

Human Rights Guide for Health Watch



Author: Julie Wall - Head of Equality, Diversity and Human Rights

NHS Blackburn with Darwen Care Trust Plus

Important

In this booklet we will explain what some of the words mean.

When we first mention any of these words, it is in **bold green writing**.

A box then shows what the words mean.

These words and what they mean are also listed in the word list at the back of the booklet.

If any of the words are used again later on in the booklet they will be in **normal green writing**, and you can look them up in the word list.

Contents	Page
What the Author has to say about the Guide	3
Why we have written the Guide	5
About human rights	6
About using a human rights approach	7
Thinking about people's rights and the human rights principles	8
Using a human rights approach to entering and viewing NHS and other public sector services	9
Appendices	
Appendix 1 - Word list	19
Acknowledgements: in developing this Guide I would like to acknowledge the input of Ellie Keen from the British Institute of Human Rights and Susan Crorcken - Head of Safeguarding at NHS Blackburn with Darwen	



Julie Wall

What Julie Wall has to say about the Guide

This document has been developed by **NHS Blackburn with Darwen** to provide **a guide** to the new **Health Watch**.

NHS Blackburn with Darwen - this is the organisation that is responsible for buying health care.

A guide - a booklet to provide information to assist people working in **Health Watch** to have more understanding of **Human Rights**

Health Watch - this is a group will ensure that the views and experiences of people living in Blackburn with Darwen will be taken into account when planning what services to buy and provide.

It will allow people to share their views and concerns about their local health and social care services and will provide people with information about their choices and what to do when things go wrong.



NHS Blackburn with Darwen has been participating in a national programme sponsored by the **Department of Health** and led by **Mersey Care NHS Trust**.

Department of Health - is an organisation which is responsible for setting out how **health and social care providers** should be run and how **buyers of health and social care** such as a **Clinical Commissioning Group** should do this to meet local people's needs.

Mersey Care NHS Trust - this is a provider of Healthcare.





NHS Blackburn with Darwen has also been involved in the **Health Watch Project Team** led by the **Borough Council**.

Health and Social Care Providers - These are organisations such as the hospital.

Buyers of health and social care - these are organisations which buy **health and social care** from providers such as the hospital

Clinical Commissioning Group - this is a group of doctors working together to buy health care from hospitals and community nurses and other suppliers to ensure all the people living in Blackburn with Darwen receive the right care from the right person in the right place at the right time.

Human Rights - These are rights that everyone has just because they are human. The right to freedom, the right not to be tortured or treated in an undignified way and the right to life are just some of the rights we have.

Respecting, protecting and promoting people's human rights - this means that Health Watch will encourage health and social care providers to look after people's human rights and make sure everyone is treated in a fair and dignified way.

This **guide** should help people working in **Health Watch** to actively work towards **respecting, protecting and promoting** people's **human rights**.



Why have we written the Guide?

This **guide** has been written to help people working in **Health Watch** to actively work towards **respecting, protecting and promoting** people's **human rights**.

Members of the existing **Blackburn with Darwen LINK** were involved in identifying what to include in the guide through the **Human Rights** Workshop held on the 24th July.

Blackburn with Darwen LINK - a group that currently do some of the work the new **Health Watch** will be doing.



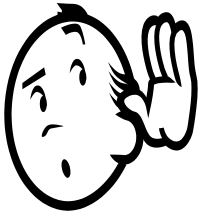
About Human rights

Human rights belong to everyone in the world.

- From when a baby is born until a person dies they have the same human rights.
- You can never lose your human rights but you may need to have them **restricted** in order to protect yourself or to secure the rights of others.

Restricting human rights means slightly reducing the freedom, choice or other 'benefits' of human rights. This might be necessary in places like hospitals so that *everyone's* rights are respected. Restricting a right needs a very good reason and must always be done as little as possible.

Human rights include all the things that are important to us as human beings such as being able to make choices about how we live our life and being treated with **dignity** and **respect**.



