

Chapter 2: Health
Getting it Right?
Human Rights in Scotland

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Theme 2: Health

Introduction

The Scottish Human Rights Commission (SHRC) seeks to empower people to know and claim their rights, and to increase the ability and accountability of public and private bodies to deliver on human rights in Scotland. In support of these goals SHRC promotes the evidence based and inclusive development of Scotland's National Action Plan for Human Rights – a road map to the further realisation of all human rights in practice in Scotland.

The report as a whole presents a summary of some of the key gaps and good practices which have emerged from a scoping project undertaken by the SHRC. This specific section summarises the findings relating to theme of Health. It is not intended to be a comprehensive 'state of human rights in Scotland' report, but a prompt for discussion in the development of Scotland's National Action Plan for Human Rights. With this in mind, individuals and organisations are encouraged to consider their views in response to two key questions as they review this thematic section:

1. Based on the evidence presented in the report *Getting it right? Human rights in Scotland*, or your own experience, what do you consider to be the most urgent human rights issues which should be addressed in Scotland's National Action Plan for Human Rights?

2. What specific and achievable actions do you consider would best address the concerns you identify in your response to question 1?

Scoping Project Methods Summary¹

The data collection began in 2010 and was divided into two phases - a first phase focussing on collating and analysing a range of secondary data sources² and a second phase where SHRC convened a series of small focus groups and in-depth interviews with a range of communities, groups and individuals in Scottish society.³ In line with the SHRC's statutory mandate, particular attention was given to hearing from those who tend to be marginalised and whose voices are less often heard in mainstream debates surrounding human rights. In taking this approach SHRC sought to put a 'human face' on the issues uncovered in the scoping project.

Introduction to Health

This thematic section explores the theme of health in Scotland, one of the eight themes that emerged from the research reviews. Following a prioritisation process, four areas within the broad theme⁴ were selected and are presented in further detail in this thematic section. These are: Integrating a human rights approach in health law and policy making; healthcare quality; health promotion; non-discrimination within health care; mental health care and treatment.

The focus of this scoping project has primarily been on issues of human rights concern that are within the competence of the Scottish Parliament. Across all thematic areas, there are some, often complex issues, which raise issues of concern

that are devolved, whilst others are reserved to Westminster,⁵ including equality legislation. The Equality Act 2010, however, does place a duty on the Scottish Government to abide by the public sector equality duty,⁶ which could bring about a more substantive role for Scottish equality duties in the future.⁷

Health is primarily a devolved matter falling within the legislative competence of the Scottish Parliament.⁸ The primary legal framework for the organisation of the NHS in Scotland and the duties in respect of the arrangement of provision of services is the National Health Service (Scotland) Act 1978⁹ and the Public Health etc. (Scotland) Act 2008. This sets out the duties of Scottish Ministers, health boards and local authorities to continue to make provision to protect public health in Scotland.

Scotland has infamously been labelled the “*sick man of Europe*” (McCartney et al., 2011). It is well known that it has very high rates of cancer,¹⁰ lower life expectancy than elsewhere in the UK, and a wide range of adverse lifestyle choices which contribute to these outcomes – notably high rates of smoking and alcohol abuse (Bromley and Shelton, 2010).¹¹ Outcomes also vary across the country. Taking life expectancy as an indicator, eight of the ten areas of lowest life expectancy for men in the UK are in Scotland, the top four of which are all on the west coast of Scotland.¹²

As the Chief Medical Officer for Scotland, Dr Harry Burns has noted there have however been:

*“...significant reductions in premature death rates from cancer (22 per cent), CHD (60 per cent) and stroke (54 per cent) between 1995-2009.”*¹³

Nevertheless:

*“The Scottish Health Survey seems to indicate that around 25[per cent] of Scots eat a poor diet, take insufficient exercise, drink too much alcohol and are overweight or obese. Numerous attempts have been made over the years to encourage individuals to alter their behaviour. Health promotion campaigns usually have a positive effect on some people but often those in most need of changing their behaviour are least likely to take notice of such campaigns.”*¹⁴

In response Dr Burns considers:

*“...if we are to make a significant impact on the incidence of ill health in Scotland, we need to pay attention to the ways in which we create health.”*¹⁵

This approach emphasises enhancing individuals’ capacities to control their own lives and to shape health responses. This appears to provide useful opportunities for encouraging human rights based approaches that emphasise principles of participation, accountability, non-discrimination, and empowerment, underpinned by legality. It also seems to have echoes in the co-production model promoted in the independent living movement in Scotland by disabled people (see the thematic section on Dignity and Care). Dr Burns concludes:

*“Instead of doing things to communities, public services need to develop a mind-set which sees them working with individuals and communities to co-create health and wellbeing.”*¹⁶

Human rights context

Health engages a very wide array of human rights. Among these are absolute rights such as the right to life and the right to freedom from torture, inhuman or degrading treatment or punishment. Each of these includes positive obligations relevant in

health policy and practice to prevent, protect and remedy. For example obligations related to the right to life (Article 2, European Convention on Human Rights [ECHR]) include: A positive obligation on the State to do “*all that could have been required of it to prevent the applicant’s life from being avoidably put at risk*” in health care,¹⁷ and in some cases an investigation or other effective remedy to ensure that the cause of death of patients in the care of the medical profession, whether in the public or the private sector, can be determined, lessons learned and where civil or criminal negligence is an issue, those responsible made accountable.¹⁸ While this includes an element of individual accountability where appropriate its purpose is constructive accountability to learn lessons and improve standards in the future. As the European Court of Human Rights [ECtHR] has stated:

*“...more general considerations also call for a prompt examination of cases concerning death in a hospital setting. Knowledge of the facts and of possible errors committed in the course of medical care are essential to enable the institutions concerned and medical staff to remedy the potential deficiencies and prevent similar errors. The prompt examination of such cases is therefore important for the safety of users of all health services”*¹⁹

Clearly there is a duty to protect mental health patients from a risk of suicide, whether they are compulsorily detained²⁰ or voluntary patients.²¹

Similar obligations exist in relation to the prohibition of torture, inhuman or degrading treatment or punishment (Article 3, ECHR). That right would be relevant to severe instances of abuse or neglect²² where for example an individual is left in degrading conditions. That may be particularly relevant in relation to patients in situations of vulnerability due to age or mental disorder or for example to those with complex needs. For example the UK was found in violation of this Article where an individual who was four limbs deficient was left in a situation in which she:

“[was] dangerously cold, risks developing bed sores because her bed [was] too hard or unreachable, and [was] unable to go to the toilet or keep clean without the greatest of difficulty”.²³

Likewise in cases of severe neglect a violation of Article 3 may be found.

Qualified rights, such as the right to respect for private and family life, home and correspondence (Article 8, ECHR), are also relevant in health policy and practice. That right has a very broad definition and includes the right to a home life, family life, physical and mental integrity, quality of life, well-being, autonomy, legal capacity and right to participate in decision-making. As a qualified right any limitation should have a basis in law, pursue a legitimate aim or goal and be proportionate— i.e. the least restriction which is capable of achieving the legitimate aim.

For example participation in decision-making and legal capacity is pivotal to the realisation of an individual’s dignity and rights.

*“The freedom to accept or refuse specific medical treatment, or to select an alternative form of treatment, is vital to the principles of self-determination and personal autonomy.”*²⁴

Capacity to make decisions should be assumed and individuals provided with such reasonable support as they require to enable them to make informed decisions – understanding the implications of their decisions. Efforts should be made to understand the previously expressed wishes of an individual who may lack capacity

and to support people to make decisions while they have capacity for what should happen to them if their capacity reduces.²⁵

Allied with the right to participate in decisions which affect the exercise of human rights is the right to information.²⁶ The right to information is a component of the right to autonomy in decision making under Article 8²⁷ and access to information is an element of the right to freedom of expression.²⁸ 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 physical and mental 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”*²⁹

In addition economic, social and cultural rights are engaged in this topic. Principal amongst these is the right to the highest attainable standard of physical and mental health (Article 12 of the International Covenant on Economic, Social and Cultural Rights). The full realisation of this right is to be achieved progressively, according to the maximum of available resources. In its authoritative interpretation of the right to health the United Nations Committee on Economic, Social and Cultural Rights has clarified the nature of states obligations (UN CESCR, 2000). In summary:

The right to health is not the right to be *healthy*,
It includes freedoms and entitlements: *“The freedoms include the right to control one’s health and body, including sexual and reproductive freedom, and the right to be free from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation. By contrast, the entitlements include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health”* (UN CESCR, 2000).

It extends to rights related to healthcare as well as to the underlying determinants of health:

“The right to health embraces a wide range of socio-economic factors that promote conditions in which people can lead a healthy life”.³⁰ “[It is] an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health. A further important aspect is the participation of the population in all health-related decision-making at the community, national and international levels” (UN CESCR, 2000).

The right to health has the following elements:

Availability – health related facilities, goods, services and programmes have to be sufficiently available across the country.

Accessibility – health facilities, goods and services have to be accessible to everyone without discrimination. This has four dimensions: non-discrimination (in law and fact), physical accessibility (including in rural areas and for disabled people), economic accessibility and information accessibility.

Acceptability – including issues related to medical ethics.

Quality - scientifically and medically appropriate and of good quality (UN CESCR, 2000).

Integrating a human rights approach in health law and policy making

Among the achievements of the Scottish Parliament in upholding human rights, as discussed in Chapter 2 of the main report on 'Our Human Rights in Context', has been the development of human rights based laws. This has been particularly clear in the thematic areas covered in this section and in that on Dignity and Care.

The Mental Health (Care and Treatment) (Scotland) Act 2003, discussed below, is built on the foundations of human rights principles. Similarly, the Patient's Rights (Scotland) Act 2011 provides that it is the right of every patient that the health care received is patient-focused, which means that the provision of health care takes into account the patient's needs. The Act, provides that regard must be had to the importance of providing the optimum benefit to the patient's health and wellbeing, allows for patient participation in decisions about their healthcare and provides appropriate information and support to allow them to do so. It provides for the development of a Patients' Rights Charter, Patients' Rights Officers and strengthened complaints' processes. Secondary legislation outlining a series of "Health Care Principles" was developed in 2011 and a consultation on the Charter of Patient Rights and Responsibilities was launched in April 2012.

SHRC welcomed the Patient's Rights (Scotland) Act, in so far as it is based on human rights principles, aims to empower health service users to claim their rights, and strengthens the accountability of NHS bodies and people who provide NHS healthcare to patients. While most who engaged supported the principles which lay behind the Act some questioned the need for legislation. The Royal College of Nursing Scotland (RCN), for example stated its view that:

"Legislation is not the best course of action to improve the rights of patients. We continue to be concerned that money spent on implementing the Act would be better used to improve patient rights through the work of the NHS Scotland Quality Strategy" (Royal College of Nursing Scotland, 2011).

RCN pointed among other things to the challenges in freeing up staff time to attend training, particularly in the current economic crisis. SHRC has recommended an explicit and consistent connection with binding human rights law, and the need to ensure clarity and consistency in the relevance of enforceable human rights in health care (Royal College of Nursing Scotland, 2011).

SHRC noted:

"Only with direct reference to the related rights in the HRA will health workers be enabled to properly assess the impact of decisions on absolute rights, which must be respected and ensured in all circumstances, and qualified rights which can be interfered with where there is a legal basis, a legitimate aim and where the interference is a proportionate means of achieving that aim" (SHRC, 2011).

The Act also introduced a Treatment Time Guarantee, which according to the consultation report was broadly welcomed by civil society, albeit questioning the

extent of limitations to it, and not welcomed by some professional bodies such as the British Medical Association and RCN (Scottish Government, 2011c).

Aside from legislation the Scottish Government and NHS Scotland has also pursued the development of strategies and concrete policy approaches which offer significant potential for the further integration of human rights based approach in practice. Key among these is the Healthcare Quality Strategy (NHS Scotland, 2010), which seeks to achieve person-centred, safe and effective healthcare for everyone. Similarly aligned is the “*assets based approach*” to health discussed above.

A significant initiative to integrate equality and human rights approaches into health policy making has been the development of Health Inequalities Impact Assessment (HIIA) processes, which includes human rights impact assessment.³¹ This was formally launched by the Scottish Government in 2011. SHRC has supported the integration of human rights into this process from the outset, most recently working with NHS Health Scotland to develop case studies demonstrating the added value of human rights in the HIIA process.

