Patient Rights (Scotland) Bill

The Scottish Commission for Human Rights

The Scottish Human Rights Commission was established by The Scottish Commission for Human Rights Act 2006, and formed in 2008. The Commission is a public body and is entirely independent in the exercise of its functions. The Commission's mandate is to promote and protect human rights for everyone in Scotland. We are a national human rights institution, established according to the United Nations Principles relating to the Status of National Institutions (The Paris Principles), one of over 80 in the world and three in the UK, along with the Northern Ireland Human Rights Commission and the Equality and Human Rights Commission.

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1. Introduction

The Scottish Human Rights Commission (the Commission) welcomes the opportunity to comment on the Patients Rights (Scotland) Bill (the Bill) ahead of its consideration by the Health and Sport Committee.

The Commission welcomes the emphasis in the Bill on elements of a human rights based approach, including participation, accountability and empowerment. In this short submission the Commission suggests ways of building on this, to ensure other elements of a human rights based approach are also emphasised appropriately. In particular, we highlight the need to ensure an explicit and consistent connection with binding human rights law, particularly the Human Rights Act 1998. In this light we look forward to supporting the planned package of training, capacity building and awareness raising, to ensure that the Bill is read and understood through the lens of the Human Rights Act, and that its implementation supports the adoption of a comprehensive human rights based approach to health care.

In reference to the issues which the Call for Evidence issued by the Committee, the Commission focuses primarily on the first point – the patient rights and health care principles, and the criteria on which those rights are based, as set out in the Bill (sections 1 to 5).

2. Legal Framework

- Scotland Act 1998
- Human Rights Act 1998
- European Convention on Human Rights
- European Social Charter
- International Covenant of Economic, Social and Cultural Rights
- Convention on the Rights of Persons with Disabilities

3. Response

The Bill proposes several potentially important initiatives which aim to promote elements of a human rights based approach to health care. For example the creation of Patients Rights Officers (section 16) and patient advice and support services (sections 14 and 15); as well as mechanisms related to complaints (section 11) and for patient feedback (section 12) have the potential to enhance constructive accountability of public authorities (duty-bearers) and empowerment of patients (rights holders) in the health sector. Likewise the Health Care Principles (Schedule, introduced by section 4(1) of the Bill) include human rights principles such as dignity, respect, and participation in decision making. In respect of these principles, which are welcomed, the Commission would like to highlight the importance of ensuring they are understood and applied in a manner consistent with public authorities' duties under the Human Rights Act 1998 (HRA).

The need to read the Bill through the lens of human rights law

The HRA and the Scotland Act 1998 incorporate the Articles of the ECHR into our domestic law. According to the HRA it is unlawful for public authorities to act in a way which is incompatible with a Convention right (section 6). Furthermore legislation must be read and given effect in a way which is compatible with the Convention rights (section 3). To support public authorities in the health sector to deliver on this duty, it will be important that training, capacity-building and guidance issued following the adoption of the Patients Rights Act, is framed in the context of the binding requirements of the Human Rights Act, and other human rights law and standards.

This will ensure not only that those rights contained in the Bill are understood in the context of the HRA, but also that they are placed in the context of the full range of human rights in health care.[1] For example, references in the Bill to a duty to "have regard to" patients' rights to participate in decisions related to their care and treatment should be understood in the context of Article 8 of the European Convention on Human Rights, included in the HRA. Article 8 guarantees the right to respect for private and family life, home and correspondence. The scope of this Article is very broad. The European Court of Human Rights (ECtHR) has stated that the element of "private life" alone encompasses, among other things, "aspects of an individual's physical and social identity including the right to personal autonomy, personal development and to establish and develop relationships with other human beings and the outside world".[2] Or even more broadly "to conduct one's life in the manner of

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[1] While one of the main purposes of the Bill is said to be to "set out the rights of patients receiving health care from the NHS in Scotland" it is not clear that all of the human rights protected in the Human Rights Act are reflected in the Bill. For example, the Bill does not directly refer to the right to life; to freedom from torture, inhuman or degrading treatment or punishment; the right to liberty and security, each of which is clearly relevant in health care settings. See for example *Human Rights in Health Care, a short introduction*, Department of Health and British Institute of Human Rights, London, October 2008. http://www.slam.nhs.uk/patients/docs/rights/Human%20Rights%20in%20Healthcare%20-%20short%20introduction%20(DoH).pdf