Dignity - Is about having your basic needs satisfied and feeling you are being treated like a human being. In a healthcare setting, dignity means:

- Not having things done to you which you find humiliating and do not want
- Being told what is happening to you, and being listened to - for example about how you like to be cared for or treated.
- Not being left in pain or suffering when something could be done about it

Respect - Treating someone with respect means treating them like a human being, in the same way that you would like to be treated. This means:

- Listening to their concerns or wishes - and taking them seriously
- Not making decisions on their behalf - unless absolutely necessary
- Valuing people as individuals.



About using a **human rights based approach**

Buyers of **Health and Social Care** and the **Providers** should consider peoples' **human rights to guide their policies /actions and** whenever they make decisions. This is called a **human rights based approach**.

A human rights based approach

This is about always putting human rights first: always making sure that people's dignity is respected, treating people equally and fairly and allowing them to take part in decisions which affect them. People should know their rights and know that they can ask questions and raise concerns. They should know that any concerns will be dealt with properly.

Using a **human rights based approach helps** to make sure that health providers are complying with the law (the Human Rights Act) and also improves the **experience** and **outcomes** for **patients, clients, service users and employees**.



Experience - this relates to how patients feel about their care and how employees feel about the work environment.

Outcomes - the results for patients being cared for

Patient - a person cared for by a **health provider** such as a hospital or a Doctor's surgery

Client - a person cared for by a **Social Services Provider** such as a care home

Service user - someone who uses a service such as a hospital or care facility

Employees - people who work for a **Health and Social Care Provider** or a **buyer of health and social care**



Thinking about people's rights and the human rights principles

If **buyers of Health and Social Care and the Providers** use a human rights based approach they will need to know what this means.

There are some human rights principles which can help guide them. The principles are:

Fairness - this is about treating people equally and not punishing them or ignoring them because of who they are or what they may have done.

Respect - this is about listening to people, valuing them and treating them like human beings.

Equality - means understanding and valuing people for who they are. It means treating people fairly, even when they seem to be different.

Dignity - this means respecting the people in your care, preserving their sense of self-respect. Whatever is important to patients should be respected, including their privacy and choices and opinions.

Autonomy - is about letting patients make decisions for themselves - and providing them with information so they can do so. Any important decision affecting a patient should not be made by other people unless there is a very good reason.

Using a Human rights approach to entering and viewing Health and Social Care Services

The information in this section of the *Guide* should help people from *Health Watch* to look for good examples where people's *human rights* have been *promoted, protected and respected*.

The *Guide* will also help people from *Health Watch* to identify if there have been some bad examples where people's *human rights* have not been *promoted, protected and respected* and *human rights principles* have not been followed.

How to use the tables

Health and social care providers need to make sure that they are not doing anything which goes against the *Human Rights Act*. In the grid on page xx some of the rights in the *Human Rights Act* are listed. These are the rights which are most relevant to patient care. People from *Health Watch* should look out for anything which might be against the *Human Rights Act* because this may mean the provider is breaking the law. Any examples you find should be raised straight away with person in charge of the area you are visiting e.g. Ward Manager, Home Owner, Commissioner, Practice Manager or Service Lead.

If nothing is done about the problem, you will need to report these to one or more of the following; CQC, Health Watch England, *Clinical Commissioning Group*, NHS Commissioning Board, Blackburn with Darwen Safeguarding Team. *The Human Rights Act* does not include all our human rights, so providers should also try to do more than this. These will be examples of good practice which can be noted by people from Health Watch.

The table in the next section looks at some of the general things you can ask about or look out for and which may indicate a violation of someone's rights. Violating someone's rights is against the law (the Human Rights Act). In the second grid (page 12) you will find some more specific examples of the different rights.

