bias or inconsistencies that can occur in methods that rely upon self-reporting.

Observational techniques permit the evaluator to understand an individual's attitudes, behaviour and relationships in the context in which they occur. This contextual information can be used to cross-check or amplify data from surveys, focus groups or interviews. Observation sessions can also be used to get to know participants and seek their consent to take part in another aspect of your evaluation, e.g. a semi-structured interview or focus group.

Observational data can include contemporaneous notes taken by the evaluator and/or video footage or photographs of the observed behaviour. This data can then be analysed using the methods of qualitative analysis explained above.

6.4 Tools used in evaluations of human rights-based interventions

This section examines the tools and techniques which have been used in previous evaluations of human rights-based interventions in health and social care, as set out in the Case Studies in [Chapter 10](#). These evaluations have used both qualitative and quantitative methods.

Figure 5 'maps' the qualitative and quantitative methods that have been used in the each of the case studies.

Case Study A: Betsi Cadwaladr University Health Board – Putting human rights at the heart of hydration and nutrition: a tool kit for ward sisters and charge nurses

Case Study B: Mersey Care NHS Trust – A human rights-based approach to assessing and managing risk: 'Keeping Me Safe and Well' risk screen

Case Study C: Mersey Care NHS Trust – A human rights-based approach to assessing and managing risk: the Human Rights Joint Risk Assessment and Management Plan and the Human Rights Benchmarking Tool

Case Study D: Mersey Care NHS Trust – 'Standing up for my human rights' group

Case Study E: Mersey Care NHS Trust – Human rights training for staff

Case Study F: Mersey Care NHS Trust – ‘Getting it Right’: Human rights-based approaches to inpatient care for people with dementia

Case Study G: Mersey Care NHS Trust – Co-producing a human rights board game with people with learning disabilities

Case Study H: Scottish Human Rights Commission - Care about Rights project (Phase 2)

Case Study I: Scottish Human Rights Commission: ‘Making it Work’ - An evaluation of the human rights-based approach at The State Hospital

Figure 5: Mapping of methods used in human rights evaluations

Case study									
QUALITATIVE METHODS	A	B	C	D	E	F	G	H	I
Semi-structured interview/s			x	x		x		x	x
Focus group/s	x	x	x						x
Thematic analysis of case note files or other documentary evidence		x				x			x
Survey of key policies and indicators of effective practice using qualitative data									x
Human rights ‘vignettes’ (story-based scenarios used to assess knowledge and understanding of human rights)				x		x			
Self-completed survey/s with ‘open’ questions					x				
Organisational case studies								x	
Observation in a real-life setting	x							x	
QUANTITATIVE METHODS	A	B	C	D	E	F	G	H	I
Statistical audit of clinical case note files or other documentary evidence		x	x			x			
Self-completed questionnaire/s with ‘closed’ questions or scales					x		x	x	
Knowledge quiz	x				x	x	x		
Survey of key policies and indicators of effective practice using quantitative data	x								x

Some useful insights emerge from this mapping exercise, which are outlined in [sections 6.5 and 6.6](#).

6.5. The importance of using mixed methods

Each of the case studies used at least two different evaluation tools and some used as many as five. In addition, apart from one, each case study used a mixture of quantitative and qualitative techniques, i.e. they were concerned both with **how many** people did or thought something, and **why** they did or thought something. It bears repeating that there is no single or 'right' way of conducting your evaluation. The mixture of methods used will depend upon who is involved, what you want to find out, and what resources are at your disposal.

However, you are likely to get more reliable findings if you combine at least two and preferably three methods of gathering data to answer the same question, in order that results can be cross-checked against each other, and to prevent reliance on a single source of data or interpretation. This process is also known as 'triangulation'.

6.6 Tailoring evaluation methods and tools to your needs

In this chapter, we have outlined some basic concepts and techniques associated with evaluation, which are drawn from social and market research. There is evident benefit in using tried and trusted techniques. However, this should not prevent you from being innovative and tailoring existing tools to meet your needs.

A good example of such innovation is the set of 'vignettes' used to assess human rights knowledge among service users ([Case Study D – Annex 5](#)) or staff ([Case Study F – Annex 6](#)) before and after a human rights-based activity. These are story-based scenarios which invite participants to say how they would respond to the scenario and why. They were developed by the evaluators because of the absence of other suitable measures for assessing knowledge and understanding of human rights – as well as assessing how that knowledge and understanding is applied in practice. The vignettes were tailored to the particular participants in terms of the level of difficulty and the content of the scenario.

Another example of innovation is the development (in [Case Study F](#)) of a set of standards by which to evaluate changes to care plans before and after the introduction of a human rights-based tool for assessing quality of life for inpatients on a dementia ward (see [Annex 10](#)). The evaluators developed these standards because existing standards were limited to the process of drawing up a care plan, and didn't capture the kind of substantive changes that the human rights-based tool was designed to bring about.

Key messages

- There is no single or 'right' way of conducting your evaluation. The methods you choose will depend upon who is involved, what you want to find out, and what resources you have.
- The findings of your evaluation will be more reliable if you use a mixture of methods. These may include both quantitative methods (to find out how many people thought or did something) and qualitative methods (to find out why people think or behave in a certain way or have certain preferences).
- Your findings will be more reliable if you combine at least two and preferably three methods of gathering data to answer the same question.
- Don't be afraid to innovate: adapt existing evaluation tools to suit your purpose - or develop new ones.

Where can I find out more?

Examples of 'road-tested' evaluation tools are contained in a separate document, *A guide to evaluating human rights-based interventions in healthcare: Annexes*. This is available at: <http://www.humanrightsinhealthcare.nhs.uk/>.

7. ETHICAL CONSIDERATIONS

This chapter addresses the question, ‘what **can’t** I do and what **must** I do with regards to my evaluation?’. It explores the ethical boundaries for the conduct of your evaluation. These are designed to protect the rights, interests and well-being of all those involved – especially people who are considered to be vulnerable.

7.1 Ethical research practice

If your activity involves other people – whether staff, service users or carers – ethical issues are raised which you will need to address, irrespective of the level of formal clearance required. The Economic and Social Research Council (ESRC) (2012: 2-3) has established six principles of ethical research, as follows:

1. Research should be designed, reviewed and undertaken to ensure integrity, quality and transparency.
2. Research staff and participants must normally be informed fully about the purpose, methods and intended possible uses of the research, what their participation in the research entails and what risks, if any, are involved.
3. The confidentiality of information supplied by research participants and the anonymity of respondents must be respected.
4. Research participants must take part voluntarily, free from any coercion.
5. Harm to research participants and researchers must be avoided in all instances.
6. The independence of research must be clear, and any conflicts of interest or partiality must be explicit.

Tools are available to help you implement these principles. In particular, they address issues of consent and confidentiality.

Consent

The ESRC guidelines (2012: 29-31) provide a useful overview of what is meant by consent and how to obtain it. It notes that the primary objective is to conduct research openly and without deception. The ESRC (2012: 29) notes that **informed** consent entails ‘giving sufficient information about the research and ensuring that there is no explicit or implicit coercion ... so that prospective participants can make an informed and free decision on their possible involvement’. Typically:

- the information should be provided in writing (by means of an informed consent form – see [Annex 1](#) for a sample from [Case Study C](#))
- time should be allowed for the participants to consider their choices, and
- the forms should be signed by the participants to indicate consent.

In all research projects, researchers should inform participants of their right to refuse to participate in, or withdraw from, the investigation whenever and for whatever reason they wish (without having to tell the researcher what the reason is).

Participants should not be coerced to take part in the research. These terms should be clearly set out in writing to the participants by means of an information sheet (see [Annex 2](#) for a sample information sheet from [Case Study C](#)).

The ESRC (2012: 29) observes that where participants are not legally responsible, their legal representatives or guardians should be consulted as well as the individual. Where participants are not literate, verbal consent may be obtained but this should wherever possible be witnessed and recorded.

The ESRC (2012: 30-31) adds that in cases where research involves potentially vulnerable groups such as children, older people or adults with learning difficulties, every effort should be made to secure actively given and informed consent from participants. Passive assent, including group assent (with consent given by a 'gatekeeper') should be avoided wherever possible, and every effort should be made to develop methods of seeking consent that are appropriate to the groups being studied, using specialist advice where necessary.

Confidentiality

Research participants should be informed (using the information sheet, as well as verbally) about how far they will be afforded anonymity and confidentiality.

Guarantees of anonymity and confidentiality must be honoured. Data should be stored securely (whether in electronic or written form). Confidentiality must be preserved when you write up your evaluation: for example, if you describe someone in generic terms, might they be identifiable if they are one of only a small group that fits that description? Researchers should not pass on identifiable data to third parties without the participant's consent.

The ESRC (2012: 46) identifies some limits to confidentiality. If a child or vulnerable person reveals that they are in significant and immediate danger, the researcher will be obliged to ensure that they are protected. This imperative must be made clear to the participant (or parent/carer) when eliciting consent. Before starting a project, it is good practice to establish a procedure as to who will take the responsibility for protecting the vulnerable person/child in the event of a disclosure.

7.2 Obtaining ethical clearance

The National Research Ethics Service (NRES) for England works with the UK Health Departments to develop and maintain a common UK-wide system for ethical review of health and social care research. Details are available here:

<http://www.nres.nhs.uk/applications/approval-requirements/ethical-review-requirements/>.

NRES has developed guidance to help you work out if your project requires:

- formal clearance by a Research Ethics Committee (REC)
- NHS Research and Development clearance
- formal clearance by another body; for example, if you wish to conduct health research in a prison or if you wish to access confidential patient information.

The guidance can be accessed from this link:

<http://www.nres.nhs.uk/applications/approval-requirements/>.

If your evaluation activity is classified as 'research' it needs clearance by a REC. If it is classified as another type of activity such as a clinical audit, service evaluation, case study or satisfaction survey, it does not. However, you may still need to obtain permission from your local Research and Development office. The guidance notes that different NHS organisations may have particular arrangements in place to review such activity and advises that you seek advice from your Research and Development office or clinical governance office in the first instance.

If you intend to involve service users in your evaluation, you will invariably need permission from your local Research and Development office to do so. In the case of research with adults who lack capacity under the terms of the 2005 Mental Capacity Act, projects must always be reviewed by the NRES Research Ethics Committee. Don't forget to factor in time in your evaluation for such permission to be obtained.

Key messages

- Before you start, check what (if any) formal clearance is required for your evaluation, and what (if any) permission you need to obtain from your local Research and Development office.
- Several key principles underpin ethical research practice. For example, participation must be voluntary and based on informed consent.
- You must be clear with participants about how far they will be afforded anonymity and confidentiality – and you must honour such undertakings in terms of how you store and use data.

8. SHARING THE FINDINGS OF YOUR EVALUATION

Once you have gathered and analysed data about the results of your activity, there are benefits to be had by sharing your findings. The audiences for your evaluation report may include:

- your immediate team
- others in your organisation
- your peers in other similar organisations
- a wider spectrum of people, e.g. advocacy groups; professional associations; inspectorates and regulatory bodies; government departments, and so on.

The likely audience for your report may, to a degree, influence the evaluation methods you choose. Some evaluations are primarily geared towards consolidating learning within an organisation; others are more 'outward facing'.

For example, **Case Study H** (Care about Rights) placed emphasis on identifying replicable good practice that could be used by other public authorities. This outward facing purpose led the evaluators to:

- conduct case study-based research in a sample of organisations demonstrating good practice in the application of human rights to the care of older people
- carry out a review of literature relating to the current policy environment in order to examine the rationale for the project; its potential long-term outcomes and its potential contribution to national strategic objectives, and
- involve in the evaluation external organisations with a strategic interest in the care sector.

8.1 Structuring your report

In spite of these differences, the evaluation reports in our case studies are broadly similar in structure. Figure 6 sets out a suggested structure that you may wish to use for your evaluation report.