Strategic, policy and practice measures have also been put in place to advance a range of core principles regarding human rights based approaches (participation, accountability, non-discrimination, empowerment and legality).

Participation

Many initiatives in Scotland reflect the value of participation of patients and others in shaping health policy and practice. These include the Patient Focus Public Involvement (positively evaluated in practice in The State Hospital) (SHRC, 2009); the emphasis on patient-focussed care in the Health Care Quality Strategy and repeated references to participation in the Patient’s Rights (Scotland) Act 2011 and related initiatives such as the Healthcare Principles and the Charter of Patients’ Rights and Responsibilities.

SHRC has expressed its view that understanding and applying the human right to participate in decisions and the right to information will be of critical importance in interpreting the application of the Healthcare Principles under the Patient’s Rights (Scotland) Act 2011 of patient participation and communication, which are closely interconnected (SHRC, 2011). The recent guidance issued by the Mental Welfare Commission for Scotland, for example, to which SHRC contributed significantly, presents a useful framework for medical decision making (Mental Welfare Commission for Scotland, 2011d).

Accountability

All duty bearers must be accountable for the realisation of human rights. To be accountable requires effective monitoring (through data collection and inspections), effective remedies (including independent complaints mechanisms and access to justice) and effective corrective action to be taken where deficiencies are identified. It requires the existence of appropriate law and policy structures, institutions, administrative procedures and other mechanisms where individuals can seek remedies and have access to justice where needed.

The scoping project review highlighted a range of inspection reports by bodies such as the Mental Welfare Commission and NHS Quality Improvement Scotland (now

Healthcare Improvement Scotland), see below. The issue of healthcare complaints processes also emerged as a recurring theme.

An essential component of accountability is a mechanism by which complaints can be made, effectively (ideally independently) investigated and action in response determined. Complaints about the NHS are handled by internal complaints processes with the Scottish Public Services Ombudsman acting as the final stage as it does for all Scottish public authorities. The Scottish Government has taken steps towards improving and strengthening complaints mechanisms under the Patient Rights (Scotland) Act 2011 by providing for the establishment of the Patient Advice and Support Service, which will have a role in advising patients wishing to give feedback or make a complaint.

In its response to a consultation related to the Patient's Rights (Scotland) Act 2011 SHRC highlighted that complaints processes must comply with the right to a fair hearing, patient confidentiality, as well as the right to a remedy – including access to justice and effective investigations in relation to serious human rights violations. Further, SHRC considered it essential that the Patient Advice and Support Service (PASS) must include human rights in the advice and support that it provides (SHRC, 2011).

In 2007 the Scottish Health Council commissioned research into the experiences of patients of the NHS complaints system (Britain et al., 2009). This scoping project found that on the whole, the majority of patients experience good quality care and more than two thirds had never experienced any problem with an NHS service, as was also the case with the majority of participants in this scoping project. Where problems had arisen, they were commonly as a result of unacceptable waiting times; poor attitudes or behaviour of staff; or poor medical care and treatment. The research also found an unwillingness to complain. Common reason for this reluctance included:

*'It wouldn't make any difference' (64 per cent);
'It might affect future treatment' (37 per cent),
'Too busy coping/caring to complain' (26 per cent); or
'I didn't know how to complain' (15 per cent)*
(Britain et al., 2009).

This research produced 15 key recommendations for action to improve the complaints process. The Scottish Health Council then identified how these recommendations could be translated into practice which included focusing on the following: developing a national feedback portal; encouraging feedback within NHS Boards; raising awareness of independent advice and support services; making the distinction between formal and informal feedback; developing good and effective practice; consistency in response times; demonstration projects and encouraging feedback and complaints from seldom heard voices (Scottish Health Council, 2010).

Research has also found a need to support staff to be supported through the process of a complaint in order that lessons are learned rather than a focus being placed on who to blame. Complaints must also be viewed as a genuine method of facilitating service improvements and a better understanding of patient needs (Walter, 2009).

In 2008-09 the Scottish Public Services Ombudsman (SPSO) received 82 enquiries and 684 complaints in relation to the health sector³² with 32 enquiries and 888 complaints for 2010-11.

Some participants in this scoping project had been involved in taking complaints against the NHS, most of whom had not had what they described as a satisfactory experience. Most described their experience using language that depicted a struggle:

I don't know how anyone manages to actually fight their way through the maze of health board protocol to make a complaint... Trying to get them to admit anything as well, very difficult.

Seamus, Addiction support case worker.

It was impossible to get anywhere; I said I would take it to SPSO and they said fine, do that then, with almost like a "see if I care" attitude.

Karen, Informal carer for a family member with physical disabilities.

In terms of patient satisfaction as a whole, results of the 2012 Scottish Inpatient Experience Survey, published in August 2012, showed that patients were most positive about the care they received from staff and least positive that they were ready for life outside of hospital on discharge.³³ On this latter issue the UK Parliament Joint Committee for Human Rights has raised concerns in particular about the premature discharge of older patients in an effort to combat delayed discharge. The Joint Committee considered that premature discharge, without effective provision of aftercare may engage the patient's right to respect for private and family life under Article 8 of the ECHR (Joint Committee on Human Rights, 2007).

In response to complaints, the Scottish Government has recently been considering changes in its approach to compensation. The general policy in relation to NHS complaints has been that financial compensation is not available, and information about NHS complaints has usually stated that if you want financial compensation you should seek legal advice.

In 2005, *the Skipton Fund* was set up³⁴ as a scheme which allowed ex-gratia payments to be made to, or in respect of, people who had been infected with hepatitis C through NHS treatment (Scottish Government, 2011b). Considering the issue more broadly, a No Fault Compensation Review Group was set up on June 2009 and tasked with considering the potential benefits for patients in Scotland of a no-fault scheme for injuries as a result of medical treatment, and whether such a scheme should be introduced alongside the existing clinical negligence arrangements. Problems with the current scheme were identified as including: length of time whereby claims can take months or even years to resolve; the adversarial culture which can lead to a lack of openness and a delay in revealing expert opinions; and the legal expenses involved can be disproportionate to the value of the claim. The report suggested that that when an error has occurred, patients expect doctors to make a meaningful apology, provide an explanation and take steps to prevent the error from recurring. The findings of their research would appear to support the contention that for many, if not most, patients this is the

primary aim, rather than a financial award. The report concluded³⁵ that if such a scheme is to be set up, it is essential that the scheme is: compatible with the European Convention on Human Rights; treats staff and patients fairly and equitably; is affordable, easy to access and use; and that decisions about compensation are timely, robust and independent. An independent appeal system would be essential and a reasonable time limit would be set (Scottish Government, 2011b).³⁶

The Scottish Government recently launched a consultation on the implementation of the recommendations of the No Fault Compensation Review Group.³⁷

A related issues emerging from research is the approach towards internal NHS staff complaints or “*whistle blowing*”. A recent survey by the British Medical Association in Scotland found that many doctors (40 per cent) failed to report concerns that they have about the care of patients by others for fear that it will damage their career and that it would not be acted upon. Moreover the research finds that ten per cent of doctors who had raised concerns were effectively told that if they were to take this further, “*speaking out could have a negative impact on their employment*” (BMA Scotland, 2010). The research made a series of recommendation to the Scottish Government including in relation to awareness raising and protection on whistle blowing (BMA Scotland, 2010).

Empowerment

In order to effectively uphold their rights people need to know what their rights are and how they can enforce them.

Health Rights Information Scotland (HRIS) publishes information on patient rights in Scotland and the Independent Advice and Support Service provides advice to patients on their rights and how to make a complaint. HRIS describes health rights as including rights enforceable in Court such as access to medical records, as well as rights in the broader sense, based on policy. Research investigating how much people knew about their health rights, and how easy it was for them to find out, revealed that only around a fifth of people surveyed felt that they knew a lot about their health rights (36 per cent knew a bit and just under 25 per cent knew very little and 16 per cent reported knowing nothing). Over 90 per cent of respondents were aware that people on a low income can get help with NHS costs and that you can refuse treatment even if recommended by your doctor. With both these questions the highest percentages of correct answers came from the 45- 64 age group (MacDonald and Pulford, 2006).³⁸

SHRC has repeatedly pointed to the importance of linking awareness-raising on broadly defined “*health rights*” with human rights in healthcare. Recent materials do make some limited reference to human rights.³⁹

Participants in this scoping project who worked within the health sector felt that they did not know enough about what human rights were in relation to health care and as such did not know how to respond effectively when someone invoked their human rights. Some felt the media confused facts in any debate around human rights and that NHS staff would benefit from having a better understanding of human rights.

Healthcare Quality

Quality of healthcare provision has been undergoing increased scrutiny in Scotland and the rest of the UK over the last two decades (Batalden and Stoltz, 1993, Ferlie and Shortell, 2001, Ham et al., 2003, Teasdale, 2008). This increased focus on quality has led to an acknowledgement that it is a complex issue and a realisation that how quality is defined and how healthcare systems are organised are integral to good quality healthcare provision (Powell et al., 2008). The conceptual definition of 'quality' in healthcare provision is contested and defined differently by a range of people (both healthcare users and providers)⁴⁰ and it is not a static concept. Rather it can change as a result of whose perspective is being taken, the timescale over which it is being examined and the purpose of any particular measures being applied (Powell et al., 2008).

This increased focus on quality has permeated throughout the healthcare system in the UK, with all systems striving to provide good quality and safe health care. The quality agenda has, however, been moving forward in different ways throughout the UK.⁴¹ In Scotland, the Government's commitment to healthcare quality and quality improvement is demonstrated through its HealthCare Quality Strategy which was launched in May 2010 (Scottish Government, 2010b). A key element of this strategy being delivered in collaboration with the Institute for Healthcare Improvement (IHI) is the Scottish Patient Safety Programme (SPS). The objective of SPSP is to steadily improve the safety of hospital care right across Scotland.

This drive for improved quality of care in recent years has been fuelled by reported estimates that one in ten patients admitted to an NHS hospital in Scotland is likely to be harmed unintentionally. This could be as a result of: contracting an infection such as MRSA; experiencing a post-operative complication or drug-error; or developing a pressure sore. It is further estimated that 50 per cent of these unintentional events could have been prevented (School of Health Nursing and Midwifery UWS, 2011). Moreover, in addition to the personal cost to and impact on patients, this reportedly is estimated to cost NHS Scotland approximately £200 million annually in lost bed days and additional treatment (Scottish Patient Safety Programme, 2011).

The NHS Scotland Quality Strategy emphasises the provision of "*high-quality, person-centred, clinically effective and safe health care services*" as the key drivers for the improvement of healthcare quality (Scottish Government, 2010b). In 2011 a Healthcare Improvement Scotland conference brought together a range of practitioners with experience in quality improvement in order to discuss different approaches to quality improvement and the merit of developing a Scottish approach to healthcare quality improvement. A key outcome of this meeting was the acknowledgement of those involved that of all the different drivers for improvement, 'patient-centeredness' was seen to be the most important criteria (School of Health Nursing and Midwifery UWS, 2011).

The Schedule to the Patient Rights (Scotland) Act 2011 describes 'Quality Care and Treatment' as based on current clinical guidelines with regard to the optimum benefit to the patient's health and wellbeing and the range of options available in each patient's case. The Schedule also refers to no avoidable harm to be caused and that patients are to be cared for in an appropriate environment. SHRC recommended to the Scottish Government that reading this Principle in the light of human rights

standards will help ensure the achievement of the aim of the Healthcare Quality Strategy that healthcare is consistently patient centred, rather than a more traditional clinical model of healthcare where patients are, in the worst case, the passive recipients of care deemed to be in their best interests. For example, a human rights based and patient focussed approach to determining what “*optimum benefit*” to the patient would be or how to avoid harm will require the participation of the patient in decision making, account of the patient’s previously stated wishes, and will usually require the patient’s consent. Consequently SHRC has recommended that this Principle must always be read in the light of the right to free, prior and informed consent to treatment, and to other rights in the Human Right Act (SHRC, 2011).

Two independent evaluations of human rights capacity building projects provide evidence of the value of human rights based approach to health and social care in achieving a more consistently patient focussed approach. First, an independently commissioned evaluation of the HRBA at The State Hospital concluded that staff, patients and carers all considered that the HRBA had meant a:

“move towards more patient-focussed approaches to care and treatment with an increased individualisation of policies and practice, ‘the end of blanket policies’” (SHRC, 2009).