[2] *Evans v UK*, Grand Chamber (2007) citing *Pretty v UK* (2002)

one's choosing".[3] It provides protection against non-consensual medical treatment or procedures.[4]

Any interference with this right, including the administration of medical treatment or procedures without free, prior and informed consent, must pass the tests outlined in Article 8(2) of the Convention. In essence it must be according to law, in pursuit of a legitimate aim, and the least interference necessary to achieve that aim (legality, necessity and proportionality). In this respect the reference in the Bill to the "desirability" of proportionality in Section 2(2)(b) of the Bill may lead to confusion with the legal requirement to justify any infringement of Article 8 rights with reference to, *inter alia*, proportionality.

Guidance and training on this principle should also link to considerations of legal capacity, and the provisions of the Adults with Incapacity (Scotland) Act 2000.

The Convention on the Rights of Persons with Disabilities[5] also contains several protections of the right to participate in decisions (Article 4 on general principles, Article 26 on support for participation, Article 29 on right to participate in public life).

Allied with the right to participate in decisions which affect the exercise of human rights is the right to information.[6] The right to information is a component of the right to autonomy in decision making under Article 8[7] and access to information is an element of the right to freedom of expression.[8] It is also increasingly recognised as a freestanding right to information in a form and language which enables an individual to participate in decisions which affect their human rights. This includes the right to accessible information for people with disabilities. The Convention on the Rights of Persons with Disabilities requires the provision of, "*other appropriate forms of assistance and support to persons with disabilities to ensure their access to information*".[9]

Understanding the rights of everyone

The Commission appreciates the focus provided by the Bill on the rights of patients. However, the experience documented in the Commission's

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[3] *Pretty v UK* 66 BLMR 147 (2002)

[4] See for example *Glass v UK* (2004) 39 EHHR 15, para 70.

[5] The UK has been a party to this convention since 2009. The Scottish Human Rights Commission, together with the Equality and Human Rights Commission, the Northern Ireland Human Rights Commission and the Equality Commission for Northern Ireland, is an independent mechanism named by the UK under the convention to promote, protect and monitor the implementation of the Convention in the UK.

[6] Information is referenced in the Bill in section 1(2) as a commitment that *"health care is to…(c) have regard to the importance of providing such information and support as is necessary to enable the patient to participate…"*

[7] See for example *Demir and Baykara v. Turkey*(2009) 48 EHRR 54 at paras 76, 78, 80, 82-4.

[8] For example Article 10, ECHR; article 21 Convention on the Rights of Persons with Disabilities, which includes a specific requirement to take appropriate measures such as: "Providing information intended for the general public to persons with disabilities in accessible formats and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost".

[9] Article 9(2)(f)

independent evaluation of the human rights based approach adopted by The State Hospital[10] suggests that it is important, in order to ensure the sustainability of a human rights based approach, that the rights of everyone involved are taken into account – patients, staff, carers, families and others – as parts of a common framework of rights, duties and shared responsibilities.

Conclusion

The Commission welcomes the Bill in so far as it:

1. seeks to strengthen awareness of human rights in health care;
2. is based on human rights principles such as dignity, respect and participation;
3. empowers health service users to claim their rights; and
4. strengthens the accountability of public authorities to respect, protect and fulfil those rights.

The Commission considers that the proposed training, awareness raising and guidance noted in the explanatory memorandum is an excellent opportunity to increase understanding of human rights in healthcare. The Commission therefore recommends that the training and awareness raising proposed in paragraphs 62-63 and 67 of the Explanatory Memorandum ensure clear links to the Human Rights Act 1998 and other relevant human rights law, including the right to the highest attainable standard of health, and the Convention on the Rights of Persons with Disabilities.

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[10] *Human Rights in a Health Care Setting: making it work for everyone*, Scottish Human Rights Commission, Glasgow, December 2009.
http://www.scottishhumanrights.com/research/ourpublications/article/healthcareresearch