Figure 6: How to structure your evaluation report

Section	Suggested content
Executive summary and Easy Read summary	<p>The summary might mirror the structure of the full report or it might be a shorter, narrative summary with a list of key points. It should be self-contained as some people will only read the summary and not the full report.</p> <p>You might also wish to include an Easy Read summary in an accessible format designed for people with a learning disability.</p> <p>You will probably find it easier to write these sections last.</p>
Introduction	<p>This section should set out briefly:</p> <ul style="list-style-type: none"> • the background and context of the activity • why you undertook the activity • the aims and objectives of the activity • the aims and objectives of the evaluation • an overview of the methods used in the evaluation and why you chose them • a guide to the rest of the report • who the report is aimed at.
Objectives and related outcomes or impacts	<p>For each of your objectives, explain:</p> <ul style="list-style-type: none"> • what data you gathered • what the analysis of the data showed, and • whether you met the objective in whole or part. <p>Discuss any attitudinal or institutional barriers you have identified to achieving the objectives and how they might be pre-empted or overcome next time.</p>
Unforeseen outcomes or impacts	<p>Describe any outcomes that resulted from the activity but were not expected.</p>
Lessons learnt in relation to evaluation	<p>Discuss any limitations relating to the evaluation itself, e.g. methodological limitations or problems associated with the wider context of the evaluation. Explain what, if anything, you would do differently next time in relation to the evaluation process.</p>
Conclusions	<p>A summary of the activity, its strengths and weaknesses and its main achievements. This section can be more discursive than the reporting of findings; for example, it might relate the findings to the broader policy environment.</p>
Annexes	<p>These could include:</p> <ul style="list-style-type: none"> • a full explanation of your methodology • information about how you analysed your data • where relevant, how you selected your sample/s • your evaluation tools, e.g. questionnaire, topic guide, consent form.

8.2 Writing your report

Each organisation has its own house style, and so you may want to take advice from colleagues about how to write your report, especially if it is aimed at an audience outside your organisation. In general:

- avoid using jargon or acronyms
- write in plain English – your audience may not be experts in evaluation or in your field
- use bullet points to break up your text
- use charts to convey statistical data
- use visuals or graphics to convey complex information
- use illustrative quotes from your qualitative data to bring the report to life, and
- recap and summarise regularly.

Key messages

- In most cases, it will be desirable for you to share the results of your evaluation – within your organisation and possibly also with external audiences.
- The likely audience for your evaluation report may, to a degree, influence the evaluation methods you choose. Some evaluations are primarily geared towards consolidating learning within an organisation; others are more outward facing. Write your report in a style which is suitable for that audience.
- Evaluation reports tend to be structured in a fairly similar way: this chapter suggests how you might set out your evaluation methods and findings.

9. POSSIBLE PITFALLS

This chapter addresses the question, 'What might go wrong with my evaluation?'. There are a number of challenges evident in previous evaluations of human rights-based interventions. Some relate to the process of evaluation itself and others relate to the context in which the HRBA (and the evaluation) took place.

Some of these difficulties are not necessarily unique to the evaluation of an HRBA as opposed to any other process of change. The generic resources on evaluation contained in the [Resources](#) section will help you identify and mitigate some potential limitations which are common to all evaluations.

9.1 Constraints of time and money

Evaluations are invariably subject to the practical constraints of staff time and financial resources. You may not be able to achieve as much in the evaluation as you would like to: compromises may need to be made. The cost and effort devoted to an evaluation of a project should be in proportion to the project itself. There is no fixed proportion that is 'right' in every case: rather, it is better to think about what information you need and how it can be collected and analysed and then to consider whether this is realistic and appropriate to the project. On the basis of this calculation, you may wish to 'scale up' or 'scale down' your evaluation.

If the project is innovative and/or high-profile, you may want to invest in a substantial evaluation; if it is not, you may want to scale it back. In any event, ensure that you only gather data that you really need and, where possible, use relevant data that is already gathered for another purpose. Always ask yourself, 'Why I am I gathering this data and is it directly relevant to my aims and objectives?'

Also ask yourself, 'Will my chosen method/s of evaluation yield evidence that is reliable?' For example, if you have a very small sample size or if you hold only one focus group rather than two or more, how reliable will your findings be (see [Case Study B](#))?

Time constraints may also be relevant in relation to obtaining the necessary ethical clearance for your evaluation, especially where you wish to engage with people using services (see [Case Study C](#)).

9.2 Determining cause and effect

[Chapter 5](#) examined the importance of setting clear and measurable objectives for your evaluation, i.e. establishing precisely what you want to change. It also reminded us of the imperative to conduct a baseline study in order that 'before' and 'after' changes can be measured and causality identified with some degree of confidence.

Other factors that may hinder the determination of cause and effect relate to the context of the service (and therefore of the evaluation). For example, it may be easier to identify causal effects in settings which are relatively closed and/or have relatively long-term, stable populations (such as prisons or secure wards) than in more open environments with relatively transient populations (such as out-patients services or social care services).

In these more open settings, observed changes to (say) attitudes and behaviour may be due to a wide variety of factors, including unrelated policy initiatives or decisions taken by other services which are not implementing a HRBA. The longer the time frame, the more difficult it may become to isolate the direct causal impact of the HRBA from impact caused by other factors. In addition, it may be that practice which has changed as a result of the human rights-based intervention may not be 'labelled' as being human rights-based, particularly as such practice becomes embedded over time.

These difficulties make it all the more important to set 'SMART' objectives – each with a single identifiable outcome – so that you can identify the changes that are directly attributable to your intervention (see [Chapter 5](#)).

9.3 The risk of bias

The team which evaluated Mersey Care's human rights-based risk assessment tools ([Case Studies B and C](#)) note that there is a risk of bias where those conducting evaluations have a high level of emotional or professional investment in the success of the HRBA. This observation does not suggest that external, independent evaluation is always necessary – or is itself always free of the pressure to produce positive findings (see [Chapter 3](#)).

However, awareness of this risk will assist the design of evaluation processes; for example, by:

- involving in the evaluation external actors or staff, service users or carers in your organisation who were not part of the project (see [Chapter 3](#)), and
- using at least two methods of gathering data to answer the same question, in order that results can be cross-checked and to prevent reliance on a single source of data or interpretation (see [Chapter 5](#)).

9.4 Taking account of attitudes and feelings towards human rights

When you implement your human rights-based project - and when you evaluate it – it will help you to be mindful of participants' attitudes and feelings towards human rights (so far as they are known). Previous evaluations have uncovered both positive and negative emotional responses among health professionals towards human rights (see [Case Study C](#)). Positive responses have included pride at the explicit adoption

of a HRBA and a sense that human rights values are congruent with those of public service. Negative responses have included feelings of guilt or anxiety about 'getting it wrong' or failing to 'deliver' human rights to service users due to scarce resources, countervailing policy initiatives or the fact that other services do not share the explicit commitment to human rights. Clinicians who have implemented a HRBA at Mersey Care NHS Trust emphasise the importance of creating a supportive learning environment to enable staff to explore ways of implementing human rights.

This experience offers useful insights for evaluation of human rights-based projects. Your evaluation may be partly designed to gauge attitudes and feelings towards human rights before and after your activity. You need to be aware that you may encounter negative as well as positive responses and this may in turn affect the design of your evaluation tools. You might also want to consider the timescale of your evaluation: for example, is it feasible to gauge participants' responses to their engagement with human rights-based practice at various intervals over a longer period of time?

Key messages

- There are some pitfalls common to all evaluations – but there are also ways of mitigating these problems to increase your chances of producing reliable findings.
- Your evaluation should be in proportion to the project itself: always ask yourself, 'Why am I gathering this evidence and is it directly relevant to my aims and objectives?'.
• Think about whether your evaluation will be – and will be seen to be – unbiased.
- Don't assume that people's attitudes and feelings towards human rights will be uniformly positive. Be open to the possibility of encountering a range of responses – and design your evaluation tools accordingly.

10. CASE STUDIES

This chapter includes nine case studies of evaluations of previous human rights-based interventions in health and social care. Most of these interventions took place within the Human Rights in Healthcare programme. We also include two evaluations of HRBAs in Scotland initiated by the Scottish Human Rights Commission.

The case studies are:

- Case Study A:** Betsi Cadwaladr University Health Board – Putting human rights at the heart of hydration and nutrition: a tool kit for ward sisters and charge nurses
- Case Study B:** Mersey Care NHS Trust – A human rights-based approach to assessing and managing risk: ‘Keeping Me Safe and Well’ risk screen
- Case Study C:** Mersey Care NHS Trust – A human rights-based approach to assessing and managing risk: the Human Rights Joint Risk Assessment and Management Plan and the Human Rights Benchmarking Tool
- Case Study D:** Mersey Care NHS Trust – ‘Standing up for my human rights’ group
- Case Study E:** Mersey Care NHS Trust – Human rights training for staff
- Case Study F:** Mersey Care NHS Trust – ‘Getting it Right’: Human rights-based approaches to inpatient care for people with dementia
- Case Study G:** Mersey Care NHS Trust – Co-producing a human rights board game with people with learning disabilities
- Case Study H:** Scottish Human Rights Commission - Care about Rights project (Phase 2)
- Case Study I:** Scottish Human Rights Commission: ‘Making it Work’ - An evaluation of the human rights-based approach at The State Hospital

CASE STUDY A

Betsi Cadwaladr University Health Board – Putting human rights at the heart of hydration and nutrition: a tool kit for ward sisters and charge nurses

Who was involved?

Betsi Cadwaladr University Health Board (BCUHB) is the largest health organisation in Wales, providing primary, community, mental health and acute hospital services for a population of around 676,000 people across the six counties of North Wales (Anglesey, Gwynedd, Conwy, Denbighshire, Flintshire and Wrexham) as well as some parts of mid Wales, Cheshire and Shropshire. BCUHB was one of the pilot trusts for the Human Rights in Healthcare programme in 2011-12.

Summary of the human rights-based intervention being evaluated

BCUHB developed a toolkit for ward managers and multi disciplinary teams to apply a human rights-based approach to hydration and nutrition to their everyday practice. The tool is a practical, user friendly document which uses a human rights-based approach to care that has been developed with the participation of service users and staff. It was championed at board level by the Director of Nursing, Midwifery and Patient Services.

The toolkit has a number of defining principles and six key components focused on the patient: Safety, Environment, Audit, Meal times, Choice and Empowerment. Each of these areas has a range of related interventions, e.g. identifying vulnerable patients at the start of each shift; establishing an alert system, and ensuring 24-hour access to food and drink. The toolkit also sets out the responsibilities of each member of a multi-disciplinary team.

Within the initial 12-month implementation period, involving six pilot wards, BCUHB aimed to increased knowledge, training and awareness about human rights, hydration and nutrition among the project steering group and operational groups, comprising:

- a project team including representatives from clinical staff, the equality and human rights team, catering, speech and language, dietetics, transforming care, education, and service user representatives.
- a 'transformational sub group' of mainly operational staff
- Director of Nursing and matrons,
- the pilot wards and wider multidisciplinary teams. Six pilot wards were identified across the three main district general hospitals, including care of the elderly, acute orthopaedic, acute surgical and acute medical wards.

The long term reasons for the development of the toolkit were to:

- adopt a human rights-based approach to hydration and nutrition as an innovative way of delivering excellence in hydration and nutrition by firmly placing the patient at the centre of care
- promote high quality nutritional care standards, and
- embed dignity and respect and promote human rights with respect to hydration and nutrition within the everyday ward routine to ensure that it becomes a fundamental aspect of care.

After the completion of the 12-month project, BCUHB intends to implement the HRBA via existing structures in order to ensure that it is sustainable. The success of the toolkit will be monitored via ward matrons.