Second, an independent evaluation of SHRC’s *Care about Rights?* project,⁴² related to the care and support of older people, demonstrated how public, private and voluntary care providers in care homes and care at home settings found that implementing human rights based approaches in practice was instrumental in helping them deliver person centred, or patient focussed care. Ninety-seven per cent of survey respondents who participated in human rights training indicated that more effective delivery of person centred care and increased quality of life for service users were potential benefits of a human rights based approach.⁴³ A further 93 per cent of survey respondents felt, following the training, that a potential benefit of applying a human rights based approach was that it helped care providers balance risk in decision making while 97 per cent felt that human rights can help providers develop positive relationships with service users and families (GEN et al., 2011). These findings strongly demonstrate how an understanding of human rights can assist the delivery of patient focussed or person centred health and social care.

While taking account of human rights is already a duty under the HRA, the Act and accompanying Directions and Regulations, represent an opportunity to ensure that this is brought to the fore in healthcare and that the other Principles are read in this light. Without this, tensions may arise between the patient focus and other Principles. In addition, there may be important rights, for example the right to freedom of religion, to respect for private, home and family life or non-discrimination (among others) which are not explicitly referenced as “*concerns, opinions and preferences*” in the Directions but are fundamental to delivering services with a patient focus (SHRC, 2011).

Participants involved in this scoping project shared some of their experiences as users of healthcare services which did vary in quality. For the most part, participants were happy with the majority of health care that they had received. Where the greatest level of dissatisfaction arose, however, was in the lack of the ‘personal’ in the care that they received. Most noted that this was not through a deliberate effort to be impersonal, but rather, a lack of staff time and resources. One participant in

this scoping project recounted what he felt was the de-personalising effect of long term care in a hospital ward:

The last time I was in for any length of time cause I've been in and out that much, I was in a month and at the start it was ok but after a while it just sort of got, they were coming round to give you your medication and one person read the number off your arm band to check it match the number on the medication and then you got the medication and that was it. You just felt as if you were on a conveyer belt.

Eric, Recipient of a rural befriending service and a person living with multiple physical disabilities

Participants involved in this scoping project who worked to support people with addiction problems also noted that often the treatment and care provided for their clients within hospital settings was often punitive and lacking in respect, as a result of personal opinions about people with addiction problems:

The main issues I have in the clinical setting is pain management of drug users, which is a clinically difficult area but there is evidence and in fact clinicians have told me that have punished people by not giving them adequate pain relief and the punitive use of naloxone which will quickly detoxify somebody over a period of seconds, just to get someone out of accident & emergency because they've turned up in some state and they're behaving badly and they just want to get them out of here. People would say that they used to do that quite often in the past, but they still do. Recently, there were quite a few cases of anthrax contaminated drugs out there and particularly in Dumfries & Galloway, we saw a lot of people being treated very poorly because the view was well, they are dependent on opiates and therefore we shouldn't give them appropriate levels of pain relief. Underlying that is the fact that drugs users are effectively being punished for their addiction, it's dressed up as something else but underneath it's a chance to hand out a little bit of retribution.

Robin, Policy officer of a drugs support organisation

There have also been some high profile cases of severely inadequate healthcare quality in recent years, such as that of Mrs V. an 80 year old woman with dementia who died after receiving care at Ninewells hospital that was “*woefully inadequate, wholly inappropriate and utterly unacceptable*”.⁴⁴ Participants in this scoping project noted that cases such as these and news stories about outbreaks of MRSA and C. diff made them less willing to go to hospital for care that was not deemed to be emergency or urgent. This heightened fear also comes at a time when cases of C. diff amongst the over 65s and MRSA are in fact at their lowest levels since recording began.⁴⁵ Efforts to reduce healthcare associated infections [HAI] have been high on the Scottish Government agenda in recent years.⁴⁶

From January to March 2012 there were:

- 48 MRSA cases - down 30.4 per cent (from 69) when compared with the same quarter last year, and a reduction of four per cent (from 50) on the previous quarter
- 334 C. diff cases in over 65s - down 6.2 per cent (from 356) when compared year-on-year and down 2.9 per cent (from 344) on the previous quarter.
- 380 cases of SAB infections overall (MRSA and MSSA combined) – a

*decrease of 10.4 per cent (from 424) when compared with the previous year, and down 6.9 per cent (from 408) on the previous quarter.*⁴⁷

A further issue of concern raised in relation to healthcare quality in this scoping project was that of delayed discharge. The issue itself has been identified as a concern throughout the UK since the Welfare State was created and there have been a number of policy responses aimed at tackling this issue.⁴⁸ Delayed discharge, where people are prevented from moving on to the next stage of their care is monitored through the Health and Social Care Programme.⁴⁹ In recent years, delayed discharge has become increasingly problematic as care in the community has become the preference to care within long stay hospitals. For example, a national review of learning disability services in Scotland in 2000 (Scottish Executive, 2000) recommended that Health Boards should close all long stay beds by 2005.⁵⁰ A review of whether or not these recommendations had indeed been met revealed that overall, 17.5 per cent of hospital based placements were defined as a 'delayed discharge', either because "*no suitable facility in the community or service development needed*" or "*social care reasons.*" Overall the report recommended pooling of resources between health boards and local authority as overuse of hospital beds can result in insufficient community placements and vice versa (Perera et al., 2009).

In their 2007 report into the *Human Rights of Older People in Healthcare*, the Joint Committee on Human Rights noted that whilst many older people received excellent care, concerns over poor treatment including ill-considered discharge were raised.⁵¹ The Committee raised concerns both about the levels of delayed discharge and also about over the operation of the Delayed Discharge Regulations, whereby often the short timescale afforded to arrange a placement led to an infringement of an individual's right to respect for private and family life (Article 8 ECHR).⁵²

Health promotion

Lifestyle choices

Lifestyle choices engage an individual's autonomy under the right to private life (Article 8, ECHR). As the ECtHR has found this includes:

*"The ability to conduct one's life in a manner of one's own choosing [which] may also include the opportunity to pursue activities perceived to be of a physically or morally harmful or dangerous nature for the individual concerned."*⁵³

This will be engaged in legal and policy measures to *restrict* ability to pursue unhealthy lifestyle choices such as smoking, alcohol abuse and unhealthy eating. This right is qualified, not absolute. As such any interference must have a legal basis, pursue a legitimate aim (such as the protection of health or the economic well-being of the country) and be a proportionate means of achieving that aim – that is the least restrictive alternative which is capable of achieving the aim.⁵⁴

This exists alongside a positive obligation under the right to health to *promote* healthy lifestyles by, amongst other things,

"(i) Fostering recognition of factors favouring positive health results, e.g. research and provision of information;

...

(iii) Ensuring that the State meets its obligations in the dissemination of appropriate information relating to healthy lifestyles and nutrition, harmful traditional practices and the availability of services;
(iv) Supporting people in making informed choices about their health” (UN CESCR, 2000).

Similarly, under the UN Convention on the Rights of the Child, adolescents have a right to access essential health related information regarding issues such as the use of tobacco and alcohol and other substances, safe and respectful social and sexual behaviours, diet and physical activity (UNCRC, 2003). In accordance with the overall Convention this should be in a manner appropriate to their age and stage of development.⁵⁵

As noted above, lifestyle choices remain a significant health challenge in Scotland. When compared to the rest of the UK, some of the biggest health-related behavioural differences in Scotland are found in relation to smoking, diet and alcohol consumption (Bromley and Shelton, 2010). Research also consistently shows poorer health outcomes for people in Scotland in relation to conditions which are considered to be connected to lifestyle choices.⁵⁶ The research review suggests key challenges in addressing these statistics include their relationship with other factors such as: deprivation and poverty; an ageing population; and a complex geography with large and sparsely populated rural areas. This is coupled with the pressures on public funds in a time of recession, where it has been estimated that NHS Boards will need to achieve efficiency savings of at least three per cent in order to break even, in addition to annual efficiency savings of two per cent since 2007/08 (Robson, 2011).

Successive Scottish Governments and the Parliament have taken a range of legislative and policy measures to address these challenges. Many of these focus on improving the health of children and young people and influencing lifestyle choices such as healthy eating, smoking and alcohol/drug misuse and on changing attitudes to mental health issues.

Over the past couple of decades, there has been a great deal of emphasis on reducing levels of smoking in Scotland,⁵⁷ including legislation banning smoking in public places,⁵⁸ raising the age at which it is possible to buy tobacco products to 18,⁵⁹ and banning tobacco displays.⁶⁰ Current initiatives include consideration of standardised packaging across the UK (Department of Health, 2012). The reduction in smoking rates and lung cancer incidence in men since the mid-1990s has been considerable, although the uneven rate of improvement has actually sharpened inequalities.⁶¹

Whilst these initiatives have been broadly welcomed, some commentators have questioned their indirect impact on some people with mental health issues. For example, Warner (2009) has noted that smoking rates among mental health service users in the community are lower than those among in-patients; however, they are still much higher than those in the general population.⁶² People with a diagnosis of a psychotic illness such as schizophrenia or bipolar affective disorder are more likely than those in the general population and other mental health service users to smoke and to smoke heavily. The risks associated with cigarette smoking are, therefore, unevenly distributed amongst the population, with mental health service users at the

'sharp-end' of risk. Warner (2009) further argues that the mobilisation of stigma that has been used to encourage people to give up smoking in the general population, in the context of mental health actually adds to the stigma that mental health service users already experience.

In 2011 the Scottish Government and NHS Health Scotland published guidance for mental health services on how to achieve a fully smoke free environment (NHS Scotland and Scottish Government, 2011). It has been argued, however, that the implications of the smoking ban for mental health service users who wish to smoke but are compulsorily detained are significant because people in this position will not be able to smoke unless they are allowed leave or are accompanied off-site or to the designated smoking area to smoke. Going out for a cigarette therefore depends on there being adequate staff numbers available (Warner, 2009). The implications of smoking cessation for people with a diagnosis of some mental illnesses may not be as straightforward as for those with good mental health.⁶³ For example smoking appears to reduce the effects of positive and negative psychotic symptoms and increase concentration levels. However, there is also evidence that smoking might intensify some forms of mental disorder such as anxiety and panic disorders. Higher doses of anti-psychotic drugs are required by people who smoke and some drugs appear to encourage smoking (Warner, 2009).

In preparation for their move to their new-build premises, The State Hospital at Carstairs took the decision to pursue their journey to a smoke-free environment in order that both staff and patients would benefit from not being subjected to the effects of smoke pollution. This journey involved a number of processes throughout 2011, including wide consultation, strong smoking cessation services and a phased approach.⁶⁴ The hospital went smoke-free in December 2011, despite legal efforts from some patients to allow the continuation of the partial ban on a permanent basis. Since the complete ban was enforced, internal research has shown that patients have noted how surprised they were at how they were coping in the new environment and were pleased with their achievements in relation to stopping smoking. The State Hospital noted that there were a number of factors that they felt were key to the successful transition to a smoke-free environment which included, strong leadership, effective planning, wide and repeated consultation of all key stakeholders; suitable funding and resources for the smoking cessation programme (including Nicotine Replacement Therapy; support of staff and the phased process of going smoke-free, allowing patients to adjust over time (The State Hospital, 2012).

Alcohol abuse in Scotland has significant financial as well as health impacts. The Scottish Government has reported the costs to the economy to be £3.5 billion a year in lost productivity, crime and hospital costs. Its human cost is put at approximately 3,000 lives a year (Carrell, 2012). In August 2011 Scotland's alcohol statistics revealed 23 per cent higher sales in Scotland than in England and Wales. It showed that on average adults in Scotland consume 22.8 units of alcohol adult per week - above the recommended upper weekly limit of 21 units for men (BBC News, 2011a, NHS National Services Scotland, 2011). In response the Scottish Government published a strategy to reduce alcohol consumption in 2009 (Scottish Government, 2009), and more recently has pursued the introduction of minimum pricing. This latter move has led to significant political debate, but remains on the political agenda⁶⁵ as the Scottish Government still considers:

*“Minimum pricing to be the most effective and efficient way of reducing alcohol consumption and hence alcohol –related harm”.*⁶⁶

Evidence regarding the effectiveness of a minimum pricing policy reveals that low minimum price thresholds (for example 25p) have virtually no impact in reducing negative outcomes. However, as the minimum price increases: alcohol related admissions and deaths; alcohol-related crimes; absenteeism from work and unemployment from work are all estimated to decrease (Meier et al., 2012).