General things to find out about		
Negative practice	Possible Signs	Things to do or look out for
<ul style="list-style-type: none"> • Poor treatment or a failure to look after patients properly 	<ul style="list-style-type: none"> • Patients in great pain or suffering when something can be done about it • Patients feeling unsafe (perhaps because they have been threatened) • Patients feeling that they are not being properly respected by staff or are being treated in an undignified way • Patients feeling they do not have enough information and would make different choices for themselves • Patients or staff feeling they are being treated less well because they are older, disabled, belong to a different culture etc. 	<ul style="list-style-type: none"> • Speak to patients, family members, advocates, members of staff. Ask them about some of the 'possible signs' • If the 'signs' seem to be there, try to find out more information. Speak to other people and members of staff. Find out how much the person seems to be suffering and if this might be a violation of one of the articles in the Human Rights Act. • Keep a careful record of all the information you have found and make sure you follow this up with the relevant authorities

Negative practice	Possible Signs	Things to do or look out for
<ul style="list-style-type: none"> • Inadequate policies and procedures 	<ul style="list-style-type: none"> • Policies do not make reference to human rights and are not assessed or reviewed from a human rights point of view • Staff are unaware of the possible human rights implications of their actions • There is a lack of accountability for any human rights issues which do arise 	<ul style="list-style-type: none"> • Do policies say anything about human rights? • Are there mechanisms for dealing with possible human rights concerns? • Are such concerns always investigated and is there accountability for any decisions made? • Are members of staff aware of the possible human rights implications of their actions? • Is any training or information provided to staff about human rights?
<ul style="list-style-type: none"> • Ineffective complaints procedures 	<ul style="list-style-type: none"> • Patients or staff saying they would like to complain but not knowing how to, or being afraid to • Patients or staff feeling they have been 'punished' for complaining or their complaint has not been taken seriously 	<ul style="list-style-type: none"> • Speak to patients, staff, family members, advocates: • Are people made aware of complaint mechanisms? • Are they encouraged to complain if they feel unhappy with their care? • Are they reassured that there will be no negative implications if they decide to complain? • How are complaints dealt with? Can you review some of the complaints and see how they were addressed and what the consequences were?

Article 2 - the right to life

Description of the Article	Possible Issues	Things to Ask or look out for
<p>This means that nobody can do anything which is likely to end a patient's life. It also means that people have the right to be protected if their life is at risk.</p> <p>Health and social care providers should consider the right to life when making decisions that might put someone's life in danger or which affect their life expectancy.</p> <p>Health and social care providers need to take appropriate steps to protect a person's life in all circumstances. This also applies to people with no recourse to public funds.</p>	<ul style="list-style-type: none"> • Patients have a Do Not Resuscitate (DNR) order and there is no advance directive or record of discussion with the patient or their advocates/family • Refusing to give lifesaving medical treatment - perhaps because of someone's age • Deaths through negligence - for example, the patient is not eating properly or has not been given water • Decisions made by the NHS Organisations e.g. CCG and Local Authority who buy health and social care which might impact on a person's right to life - for example, a decision not to buy or pay for cancer care 	<p>Patients & family members/advocates:</p> <ul style="list-style-type: none"> • Find out from staff how a DNR patient is identified. Try to check with family members / advocates / patients whether they are being applied properly (i.e. has there been consultation and an advance directive) • If patients have been told they can't have a life-saving procedure or medication, find out what the reason is. Are other patients being given this treatment? • Make sure all patients are being given sufficient food and drink, and that they are able to access it. • Find out whether there are any safeguarding issues which are not being dealt with properly. Does anyone feel their life is at risk because of something the Provider is doing or not doing? <p>Policies and procedures:</p> <ul style="list-style-type: none"> • Check on DNR policies and make sure members of staff know about them and are applying them properly. • Have the buyers of health and social care got in place Human Rights assessments on all decisions to buy or not to buy life-saving services or treatments? • Look at safeguarding / risk assessment policies and make sure they do not leave any possibility of a patient's life being put at risk.