Aims and objectives of the evaluation

Examples of how the Health Board will demonstrate that the development and implementation of the human rights based toolkit has changed practice include:

- knowledge of human rights or claiming of human rights by patients/service users and the development of information for patients and service users with respect to increased awareness of human rights, hydration and nutrition, e.g. poster, leaflet
- the experience of patients/service users, e.g. increased compliments and decreased complaints relating to hydration and nutrition
- outcomes for patients/service users, to be identified through audits of i) use of the toolkit; and ii) specific aspects e.g. nutritional screening, protected mealtimes; general surveys (such as the patient surveys co-ordinated by the Picker Institute Europe in NHS acute, mental health and primary care services on behalf of the Care Quality Commission). In addition, an annual Fundamentals of Care audit demonstrating improved scores for both service user and operational aspects
- changes in knowledge of human rights, attitudes and behaviour of staff, e.g. increased uptake of training; practical application of toolkit, and
- changes in the policies, practices or culture of the organisation, such that the application of human rights to nutrition and hydration becomes an integral aspect of high quality care and at the heart of everyday ward routine.

Evaluation framework and methods

The evaluation framework to date (November 2012) has included the use of an improvement methodology where tests of change are carried out using 'Plan-Do-Study-Act' (PDSA) cycles. The PDSA cycle is a model for testing a change in the ward setting — by planning it, trying it, observing the results, and acting on what is

learned. The PDSA model has been used successfully by many healthcare organisations internationally to improve health care processes and outcomes. At BCUHB, the aim is to improve compliance with the processes associated with the key components of the human rights-based toolkit – and, in relation to evaluation, to identify those improvements.

First, the team created measurement plans with operational definitions. Baseline data was collected in the pilot wards in relation to the key individual components, so that compliance was measured against the baseline and plotted on charts on a weekly basis. Weekly ‘snapshot’ meetings were held in the pilot wards where PDSA cycles were discussed, and ideas were generated to ensure that processes associated with the component of care were reliable at least ninety-five per cent of the time. This approach has been taken to ensure that, over time, changes in practice are sustainable.

Various methods have been used to collect the data depending on the need, e.g. direct observation and surveys. Teams use quantitative measures to determine if a specific change in practice actually leads to an improvement. Staff at all levels have been involved in implementing tests of change and collecting data. After successful implementation of the desired changes in the pilot areas, the team will broaden implementation to other parts of the organisation.

Future evaluation methods will include staff and patient surveys, which will be carried out on a yearly basis to establish change in culture and practice.

Evaluation will also be made through the Picker Survey; Fundamentals of Care Audits and by identifying the percentage of staff who have undertaken an e-learning nutrition package. Patient and staff stories will also be gathered to evaluate work undertaken and further influence the design of the project.

Timescale of the evaluation

At time of writing in November 2012 is still under way. It is anticipated that it will take one year to evaluate all areas of the toolkit in the pilot areas.

Summary of findings of the evaluation

Findings are emergent as of November 2012. There are varying degrees of compliance associated with the ‘nutrition and hydration’ patient safety dimension between wards. This is possibly due to inconsistent leadership and ownership at ward level. Despite this there has been significant improvement in compliance associated with the organisation of care and ward routine. Interesting data associated with the ‘empowerment’ dimension of the toolkit has emerged. The baseline data demonstrates that wards did not consistently provide information to

patients and carers/relatives on what patients should expect in relation to nutrition and hydration whilst in hospital.

Lessons learnt in relation to evaluation

The team at BCUHB observes that, from the outset, clear leadership and commitment must be established 'at the coal face'. To ensure sustainability, a lot of energy and enthusiasm, coupled with an appropriate leadership style, are essential. These lessons are suggested as important in relation to both implementation and evaluation of the human rights-based intervention.

Where can I find out more?

For more information about the BCUHB project, contact:

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CASE STUDY B

Mersey Care NHS Trust – A human rights-based approach to assessing and managing risk: ‘Keeping Me Safe and Well’ risk screen

Who was involved?

Mersey Care NHS Trust provides specialist mental health and learning disability services, including low, medium and high secure services. This case study describes the experience of staff, service users and carers within three Community Learning Disability Teams (CLDTs) in Crosby, Liverpool and Southport.

Summary of the human rights-based intervention being evaluated

During Phase II of the Human Rights in Healthcare programme (2007-08), Mersey Care developed three practical resources designed to support staff and service users with learning disabilities to recognise the human rights implications of assessing and managing risk.

The premise of the project was that ‘positive risk management’ is preferable to traditional risk management which (i) focuses on assessing and managing ‘threats’ to the service user, their carers or community members, and (ii) is viewed as the preserve of professionals. Staff and service users at Mersey Care developed a ‘positive risk management’ approach by using human rights standards and principles. Its key elements include:

- using the principle of **proportionality** in order to make decisions which balance the rights involved the person’s risky behaviour against the rights (or restriction of rights) involved in the strategy being proposed to manage that risk,
- being **proactive** rather than reactive in assessing and managing risk, by analysing the individual’s life history and the context in which any difficult behaviour occurs,
- maximising the **participation** of the service user, and
- using human rights as a unifying framework to integrate **equality and diversity** considerations into the management of risk.

This case study examines the evaluation of one of the tools: the Keeping Me Safe and Well Risk Screen. **Case Study C** examines the evaluation of the other two: the Human Rights Joint Risk Assessment and Management Plan and the Human Rights Benchmarking Tool.

The Keeping Me Safe and Well Risk Screen was designed to support the involvement of adults with learning disabilities in assessing risk to themselves and others. It was felt that using a human rights-based approach to risk meant upholding the basic values of fairness, respect, equality, dignity and autonomy (FREDA) that underpin the Human Rights Act from the earliest point of contact with the Service.

The risk screen is accompanied by guidance notes for clinicians and good practice examples. Questions and prompts are provided in relation to four areas:

- risk to self
- risk to others
- risk from others, and
- risks to property.

In each area, explicit connection is made to the human rights which might be affected and a traffic light system is used to highlight levels of concern, based on the likelihood and severity of the risk/s. An easy read format was also produced, with pictures to support service users to express their own perceptions of risk.

Aims and objectives of the evaluation

The aim was to evaluate:

- (i) how effectively the risk screen had been integrated into the routine risk assessment work of the CLDTs in Crosby, Liverpool and Southport, and
- (ii) whether, from the perspective of staff using it, the screen makes a difference to service users' human rights being better recognised and supported during the risk assessment and management process.

Evaluation framework and methods

The evaluation comprised:

- (i) A **clinical audit** of 'live' nursing/medical and psychological case note files to assess the uptake of the risk screen in the three CLDTs, in relation to:
 - frequency data for completion of the screen
 - percentage of risk screens completed jointly with the service user, and
 - which version of the screen (with or without pictures) was used most frequently.
- (ii) A **thematic analysis** of a sample of five clinical case notes (and supporting documentation such as care plans, care plan reviews, capacity

assessments and management plans) chosen on the basis that they had risk assessments completed both before and after the introduction of the human rights-based screen. Researchers did a 'before and after' analysis based on, for example, the use of explicit human rights language.

- (iii) A **focus group** was held on each site to understand clinical staff's views and perceptions of using the risk screen to investigate whether it had furthered a human rights-based approach to risk assessment and management. Thirty-one staff took part across the three sites, spanning different professional disciplines and levels of experience. Anonymity was guaranteed for individual clinicians. Each session lasted around one hour and was recorded and transcribed in order to permit thematic analysis.

Focus group questions were designed to address:

- the usability of the screen compared to its predecessor
- barriers and facilitators to using the risk screen, and
- questions relating to key human rights principles (the PANEL principles; see [Chapter 2](#)).

Timescale of the evaluation

The evaluation took place in 2009-10, around six months after the introduction of the risk screen.

Summary of findings of the evaluation

Overall, the evaluation of the Keeping Me Safe and Well Risk Screen was promising. However, it identified a degree of resistance from staff to the introduction of the risk screen and identified several aspects of the screen that needed to be changed.

- The **clinical audit** to assess uptake of the risk screen showed that between one-fifth and one-third of eligible files across the three sites contained a completed risk screen. Of these eligible files with completed risk screens, levels of service user participation varied widely across the sites (from 38 to 80 per cent). Use of the pictorial version of the screen also varied (from 21 to 61 per cent). The audit suggested that when the human rights-based risk screen was used (particularly the version with pictures) service users were more involved in the process than previously.
- Thematic analysis comparing the language used in **clinical case notes** before and after the introduction of the risk screen showed a subtle shift from implicit to explicit discussion of the FREDA values. In addition, there was a shift from crisis interventions to early reactive interventions. Further, there was

a shift towards more empathetic and respectful constructions of service users' difficulties, with an emphasis on communication rather than blame.

- Staff who participated in the **focus groups** were generally positive about the integration of a HRBA into the risk assessment and management process. Clinicians felt that it was a useful tool of reference, enabling them to influence other agencies by highlighting the specific needs of the client.

However, the evaluation revealed mixed views across the three sites about the importance of service user and carer participation. For some, it was 'tokenistic', 'patronising', 'good in theory but not practice', or too rigid, provoking feelings of guilt when participation did not prove possible. For others, it had the potential to address power imbalances between staff and service users and help fulfil related duties such as those under equality law.

Some clinicians perceived the implementation of the screen as a top down process from management i.e. it felt imposed upon them. This was despite the fact that all CLDTs had been given the opportunity to contribute to its development. A clear lesson was that perceived ownership by staff is essential to effective implementation.

Clinicians recommended various changes to the screen. These included the development of a shorter screen to be completed at the point of intake and a more in-depth version to be used later on, when more appropriate clinically. Clinicians also recommended changes to the style of graphics used.

Lessons learnt in relation to evaluation

As regards the **clinical audit**, the researchers conclude that analysing the risk screen once it is more embedded the service may yield richer data. They also propose that future evaluations analyse the differing uses of the screen by different professional groups, which was not attempted here.

The researchers acknowledge that the **thematic analysis** of case note files is subject to several methodological limitations and findings should therefore be viewed as tentative. The limitations are summarised as follows:

- The small sample size of five case note files was problematic: a future evaluation should consider examining 15 files.
- The limited amount of text on the completed risk screens necessitated analysis of supporting documentation and not only the risk screen itself.
- Due to the small number of eligible files, 'before' and 'after' analyses sometimes involved different practitioners, whereas the original aim (and a

goal for future evaluations) was to assess changes involving the same practitioner.

- Specifically looking for 'human rights talk' may have inferred a particular construction of 'rights' and 'risk' from the text.
- Service users' presentations may change over time and in the case of dementia symptoms are progressive: this has implications for comparing the proportionality of a risk management strategy for the same patient at different times.

In addition, the **focus groups** were viewed as having some limitations, as follows:

- Only one focus group was held on each site: conducting more than one may have increased the reliability of the data.
- The use of single focus groups increased the risk of dominant participants in each group monopolising the data.
- The presence in some groups of senior staff may have inhibited frank discussion.
- Ensuring the validity of the themes is a common issue with focus groups. The researchers addressed this by cross-referring the themes they had each identified with other members of the research team.

The researchers conclude that future evaluations involving clinicians may need to include demographic information about their professional background and level of experience, as well as the complexity of cases in which they have used the screen. This could have provided further useful information about the screen's utility as other extraneous variables could have been controlled.

Where can I find out more?

This case study is based on: Roberts, A., Vyas, J., McEwan, L., Evans, G., Khawaja, Z., Punshon, C. and Greenhill, B. (2010b) *Human Rights in Healthcare Project Phase III: Part 1: A Human Rights Based Approach to Risk - Evaluating the Incorporation of the 'Keeping Me Safe and Well' Risk Screen into Community Learning Disability Services*. Liverpool: Mersey Care NHS Trust.

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CASE STUDY C

Mersey Care NHS Trust – A human rights-based approach to assessing and managing risk: the Human Rights Joint Risk Assessment and Management Plan and the Human Rights Benchmarking Tool

Who was involved?

Mersey Care NHS Trust provides specialist mental health and learning disability services, including low, medium and high secure services. This case study describes the experience of staff, service users and carers within three Community Learning Disability Teams (CLDTs) in Crosby, Liverpool and Southport.

Summary of the human rights-based intervention being evaluated

During Phase II of the Human Rights in Healthcare programme (2007-08), Mersey Care developed three practical resources designed to support staff and service users with learning disabilities to recognise the human rights implications of assessing and managing risk.