Others firmly believe that minimum unit pricing of alcohol is illegal and will both damage the alcohol (whisky) industry in Scotland and be ineffective in tackling alcohol misuse.⁶⁷ Whilst the Scotch Whisky Association clearly have a vested interest in this issue, they use the same research (Meier et al., 2012) as the Scottish Government to make their points, namely, that evidence shows that minimum pricing will not reduce the number of drinkers at hazardous levels. They further argue that whilst there is clearly an alcohol misuse problem in Scotland, recent statistics show that alcohol-related harms and deaths are decreasing, including deaths from alcoholic liver disease, rates of which have been in decline since 2006 (The Scotch Whisky Association, 2012).

Participants in this scoping project readily acknowledged the health problems that existed in Scotland with respect to alcohol and accepted that there was need for some kind of action. Many thought that legislation regarding alcohol would, however, wrongly impact on the majority rather than tackling the problem minority, as one participant noted:

I don't know about minimum pricing, will it really impact on the ones it needs to? And to be honest do we know who 'they' are? It's easy for me to sit at home and say, oh those kids and their irresponsible drinking, while I sit there and drink half a bottle to a bottle of wine most nights if I'm honest. And why on earth is the extra money raised going to the supermarkets as profit? Surely it would make more sense if that money went back into NHS frontline services that have to deal with the after effects of alcohol abuse?

Alice, School teacher.

A number of initiatives have also been developed to improve Scotland's diet. An independent evaluation of a 1996 UK Government action plan showed poor results, partly relating as it lacked intensity, resources and focus.⁶⁸ More recent measures have been more focussed, in particular on nutrition of children and school meals.

The Schools (Health Promotion and Nutrition) (Scotland) Act builds on the work of *health promoting schools*⁶⁹ and *Hungry for Success* (Scottish Executive, 2003). The Act ensures that food and drink served in schools meets nutritional requirements specified by the Scottish Ministers by regulations. It seeks to reduce the stigma associated with free school meals by requiring local authorities to protect the identity of those eligible for free school meals, gives local authorities the power to provide pupils with healthy snacks and drinks, either at a cost or free of charge and requires local authorities to consider sustainable development guidance when they provide food or drink in schools. The Nutritional Requirements for Food and Drink in Schools (Scotland) Regulations 2008 commenced in primary schools on 4 August 2008. The regulations commenced in secondary schools on August 3, 2009. The duty to

provide free drinking water to pupils at all times commenced in both primary and secondary schools on August 4, 2008.

According to the Scottish Government website,

*“Access to free school lunches is an important part of the school lunch service in Scotland. It is important that pupils entitled to free school lunches get them without fear of stigmatisation. They should not be made to feel different from those who pay nor be readily identified by others. Local authorities should work to promote increased uptake of free school meals amongst those currently eligible”.*⁷⁰

Pupils entitled to free school meals are those within families who receive Income Support (IS) or Income-based Job Seekers Allowance (IBJSA). Those within families who receive support under Part VI of the Immigration and Asylum Act 1999 may also be entitled. Children who receive IS or IBJSA in their own right are also entitled to receive free school meals. Also entitled are children whose parents or carers receive Child Tax Credit, do not receive Working Tax Credit and had an annual income (as assessed by the Inland Revenue) of below £16,040 in 2009/10. As of August 2009 eligibility was extended to include children whose parents or carers are in receipt of both maximum child tax credit and maximum working tax credit and an annual income below £6,420. In October 2008 following a pilot project in several areas which provided free school meals to all children in primary 1-3, the Government announced plans to roll out the project across Scotland. The £5m pilot was reported to be a success with teachers positive about the outcomes of the scheme (BBC News, 2008).

The Scottish Government pledge to roll out free school meals to all children for the first three years of school, however, did not meet with complete success by April 2010. Only one local authority had succeeded in meeting this goal as many local authorities struggled to fund the initiative (Seith, 2012). Furthermore it was reported that Edinburgh and Glasgow had no plans to change their policy as they were providing free school meals to 20 per cent of pupils.

Some research has questioned whether information campaigns on healthy eating are sufficient to improve the diet of Scotland's children. Crombie et al. (2008) reported on a survey of 300 mothers⁷¹ of 2-year-old children from areas of high deprivation in Scotland deriving a “diet quality score” from reported consumption of carbohydrates, protein, fruit and vegetables, dairy products and restriction of sugary fatty foods. The results demonstrated that 85 per cent of children were classified as having a poor quality diet. Mothers' general knowledge about healthy eating was high, but did not predict the quality of the children's diet. A significant contributor was high intake of sweets and reported difficulty in providing two to three portions of fruit a day. The authors concluded that interventions to improve children's diet could promote more positive intentions about preparing and serving of foods, particularly of specific meals at which the family eats together. The benefits of these behaviours to the child (improved diet, weight control) should be emphasised (Crombie et al., 2008).

In an interesting case study on measures to promote healthy eating, The State Hospital attempted to improve the dietary health of patients by reducing their access

to food and drink that was high in fat and sugar.⁷² The move was, however, successfully challenged in a judicial review.⁷³

Non-discrimination within health care service provision

“Health inequalities are complex. Socio-economic factors such as low income, gender, social position, ethnic origin, age and disability increase the risks of poor health. Behavioural factors such as smoking, alcohol, drugs, poor diet, poor sexual health and low physical activity also increase the risk of health-related problems. Many of these factors are interlinked and further increase the risk of health problems. A key function of Community Health is to ‘tackle health inequalities, enhance anticipatory and preventative care, shift resources to community settings and provide a wider variety of services at local level’” (Audit Scotland, 2011).

As noted above the right to health includes an obligation to ensure that health facilities, goods and services are accessible to all without discrimination. This has four dimensions: non-discrimination (in law and fact), physical accessibility (including in rural areas and for disabled people), economic accessibility and information accessibility (UN CESCR, 2000).

Economically, a bedrock of health service provision in Scotland is that the NHS is free at the point of access and access is based on need.⁷⁴ A point that was acknowledged by many participants in this scoping project:

People I have spoken with as well who have come to live in Scotland have been very impressed with the NHS, with all its faults... they recognise that the system is much better than what they had at home. For me too, I lived in London for a couple of years before coming up here and the provision difference is like chalk and cheese. I would much rather get sick in Scotland. In that way, you do something right here.

Gregory, Member of a rural mental health support group

A key *Quality Ambition* in the *Healthcare Quality Strategy* (NHS Scotland, 2010) is that interventions, support and services will be provided at the right time to everyone and this section will review literature which discusses strategies working towards equal access to public health services for all.

Overall there has been significant policy attention towards addressing health inequalities in Scotland, including inequalities in access to healthcare as well as inequalities in health outcomes. A Ministerial Task Force produced a report *Equally Well* which led to a joint action plan with COSLA (Donnelley, 2008a). Reconvening to review progress in 2010 the Ministerial Task Force agreed new actions including that the Scottish Government and the Local Government Improvement Service would support Community Planning Partnerships to deliver change (Scottish Government, 2010a).

An independent evaluation of the implementation of *Equally Well* (Fyfe et al., 2011) found that all test sites had made progress towards partnership working, although far fewer had yet (after 30 months) made progress on improving outcomes for service users (only 3 per cent of respondents felt such change had been achieved). There were concerns that reducing public sector budgets may threaten the sustainability of

progress. When asked for views on how national policy could help deliver local results in advancing health equality, respondents suggested a range of measures, including a greater focus on early intervention; linking different Scottish Government approaches better; making sure that all relevant parts of the NHS were fully involved; national outcomes and targets for public sector organisations should clearly reflect the need to tackle health inequalities; spreading learning widely, so that approaches could be transferred to other areas where this was appropriate (Fyfe et al., 2011).

Ethnic and religious minorities

Despite such policy attention to address health inequalities, life expectancy still remains markedly lower for some minority groups – notably Scottish Gypsy/Traveller communities.⁷⁵ There are also varying rates of difference pathologies within different ethnic groups population with debate having centred on the relative causalities of genetic and socio-economic factors (Coccia, 2010). Rates vary, with some ethnic minorities reportedly having significantly higher rates of cardio-vascular disease (notably South Asians) and diabetes, and lower rates of cancer than median rates in Scotland (Coccia, 2010).

Despite some policy initiatives to promote racial equality in access to healthcare (e.g. Fair for All (NHS Scotland, 2002)), there is continued evidence of inequality in practice. For example, in 2005 the Mental Welfare Commission (MWC) carried out simultaneous unannounced visits to 19 acute admission wards. The report noted that there were 240 patients in the 19 wards visited, of which 13 were from a minority ethnic group and 8 of those did not speak English as a first language. While all wards reported that there was access to an interpreting service, the MWC made a series of recommendations on how communication could be improved with patients whose first language was not English. These a review of written guidance information to make sure that it is available, as far as practicable, in the languages of the people who receive treatment in hospitals (Mental Welfare Commission for Scotland, 2005).

Research on the experiences of Polish immigrants accessing health services in Aberdeenshire reported many positive experiences. However, key among the research recommendations were addressing language barriers through availability of translation or Polish language medical staff and the translation of written material into Polish (Love et al., 2007b).

Recent research has also suggested that there is a lack of awareness and understanding of the needs of Muslims within public services. For example, it has been suggested that often mainstream mental health and maternity services do not operate in a religiously and culturally sensitive manner. Therefore young British Muslims do not feel comfortable accessing mainstream support services, for fear of being misunderstood (Kidd and Jamieson, 2011).

Worth et al (2009) have also concluded⁷⁶ that despite a robust Scottish diversity policy, services for South Asian Sikh and Muslim patients with life limiting illness were wanting in many key areas. They propose that active case management of the most vulnerable patients and carers, and “real time” support, from where professionals can obtain advice specific to an individual patient and family, are the

approaches most likely to instigate noticeable improvements in access to high quality end of life care.

Participants in that scoping project suggested that the low level of uptake of hospice places in Scotland, compared to that in England, arises in part from cultural differences, language barriers and lack of culturally appropriate dietary options, whereas in England there are more hospices run by Asians for Asians. Moreover, patients may feel uncomfortable in accepting care from non-Asian care givers and may be concerned at potential lack of sensitivity or discriminatory treatment from staff (Worth et al., 2009). The research concluded that within minority ethnic groups the most vulnerable people, such as recent migrants, have the poorest access to services. Active case management of high risk patients should help to overcome many of these barriers and Professionals need ready access to information and support specific to an individual patient and family (Worth et al., 2009).

Participants in this scoping project referred to recent efforts within their local area to work with minority ethnic groups to ensure that they understood their health rights, as noted by a trainee social worker:

...we did a dialogue day between the NHS and ethnic minorities, we did a couple and that's one of the things that popped up all the time, people not knowing what services to access, things like going to an optometrist is free for a child, they said that the only way they found out about services was through friends. Information when people arrive in the country would have been useful.

Eric, Trainee Social Worker.

Perth and Kinross Council also ran a similar event for Scottish Gypsy/ Travellers aimed at improving the health and wellbeing by promoting different services to members of the Gypsy/Traveller community. Services represented at this event included health but also included: the Council; Police; Live Active; and the voluntary sector. Members of the local Gypsy/Traveller community were involved in planning the event by advising on different activities that may be of interest to their community. Forty-five Gypsy/ Travellers attended the event which was very well received by the community and perceived by those who attended as a model of good practice for engaging with Scottish Gypsy/ Travellers on health and wellbeing (McPhee, 2012).

During the past decades, the UK has become an increasingly multicultural society and in the UK, all minority ethnic groups have a higher incidence of diabetes than the general population (Baradaran et al., 2006).⁷⁷ Previous research assessing diabetes care in minority ethnic groups has found that recording of ethnic group has not been considered a priority by Local Health Care Cooperatives. This information is an important starting point in the ability of NHS organisations to reach a position to target their finite resources more effectively. The absence of robust information is concerning given that diabetes is reported to be specifically identified by 71 per cent of Local Health Care Cooperative plans (Baradaran et al., 2006).⁷⁸

Research also indicates that many failed asylum seekers are unaware that they are eligible for free healthcare or are anxious about contact with authorities so do not seek medical help (Smith et al., 2010a). Asylum seeking participants in this scoping

project were, thanks to the help of a support group, aware of their health rights, and the majority faced no problems in accessing primary health care services. They did, however, highlight cases where access had not been straightforward due to a lack of knowledge amongst service providers, as the following case shows:

We had a woman who was told she would not get any care for her maternity, ante or post natal. She went twice during her pregnancy to A&E at the [hospital] and the second time she was told you have no GP you cannot come back to A&E. So we had a lady who was one of our volunteers and she took [the pregnant woman] to every single GP, because [the pregnant woman] had gone and every GP had said no. So [the volunteer] went to her best determined upper class accent and said 'someone must give this woman attention, she is having a baby' and no she never got a GP. How could you deny this woman a GP? They did the same thing that we have experienced with the solicitors, they would say of course and then sometimes they would phone [the volunteer], never [the pregnant woman], and say sorry we checked into it and we can't.