Article 3 - the right not to be tortured or treated in an inhumane or degrading way

Description of the Article	Possible Issues	Things to Ask or look out for
<p>This means that health and social care providers should never allow their patients to experience extreme suffering if something can be done about it. Extreme suffering includes anything which is "inhumane and degrading.</p> <p>Inhuman treatment means treatment causing very severe mental or physical suffering.</p> <p>Degrading treatment means treatment that is very humiliating and undignified.</p> <p>Inhuman or degrading treatment does not have to be inflicted deliberately. Not protecting someone from such suffering is also against the Human Rights Act.</p> <p>Everyone is protected by this article - including people with no recourse to public funds.</p>	<ul style="list-style-type: none"> • Patients being abused either physically or mentally (by other patients or by members of staff) • Patients being left in a soiled state • Patients suffering from dehydration or malnutrition - perhaps because they cannot reach their food or are too frail to feed themselves • Staff using too much force to restrain patients, locking them in or preventing them from any movement for a long period of time • Patients in severe pain and not being given anything to relieve this • Patients being 'punished' for making complaints - perhaps by making them miss meals or not washing them regularly. • Treatment which is very painful and humiliating and which the patient has not given consent for 	<p>Patients & family members/advocates:</p> <ul style="list-style-type: none"> • Find out whether any of the issues in the previous column are likely to be happening. Does anyone feel badly neglected, humiliated or ignored? • Is anyone aware of patients suffering in the past from any of these issues - and was anything done about it? • Is the consent of patients or their advocates always asked for when treatment may be painful or humiliating? • Do people feel able to complain and have their complaint taken seriously? <p>If there is ANY concern that a patient has suffered from inhuman and degrading treatment this needs to be addressed by the Provider immediately. It is against the law.</p> <p>Policies and procedures:</p> <ul style="list-style-type: none"> • Safeguarding policies: do these address concerns in the 2nd column? <p>Is it made clear to staff that extreme suffering has to be addressed immediately, unless nothing can be done about it</p>

Article 5 - the right to liberty and security

Description of the Article	Possible Issues	Things to Ask or look out for
<p>This means that health and social care providers can not deprive a person of their liberty except when it is strictly necessary to protect the patient or other people, <i>and</i> when there is a law which allows it (eg the MHA).</p>	<ul style="list-style-type: none"> • Patients being restrained for a long period and for no good reason • Patients who have cot sides attached to their bed without a clear reason on their care plan e.g. for the patient's safety. They must be helped to get out of bed and move around at regular intervals • Patients being locked into rooms or wards for a long period of time • Informal detention of patients who do not have the capacity to decide whether they consent to be admitted into hospital e.g. learning disabled or older patients with dementia. If they need to be detained for their safety or for the safety of others, this must be done through a DOLs procedure. • Improper use of DOLs - e.g. when a patient does have capacity to make the decision • Delays in reviewing whether mental health 	<ul style="list-style-type: none"> • Find out whether any of the examples in column 2 seem to be happening. Talk to patients, family members and advocates about whether they may have happened in the past. • Find out how the informal detention of patients without capacity is carried out: is a DOLs procedure always applied? Is the assessment of capacity always correct (speak to advocates)? Is the assessment repeated whenever an important decision affecting the patient's rights is made? • How adequate is training on the Mental Capacity Act? Do staff feel they understand how it is to be applied? • Is removing someone's liberty a 'last resort' for the Provider or is it sometimes applied for the convenience of staff? • REMEMBER that depriving someone of their liberty is a very serious act and there must always be a law which allows it and a very good reason for doing so.

	patients who are detained under the Mental Health Act should still be detained	
--	--	--

Article 6 - the right to a fair trial

Description of the Article	Possible Issues	Things to Ask or look out for
<p>This right means that important decisions affecting civil rights around patient care should be made in a fair and open way. It could be relevant to decisions affecting the care of a particular patient, the way policies are drawn up by providers and buyers of health and social care, and the relationship between providers and buyers of health and social care</p> <p>The right to a fair trial may also be important for staff because it can apply to employment and disciplinary issues and rights to practice professions</p>	<ul style="list-style-type: none"> • If a decision is made which affects a patients civil rights they should be allowed to know why the decision has been made and ask for it to be reviewed. • Patients should be given the chance to say why they disagree with the decision or policy and these be considered in a fair way. • Changes in employment practice for staff or decisions which affect their civil rights should be made in a fair way and staff should have the chance to put their side. It should be possible to review any such decisions. • Where provider/supplier lists are used there should be proper procedures in place for removing providers from lists 	<p>Check whether key decisions affecting civil rights are made according to fair trial principles. These include:</p> <ul style="list-style-type: none"> • A fair hearing • Within a reasonable time • Open to the public (except in cases when privacy may be important eg. for safety reasons) • An independent and impartial tribunal established by law.