The premise of the project was that 'positive risk management' is preferable to traditional risk management which (i) focuses on assessing and managing 'threats' to the service user, their carers or community members, and (ii) is viewed as the preserve of professionals. Staff and service users at Mersey Care developed a 'positive risk management' approach by using human rights standards and principles. Its key elements include:

- using the principle of **proportionality** in order to make decisions which balance the rights involved the person's risky behaviour against the rights (or restriction of rights) involved in the strategy being proposed to manage that risk,
- being **proactive** rather than reactive in assessing and managing risk, by analysing the individual's life history and the context in which any difficult behaviour occurs,
- maximising the **participation** of the service user, and
- using human rights as a unifying framework to integrate **equality and diversity** considerations into the management of risk.

This case study examines the joint evaluation of two of the tools: the Human Rights Joint Risk Assessment and Management Plan (HR-JRAMP) and the Human Rights Benchmarking Tool (HRBT). The third tool – the Keeping Me Safe and Well Risk Screen - is examined in [Case Study B](#).

Human Rights Joint Risk Assessment and Management Plan (HR-JRAMP): This tool provides a human rights-based framework for use by social workers and clinicians to assess and manage risks associated with adults with a learning disability who present a likely and serious risk of harm to either themselves or others. Its approach is to balance the human rights of service users, their carers and their communities. In summary, the HR-JRAMP attempts to understand the risky behaviours of people with a learning disability in the context of their personal history, through looking at 'critical life events' and analysing these to formulate the meaning of risky behaviours for the person.

Human Rights Benchmarking Tool: This tool is designed to assess how human rights are being incorporated into the lives of people supported by 'complex care pathways'. It can be used to evaluate the extent to which a human rights-based approach is taken by the services they use, regardless of whether these services are being provided by health, local authorities, or private/voluntary sector organisations. It assesses the incorporation of human rights in relation to different areas, such as risk assessment, health, physical intervention, daily living and housing.

Aims and objectives of the evaluation

The overall aim was three-fold:

- to establish and evaluate whether the introduction of the HR-JRAMP had improved service user access to their human rights
- to establish and evaluate how effective the HRBT had been at monitoring the HR-JRAMP in supporting service users with learning difficulties in accessing their human rights across the three sites (Crosby, Liverpool and Southport) within the learning disabilities service, and
- to gain a deeper understanding into any organisational factors that may facilitate or obstruct the introduction of a human rights-based approach.

Researchers set seven specific objectives. These were to:

- **Objective 1:** conduct a clinical audit of the uptake of the HR-JRAMP and HRBT for service users with 'complex care pathways' across the three sites
- **Objective 2:** conduct a series of semi-structured interviews with staff across the three sites (including those who had used the tools and those who had not), to explore their views, perceptions and experiences about the tools.
- **Objective 3:** explore whether any personal, contextual or organisational factors facilitate or obstruct the introduction and effectiveness of the tools, within and between the three sites

- **Objective 4:** explore and assess what impact the introduction of both tools has had on the life experiences of people with learning disabilities
- **Objective 5:** evaluate how sensitive the HRBT is to changes in the extent to which service users are able to access their human rights (Liverpool site only)
- **Objective 6:** conduct a time analysis to assess additional contact needed to complete both the HR-JRAMP and the HRBT (Liverpool site only) (however, this was not completed), and
- **Objective 7:** conduct an iterative process of adaptation of both tools. (This process of adaptation did not take place within the lifetime of the evaluation but was completed later.)

Evaluation framework and methods

The evaluation is described as a ‘process evaluation’, i.e. one which examines how a process works and how different factors combine to produce particular outcomes, rather than focussing solely on the measurement of outcome/s as such (see [Chapter 4](#)).

The evaluation used a variety of methods in order to permit the double- or triple-checking of results (a process known as ‘triangulation’). The different types of evidence gathered were:

- the measurement of specific outcomes
- a detailed description of process, and
- the sampling of views of different interested parties.

The specific methods chosen to gather this evidence were:

- a clinical audit of a sample of ‘complex cases’ where the human rights tools had been used. In order to validate the results (i) two clinicians used the HRBT concurrently to rate the same HR-JRAMP and (ii) the results were ‘benchmarked’ using another ‘quality of life’ measure - the ‘Life Events Checklist’ developed by the British Institute of Learning Disability (BILD) (objectives 1 and 5)
- a series of semi-structured interviews with CLDT staff, including both those who had used the tools and those who had not, as well as those involved in the design and implementation of the tool (objective 2)
- a focus group was conducted to access staff views on how a HRBA had been integrated into the organisational culture (objective 3)
- semi-structured interviews with service users (objective 4); however, ethical clearance was not obtained in time to make this possible
- an analysis of the clinical and administrative time used to complete the tools (objective 6) (however, this was not completed)

Timescale of the evaluation

The evaluation took place in 2009, six months after the introduction of the tools. It set out to measure the impact of the tools in relation to the specific objectives over a 12 month period.

Summary of findings of the evaluation of the HR-JRAMP

- The interviews showed that, in general, the implementation of the human rights-based approach to the HR-JRAMP was seen to encourage clinicians to be reflective of their work, including its ethical dimensions.
- The clinical audit revealed great variation between clinician's ratings for particular dimensions. These discrepancies may be due to the lack of training in using the tools and/or to varying levels of experience and differences between professional roles.
- A detailed case study undertaken as part of the clinical audit highlights the positive impact that the HR-JRAMP appears to have made in terms of improving an individual service user's access to his or her human rights.
- The focus groups revealed a high level of uniformity between clinicians' personal beliefs and values and the organisational focus of a HRBA. This finding indicates the presence of a strong organisational culture, with a cohesive set of core values between its members and strong commitment to those values.
- There was also consensus that a HRBA is the 'right approach' and should be located within the remit of health and social care staff. However, this sometimes produced resistance to the HRBA, typically expressed as 'we do it anyway'.
- The focus groups highlight the extent to which clinicians rely on informal peer support in formulating and implementing HRBAs. Implementing a HRBA sometimes caused feelings of anxiety for fear of 'letting down' patients. Anxiety is increased by two other factors: a sense that other agencies do not follow the same approach and the pressure to provide holistic care at a time when service remits are perceived to be narrowing. Mersey Care has identified the consequent need to offer emotional support to frontline clinicians when using a HRBA, to enable shared decision-making and thereby help alleviate the amount of 'emotional labour' required.

Summary of findings of the evaluation of the HRBT

- The clinical audit found that the HRBT's ability to assess packages of care is as consistent as the BILD Life Events Checklist and is therefore worthy of further development.
- The HRBT appeared to be effective at highlighting areas within care packages where there is greater need for improvement.

Lessons learnt in relation to evaluation

Time constraints were an issue for several aspects of the evaluation. The researchers note that time pressures prevented them from obtaining ethical clearance to interview service users within the life of the evaluation project. Time constraints also meant that the data could not be cross validated by an individual that was not directly involved in the project. This exacerbated the risk of possible bias, in the sense that the positive drive to implement human rights in the service might have inhibited discussion about any negative views participants might have had.

Time constraints and clinical considerations also prevented the evaluators from completing the clinical audit for all the sampled patients (i.e. the 'before' and 'after' measure). The second stage was initially completed for only one of the five patients sampled.

In relation to the interviews, the main analyst of the data was also the interviewer. The evaluators note that it is possible for the relationship between interviewer and participant to be reflected in the way the data is analysed by the interviewer. In order to minimise these implications the themes were reanalysed by two other clinicians.

The researchers identify several limitations of the focus groups as a means of examining organisational culture:

- The focus group provides only a snapshot of the culture of the organisation and of a sub-culture of professionals within it. Other focus groups may have produced a different picture of the beliefs, perceptions and experiences of clinicians.
- The analyses of the transcript could also be suggested to contain an element of bias having been conducted by a member of staff working on the Human Rights in Healthcare project, who may have a vested interest in its success.

In relation to future evaluations of these tools, the researchers recommended:

- capturing the views of service users who have been through the 'complex care pathway' (as per the team's original objectives)
- continuing the assessment at the beginning and end of a 12 month period across more packages of care to see if the HRBT effectively improves service users' access to their human rights
- ensuring that a range of clinicians are involved in rating the same 'complex care packages'
- replicating the process of evaluating the HR-JRAMP after the document has been more deeply embedded within the service in order to provide richer evidence, and
- comparing responses within and between different professional groups.

Where can I find out more?

This case study is based on:

Roberts, A., Vyas, J., Cookson, A., Redman, M., Hiley, B., Hornby, Y., Howard, D. and Greenhill, B. (2010a) *Human Rights in Healthcare Project Phase III: Parts 2 & 3 - Evaluation of the Human Rights Joint Risk Assessment and Management Plan (HR-JRAMP) and Human Rights Human Rights Benchmarking Tool*. Liverpool: Mersey Care NHS Trust.

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CASE STUDY D

Mersey Care NHS Trust – ‘Standing up for my human rights’ group

Who was involved?

Staff of Mersey Care NHS Trust worked with a group of six to seven service users with learning disabilities and/or additional complex needs who were receiving specialist input from a Community Learning Disability Team (CLDT). Facilitators volunteered from the CLDT and comprised: a nurse; an equality, diversity and human rights lead; a trainee clinical psychologist and two assistant psychologists.

Summary of the human rights-based intervention being evaluated

Through the Human Rights in Healthcare programme, Mersey Care aimed to alter the organisational culture of its learning disability services. Practical tools were developed, enabling NHS staff and service users to recognise the human rights implications of risk assessment and management ([Case Studies B and C](#)). In addition, human rights training was provided to staff ([Case Study E](#)). This case study examines a training component developed for service users; it was initially called the ‘Speaking up for Myself’ human rights group.

The initial aims of the group were to:

- increase service users’ knowledge of human rights;
- facilitate service users claiming of rights, through increased levels of assertiveness, confidence and self-esteem, and
- enable service users to become more visible and integral within the service.

The group ran for 24 weekly 90 minute sessions over six months. A facilitator’s pack was devised covering:

- human rights knowledge, and
- skills which might be relevant to claiming rights, such as assertiveness and complaints procedures.

As the group progressed, several important changes occurred as service users began to challenge the way in which the group ran. The changes were as follows:

- After a request by group members, the Trust agreed to pay service users for their time; this was a ‘true turning point’ as members felt their time and experience was being properly valued.

- The group changed its name to the ‘Standing up for my human rights’ group – a sign of a developing sense of ownership and of ‘standing up’ as opposed to merely ‘speaking up’.
- After facilitators struggled to present the FREDA values in non-abstract terms, the group characterised FREDA as a person who believed in five principles: treating others with fairness, respect, equality, dignity and autonomy. The group designed a FREDA Christmas card which was used across the Trust.
- The facilitators abandoned didactic ‘teaching’ methods and adopted a more organic approach of small group exercises in which service users explored their experience of human rights and of restrictions of their rights.

Aims and objectives of the evaluation

The group was based on an ‘action research’ framework, with evaluation being undertaken by members of the group. Action research was defined as a process aiming collaboratively to ‘harness the insights of participants, employing practical joint action and empowering all those involved’.

Evaluation framework and methods

The original design included pre-defined outcome measures to assess whether the group’s aims had been achieved. The impact of the group was captured using two methods:

Semi-structured interviews: group members consented to take part in individual interviews pre-group and post-group. Individual responses were recorded verbatim and explored for themes. The questions were:

- What do human rights mean to you?
- What does ‘speaking up for myself’ mean to you?

Human rights case vignettes: in the absence of suitable measures for assessing human rights knowledge, a series of human rights-based vignettes was developed in an accessible format (see [Annex 5](#)). These comprised a short story based on human rights violations followed by questions designed to ascertain the service user’s views and what they would do if they were in that situation. Two vignettes were given to service users before and after the group at the same time as the semi-structured interview. An analysis of themes was conducted to compare human rights understanding pre- and post-group.

Timescale of the evaluation

The interviews and vignettes were used before the group began meeting (August-September 2009) and after the group (June 2010).