Claire, Support worker for women seeking asylum.

People with disabilities

Article 25 of the UN Convention on the Rights of Persons with Disabilities guarantees the right to health for disabled people and includes a range of specific obligations on States to realise that right. These include: requiring the same quality of care is provided to disabled people, including raising awareness of the right to free and informed consent of disabled people (including those with mental disorders); prohibiting discrimination against disabled people in life insurance.

Participants in a joint SHRC and Equality and Human Rights Commission [EHRC] participation event with disabled people (EHRC and SHRC, 2011), noted problems in accessing health services, as the following two cases illustrate:

"In my local hospital, a wheelchair [user] inpatient cannot independently access a toilet and close the door - meaning anyone can see them on the toilet. More needs to be done to ensure the rights of disabled people and that they are treated in a dignified manner. No able bodied inpatient would accept treatment like this but disabled people are expected to shut up and put up with it. All public buildings should be forced, by law, to have properly qualified Access Auditors undertake access audits and be forced, by law, to complete the work recommended by the Access Auditor".

Another woman told of how her GP arranged with her to meet with another doctor at a clinic where there was no disabled access. She was, therefore, made to meet with the doctor in the back of a taxi because she could not access the doctor's office in her wheelchair. The subject matter of their discussion was very personal and both she and the taxi driver sitting in the front were left embarrassed at the end of what was supposed to be a confidential meeting (EHRC and SHRC, 2011). This level of care would raise issues of compatibility with ECHR Article 8 on the right to respect for private and family life. The underlying apparent failure to ensure reasonable accommodation and access to health services to people with disabilities also raises compatibility issues with both the Convention on Persons with Disabilities and the Equality Act.

Similarly, people with sensory impairments have been found to face numerous hurdles in accessing services. Lack of access to sign language interpreters compounds common feelings of social exclusion and hearing impaired people felt that they waited too long for allocation of equipment (Skellington Orr and Leven, 2006).

As part of its work towards reducing health inequalities, NHS Quality Improvement Scotland⁷⁹ has taken steps to improve and encourage the involvement of people with learning disabilities in health service review teams. An independent evaluation concluded that the inclusion of people with learning disabilities in NHS QIS review teams in Scotland was an innovative step, and the evaluative feedback from everyone involved was generally very positive. The makeup of review teams also had a positive impact on how health services viewed these 'expert patients' and how their health needs can be met in a more inclusive way. This methodology adopted by NHS QIS showed the importance that the evaluation team attached to the principle of 'participation' and to both understanding and valuing the perspectives of those who are in receipt of these particular services. The innovation also resulted in a number of unforeseen consequences, during and after reviews, which challenged traditional assumptions about the balance of power between professionals and people with learning disabilities (Campbell and Martin, 2010).

Further work has been carried out in respect of a small number of patients with learning disabilities suffering cancer (Forbat and McCann, 2010).⁸⁰ The research noted that people with learning disabilities have traditionally been excluded from involvement in decision making about services that affect their lives. The research noted positive experiences of communication where people with learning disabilities were provided with adequate information and were able to ask direct questions of the healthcare practitioners. It was commonly reported that people were being bypassed with information provided to their families. This was occasionally the case even when the intellectually disabled person asked direct questions of healthcare practitioners. Other negative experiences which were reported included a lack of patience demonstrated by some health workers (Forbat and McCann, 2010). The researchers reported a paternalistic approach in failing to discuss "taboos" of the reality of life with cancer and an overall feeling amongst 'gatekeepers' i.e. friends and relatives, that discussing experiences of cancer would be too upsetting for people with learning disabilities.

Sexual Orientation and Gender Identity

The research review identified a relative lack of consideration of the experience of LGBT people, and Transgender people in particular, in health care. Macpherson and Bond (2009) reported that a significant percentage of research on access to healthcare by LGBT people has focused on HIV which is most common among gay men, at the expense of broader health and wellbeing (Macpherson and Bond, 2009). An exception is research commissioned by Stonewall Scotland into the experiences of 500 lesbian and bisexual women in the health sector in Scotland. Of the participants, half had negative experiences in the health sector in the previous year. One in ten said that a healthcare worker ignored them when they did reveal their sexuality/sexual identity. Seven in ten reported that healthcare workers made inappropriate comments when they came out. Just one in nine felt that their partner was welcome during a consultation (Hunt and Fish, 2008).

One participant in this scoping project talked about the inappropriate treatment she had received whilst in hospital, which she perceived to be the result of a lack of quality diversity training:

I think the problem with health is sometimes a lack of dignity and I think that that is down to a lack of training, I don't think health boards pay any more than lip service to training people. If you've never met a Trans [gender] person, you have no idea... I was in casualty and when they cut my trousers off due to an injury to my legs and they found tights underneath and they all had a little giggle and then when they cut the tights off I still had my toe nails done and that caused another giggle and I saw more medical staff than I have ever seen in my life because they were all coming to have a gawk at me, being voyeuristic. Now that was wrong and I was strong enough to call the senior consultant out and say what was wrong with the way the staff were acting. But I am a strong person and what about those people who are not, what about those whose voice isn't strong enough? I said to him, this is not professional conduct from your staff, I am here as someone who has had an accident and I said here I am in your unit being treated like some kind of freak, it's not good enough and there was an apology. In the initial stages, Trans [gender] people are not just in the closet, we are so far back we're in a cave, and so the dignity of Trans [gender] people is so important.

Catriona, Trans [gender] woman, diversity trainer for public bodies

Research supported by Engender into the experience of trans women in gender reassignment services (Burrows et al., 2011). The research involved a number of methods including the largest survey of trans [gender] women to date (49 participants across nine Scottish health boards). The survey revealed a relatively positive picture in relation to support provided by GPs (92 per cent had good support).⁸¹ This was supported by participants in this scoping project, who on the whole found their own GPs were supportive:

My GP is very good... But the GP didn't really know anything, so when I said this is what I am going to do, she was quite enlightened and she asked me if we could grow together, which I thought was really nice. So whenever I went to appointments at the Sandyford I'd fill her in and tell her next steps and who she would hear from and so on. So we went on a discovery path together and it was advantageous to her and to me, the two nurses at the practice were also very supportive especially after my surgery. It's great except on the odd occasion when they get a locum in and then that's a laugh. By and large I am lucky, but also now as a result of my experience, several Trans [gender] people now go to my surgery to see that doctor because they feel comfortable. But I know people who have not had that experience and have had to move.

Jane, Trans [gender] woman.

Access to Gender Reassignment health services, however, has not been found to be as common (Burrows et al., 2011). One participant in this scoping project reported that it can be very difficult for anyone who lives outside of the central belt as no matter where you live, you must attend pre-surgery specialist counselling at the Sandyford clinic in Glasgow. Further, only a fifth of the Engender participants had received NHS funding for the treatment of facial hair removal (43 per cent had paid

privately); 29 per cent of respondents had received Health Board funding for private surgery, with only six per cent having had NHS surgery.

Almost a fifth of the respondents in the Engender survey (Burrows et al., 2011) had to wait over two years for this surgery, which had brought about episodes of anxiety, depression, self-harm and attempted suicide for two-thirds of those required to wait so long. As a participant in this scoping project said:

One woman I talked to, when I met her I was so upset because she sat and told me how she had tried to end it all because she couldn't cope anymore, not being able to get treatment and no matter what she did, no one at the NHS was listening. She was a woman at the end of her tether and I'd never met someone like that before and it really hit me and it hurt... How can there be women and all they want to do is live their lives as a woman and everyone seems to be against them? No-one is listening. We don't want preferential treatment, we just want treatment.

Catriona, Trans [gender] woman, diversity trainer for public bodies

Overall the Engender research highlighted a need for greater funding both in Gender Clinics and for Gender Reassignment treatments. This was seen as crucial given the serious mental health problems that delays in funding and lack of access to services has led to. They suggest that a “*funded patient pathway*” would be one means by which to improve the treatment of Trans women as well as reducing the impact of funding delays and refusals (Burrows et al., 2011).

Economic and social situation

While domestic equality legislation is limited to enumerated grounds or ‘protected characteristics’, international human rights law is non-exhaustive in its approach to non-discrimination and equality. Both the ECHR and the International Covenant on Economic, Social and Cultural Rights prohibit discrimination on a range of enumerated grounds “*...or other status*”. The UN Committee on Economic, Social and Cultural Rights has authoritatively interpreted, this extends, in relation to the right to health, to economic and social situation (UN CESCR, 2009).

Patterns of illness are inequitably spread across the socio-economic spectrum, with those living in poverty more likely to die early and to suffer from a range of health problems (Donnelley, 2008a, O’Flaherty et al., 2009, Conway et al., 2007). The EHRC Triennial Review reported that in Scotland 32 per cent of adults over sixteen in the most deprived areas reported a longstanding illness, disability or health problem compared to only 14 per cent in the least deprived areas (EHRC, 2010).

Research suggests that poor health is an even greater problem amongst the homeless population. Research amongst homeless people in Aberdeenshire revealed that homeless people suffer higher levels of morbidity than people in the general population (Love et al., 2007a). Moreover, in relation to long-standing illness and disability, the research established that three-fifths of participants reported having such a condition (61 per cent), with drug problems, mental health problems and alcohol problems the most reported conditions suffered. Fifteen per cent of those, reported some kind of long-term physical illness or disability such as heart disease, paralysis, joint problems (i.e. painful legs), back trouble, blindness epilepsy,

kidney disease, asthma, osteoporosis and a general lack of fitness (Love et al., 2007a).

Pilot projects were established in 2004 to provide evidence in relation to whether increasing resources to deprived areas would lead to an improvement in access to NHS services. These pilot projects ran in Argyll and Clyde, Greater Glasgow⁸² and in Tayside Health Boards. Examples of unmet need included access by people with coronary heart disease in deprived areas to a range of services, attendance at breast screening clinics, uptake of winter flu vaccinations (Donnelley, 2008b).

Evaluating the pilots Donnelley (2008b) recommended, amongst other things that services should be shaped and adapted to fit the needs of service users, adapted to times which accommodate lifestyles and childcare; delivered in community based venues; integrated; provided with consistent support along the whole patient pathway and personal for example considering the allocation of a specific health worker.

Access to health care in rural areas

Research on the differential access to health care in rural areas is considered in the thematic section entitled “Where We Live”.

Mental Health

Strategy

Following consultation the Scottish Government launched a new Mental Health Strategy in August 2012 focussing on four main areas of challenge: child and adolescent mental health services; rethinking approaches to common mental health problems; community; inpatient and crisis services; other services and populations (Scottish Government, 2011a). The strategy contains a number of commitments, including that the Government will:

“work with the Scottish Human Rights Commission and the Mental Welfare Commission to develop and increase the focus on rights as a key component of mental health care in Scotland.” (Scottish Government, 2011a)

On the specific issue of suicide, the UN Committee on Economic, Social and Cultural Rights recommended in 2009 that the UK intensify the efforts to decrease the number of suicides (UN CESCR, 2009). The Scottish Government’s ten-year ‘Choose Life’ strategy and action plan was launched in 2002 and evaluated in 2009. The evaluation concluded that there was a continuing need for action on suicide prevention and to link with drug and alcohol services, primary care and clinical mental health services (Russell et al., 2010). Statistics indicate that suicide rates fell by 13.8 per cent in Scotland between 2000-2002 and 2008-2010 (Scottish Government, 2011a). Further areas where the Government reports success include significant reductions in readmission rates, and increasing rates of dementia diagnosis.

In relation to dementia, Alzheimer’s Society and Alzheimer Scotland mapped rates of dementia diagnosis finding the highest rates of diagnosis in Scotland (64.5 per cent in 2011, in comparison to 61.5 per cent in Northern Ireland, 41.1 per cent in England and 37.4 per cent in Wales). Five of the top ten NHS areas and eight of the top ten

most improved in diagnosing dementia were also found to be in Scotland (Alzheimer's Society and Alzheimer Scotland, 2012).

The Government has committed to reviewing the state of all mental health services in Scotland in 2013-2014 (Scottish Government, 2012).