Article 8 - the right to respect for private and family life

Description of the Article	Possible Issues	Things to Ask or look out for
<p>1. Private life This right protects patients' basic dignity and their autonomy. Patients should not feel things are being 'done' to them in a way which ignores their personal wishes or makes them feel vulnerable, or treated as an object rather than a person. Although patients' private life is bound to be less 'private' in a hospital, staff should always try to respect patients' important personal needs and beliefs. Any treatment or aspect of care which interferes with these must be very well justified and there should always be as little interference as possible</p>	<ul style="list-style-type: none"> • Not giving patients enough privacy or not respecting the privacy of their medical records • Not giving patients information about their treatment or care, or ignoring their wishes • Leaving patients' needs unattended, making them feel vulnerable (this includes issues around personal hygiene or leaving them in pain) • Not respecting patients' need for a care plan which respects their individual needs, abilities and wishes. This may be particularly important for disabled patients, patients with particular religious, cultural or ethnic needs etc. • Treating patients in a rough manner, 'punishing' them, ignoring strong personal concerns 	<p>Patients' own sense of self-respect:</p> <ul style="list-style-type: none"> • Find out whether patients feel their basic needs and wishes are being respected. Do they express concern about any of the other examples in column 2? • Speak to patients, advocates and family members. Find out whether they have information about any of the Possible Signs. <p>Policies and procedures to look for on visiting a provider</p> <ul style="list-style-type: none"> • Vulnerable Adult Guidelines • Access to Medical Records • Caldicott Guidelines • Consent Policy and other related guidance on patient confidentiality. • Safeguarding policies and procedures in place • Care Quality Commission safeguarding and quality reports •

<p>2. The right to respect for family life</p> <p>This part of Article 8 should ensure that patients are able to continue to be in contact with close family members while they are receiving care. 'Family members' may also include foster parents, siblings, or children and anyone else who is regarded as a very important part of the patient's outside life.</p>	<ul style="list-style-type: none"> • Inadequate arrangements to allow patients to remain in touch with family members - for example, if the visiting hours are very short and very restrictive. • If there is a visiting policy, does it allow for the different needs of particular patients? For example, if someone always has a rest during visiting hours, are there other possibilities for family members to remain in touch? 	<ul style="list-style-type: none"> • Speak to patients and family members <ul style="list-style-type: none"> - Do they have any particular difficulty in keeping in touch? - Do they feel the visiting hours are too short or that there is too little opportunity to speak privately with the patient?
--	--	---

Article 14 - The right to be free from discrimination in the enjoyment of Convention rights