Summary of findings of the evaluation

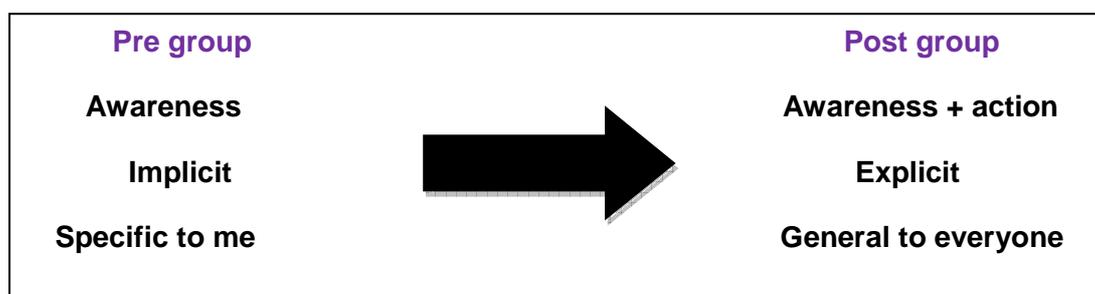
'Real-life' meaningful outcomes were captured as follows.

What do human rights mean to you?: Before the group, members tended to speak about their own rights (if they spoke of rights at all) but not those of others. Many 'should' statements were used, suggesting an awareness of what should be happening but a sense of not being able to make it happen. Post-group responses suggested a greater collective sense of human rights as being held by everyone with, for example, more frequent use of 'we' as opposed to 'I'. There was also increased use of human rights language and reference to the FREDA values, and a more active element running through the narrative as opposed to simply awareness.

What does 'speaking up for myself' mean to you?: Before the group, members had different and sometimes negative understandings of 'speaking up'. Afterwards, some group members said they would like to 'speak up' not only for themselves but also for others. The notion of 'speaking up' appeared to have become more active and positive and more geared towards dialogue.

Human rights vignette: one vignette concerned Petra, a woman with a respiratory problem who was denied the best medical treatment because of her learning disability. Before the group, service users had a good awareness of what was wrong with Petra's treatment and the importance of equal treatment regardless of her learning disability. Post-group responses differed in the active nature of the language used and suggestions for action to report and remedy actions which are inconsistent with human rights.

The overall impact of the group was summarised as follows:



In addition, the group produced outcomes that were not originally foreseen. Among these were:

- the decision by service users to produce their own booklet about human rights, which brought articles of the Human Rights Act to life by telling stories and asking 'what would FREDA say?'
- The group co-designed a 'map' of their human rights journey, describing how services had made them feel in the past; how the group experience had been different and what they would like to do in the future with regards to service design and delivery.

Lessons learnt in relation to evaluation

An analysis of the group's experience written up by staff observes that 'the group achieved all its aims, just not in the way that was originally envisaged' (Roberts et al, 2001: 7). Through a process of 'co-production' – as opposed to the more traditional approach of consultation - members of the group had produced several more meaningful outcomes than those originally envisaged.

The report of the evaluation notes that the decision to adopt an approach synonymous with the principles of 'action research' was vindicated. It had allowed service users to form relationships with the facilitators on the basis of equality and had encouraged an approach founded on reciprocity and shared risk.

One lesson to be drawn from the experience was the importance of service users themselves making decisions about the format of the evaluation (see [Chapter 3](#)). The report notes that the next step is for people with learning disabilities to work with staff to set up, run and evaluate future groups as service user facilitators.

Where can I find out more?

This case study is based on:

Roberts, A., Greenhill, B., Talbot, A. and Cuzak, M. (2011), 'Standing up for my human rights': a group's journey beyond consultation towards co-production'. *British Journal of Learning Disabilities*, doi: 10.1111/j.1468-3156.2011.00711.x.

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CASE STUDY E

Mersey Care NHS Trust – Human rights training for staff

Who was involved?

The 'Rebuild' Clinical Business Unit, part of Mersey Care NHS Trust, developed a variety of human rights training packages with the British Institute of Human Rights. This case study examines the results of the training in relation to changes in participants' knowledge and attitudes.

Summary of the human rights-based intervention being evaluated

Through the Human Rights in Healthcare programme, Mersey Care aimed to alter the organisational culture of its learning disability services. Practical tools were developed, enabling NHS staff and service users to recognise the human rights implications of risk assessment and management ([Case Studies B and C](#)). In addition, staff and service users developed a 'Speaking up for Myself' human rights group in order to strengthen service users' knowledge of human rights and confidence to claim them ([Case Study D](#)).

This case study examines the other component of Mersey Care's HRBA: human rights training for staff. Training sessions or presentations were delivered to 755 staff from health, social care and the voluntary sector, with 240 staff receiving specific training in human rights and risk assessment and management. The training consisted of experiential and didactic teaching methods, using material developed in conjunction with the British Institute of Human Rights.

Training sessions, workshops and presentations were delivered over different timescales, ranging from one hour to two days. They focused on:

- human rights awareness
- what is a human rights-based approach
- use of the practical human rights-based resources ([Case Studies B and C](#))

Aims and objectives of the evaluation

The overall aim was to evaluate staff uptake of and satisfaction with the staff training package and assess the impact of training on staff knowledge and attitudes. The evaluation was divided into two parts, as follows:

- **Part 1:** to evaluate uptake of and satisfaction with the human rights training which had been rolled out to a number of staff from various disciplines, and
- **Part 2:** to investigate whether human rights awareness training had had a significant effect on human rights knowledge and attitude towards human

rights (and whether or not there was a relationship between knowledge and attitudes).

Evaluation framework and methods

In **Part 1**, data was collected via an evaluation questionnaire which was completed by 104 participants after training sessions and presentations. The questionnaires consisted of:

- eight closed questions each with five responses (very poor, poor, average, good, excellent) relating to the usefulness, pace, format and structure of the training, and
- six further open questions, which explored these areas in greater detail. The answers were thematically analysed by an assistant psychologist who had taken part in one of the training sessions, under supervision of a clinical psychologist who had a pivotal role in developing the training sessions.

Thus, Part 1 yielded both quantitative data (responses to the closed questions) and qualitative data (responses to the open questions).

Part 2 of the investigation was purely quantitative. It involved support workers from an NHS provider service who completed a one-day human rights awareness training course. All the participants support people with learning disabilities who have complex needs to live in their own home within their local community. Participants were recruited using a random sample. Demographic data including age, gender, sexual orientation, disability, length of employment (in current and similar post), previous human rights training and choice of newspaper was collated. Before and after taking part in the training, participants completed:

- an 'attitudes to human rights questionnaire', which aimed to measure participants' thoughts and feelings towards human rights (see [Annex 3](#) for a copy of this questionnaire). Participants were asked to respond to 13 statements, using a 5-point scale. Only where a participant had completed both the 'before' and 'after' questionnaires were their responses analysed, resulting in a sample size of 23.
- an HRBA knowledge quiz, which aimed to measure their knowledge and understanding of human rights. It consisted of multiple choice questions which required participants to circle the correct answer (see [Annex 4](#) for an updated version of this quiz).

Timescale of the evaluation

The human rights training took place in sessions in 2008-10. The evaluation tools were completed by participants immediately before and after their training session.

Summary of findings of the evaluation

Part 1: The training sessions and presentations were rated very highly for usefulness, pace, format and structure: in each area, more than 90 per cent rated these factors as good or excellent.

From the qualitative data it emerged that participants found the most useful aspects to be: group interaction, 'walked examples' and an increase in their human rights knowledge. There was broad agreement that the training would be better if it:

- was longer
- was more interactive
- involved more diverse participants, such that experience could be shared by people from different teams, and
- involved more examples of client cases relevant to trainees' specific roles.

Part 2: the 'headline' results were as follows:

- there was a significant increase in participants' knowledge of human rights pre- and post-training.
- there was no significance difference between the attitude scores pre- and post-training, and
- there were no significant correlations between participants' knowledge of and attitudes towards human rights. The researchers note that this may be due to the small sample size.

According to the researchers, the lack of change in pre- and post-training attitudes may lie with the content of the training and, in particular, the components required for development of positive attitudes towards a given behaviour. Where participants feel that they are under pressure to adopt a certain approach, this can produce a response known as reactance, i.e. the strengthening or adoption of a contrary approach. One conclusion drawn is the need for human rights to be presented as congruent with trainees' existing values (and those of the public sector) in order to ensure that they don't feel 'railroaded' into change. The researchers also conclude that the human rights training may need to place greater emphasis on emotional responses as opposed to cognitive change, in order to promote personal reflection and thereby attitudinal change.

Lessons learnt in relation to evaluation

The researchers identify several lessons for future evaluations:

- The attitudes questionnaire was a newly-developed measure created 'in house' by one of the researchers in collaboration with Ipsos MORI. The team recommends further validation of the questionnaire to establish whether the apparent absence of attitudinal change among participants is partly a function of the evaluation tool, as well as the content of the training.
- The length and focus of the training sessions being evaluated differed, which produced some apparently conflicting results. In future evaluations, better documentation should be kept of which respondent attended which training event in order to gain more useful results from evaluation forms.
- In future evaluations, researchers should emphasise to the participants the importance of completing the evaluation tools fully, both pre- and post-training, to increase the number of eligible responses. Where verbal feedback is communicated to the facilitators, this should be written down at the time.
- In relation to the quantitative element of the research, for future evaluations it would be beneficial to have a larger sample in order to increase the chance of finding significant data.
- Although a significant difference in human rights knowledge scores was found pre- and post-training, some participants scored highly on the knowledge quiz pre-training, suggesting that there might have been a 'ceiling' effect in relation to detecting increases in knowledge in those participants.

Where can I find out more?

This case study is based on:

Taylor, E., Redman, M., Roberts, A., and Furlong, R. (2010) *Human Rights Training Evaluation: Descriptive Results and Thematic Analysis of Responses*. Liverpool: Mersey Care NHS Trust.

Redman, M., Taylor, E., Furlong, R., Carney, G. and Greenhill, B. (2012) 'Human rights training: impact on attitudes and knowledge', *Tizard Learning Disability Review* 17(2), 80-87.

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CASE STUDY F

Mersey Care NHS Trust – ‘Getting it Right’: Human rights-based approaches to inpatient care for people with dementia

Who was involved?

In 2011-12, a project team from Mersey Care NHS Trust worked alongside staff and service users to run and evaluate the project.

Summary of the human rights-based intervention being evaluated

The project developed a new human rights-based Quality of Life Assessment Tool for use in the ward environment. The assessment tool integrates existing principles of person-centred dementia care with a human rights-based approach. It focuses on the individual’s quality of life and well-being rather than their level of function. For example, it examines areas such as the patient’s choices and preferences in relation to their personal care, relationships with others and opportunities for autonomy in decision-making. The ‘domains’ were identified collaboratively with dementia patients and carers.

The assessment tool is based on:

- the principle of proportionality to ensure the use of the least restrictive alternatives for each individual, and
- the use of proactive rather than reactive strategies.

It aims to balance risk; maximise quality of life and ensure that people with dementia are aware of their rights and are treated with fairness, respect, equality, dignity and autonomy (the FREDA values).

The assessment tool also draws on the idea of ‘enhanced care planning’ as developed by the Bradford Dementia Group (based at the University of Bradford). These are in turn based on the ‘enriched model of dementia’ developed by Tom Kitwood. This model seeks to explain the varied factors which can affect the way in which a person with dementia acts, feels and thinks. Rather than attributing everything a person does to their illness, the model focuses on the whole person and aims to improve understanding of the individual’s condition so that meaningful care plans can be developed.

The project produced a guide for staff to use when completing the tool. The tool is colour-coded to indicate when the different sections should be filled in during a person’s stay on the ward, e.g. red sections must be filled in within 24 hours but green sections can be completed within a week. In addition, staff received training on

human rights in relation to dementia care and, at time of writing this guide (November 2012), a DVD was being produced for use during the training.