Addressing mental health stigma

Research found that 81 per cent of people you had experienced mental health problems had been subject to stigma, with reporting that they found the stigma worse than the mental health problem itself (McArthur and Dunion, 2007). As SAMH has reported experience of such stigma can also be at the hands of medical practitioners, including psychiatrists (Stuart, 2006).

The 'See Me' campaign was launched in October 2002, with the aim of addressing the negative attitudes and behaviours which systematically disadvantage people with mental health problems and those close to them and with the purpose of tackling the stigma and discrimination experienced by people with mental health problems (Myers et al., 2009).

An evaluation of its first four years found the campaign had drawn attention to the stigma and discrimination experienced by people with mental health problems. It recommended further consideration of equality and diversity in campaign targeting, design and delivery. Progress was seen to be hindered by a lack of funding, of strategic approach and a failure to encourage others to take responsibility for overcoming the inequality and exclusion faced by people with mental health problems (Myers et al., 2009). Scottish Government also surveys public attitudes to mental health, with results continuously improving (Davidson et al., 2009).

The campaign has achieved international recognition in a publication of the World Health Organisation (World Health Organisation Europe, 2008) and was well-known amongst most participants in this scoping project. Participants considered 'See Me' has slowly begun to dig away at entrenched societal attitudes about mental health. As one participant with longstanding mental health problems explained:

I am much older than most of you and in our generation until quite recently we did not talk... talking about mental health issues was an absolute taboo. It was a shame to the family. If a member had mental health problems, it was not spoken about and that meant that people with mental health problems felt isolated, they thought that there was nobody else in the same situation. We didn't know that anybody else was suffering, we were freaks. We were to keep our problems under wraps. So the openness that has been developing since I got involved in helping with See Me is great... Nothing will change overnight but in these ten odd years that I have been actively involved, I have started seeing a change in attitudes and increased knowledge which is the most important thing in my mind, because the stigma that is experienced by all of us, it is largely fear of the unknown and if we don't talk about these things, we will never learn and nothing would ever change.

Clarissa, Participant at a rural mental health association

Participants involved in a joint Voices of Experience, SHRC and EHRC event

(VOX Scotland et al., 2012) were critical of some aspects of the 'See Me' campaign, believing it to be directed too much at educating professionals rather than aiding people with mental health problems. Some felt that the youth campaign 'Free Your Mind' run by the Highland Users Group (HUG)⁸³ was a more effective model as it targeted mental health stigma among schoolchildren.

In 2012 the revised campaign strategy for See Me was one of four case studies which used integrated Health, Inequality and Human Rights Impact Assessment in policy and strategy setting processes. This drew out various ways in which a reframing of the campaign strategy could further advance the human rights of people with mental health problems by emphasising that people with mental health problems have the full range of human rights and that Government and other public authorities have obligations to identify and address barriers to the realisation of those rights.⁸⁴

Access to mental health care

Previous research highlights that one in four people is not provided with the access to mental health services that they require (Beaton, 2001, Spicker et al., 2002, Love et al., 2007a, Green, 2007, VOX Scotland et al., 2012, Mental Welfare Commission for Scotland, 2011b, BMA CCSC Psychiatry Subcommittee, 2008).

Scotland has a target to ensure access to specialist Child and Adolescent Mental Health Services within 26 week by March 2013. The Scottish Government reports it is on track to meet this goal (Scottish Government, 2012). However, freedom of information requests by Mary Scanlon MSP in 2011 demonstrated that delays at that time range from 16 weeks in Dumfries and Galloway, to 182 weeks in Tayside (National Health Executive, 2011). Citing a MWC report from 2008, the Scottish Association for Mental Health (SAMH) has raised also concern at reported increases in the numbers of young people admitted to adult psychiatric wards in some areas.⁸⁵ Together also raise this issue in their most recent report on the *State of Children's Rights in Scotland* (2012), noting that even a 26-week waiting period still leaves many children waiting too long for the support that they need. They state that:

"A more ambitious target for access to CAMHS is needed to send a message to health boards that this is a priority" (Together, 2012).

In 2009 the UN Committee on Economic, Social and Cultural Rights recommended that the UK strengthen the provision of psychological counselling services (UN CESCR, 2009). Scotland has a target of ensuring access to psychological therapy, irrespective of age or disorder within 18 weeks by 2014. This is described by the Government as uniquely ambitious (Scottish Government, 2012).⁸⁶ The target has been welcomed by mental health service user representatives such as Voices of Experience (VOX) who note the value of cognitive behavioural therapies (CBT)⁸⁷ and other psychological therapies and the need to address current delays in accessing them. As Gordon Johnston of VOX stated:

"I have personal experience of this: my GP referred me for cognitive behavioural therapy some ten months ago. I have still to receive an appointment."⁸⁸

Almost every participant in this scoping project who had the need for mental health services had had to wait considerable lengths of time to be seen by an appropriate

service. This was the case whether they lived in urban or rural areas. However, participants reported particular challenges for those living on outer lying Scottish islands. For example, participants in this scoping project reported that anyone living on the outer Orkney Islands who required mental health contact time must travel, often at their own expense, to the main island.

Most participants who had experienced mental health problems had had to wait for access to services, often causing additional stress to themselves and others such as family members:

Over a year ago I had to put my daughter into care because I wasn't well enough to look after her because my mental health was so bad, and she was in care for 14 months and it should have been 6 weeks, while I waited for CBT treatment, I am still waiting for CBT treatment. They gave me my daughter back because they couldn't afford to keep her in care and my husband has had to give up his job which he has had for 38 years to look after my daughter and I am still waiting.

Cherie, Participant at a rural mental health association

This scoping project also revealed problems faced by asylum seekers in accessing mental health services.

Access to mental health appears to be a different story [compared to access to a GP]. It took a very long time before Meena eventually got an appointment...two years ... In that two years her memory was impacted by stress levels, her sleep patterns were impacted by stress levels and ... she has got some joint and muscle skeletal problems... And that is outrageous; they have ruined this woman's health... You cannot leave someone who has expressed a need to engage with mental health services two years, that is like saying it's hopeless anyway there is no point in trying. You need someone to at least assess you to see how pertinent your needs are.

Claire, Support worker for asylum seeking women.

Further, as Claire described, often there may be underlying cultural or religious barriers to accessing mental health services which should be considered:

... to get mental health support you have to say you are 'suicidal' – it is not an African thing to say 'I feel suicidal'... and it is completely taboo to talk about suicide in both Christianity and Islam, so you've got cultural taboos, faith taboos and I think it would be incredibly difficult to expect one of these women to have to say to a health care worker, it's bad, I need help because I no longer wish to live, I don't think they can say that. And I don't think it is fair, because if I go to my GP and say that I will be triaged and get help straight away. I couldn't tell Meena to say that, she couldn't say that and then go to church on Sunday.

Claire, Support worker for asylum seeking women.

Mental health treatment and care

The relevance of human rights in mental health care and treatment is perhaps more often recognised than in any other area of healthcare. In this section we are concerned not with the liberty of patients subject to mental health detention (which is considered in the thematic section entitled 'Living in Detention') but with care and treatment in and outside of mental health institutions. This raises issues under a

wide range of human rights, including but not limited to the right to life (and positive obligations noted at the start of this thematic section to protect people from real and immediate threats to their life from themselves or others); the right to be free from torture, inhuman or degrading treatment or punishment; and the right to respect for private and family life (including autonomy, physical and mental integrity) (Bartlett et al., 2007). Persons deprived of their liberty on mental health grounds (under Article 5(1) (e) of the ECHR) must be detained in an appropriate therapeutic environment.⁸⁹ Such a requirement does not apply to those detained under Article 5(1) (a) (those detained upon conviction by a competent court).

The Mental Health Care and Treatment (Scotland) Act 2003 (2003 Act), which came into force in October 2005, is described as having brought the most fundamental change to mental health law in 40 years (Ridley et al., 2009). It draws on the Millan Principles (2001) of non-discrimination, equality, respect for diversity, informal care, participation, respect for carers, least restrictive alternative, child welfare, reciprocity and benefit. In this way the 2003 Act has been recognised nationally and internationally as human rights based and described by among others SAMH as “one of the most advanced pieces of mental health legislation in the world”.⁹⁰

A 2009 review⁹¹ of the Mental Health (Care and Treatment) (Scotland) Act 2003 found amongst other things:

- awareness and use of advance statements⁹² (whereby a patient can set out the way they would like to be treated in the event of becoming mentally unwell) had had low take up and needed further promotion;
- That the provision of advocacy services to everyone with a mental disorder (as outlined in the Act) should be pursued in practice by increasing their availability in some areas;
- The Scottish Government’s response proposed, amongst other things, a general duty to promote the use of advance statements.⁹³

Much research has focussed on the extent to which the human rights based approach in mental health legislation has consistently translated into realisation of human rights in practice. Among the specific issues which have been the focus of attention are: restraint and seclusion; consent and necessity of medication; and locked door policies (Mental Welfare Commission for Scotland, 2010c, SHRC, 2009, Mental Welfare Commission for Scotland, 2006, Mental Welfare Commission for Scotland, 2007, Mental Welfare Commission for Scotland, 2010b, Mental Welfare Commission for Scotland, 2010a, Scottish Government, 2011e, Scottish Government, 2011d, Care Commission and Mental Welfare Commission for Scotland, 2009, Mental Welfare Commission for Scotland, 2011c, Mental Welfare Commission for Scotland, 2011d, Mental Welfare Commission for Scotland, 2011e, SPSO, 2011).

In 2010 NHS QIS published the results of a national audit of Intensive Psychiatric Care Units (IPCUs), conducted in collaboration with the MWC, VOX and Better Together. It found in general a high quality of care but nonetheless found a range of areas in which there was scope for improvement. These included that some people remained in IPCUs longer than necessary; that problems exist in accessing IPCUs, particularly where such services are not available locally; a “range of unmet needs” in terms of activities, rehabilitation and a therapeutic environment; a “one size fits all”

approach to risk management; a lack of opportunities for meaningful involvement in the care process. In response a series of recommendations were made for national and local level improvements (NHS QIS, 2010).

In 2011 MWC published an overview of findings and recommendations on visits to individuals with severe and enduring mental illness in rehabilitation and continuing care in psychiatric hospitals. Whilst it reported improvements since it last considered this group of patients it nonetheless recorded “*serious concerns about their care*” including that:

- *“Almost half did not have an individual activity plan tailored to their needs.*
- *Many were subject to unnecessary restrictions because of blanket policies.*
- *Many felt unsafe and did not feel that staff acted on their concerns.*
- *We were not convinced that enough was being done to check their physical health.*
- *Some were still being subjected to the outdated and institutional practice of queuing for medication.*
- *We found that most of them were living in environments that were poorly deco-rated or maintained”.*

(Mental Welfare Commission for Scotland, 2011a)

It made a series of recommendations as a result.

SAMH has called for “*targets and incentives for NHS Boards to act upon ... recommendations [in the 2010 NHS QIS and the 2011 MWC reports]*” (SAMH, 2011).

Dementia Care

MWC investigations into the living environment for dementia patients in hospitals found that only half of the 29 patients’ records examined showed the recording of a life history (Mental Welfare Commission for Scotland, 2007). This is despite the importance of the recording of a life history for dementia patients, given that it helps staff to understand the patient as an individual including his or her likes and dislikes, cultural and ethnic backgrounds. This person-centred approach is central to a human rights based approach to care, as outlined by SHRC in its training on social care and human rights, *Care about Rights?*⁹⁴

The difficulties associated with provision of appropriate support and care for those people with dementia are reported to be particularly acute in rural areas of Scotland (Innes et al, 2006). Four key problems have been identified in providing quality dementia services in rural areas, namely: distance and transport; the cost of the service for the user; the lack of choices in services; and a shortage of skilled staff. The use of generic mental health services means that the specialist needs of dementia sufferers are not being met. Research has highlighted, therefore, that health and social policy in Scotland needs to consider a rural dimension to training and education to ensure that practitioners in rural areas are appropriately skilled and policy makers need to base their rural decisions about service provision on research and consultative based evidence which reflects the unique requirements of remote and rural dementia care service users (Innes et al., 2006).

