

Human Rights Survey: Hospital Patients

GUIDANCE NOTES

The Human Rights in Healthcare Programme 2011 - 2012

The Human Rights Survey: Hospital Patients was developed through the Human Rights in Healthcare Programme 2011 -2012 which was funded by the Department of Health and coordinated by Mersey Care NHS Trust. The British Institute of Human Rights were involved as consultants to the programme and the work is designed to demonstrate how a human rights based approach can improve the quality of health services. Information on the work of the pilot trusts and the programme as a whole can be found at the website of the Human Rights in Healthcare Programme: www.humanrightsinhealthcare.nhs.uk

What is human rights based approach?

A human rights based approach builds human rights principles and the legal standards established by international human rights law into policies and practices. Decisions are viewed through a human rights 'lens' - in other words, taking full account of individuals' need for dignity, self-respect and autonomy. The aim of a human rights based approach is to move towards a position where all the rights of individuals concerned are fully realised.

In practice, this means that:

- Patients and staff should be sure that standards of care are consistent with human rights principles
- Patients and staff should be given full opportunity to participate in decisions which affect them – and are empowered to do so
- Policies and the practice of care should be non-discriminatory and pay particular attention to ensuring that standards are equally high for all individuals concerned
- Public bodies such as health Trusts should actively protect and promote and human rights and there should be full accountability for any instances of human rights abuses

Further information about human rights can be found in the training pack.

The Human Rights Survey: Hospital Patients

City Hospitals Sunderland NHS Foundation Trust (CHS) decided to conduct a review of the patient experience of human rights in 3 different settings – inpatient wards, outpatient clinics and residential settings. CHS used their own version of the patient survey which is on the Human Rights in healthcare website and their survey was conducted by volunteers to ensure objectivity.

The Human Rights survey of Hospital Patients to which this Guidance refers is an innovative project and should ensure that many human rights issues relating to the patient experience are identified, and where necessary addressed.

CHS are also developing human rights based surveys for staff and carers so that human rights practice can be viewed and compared from a range of perspectives.

Older people and human rights

CHS' decision to focus on older people's services makes this a particularly interesting and potentially very valuable contribution to the human rights programme. A number of recent reports on older people's services in Trusts around the country have highlighted a number of serious cases of neglect and poor practice, often resulting in periods of great suffering for the older people concerned, and occasionally in premature death. Instances of malnutrition and dehydration have been identified by CQC in their inspections of various Trusts and Care Homes, as have other cases of neglect or discrimination. Many older people receiving treatment or being cared for have been found to experience a very poor quality of life, unreasonable restrictions on their movements, decisions being made on their behalf - in extreme cases, not to resuscitate - and a general lack of consultation or information about their patient experience. In most cases, such examples are instances of discrimination and violations of the patient's human rights.

However, while such examples are far more common than might be desired, they are still very much the exception. CHS' attempt to measure the patient experience of human rights is an important step in taking preventative measures to ensure good practice and that possible concerns are identified early on, and do not reach the levels described in the previous paragraph.

About the surveys

The surveys have been designed to pick up examples of good practice and instances where there may be potential human rights concerns. For the surveys to provide a true account of the services, respondents should understand the importance of answering as objectively as possible. The management of CHS gave its full support to the project and is interested both in the methodology of the pilot and in the results that emerge. The survey results will be built into CHS' future planning and practice. The surveys themselves may be changed and improved and used in other Trusts around the country.

- Any feedback from volunteers on the experience of conducting the surveys, including any particular difficulties, will be highly valuable.

Training

The British Institute of Human Rights provided a training day about human rights and healthcare for volunteers undertaking the surveys at CHS. Background materials were provided which addressed the specific human rights issues being considered through the survey.

It is strongly recommended that those conducting the survey receive training in human rights and healthcare beforehand. For information about training available contact the British Institute of Human Rights (bihr.org.uk).

Conducting the surveys

The following general points should be emphasised:

1. The survey should be conducted by an organisation independent of the NHS trust concerned.
2. The survey is focused on the patient experience of human rights.
3. The survey contains relatively detailed notes on each question and on the survey as a whole. It is strongly recommended that you familiarise yourself beforehand with these notes, identifying any areas where you feel you may need further support before carrying out the survey. Support will be made available if necessary (details to be given at the training).
4. You might find it necessary to conduct the survey in 2 parts. It is fairly long, and it may be difficult for patients to cover all the questions in sufficient detail in a single sitting. You should feel free to adapt to the particular wishes of each respondent, conducting the surveys as you and they feel will be most effective
5. It is worth emphasising to staff and patients that the surveys are not supposed to be intimidating: they are designed to identify areas where possible improvements may be made – including rolling out examples of good practice.

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