The patient holds their own copy, 'Getting it right' which contains a 'user friendly' version of the personalised care plan generated by the assessment tool.

Aims and objectives of the evaluation

The aim was to evaluate the efficacy of the tool and training in relation to three areas: care, rights and well-being. The objectives were to evaluate:

- whether implementing the tool improves the quality of the person's care plan
- whether using a human rights-based approach provides a more robust framework for clinical decision making for staff, and
- whether the training package increases staff's knowledge of human rights.

Evaluation framework and methods

At the time of writing this guide, the evaluation is not yet complete. The evaluation has been designed in three parts, as follows:

Evaluating whether using the human rights-based assessment tool improves the degree of person-centeredness of care plans for people with dementia:

It was decided that by taking measures of care plans before and after the new tool came into use, the degree of impact of the tool could be measured in terms of changes (or not) to the person-centeredness of the care plans. As existing standards for care plans are mainly related to process rather than outcomes, the project team developed a set of standards that were based on the idea of 'enhanced care planning' (see above and [Annex 10](#)). The care plans were audited against these standards pre-implementation and will be audited again after the implementation of the new tool.

Evaluating whether using a human rights-based approach enables staff to have a more robust structure to help them make decisions with regards to human rights issues faced in day-to-day practice:

The second part of evaluation involved using semi-structured interviews with staff on the ward. The project team developed 10 scenarios which occur commonly in practice and relate to human rights issues (see [Annex 6](#)). Staff were presented with five scenarios pre training and will be presented with five different scenarios post-training. Staff are asked simple questions about what decisions they would make in each situation and why. The scenarios and questions are designed to establish whether a human rights-based approach enables a more robust framework for decision-making.

Evaluating whether the training increased staff’s knowledge of human rights issues in day-to-day practice: Before and after the training, staff complete a Human Rights Knowledge Quiz to establish whether the training increases their knowledge with regards to human rights (see [Annex 4](#) for a modified version of the quiz).

Timescale of the evaluation

The project was implemented in 2011-12. As of September 2012, the ‘baseline’ measures have been taken.

Summary of findings of the evaluation

At the time of writing, no findings are available as the evaluation is not complete.

Lessons learnt in relation to evaluation

The project team suggest the following lessons from the early stages of their evaluation:

- Keep it simple: don’t bit off more than you can chew.
- Keep it specific: ensure that your project (and your evaluation) identify specific areas that you want to change.

Where can I find out more?

The lead contact for the project is:

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CASE STUDY G

Mersey Care NHS Trust – Co-producing a human rights board game with people with learning disabilities

Who was involved?

The Liverpool Community team of Mersey Care NHS Trust has worked with service users with learning disabilities to co-produce a ‘human rights board game’.

Summary of the human rights-based intervention being evaluated

The board game – the first of its kind in the UK - is called the ‘FREDA Challenge’. FREDA is a character developed by the ‘Standing up for my human rights’ group, which is formed of individuals with learning disabilities or additional complex needs. FREDA was conceived by the group as a character who believes in five human rights values: treating others with fairness, respect, equality, dignity and autonomy. The board game involves players throwing dice and moving around a square board, picking up cards that prompt them to discuss various scenarios.

Aims and objectives of the evaluation

The evaluation attempted to answer the following questions:

- Will there be any change in people’s attitudes toward human rights after playing the board game?
- Will there be an increase in knowledge of human rights after people play the board game?
- What will be people’s levels of satisfaction after playing the board game?

The evaluation aimed to:

- evaluate the board game as a tool to facilitate human rights education for people with learning disabilities, carers and professionals
- make recommendations on improvements to the board game, and
- provide feedback to the Human Rights in Healthcare programme, learning disability service and participants.

Evaluation framework and methods

Thirty-three people were strategically sampled for the evaluation; including 20 people with learning disabilities and 13 carers/professionals from both the NHS and voluntary organisations. Of these, 31 agreed to take part: 18 service users and 13 carers and/or professionals. People were asked to play the game in mixed-groups of two to five players each.

Recruitment of participants: Participants were identified via nurses and psychologists within the services. The inclusion criteria were: any person with a mild to moderate learning disability with some level of literacy; carers of people with learning disabilities; and professionals working within the Learning Disability services. People without verbal and literacy skills; people under 18 years of age; people unable to provide informed consent; and people who had helped to develop the board game were excluded.

Consent: Informed consent was sought from each participant who had initially agreed to take part in this evaluation. All information was adapted to participants' abilities.

Design: The evaluation used a 'within/between-groups' design. This approach allowed the evaluator to measure changes in attitudes and knowledge after an intervention and to make group comparisons.

Materials: Before and after playing the board game, participants completed an 'attitude to human rights' questionnaire (see [Annex 3](#)) and a multiple choice human rights quiz (with support where required) (see [Annex 4](#)). After playing the game, they also completed a satisfaction questionnaire, rating the game for simplicity, enjoyment and stimulation and answering open-ended questions about whether they liked the game and how, if at all, they would change it. The resulting data were analysed using a statistical software package.

Timescale of the evaluation

The evaluation was conducted between October 2011 and April 2012.

Summary of findings of the evaluation

Attitudes: Overall, service-users and carers alike had a positive attitude towards human rights both before and after playing the game. However, scores of service users significantly increased after the game compared to before, while the scores of carers did not.

Knowledge: Carers' and professionals' knowledge scores were equally high before and after playing the board game. On the other hand, scores achieved by service users demonstrated an increase in knowledge after playing the board game. This finding suggests that it is possible significantly to increase knowledge about human rights after a single session. The evaluation report found that the board game takes human rights from abstract or technical realms into 'real and experiential discussion points, and appears to provide people with social validation and empowerment to speak up about fair/unfair treatment, by giving them a vocabulary they can use to identify abuse'.

Satisfaction: Overall, service-users and carers presented equally positive feedback about the experience and related to the topic of human rights. The majority of participants thought that the game was simple and stimulating, and the experience was enjoyable. However, some found the game too complicated, and only two-thirds said they would recommend the game to others. As a result, the game was revised to make it more accessible to people with more severe cognitive impairments or limited verbal and literacy skills.

Implications for the service: The evaluation concludes that the board game appears to be a tool to elicit learning about human rights among service users, carers and health and social care professionals. This learning can be accompanied by changes in attitudes towards human rights, as the game can provide validation and awareness of what human rights are and how they can be applied in real life. The report adds that increases in knowledge and attitudes can improve staff-client relationships: when people play the game together they may experience high levels of satisfaction and interaction by discovering each other's strengths and fostering empathy.

Lessons learnt in relation to evaluation

The report identifies issues that might influence the design of future evaluations:

- There is a need to measure more effectively how the game interacts with different levels of learning disability, principally by expanding the sample size.
- Some service-users received support from staff when completing the attitudes questionnaire and the knowledge quiz. This could have biased the data in the sense that staff might have attempted to apply their own attitudes towards or knowledge of human rights. The evaluator mitigated this effect by taking into account other observational evidence gathered on the day and responses to the satisfaction questionnaire.

Where can I find out more?

This case study is based on:

Montenegro, J. M. (2012) *Evaluating the 'FREDA' Challenge – a Human Rights Board Game – in Learning Disabilities Services* (submitted in partial fulfilment of the degree of Doctorate in Clinical Psychology at the Division of Clinical Psychology, University of Liverpool).

Correspondence relating to the evaluation should be addressed to Miguel Montenegro at The University of Liverpool (mmiguel@liv.ac.uk). Correspondence relating to copies of the board game itself should be addressed to Anna Sharp (anna.sharp@merseycare.nhs.uk) and Sam Townsend (sam.townsend@merseycare.nhs.uk).

CASE STUDY H

Scottish Human Rights Commission - Care about Rights project (Phase 2)

Who was involved?

The Care about Rights project was developed by the Scottish Human Rights Commission (SHRC) with the support of Scottish Care, the Care Inspectorate, Age Scotland and a number of other organisations and individuals. The evaluation of Phase 2 of the project was conducted by an independent research organisation, ekosgen, using evaluation specialists and experts in the field of dignity in care from Queen Margaret University and the University of Bedfordshire.

Summary of the human rights-based intervention being evaluated

Care about Rights is an awareness raising programme which highlights the practical applications of human rights in care for older people. It consists of interactive training materials, based largely on hypothetical scenarios, which can be accessed by individuals online or by CD/DVD. The SHRC also delivered the training to organisations face-to-face and has run 'training for trainers' sessions in order to increase the reach of the programme. Care about Rights was initially targeted at three key audiences:

- those who deliver care to older people
- older people, their families and carers, and
- care policy makers, inspectors and regulators.

Aims and objectives of the evaluation

In May 2010, the SHRC commissioned ekosgen to carry out a longitudinal evaluation of Care about Rights over the course of the project. The broad aims of the evaluation were to examine:

- the effectiveness of project processes, and
- the impacts of the project for its key audiences.

The specific objectives of the evaluation were to:

- provide a baseline of information about the knowledge, awareness, and perceptions of human rights held among the project participants
- assess the process of the project from content development through to the roll-out of materials
- collect and collate participant responses to the awareness raising materials, both written and film

- collect and collate participant responses to the delivery and effectiveness of the awareness raising sessions
- assess participants' knowledge, awareness and perceptions about human rights following their attendance at the awareness raising sessions
- identify whether the awareness raising sessions have contributed to changes in practice and cultural change within the care provider organisations or the Care Commission, and
- assess whether, as a result of the awareness raising programme, participants are more or less likely to frame care of older people policy issues as human rights issues.

Evaluation framework and methods

In Phase 1 of Care about Rights, the evaluation team developed a 'logic model' illustrating the intended aims and outcomes of Care about Rights and how these were to be achieved (see [Annex 8](#) for a copy of this logic model).

The evaluation of Phase 2 of the project consisted of:

A review of literature and the current policy environment to examine the rationale for the project; its potential long term outcomes (particularly in relation to the changing environment of the social care sector and the personalisation agenda); and its contribution to national strategic objectives.

Consultation with strategic bodies : This included external organisations such as Scottish Care, the Scottish Social Services Council; the Scottish care inspectorate; Age Scotland and the Convention of Scottish Local Authorities.

Consultation with older people involved in the outreach programme: The study team attended a selection of outreach sessions to observe activity and gather consent to contact participants for follow up consultations. Consent was gathered at the final outreach sessions for each group and consultations took place shortly after completion of the awareness-raising sessions (generally within two weeks). Consultations were completed with 20 older people who participated in the outreach programme; 25 per cent of those who participated in one or more of the sessions. Consultations investigated views on:

- the set up and delivery of awareness raising sessions
- the outcomes of involvement for older people, and
- views on the potential impact of the project for older people more widely and the future delivery of care services.

Base- and end-line survey of care providers: throughout Phase 2 the study team continued to collate and analyse the base-line surveys completed by care workers prior to participating in Care about Rights training. A total of 799 baseline responses was received at the time of reporting. As the training was delivered in numerous locations, it is not possible to say precisely what response rate this represents. In July 2011, a follow up survey was distributed electronically to care workers who provided their contact details and their permission to be re-contacted. The survey was sent to around 400 participants and responses were received from 82 (a response rate of approximately 20 per cent).

Organisational case studies: The study team carried out case study research with a sample of organisations demonstrating good practice in the roll out and embedding of Care about Rights. Case study visits involved consultation with those with strategic responsibility for the roll out of Care about Rights, and, where appropriate given the stage of development, a number of operational staff. Case studies were carried out with two private residential care providers and a care at home provider. Plans were also in place to conduct case study research within a local authority.

Timescale of the evaluation

The project began in September 2010. The evaluation was undertaken between January and July 2011.

Summary of findings of the evaluation

The full findings can be accessed from the published sources in the box below. On its website, the SHRC highlights the results of the follow-up survey distributed to training participants. The survey found that:

- 99 per cent said they understood what human rights are and how they are applicable to their work (compared to 56 per cent before)
- 90 per cent agreed or strongly agreed that they could communicate with colleagues about how human rights could improve the delivery of care (compared to 54 per cent before).
- 94 per cent said they understood the relationship between human rights and other legislation after taking part in Care about Rights (compared to 39 per cent before).
- 94 per cent said they understood the relationship between human rights and the National Care Standards (compared to 54 per cent before).
- In all the above more than half of respondents feel that Care about Rights has contributed positively to their increased understanding.