Scotland’s National Dementia Strategy, adopted in 2010 includes explicit commitments to apply human rights based approach principles of participation,

accountability, non-discrimination, empowerment and legality (the so-called PANEL approach which SHRC has promoted).⁹⁵ This built on work of the Cross Party Group on Alzheimer's at the Scottish Parliament, supported by SHRC and the organisation Alzheimer Scotland, to produce a Charter of Rights for People with Dementia and their Carers.⁹⁶

Restraint and seclusion

The use of seclusion, restraints or other interventions with physical and mental integrity must be carefully considered to ensure that their use is consistent with human rights in each case.⁹⁷ In recent years both UN human rights bodies and the European Court of Human Rights have been specific that the prohibition of inhuman and degrading treatment includes a prohibition of mental, as well as physical trauma. For example the UN Human Rights Committee states that:

“Article 7 [of the ICCPR] relates not only to acts that cause physical pain but also to acts that cause mental suffering to the victim” (UN Human Rights Committee, 1992).

The European Court of Human Rights has also stated that special scrutiny is necessary where people have been detained in psychiatric facilities⁹⁸ and whether an act is classed as amounting to ill-treatment will depend on the situation of the individual:

“The Court recalls that ill-treatment must attain a minimum level of severity if it is to fall within the scope of [the convention.] The assessment of this minimum level of severity is relative; it depends on all the circumstances of the case, such as the duration of treatment, its physical and mental effects and, in some cases, the sex, age, and state of health of the victim.”⁹⁹

UN and other regional human rights bodies consider that the use of seclusion, particularly for people with mental disabilities, may amount to ill-treatment.¹⁰⁰

In Scotland the National Care Standards¹⁰¹ define restraint as control to prevent a person from harming themselves or other people by the use of:

- physical means (actual or threatened laying on of hands on a person to stop them carrying out a particular action);
- mechanical means (for example, wrapping someone in a sleeping bag or strapping them in a chair);
- environmental means (for example, using cot sides to prevent someone from getting out of bed); or
- medication (using sedative or tranquilising drugs for the symptomatic treatment of restless or agitated behaviour) (Scottish Government, 2007b)

Care facilities using restraint techniques must have a written policy and staff must be fully trained and supported in the use of restraint. Where it is necessary to restrain a resident, this must be recorded in the personal plan and records kept of any incidents requiring restraint.

The MWC has also produced detailed guidance on the use of restraint in residential care setting (Mental Welfare Commission for Scotland, 2006). The fundamental principle of the guidance is that restraint is a last resort where there is no other alternative. The MWC take a similar definition of restraint, to include the planned or unplanned, conscious or unconscious actions of staff to prevent a resident or patient

from doing what she or he wishes to do and as a result, places limits on his or her freedom.

In a series of unannounced visits to investigate the conditions in 16 continuing care dementia wards, the MWC found that whilst in 12 of the 16 wards there was a policy in place regarding the use of restraint, 14 wards indicated that mechanical restraint was used at times (mostly bed rails or lap straps), with 11 using some form of restraint at the time of the visit. The MWC noted concern that training in restraint had been undertaken by staff in only 7 of the wards visited (Mental Welfare Commission for Scotland, 2007). The use of restraints is an area highlighted in a review of the Mental Health (Care and Treatment) (Scotland) Act 2003 as one which requires clarification and where Scottish hospitals require additional guidance.¹⁰²

In its independent evaluation of the use of a human rights based approach at The State Hospital¹⁰³ SHRC reported that staff, patients and carers noted a shift towards more patient-focussed approaches to care and treatment where individual risks and needs were assessed (SHRC, 2009). As part of this approach SHRC found that the policy on the Prevention and Management of Violence and Aggression was revised in 2006 to make extensive reference to human rights and highlight in particular the need to ask three key questions of legality, necessity and proportionality:

“In the case of procedures for the prevention and management of violence and aggression, especially those that potentially may involve greater infringement of patients’ rights, the staff response must be justified, appropriate and proportionate to the assessed actual or potential risk.”
(SHRC, 2009)

Following the introduction of this policy number of recorded violent incidents was found to have fallen by 25 per cent and seclusion was no longer used routinely, but rather only as a last resort.¹⁰⁴ In relation to the use of seclusion SHRC found “striking” results:

*“In statistical terms the reduction in the use of seclusion is striking. Figures provided from the late 1990s, prior to the human rights-based approach, show that it was not be unusual for the number of seclusions on **one ward** in the period of **one month** to be over 30. Last year 12 seclusions were reported for the **whole year**, across the **whole hospital**”* (SHRC, 2009) [emphasis added].

Consent to medication

SHRC worked with the MWC to produce extensive guidance on consent to treatment in 2010 (Mental Welfare Commission for Scotland, 2010a). The guidance took a human rights based approach - emphasising the presumption in favour of capacity and the importance of providing sufficient information to the patient to facilitate an informed choice. The guidance notes the importance of taking a functional approach to determining capacity, focussing on whether an individual is capable of making a specific decision at a specific time and outlines factors to be taken into account when determining whether a patient has capacity, as well as awareness of potential coercion. The guidance also covers the provisions of the Act which relate to situations in which treatment can be provided to a patient with capacity that nonetheless refuses treatment.¹⁰⁵

Specific guidance also exists on the use of covert medication. In general terms, the decision to give medication to an individual without their knowledge requires

consideration of issues including: capacity; least restriction; consultation with relevant others; taking account of past and present wishes; and there are specific steps to be taken to record the use of covert medication and to keep it under review (Mental Welfare Commission for Scotland, 2006).

The 2011 Scottish Government dementia review addressed the need to respond better to behaviours that staff and carers find challenging, and discussed the overuse of psychoactive medication for dementia patients in all care settings¹⁰⁶. The Dementia Strategy commits to reducing the use of this medication in 2011 and beyond:

This commitment is designed to help drive wider changes such as involving those with dementia and their carers in promoting positive care in order to help behavioural issues from arising; always exploring therapeutic approaches as the first alternative in intervening in such circumstances; always regarding the use of psychoactives as the last treatment option and complying fully with the law in assessing someone's capacity to consent to treatment ; and always reviewing prescribing at regular intervals to assess its continued appropriateness (*Scottish Government, 2011d*).

Research has shown, however, that 33 per cent of care home residents are taking antipsychotic medications and 6 per cent were taking olanzapine or risperidone, despite warnings about the use of these drugs (Care Commission and Mental Welfare Commission for Scotland, 2009).¹⁰⁷ This scoping project also raised concerns relating to prescription medication such as: over prescribing; failure to keep prescriptions under review; little input from pharmacists; and a lack of a comprehensive medication recording system. Medication to manage challenging behaviour should always be a last, not a first resort. Nine out of the thirty care homes inspected in this research used covert medication (Care Commission and Mental Welfare Commission for Scotland, 2009).

The MWC also reported on lessons to be learned from the death of Mrs V, an 80 year old lady who died whilst on a Compulsory Treatment Order. An independent doctor had raised concerns about discomfort caused by being prevented from eating and from receiving intramuscular and rectal medication. In the 16 days between 3 December 2008 until her death on 19 December 2012 she received a total of:

- 13 intramuscular injections of chlorpromazine;
- 16 intramuscular injections of lorazepam;
- 57 administrations of rectal diazepam
- Latterly, 9 administrations of oral chlorpromazine

The MWC were extremely concerned about the amount, frequency and route of administration of medication and about why the medication was being given (Mental Welfare Commission for Scotland, 2011e).

The Scottish Public Services Ombudsman has also upheld a number of complaints¹⁰⁸ relating to the use of unlawful injections of antipsychotic drugs such as haloperidol. Many recommendations have emerged from these cases including the need to: review the means by which medical and nursing staff are trained in the assessment and management of acute confusion, including use of appropriate

legislation and documentation; and undertaking peer review on the use of physical restraint and restraint by medicines.

Moving Forward

This section, alongside the other thematic sections and the overarching contextual chapter, has highlighted gaps, and inconsistencies, as well as good practices in the realisation of human rights in practice in Scotland. Addressing these shortfalls should be a concern of all bodies with responsibilities, including Government, local authorities, other public authorities and private providers of public services.

Identifying the shared framework of responsibilities and agreeing steps to address gaps requires an inclusive process of engagement. It should result in clarity on what action such bodies will take and when concrete improvements can be expected – it should result in specific, measurable, achievable, relevant and time-bound objectives. An independent system for monitoring progress should also be agreed. In short, the report supports the conclusion that Scotland needs a National Action Plan for Human Rights. To develop this SHRC will host human rights InterActions involving a broad range of public and private bodies, civil society and individuals. These InterActions will follow a FAIR approach:

Facts: What are the key gaps and the good practices in the realisation of human rights in Scotland?

Analysis of rights at stake: Which human rights are at stake? Is any restriction on the rights justified? Is the extent of realisation of the right reasonable?

Identify responsibilities: What changes are necessary? Who has responsibilities for helping to make the necessary changes?

Recall and review progress: Independent monitoring according to agreed indicators and periodic review of progress.

This process will allow for constructive dialogue between those with responsibilities and those whose rights are affected. Further, it will clarify the steps that are required to improve human rights practice in Scotland taking a pragmatic approach to understanding financial and other constraints. It is hoped that Scotland's National Action Plan for Human Rights will launch in summer 2013.

To inform the process of developing Scotland's National Action Plan for Human Rights responses are requested to the following questions:

1. Based on the evidence presented in this report, or your own experience, what do you consider to be the most urgent human rights issues which should be addressed in Scotland's National Action Plan for Human Rights?

2. What specific and achievable actions do you consider would best address the concerns you identify in terms of question 1?

Please use the form at the end of this section and send your responses to actionplan@scottishhumanrights.com or post it to us at Scottish Human Rights Commission, 4 Melville Street, Edinburgh, EH3 7NS

Table 1: Key Dates

Date	Action
May 2012	The UK Universal Periodic Review at the United Nations begins.
September 2012	The final report and recommendations of the UK's Universal Periodic Review is anticipated
October 2012	Publication of SHRC's Report and launch of a process of participation to shape Scotland's National Action Plan for Human Rights
December 2012	SHRC hosts a National InterAction to address the findings of the scoping exercise and facilitate negotiation of commitments to address them
Aiming for Spring 2013	A draft of Scotland's first National Action Plan for Human Rights is published for comment
Aiming for Summer 2013	Scotland's National Action Plan for Human Rights will be launched
June 2014	UK's progress on Universal Periodic Review recommendations is considered in a mid-point review. Progress on Scotland's National Action Plan for Human Rights to feed into this process.

PARTICIPATION FORM

SCOTLAND'S NATIONAL ACTION PLAN FOR HUMAN RIGHTS

Views are sought from all individuals and organisations who have experience or expertise which can help to shape Scotland's National Action Plan for Human Rights.

The Scottish Human Rights Commission will be collecting and analysing all responses receive before the **29 March 2013**. Early responses are encouraged.

Unless respondents request that their views remain confidential or anonymous all responses will appear online with the organisation or individual named as the respondent. Contact details for the respondent will not appear online.

- Please tick this box if you do not wish your response to appear online:
- Please tick this box if you are happy for your response to appear online but not your name or organisation's name to appear:
- Please tick this box if you would prefer we did not link to your website:

Name: _____

Organisation: (where appropriate) _____

Website: _____

Email address: _____

Contact telephone number: _____

This form can be returned by post to: Dr Alison Hosie, Scottish Human Rights Commission, 4 Melville Street, Edinburgh, EH3 7NS, or sent as an electronic or scanned document to actionplan@scottishhumanrights.com

You can also fill out this form online at www.scottishhumanrights.com/actionplan

1. Based on the evidence presented in the report *Getting it right? Human rights in Scotland*, or your own experience, what do you consider to be the most urgent human rights issues which should be addressed in Scotland's National Action Plan for Human Rights?

2. What specific and achievable actions do you consider would best address the concerns you identify in your response to question 1?

Thank you for sharing your experience or expertise and helping to shape Scotland's National Action Plan for Human Rights.

Contact point: Dr Alison Hosie / actionplan@scottishhumanrights.com / 0131 240 2989 / www.scottishhumanrights.com/actionplan / @scothumanrights

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with life limiting illness in Scotland: prospective longitudinal qualitative study.
British Medical Journal, 338, 1 - 11.

Appendix 1: Prioritisation criteria to select Phase 2 issues for further study

Occurrence: Number of Phase 1 sources commenting on a particular issue in relation to the Right being examined.

Devolved competence: Allows scoring according to whether an issue is reserved and wholly beyond the powers of devolved government, partly within the powers of devolved government, or fully within the powers of devolved government to address.