Description of the Article	Possible Issues	Things to Ask or look out for
<p>Article 14 of the Human Rights Act can only be used if one of the other rights is also affected. For example, if someone's right to private life is not being respected because they have dementia, or because they are an immigrant, or because they are disabled, this is likely to be a violation of Article 14. But Article 14 is not like the Equality Act: it cannot be used on its own in all cases of discrimination.</p> <p>Article 14 does allow for many more examples of 'protected characteristics' than the Equality Act does. Discrimination on any grounds at all is forbidden, as long as one of the other rights can also be referred to.</p>	<p>Any of the concerns listed under the other rights which seem to be a result of discrimination will be against the law. For example:</p> <ul style="list-style-type: none"> • Older people not being given the same cancer drugs as younger patients because they are thought to be 'too old' for it to be justified on cost grounds • Non-English speakers not being given information about their care because they will not understand it (in English) • Patients with dementia or mental health issues not being washed as frequently as others because it is thought that 'they will not notice'. 	<ul style="list-style-type: none"> • Look for any examples of different treatment which is not justifiable on medical grounds. Ask patients, carers, family members, advocates, whether they think there has been any discrimination or unfair treatment because the patient belongs to a particular group • Check that patients with particular needs - for example, religious, gender-related or cultural needs - are having these needs addressed in an appropriate way. Check that information given out to all patients is accessible - for example, to those who have learning disabilities or particular language needs. • Check that members of staff do not feel that their needs are being ignored or are being used as justification for unfair treatment - for example, if they have caring responsibilities or a disability. <p>Policies and Procedures to look for on a visit - ask staff about these - do they know about them and how are they implementing them?</p> <ul style="list-style-type: none"> • Vulnerable Adults Guidelines, • Consent Policy, <p>Mental Capacity Act Policy, where the right not to be discriminated against is also placed.</p>

Appendix 1 - The Word List

Autonomy - is about being able to make decisions for yourself. Any important decision which affects you should not be made by other people unless there is a very good reason.

A guide - a booklet to provide information to assist people working in Health Watch to have more understanding of Human Rights

A human rights based approach - This is about always respecting human rights, always making sure that people's dignity is respected, treating people equally and fairly and allowing them to take part in decisions which affect them. People should know their rights and know that they can ask questions and raise concerns. They should know that any concerns will be dealt with properly.

Blackburn with Darwen LINK - a group that currently do some of the work the new Health Watch will be doing.

Buyers of Health and social care - they buy health and social care from providers such as the hospital

Clinical Commissioning Group - this is a group of doctors working together to buy health care from hospitals and community nurses and other suppliers to ensure all the people living in Blackburn with Darwen receive the right care from the right person in the right place at the right time.

Client - a person cared for by a **Social Services Provider** such as a care home

Department of Health - is an organisation which is responsible for setting out how Health and social care providers should be run and how buyers of Health and social care such as a Clinical Commissioning Group should do this to meet local people's needs.

Dignity - Is about feeling you are being treated like a human being, with respect. The right to have your dignity respected includes:

- Having your privacy respected.
- Being told what is happening to you, and being listened to - for example about how you like to be treated.

Experience - this relates to how patients feel about their care and how employees feel about the work environment.

Employees - people who work for a Health and Social Care Provider or buyer of health and social care

Equality - is understanding and valuing people for who they are. It means treating people fairly, even when they seem to be different.

Fairness - this is about treating people equally and not punishing them or ignoring them because of who they are or what they may have done.

Health Watch - this is a group will ensure that the views and experiences of people living in Blackburn with Darwen will be taken into account when planning what services to buy and provide.

It will allow people to share their views and concerns about their local health and social care services and will provide people with information about their choices and what to do when things go wrong.

Health and Social Care Providers - These are organisations such as the hospital.

Human Rights - These are rights that everyone has just because they are human. The right to freedom, the right not to be tortured or treated in an undignified way and the right to life are just some of the rights we have.

Mersey Care NHS Trust - this is a provider of Health Care.

NHS Blackburn with Darwen - this is the organisation that is responsible for buying health care.

Outcomes - the results for patients being cared for in health or social care

Patient - a person cared for by a Health Providers such as a hospital or a Doctor's surgery

Respecting, protecting and promoting people's human rights - making sure that human rights are not violated by Health and Social Care Providers and buyers, and that they step in to protect rights where they are under threat.

Respect - Treating someone with respect means treating them like a human being, treating them as you would like to be treated this means:

- Listening to their concerns or wishes.
- Not making decisions on their behalf - unless absolutely necessary
- Valuing people as individuals.

Restricted - this means that sometimes things can be limited such as the right to liberty - this can be restricted or limited if the intention is to protect a person under the Mental Health Act, or to lock people up in prison if they have broken the law.

Service user - someone who uses a service such as a hospital or care facility