- 97 per cent of respondents feel that a human rights based approach can help care providers develop positive relationships with service users and their families.

Lessons learnt in relation to evaluation

The report acknowledges that effective evaluation of longer-term impact is complex. Perceptions of the quality and value of Care about Rights are measurable, as are some of its short-term outcomes (see above). However, taking the next step to measure medium- and longer-term impacts is challenging. This is because such measurement requires a sustained approach and longer term collection of data from people who use services. The report concludes that, at this stage of the project, this is not possible (ekosgen et al, 2011: 55).

Where can I find out more?

This case study is based on:

ekosgen, The University of Bedfordshire and Queen Margaret University (2011) *Evaluation of Care about Rights – Phase 2: Report to the Scottish Human Rights Commission* - <http://scottishhumanrights.com/careaboutrights/evaluation>

Scottish Human Rights Commission (2011) *Care about Rights Evaluation Research* (a summary of the full report) -

<http://www.scottishhumanrights.com/application/resources/documents/CareAboutRights8pagedoc.pdf>

CASE STUDY I

Scottish Human Rights Commission: 'Making it Work' - An evaluation of the human rights-based approach at The State Hospital

Who was involved?

In 2009, the Scottish Human Rights Commission (assisted by an independent human rights expert) undertook an evaluation of the experience of a Special NHS Health Board which, since 2002, has sought to adopt a 'human rights culture'. The State Hospital in Lanarkshire is the high security forensic mental health hospital for Scotland and Northern Ireland. It provides psychiatric care in conditions of high security for people with mental illness who are compulsorily detained under mental health or criminal law.

Summary of the human rights-based intervention being evaluated

In 2000, a critical report into the treatment and care of a patient was among the factors that prompted The State Hospital fundamentally to examine its practice. A decision was taken to use the Human Rights Act as 'a vehicle for cultural change' in order to move away from a custodial and punitive regime towards one that put the human rights of everyone – staff, patients, carers and family members – at the heart of the hospital's services.

In 2002, The State Hospital established a Human Rights Working Group led by senior managers and involving both clinical and non-clinical members of staff. The Group underwent training in human rights with an external expert who helped them to identify specific human rights which were relevant to The State Hospital. The Working Group asked three questions three key questions in relation to all policy and practice at TSH:

- Is the policy/practice legal?
- Does it have a legitimate aim?
- Is it proportional?

Through discussions with around 100 staff and patients, the group assessed all policies and practices using a 'traffic light' tool, where red signalled non-compliance with human rights; amber signalled a risk of non-compliance, and green signalled compliance.

No policy or practice was given the red light. Some - such as those related to seclusion and restraint - were graded as amber. The group worked with the human rights expert to develop human rights training for staff and tools for the assessment

of future policy and practice. Other steps included the creation of a forum for staff, patient, and carer participation in decisions, and the establishment of an Equality, Diversity and Human Rights Group to ensure a human rights-based approach to the fulfilment of equality duties.

Aims and objectives of the evaluation

The core aim was to evaluate the procedural steps and the outcomes of the human rights-based approach to facilitating cultural change at The State Hospital. The intention was to enable the SHRC to identify key lessons that could help the hospital further improve its policies and practices. More broadly, the SHRC aimed to help other organisations to facilitate cultural change and integrate human rights into their day-to-day operations, behaviour and policy development.

In order to achieve this, six specific objectives were set. These related to both **actual** and **perceived** impact:

- **Objective 1:** to understand the process of developing and implementing an effective human rights-based approach and to draw out key learning for replicating this process successfully in other settings both within and beyond health and social care settings.
- **Objective 2:** to assess the perceived impact of implementing a HRBA, including benefits for patients, staff and carers from the perspectives of all involved.
- **Objective 3:** to identify the extent to which human rights outcomes were perceived to have changed as a result of the adoption of a HRBA.
- **Objective 4:** to evaluate the extent to which human rights are now respected in practice at The State Hospital.
- **Objective 5:** to develop effective human rights-based tools and materials that can be used by other public authorities to bring about positive cultural change.
- **Objective 6:** to develop an effective human rights-based approach to evaluation methodology that can be replicated by those introducing a HRBA to their service.

Evaluation framework and methods

The evaluators used a range of methods to gather evidence. Sources included documentary evidence, limited statistical data and a range of qualitative testimony. The evaluators were assisted throughout by a group of national and international experts in the fields of mental health, human rights law and/or research methods.

The PANEL principles (participation, accountability, non-discrimination, empowerment and legality - see [Chapter 2](#)) were integral to the evaluation: they

were used to develop indicators of effective practice and questions for semi-structured interviews and focus groups (see [Annex 9](#)).

The following table shows the methods used and how they related to each objective:

Method	Objectives					
	1	2	3	4	5	6
Review of documentary evidence from the State Hospital relating to implementation	x		x	x	x	
Review of other HRBAs and evaluations	x				x	x
Review of other legislative obligations with potential impact on development of policy and practice at The State Hospital	x			x	x	
Survey of existence of key policies and indicators of effective practice, with qualitative and quantitative data supplied by a range of departments at The State Hospital	x		x	x	x	
Semi-structured interviews with 6 key stakeholders at The State Hospital	x	x	x	x	x	
Semi-structured interview with external expert (Professor Alan Miller)	x	x	x		x	
Semi-structured interviews with at least 7 external organisations in Scotland	x	x	x		x	
Focus groups with staff: members of the initial Human Rights Working Group (2 groups of 6-7 staff members)	x	x	x		x	
Focus groups with staff: cross section of front-line clinical & non-clinical staff (around 35 staff in 5 groups, lasting 90 minutes), plus one group of psychiatrists (5 staff, lasting 30 minutes)		x	x		x	
Focus groups with both recently-admitted and longstanding patients (5 groups of varying sizes ranging from 3 to 11 patients, both on wards and in Patient Partnership Group meetings, and lasting between 30 and 75 minutes)		x	x		x	
Focus groups with carers of both recently-admitted and longstanding patients (2 groups, one with 10 carers and the other with 2 carers, each lasting 30 minutes)		x	x		x	

Timescale of the evaluation

The HRBA at the State Hospital began in 2002. The evaluation by the SHRC was the first thoroughgoing evaluation of the HRBA. Research began in May 2009 with the collection of documentary evidence. The majority of interviews and focus groups took place from July to November 2009 and survey information was collected throughout the process.

Summary of findings of the evaluation

The experience of The State Hospital provides one of the longest standing and best documented examples of the impact applying human rights in health and social care. Below is a summary of the main findings of the SHRC evaluation (see SHRC, 2009: 69-73):

A human rights-based approach is ‘better for everyone’: The adoption of a HRBA was successful in supporting cultural change at The State Hospital. It had changed from an institution with a ‘them and us’ culture in which human rights were largely ‘left at the door’ towards one with a more positive and constructive atmosphere and mutual respect between staff and patients. Among other outcomes, the HRBA had led to:

- increased staff and patient engagement
- increased work-related satisfaction amongst staff
- reduced stress and anxiety amongst staff
- increased satisfaction among patients over their care and treatment
- a reduction in ‘blanket’ policies and a greater focus on individual patients’ risks
- an end to the routine use of seclusion as punishment.

Taking a rights-based approach reduces risks: By adopting a HRBA an organisation can reduce its risk of having to react to critical media comment, negative public perceptions or legal proceedings when its policy or practice is shown to breach human rights. The support of tailored human rights expertise to audit policy and practice and use of a ‘traffic light’ warning system made human rights ‘user friendly’, and reduced both organisational risks and risks to people.

Human rights are the foundation for other duties: Since the HRA, all relevant legislation has to be read through the lens of human rights. Taking a HRBA at The State Hospital made the implementation of other duties a less daunting process. It laid the foundations for the integration of new equality, freedom of information and mental health duties. In particular, The State Hospital’s experience demonstrates that human rights can provide the ‘bedrock’ for implementing equality duties.

Why it worked: The experience of The State Hospital provides organisational lessons for the integration of human rights into other public authorities in the health and social care sectors. These lessons are reflected in [Chapter 2](#).

There is no room for complacency: Crucial to the success of The State Hospital's HRBA was the involvement of staff, and the reflection of their rights throughout the process. There is a need regularly to refresh the HRBA to respond to changes in personnel and in circumstances. Explicit linking of human rights and the HRA to other duties such as those under equality or mental health laws will help to ensure the sustainability of a HRBA.

Lessons learnt in relation to evaluation

The need for a base-line study: The evaluation of the HRBA at The State Hospital notes that 'an ideal evaluation would involve an evaluation team undertaking a base-line study prior to the human rights-based ... intervention in order to have a high degree of casual probability that an intervention has resulted in certain outcomes or improvements' (Scottish Human Rights Commission, 2009: 76). No base-line study was done in this case, and therefore the evaluation had to rely on documentary evidence, limited statistical data and a range of qualitative testimony to present a comparative picture of what the policy, culture and day-to-day practice was like at the hospital before and after the introduction of the HRBA. The evaluators combined the different sources of data, especially the testimony of the stakeholders about what was said to have happened with the 'fairly consistent' views of staff, patients and carers about what they feel actually happened, in order to assert 'a degree of reliability' in the data collected (Scottish Human Rights Commission, 2009: 76).

Setting objectives: setting clear and measurable objectives at the start of a project is crucial. The SHRC notes that such an approach will permit evaluations to move beyond the 'implementation stage' to examine outcomes and impact with more confidence. In addition, using such an evaluation framework provides a means of monitoring the progress of an initiative as it unfolds (SHRC, 2009: 77). In its evaluation of The State Hospital, the SHRC developed a framework based on the PANEL principles to:

- shape the initial objectives of the evaluation
- develop indicators of effective practice
- devise questions for semi-structured interviews and focus groups
- identify the data required, and
- identify mechanisms for the collection of such data.

See [Annex 9](#) where a section of the SHRC's evaluation framework (based on the principle of participation) is reproduced by way of example.

Where can I find out more?

This case study is based on:

Scottish Human Rights Commission (2009) *Human Rights in a Health Care Setting: Making it Work - An Evaluation of a human rights-based approach at The State Hospital*. Available at:

http://www.scottishhumanrights.com/application/resources/documents/HRHCSFINA_LVERSION.pdf.

CHECKLIST FOR EVALUATORS

This checklist is a reminder of the decisions you need to make in designing your evaluation.

- Don't forget to take the baseline – that is, the state of affairs before your activity – in order that you can assess 'before' and 'after' changes.
- Think carefully who should be involved in your evaluation. How will you involve service users or carers? Can the evaluation be done by your team, or should it involve people from outside your team – or outside your organisation?
- Decide at what stage/s you will evaluate: is it useful to 'road test' all or part of your activity? Will you evaluate the implementation of your activity? And at what stage/s will you evaluate the results of your activity?
- Set clear aims and objectives for your activity: think in terms of **what** you want to change and **who** will be involved in, and/or affected by, the change. Keep your objectives specific and realistic.
- Decide what evidence you need to show if you have achieved your aims and objectives and how you will gather it. Keep the scope of the evaluation in proportion to the size of the activity you are evaluating.
- Your findings will be more reliable if you use a mixture of methods. These might include both quantitative methods (to find out how many people thought or did something) and qualitative methods (to find out why people think or behave in a certain way or have certain preferences).
- Your findings will be more reliable if you combine at least two methods of gathering data to answer the same question.
- Don't be afraid to innovate. Adapt existing evaluation tools to suit your purpose – you can find some road-tested tools in the [Annex](#) document which accompanies this guide (available at: www.humanrightsinhealthcare.nhs.uk).
- Think carefully through the ethical implications of your evaluation research and if you are in doubt, take advice.
- Check what (if any) formal clearance is required for your evaluation, and what (if any) permission you need to obtain from your local Research and Development department.
- Anticipate possible pitfalls: could your evaluation be biased (or appear to be so)? How will you demonstrate cause and effect?

GLOSSARY

Aim

The aim of your activity is what you ultimately want to achieve. This longer-term aim is supported by a number of objectives that will help you to realise the overall goal.

Baseline

A measure at the beginning of an activity that enables you at a later point in time to determine whether or not there has been any change.

Evaluation

Evaluation helps you to see whether or not you have achieved your aims and objectives and identify ways to improve what you do during and after your activity.

Focus group

A research method that involves a group of around 6-8 people convened to discuss a particular topic, usually with a facilitator (and if not, with an observer).

Formative evaluation

Research that takes place during the development of an activity in order to 'road-test' all or part of it.

FREDA

A set of values which encapsulate how, in human rights terms, people wish to be treated and should treat others. These are: fairness, respect, equality, dignity and autonomy.

Human rights-based approach

There is no single definition of a human rights-based approach, but many overlapping definitions. The Department of Health (2008: 35) states that a HRBA 'is a way of ensuring that human rights principles and standards are made real in practice' and is based on a set of core principles. These principles are commonly referred to as the PANEL principles of participation, accountability, non-discrimination, empowerment and legality.

Impacts

For the purposes of this guide, impacts are the longer-term changes that result from a human rights-based intervention. Such changes may be cumulative and may affect a wider group than the original 'target' group. Intended impacts are generally closely tied to the strategic aim of the project.

Longitudinal study

A research study that involves repeated observations of the same variables over long periods of time

Objectives

Objectives are the specific activities through which you will achieve your overall aim/s. They should be 'SMART' (see below).

Outcomes

For the purposes of this guide, outcomes are the short-and medium-term changes that result from a human rights-based intervention. Intended outcomes are generally closely tied to the specific objectives of the project.

Outputs

Outputs are the tangible things you produce as part of an activity, e.g. a toolkit or DVD.

PANEL

A set of principles which underpin how a human rights-based project should be designed and evaluated. These are: participation, accountability, non-discrimination, empowerment and legality.

Proportionality

The principle of proportionality can be summarised as 'not using a sledgehammer to crack a nut'. Making decisions in a proportionate way ensures that any restriction of a person's human rights is kept to a minimum.

Qualitative research

Qualitative research methods allow participants to express themselves freely in their own words, usually via semi-structured interviews and/or focus groups conducted by researchers. By analysing the themes and language used, researchers can gain an understanding of why people think or behave in a certain way.

Quantitative research

Quantitative research methods ask people the same questions in such a way as to enable the answers to be added together and provide a representative sample of the entire target group. Quantitative techniques thus generate reliable statistical data on the percentage of people with particular views or behaviour.

Questionnaire

A quantitative research tool comprising a structured set of questions calling for precise responses that allows answers from all those who complete it to be added together.

Quota sampling

Setting 'quotas' to ensure that a sample contains the same percentage of people with specific characteristic/s as the wider group of interest.

Sampling

A way of selecting people to take part in research that ensures they are chosen to be representative of the population of interest; for example, in relation to age, gender or ethnicity.

Summative evaluation

Evaluation at the end of an activity or at a defined interim stage to see if the stated aims and objectives have been met.

Systematic sampling

Taking every 'nth' person who participates in an activity, thereby producing a statistically representative sample.

Semi-structured interview

An interview conducted by a researcher using a 'topic guide', which allows respondents to express themselves in their own way. This is sometimes also referred to as an 'in-depth' interview.

SMART

All objectives should be SMART, which stands for: specific; measurable; achievable; relevant; and time-bound.

Topic guide

A qualitative research tool comprising a list of questions and/or issues that a researcher wants to cover during a focus group or semi-structured (in-depth) interview. This is sometime also referred to as an 'interview schedule'.

Triangulation

In social scientific research, triangulation refers to the use of three methods to answer a single question in order triple-check the result. The intention is that at least two of the three methods will produce similar findings, in order that the investigator can have confidence in the result. If the three methods produce three sets of contradictory results, the investigator may want to reframe their questions and/or methods.

THE PANEL PRINCIPLES

Participation: everyone has the right to participate in decisions which affect their human rights.

Accountability of duty-bearers to rights-holders: this requires both effective monitoring and effective remedies.

Non-discrimination and equality: all forms of discrimination in the realisation of rights must be prohibited, prevented and eliminated.

Empowerment of rights-holders: everyone should know their rights and be supported to participate in decision making, and to claim their rights where necessary.

Legality: public authorities should expressly apply the Human Rights Act and link to international and regional rights standards.

Source: Scottish Human Rights Commission (2009) *Human Rights in a Health Care Setting: Making it Work - An Evaluation of a human rights-based approach at The State Hospital*, Glasgow: SHRC, pp. 10-11.

RESOURCES

Evaluation reports

Listed below are the evaluation reports referred to in the case studies in [Chapter 10](#), as well as selected articles based upon these reports.

Ekosgen, The University of Bedfordshire and Queen Margaret University (2011) *Evaluation of Care about Rights – Phase 2: Report to the Scottish Human Rights Commission*. Available at: <http://scottishhumanrights.com/careaboutrights/evaluation>.

Greenhill, B. and Whitehead R. (2010) 'Promoting Service User Inclusion in Risk Assessment and Management: A Pilot Project Developing a Human Rights Based Approach', *British Journal of Learning Disabilities* 39, 277–283.

Ipsos MORI (2010) *Human Rights in Healthcare Project Phase III: Evaluative Review*. Ipsos MORI for the Department of Health.

Mersey Care NHS Trust (2011) *An Evaluation of Service User and Carer Involvement in Mersey Care NHS Trust*. Liverpool: SURE (Service User Research and Evaluation).

Redman, M., Taylor, E., Furlong, R., Carney, G. and Greenhill, B. (2012) 'Human rights training: impact on attitudes and knowledge', *Tizard Learning Disability Review* 17(2), 80-87.

Roberts, A., Greenhill, B., Talbot, A. and Cuzak, M. (2011), 'Standing up for my human rights': a group's journey beyond consultation towards co-production'. *British Journal of Learning Disabilities*, doi: 10.1111/j.1468-3156.2011.00711.x.

Roberts, A., Vyas, J., Cookson, A., Redman, M., Hiley, B., Hornby, Y., Howard, D. and Greenhill, B. (2010a) *Human Rights in Healthcare Project Phase III: Parts 2 & 3: Evaluation of the Human Rights Joint Risk Assessment and Management Plan (HR-JRAMP) and Human Rights Human Rights Benchmarking Tool*. Liverpool: Mersey Care NHS Trust.

Roberts, A., Vyas, J., McEwan, L., Evans, G., Khawaja, Z., Punshon, C. and Greenhill, B. (2010b) *Human Rights in Healthcare Project Phase III: Part 1: A Human Rights Based Approach to Risk - Evaluating the Incorporation of the 'Keeping Me Safe and Well' Risk Screen into Community Learning Disability Services*. Liverpool: Mersey Care NHS Trust.

RESOURCES

Scottish Human Rights Commission (2011) *Care about Rights Evaluation Research* (a summary of the full report) -

<http://www.scottishhumanrights.com/application/resources/documents/CareAboutRights8pagedoc.pdf>

Scottish Human Rights Commission (2009) *Human Rights in a Health Care Setting: Making it Work - An Evaluation of a human rights-based approach at The State Hospital*. Glasgow: SHRC. Available at:

<http://www.scottishhumanrights.com/application/resources/documents/HRHCSFINALVERSION.pdf>.

Taylor, E., Redman, M., Roberts, A., and Furlong, R (2010), *Human Rights Training Evaluation: Descriptive Results and Thematic Analysis of Responses*.

Liverpool: Mersey Care NHS Trust.

Whitehead R., Carney G. and Greenhill B. (2011) 'Encouraging positive risk management: Supporting decisions by people with learning disabilities using a human rights-based approach'. In: R. Whittington and C. Logan (eds), *Self-Harm and Violence: Towards Best Practice in Managing Risk in Mental Health Services*, pp. 215-236. Chichester: Wiley-Blackwell.

Resources about implementing human rights in public services

This section lists selected publications and websites which are concerned with implementing human rights and/or involving service users and carers in public services in the UK.

Audit Commission (2003) *Human Rights: Improving Public Service Delivery*. London: Audit Commission. Available at:

<http://webarchive.nationalarchives.gov.uk/+http://www.justice.gov.uk/guidance/docs/acrep03.pdf>.

Boyle D. & Harris M. (2009) *The challenge of co-production. How equal partnerships between professionals and the public are crucial to improving public services*.

Discussion Paper. London: New Economics Foundation & NESTA. Available at:

<http://www.nesta.org.uk/library/documents/Co-production-report.pdf>.

Bray (2010) *Developing and Evaluating the Practical Application of a Human Rights Framework in Cancer Care – a report for MacMillan Cancer Support*. Available at:

<http://www.macmillan.org.uk/Documents/AboutUs/WhatWeDo/HumanRightsFrameworkForCancerCareReport.PDF>.

Department of Health and British Institute of Human Rights (2008) *Human rights in healthcare: A framework for local action (2nd edition)*. London: Department of Health. Available at:

http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/document_s/digitalasset/dh_088972.pdf.

Dyer, L. (2010) 'A Human-Rights Based Approach to Involving Service Users and Carers' *British Journal of Well-Being* 1, 3: 26-27.

Equality and Human Rights Commission – Human rights: practical guidance website: <http://www.equalityhumanrights.com/human-rights/human-rights-practical-guidance/>. You can search this website by public sector area and theme to find guidance that is relevant to you.

Human Rights in Healthcare programme:
<http://www.humanrightsinhealthcare.nhs.uk/>.

Institute for Public Policy Research/Butler F. (2005) *Improving Public Services: Using a Human Rights Approach*. London: IPPR and DCA. Available at: <http://www.ippr.org/ecomm/files/ippr%20human%20rights%20report%20June%202005.pdf>.

Kinderman, P. and Butler, F. (2006) *Implementing a Human Rights Approach within public services: an outline psychological perspective*. A report for the Department of Constitutional Affairs. Available at: http://www.mhe-sme.org/assets/files/Human%20Rights%20committee/Implementing_a_Human_Rights_Approach_within_Public_Service.pdf.

NHS Litigation Authority's Human Rights Act Information Service:
www.nhs.uk/nhsa/humanrights.

Office of Public Management (2009) *The impact of a human rights culture on public sector organisations: lessons from practice*. Manchester: Equality and Human Rights Commission. Available at: http://www.equalityhumanrights.com/uploaded_files/the_impact_of_a_human_rights_culture_on_public_sector_organisations.pdf.

Resources on monitoring and evaluation

The resources listed below are generic, step-by-step guides to monitoring and evaluation which have been created for public and voluntary sector organisations in the UK.

RESOURCES

Charities Evaluation Service (2008) *Practical Monitoring and Evaluation: A guide for voluntary organisations (3rd edition)*. London: Charities Evaluation Service.

Charities Evaluation Service online guidance on monitoring and evaluation:
<http://www.ces-vol.org.uk/about-performance-improvement/about-monitoring-evaluation>.

National Council for Voluntary Organisations online guidance on measuring impact:
<http://www.ncvo-vol.org.uk/strategy-impact/learn/impact/measuring-impact>.

Research Councils UK (2011) *Evaluation: Practical Guidelines*. London: Research Councils UK. Available at:
<http://www.rcuk.ac.uk/documents/publications/evaluationguide.pdf>.

Resources on research ethics

Economic and Social Research Council (2012), *ESRC Framework for Research Ethics (FRE) 2010* (Updated September 2012). Available at:
http://www.esrc.ac.uk/_images/Framework-for-Research-Ethics_tcm8-4586.pdf.

NHS Health Research Authority – ethical review requirements. Available at:
<http://www.nres.nhs.uk/applications/approval-requirements/ethical-review-requirements/>.

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