Gravity: Score reflects the nature of the rights at stake:

Category 1. Qualified & limited Rights, Economic, Social & Cultural Rights, the Right to an Effective Remedy, Non-discrimination in the Exercise of Rights

Category 2. The Right to Life, Retrospective Criminal Law and Absolute Rights (Right to be Free from Torture & Inhumane and Degrading Treatment and Prohibition of Slavery).

Imprint: Score reflects the extent to which the issues raised in a particular category would affect a large number of people

Vulnerability/ Marginalisation: Score reflects the extent to which the issues raised affect vulnerable or marginalised groups/communities.

Added value: Scores reflect whether the issue contributes to the human rights culture of Scotland without duplicating research work already being done by other bodies (or within the clear remit of other organisations)?

Opportunity: Scores reflect whether the issue creates/ensures the establishment of positive, supportive interaction and understanding between the SHRC and institutions or individuals where previously this did not exist?

1 Further details on the methods and methodology of this scoping project can be found in the main report which can be accessed at: <http://www.scottishhumanrights.com/actionplan>

² The data sources collated and analysed in the first phase included:

An annotated bibliography of published and “grey” social research. DRIVER, S., LAMB, M. & WILSON, C. 2010. Annotated Bibliography of Published and Grey Non-Legal Literature on Human Rights in Scotland since 2006. London: The Crucible Centre and Social Research Centre, ROEHAMPTON UNIVERSITY. See also Hosie & Lamb (2013 forthcoming) for further information on the methodology of this aspect of the research <http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=8685263>

Three legal literature reviews exploring specific Conventions/Acts in relation to the law in Scotland. (Convention against Torture, Inhumane and Degrading Treatment, International [CAT] SMITH, R., TAIT, L., BALES, K., MCCONNELL, L. & RABAN-WILLIAMS, R. 2010. Mapping the Law of Scotland in Relation to International Human Rights Treaties: CAT & CPT. Newcastle: Northumbria Law School, *ibid.*, International Convention of Economic, Social & Cultural Rights [ICESCR] FLANIGAN, D. 2011. Mapping the Law of Scotland in Relation to Economic, Social & Cultural Rights. Glasgow: Scottish Human Rights Commission, *ibid.* and Human Rights Act/ European Convention of Human Rights] NORMAND, A. & WEBSTER, E. 2010. Mapping the Law of Scotland in relation to International Human Rights Treaties – Civil and Political Rights. Glasgow: University of Strathclyde.

An analysis of all individual enquiries received by SHRC and all general intelligence on systemic human rights issues in Scotland collated by SHRC (2008-2010). Whilst only those inquiries received between 2008 and 2010 were analysed as part of Phase one of this scoping project, the mapping project continued to collate and review inquiries during 2011 as part of Phase two. All responses to SHRC’s 2009 national consultation. The original consultation document can be accessed at <http://www.scottishhumanrights.com/ourwork/publications/article/reportofthenationalconsultation>

Initial Scottish data from the development of a “Human Rights Measurement Framework”. The HRMF is a new tool for evaluating the human rights position of individuals and groups in England, Scotland and Wales. It was developed by the London School of Economics and Political Science, CASE and the British Institute for Human Rights within a partnership project of EHRC and SHRC. More information can be found here: <http://personal.lse.ac.uk/prechr/>

3 During this process SHRC also developed a Stakeholder Database of third Sector organisations involved to some degree in the promotion of human rights in Scotland. This database provides SHRC with a greater understanding of the range of groups and organisations which view part of their work to be promoting human rights in Scotland and provided a sampling framework for groups to approach to participate in the primary data collection of this scoping project. This database is available to the public [<http://maps.scottishhumanrights.com/>] For further information on this project see: CRAIG, G. 2011. Mapping human rights organisations in Scotland. Durham: University of Durham, School of Applied Social Sciences.

4 Not all of the many issues identified within this framework could, however, be explored further in Phase 2. Accordingly, a prioritisation criteria filter was applied (see Appendix 1) in order to determine which would be explored in the focus groups. Other issues related to health such as quality of care within healthcare settings are presented within the thematic section entitled Dignity and Care.

⁵⁵Since 1999 the way the United Kingdom is run has been transformed by devolution - a process designed to decentralise government. Devolution essentially means the transfer of powers from the UK parliament in London to the Scottish Parliament and the Scottish Executive (officially referred to as the Scottish Government since August 2007) in Edinburgh. The Scottish Parliament is a legislation-making body, passing bills in various areas of its many devolved responsibilities. The Scottish Parliament also has the power to raise or lower income tax (as changed by the Scotland Act 2012). Devolved areas of legislative competence to the Scottish Parliament include agriculture, forestry & fishing, education, environment, health, housing, justice, policing and courts, local government, fire service, economic development, some transport responsibilities and human rights. The UK government is responsible for national policy on other powers which have not been devolved - these are known as “reserved powers”. These include the constitution, defense and national security, foreign policy, energy, immigration and nationality, social security and some transport responsibilities. Many themes in this scoping project engage equality legislation in relation to combating discrimination. Equal opportunities is a reserved matter (under Schedule 5 of the Scotland Act 1998 (Reservation - L2)), however, the reservation incorporates an exception in so far as the

Scottish Government and the Scottish Parliament can impose certain duties which allows for scope for positive steps to be taken in relation to equality despite limitations on the powers available to the devolved administration.

6 Section 149 of the Act.

7 *“The public sector equality duty requires equality to be considered in all the functions of public authorities, including decision-making, in the design of internal and external policies and in the delivery of services, and for these issues to be kept under review. The public sector equality duty is set out in sections 149-157 and schedules 18 and 19 of the Equality Act. The general equality duty covers all public authorities named or described in Schedule 19 – Part 3 of the Equality Act 2010 together with those listed in the Equality Act 2010 (Specification of Public Authorities) (Scotland) Order 2010. The specific duties were created by secondary legislation in the Equality Act 2010 (Specific Duties) (Scotland) Regulations 2012. These specific duties came into force on 27 May 2012. Under the specific duties each listed authority is required to assess and review policies and practices i.e. impact assess”.* See

<http://www.equalityhumanrights.com/scotland/public-sector-equality-duty/non-statutory-guidance-for-scottish-public-authorities/> for further details.

8 With the exception of reserved matters in terms of Schedule 5 of the Scotland Act 1998. These include abortion, xenotransplantation, embryology, surrogacy and genetics, medicines, medical supplies and poisons, and welfare foods alongside regulation of the health professions (head G) and health and safety (head H).

9 The Chief Medical Officer for Scotland is the Scottish Government’s principal medical adviser and Head of the Scottish Medical Civil Service. The Scottish Government Health Directorate provides central management of the NHS with a Management Executive that oversees the work of the fourteen area NHS boards which in turn plan and deliver health services for people in their area and is responsible both for NHS Scotland and for the development and implementation of health and community care policy. The NHS in Scotland has around 132,000 staff, including more than 63,000 nurses, midwives and health visitors and over 8,500 doctors (www.show.scot.nhs.uk). Scotland’s eight special health boards are: NHS National Services Scotland which provides specialist services such as the blood transfusion service and surveillance of communicable diseases, the Scottish Ambulance Service, NHS 24 (24 hour telephone access to advice from clinical professionals), The State Hospital at Carstairs which provides care for around 100 patients requiring care in high security, NHS Health Scotland which promotes and encourages healthy lifestyles and NHS Healthcare Improvement Scotland which sets and monitors clinical standards, [NHS Education for Scotland](#)- the training organisation of NHS Scotland and [National Waiting Times Centre Board \(The Golden Jubilee National Hospital\)](#) -a dedicated elective facility in key specialties for patients throughout Scotland to assist in reducing waiting times.

¹⁰ According to recent NHS statistics, one in three people in Scotland will be diagnosed with cancer at some stage in their lives and the current figure of 27,000 annual diagnoses will continue to rise as Scotland’s population ages CHIEF MEDICAL OFFICER OF SCOTLAND 2010. Health in Scotland 2009: Time for Change. Edinburgh: Scottish Government, MONK, S., TANG, C. & WHITEHEAD, C. 2010. What does the literature tell us about the social and economic impact of housing? Report to the Scottish Government: Communities Analytical Services. Edinburgh: Cambridge Centre for Housing and Planning Research, University of Cambridge, ISD SCOTLAND. 2010. *Cancer Statistics* [Online]. Edinburgh: Scottish Government. Available: <http://www.isdscotland.org/Health-Topics/Cancer/Cancer-Statistics/All-Types-of-Cancer/#all-cancer-types> [Accessed 29th March 2012], BBC NEWS 2011b. Figures warn one in three Scots will get cancer. Glasgow: BBC News.

¹¹ In 2009 there were 1,282 Alcohol Related Deaths in Scotland NHS NATIONAL SERVICES SCOTLAND 2011. Alcohol Statistics Scotland 2011. Edinburgh: Information Services Division. Smoking is still the biggest cause of premature death in Scotland. There are numerous other serious health concerns facing Scotland including high rates of alcohol and drug-related deaths, suicide, violence, cardiovascular disease and strokes SCOTTISH GOVERNMENT 2007a. Better Health, Better Care: A discussion document. Edinburgh.

¹² ONS. 2010. *Interim Life Tables* [Online]. London: Office for National Statistics. Available: www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-61850 [Accessed 3 October 2011]. The “Glasgow Effect” is noted here with men and women in Edinburgh having 6.2 (83.1 vs 78.3) and 5.6 (77.5 vs 71.1) more years life expectancy than their counterparts in the City of Glasgow *ibid*.

¹³ Chief Medical Officer for Scotland, *Annual Report 2010*, Scottish Government.

¹⁴ *Ibid*.

¹⁵ Chief Medical Officer for Scotland, *Annual Report 2010*, Scottish Government.

¹⁶ *Ibid.*

¹⁷ *Powell v United Kingdom* (2000) 30 EHRR CD 362 and *Calvelli and Ciglio v. Italy* [2002] Grand Chamber, application no. 32967/96, 17 January 2002.

¹⁸ *Silih v Slovenia*, Grand Chamber, 9 April 2009, application no. 71463/01, para. 192.

¹⁹ *Ibid.*, para 196.

²⁰ *Savage (Respondent) v South Essex Partnership NHS Foundation Trust* [2010] EWHC 865. NB. This is an English case but the relevant element is its interpretation of Article 2, ECHR in the Human Rights Act 1998.

²¹ *Rabone and another (Appellants) v Pennine Care NHS Trust*, [2012] UKSC 2.

²² such as denial of food, water, sanitation See e.g. *KALASHNIKOV v. RUSSIA*, (*Application no. 47095/99*), JUDGMENT of 15 July 2002
CASE OF DOUGOZ v. GREECE, (Application no. 40907/98), JUDGMENT of 6 March 2001
CASE OF PEERS v. GREECE, (Application no. 28524/95), JUDGMENT of 19 April 2001
CASE OF PRICE v. THE UNITED KINGDOM, (Application no. 33394/96), JUDGMENT of 10 July 2001. Thus far this has generally been considered in detention settings, however it is important to recognise the broad definition of detention which the Council of Europe Committee for the Prevention of Torture uses to include places where people are *de facto* detained (including e.g. care homes with entry codes which they may not remember). This will certainly apply to secure wards and may also apply to others where older or vulnerable patients are held. Potential also e.g. infectious disease wards.

23 *CASE OF PRICE v. THE UNITED KINGDOM*

²⁴ *Case of Jehovah's Witnesses of Moscow and others v Russia*, (application no. 302/02), judgment of 10 June 2010, paras 135-6.

²⁵ Both Article 8 of the ECHR and the Convention on the Rights of Persons with Disabilities contains several protections of the right to participate in decisions. Regarding the ECHR see for example *Glass v UK*, (application no. 61827/00), judgment of 9 March 2004.

²⁶ Information is referenced in the Act in section 3(2) (d) as a commitment that "health care is to... (d) have regard to the importance of providing such information and support as is necessary to enable the patient to participate..." and taking all reasonable steps to ensure that "information and support is in a form that is appropriate to the patient's needs"

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

28 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".

29 Article 9(2)(f)

³⁰ *Ibid.*, para 4.

³¹ <http://www.healthscotland.com/equalities/eqia/health-inequalities.aspx>

32 A total of 766, around 100 less than the total applications for legal advice and assistance for medical negligence in the same period, as set out above

³³ <http://www.scotland.gov.uk/News/Releases/2012/08/inpatientsurvey28082012>

34 As set out in the Smoking, Health and Social Care (Scotland) Act 2005.

35 In reaching these conclusions, the report considers the existing mechanisms for pursuing compensation by delict. Information was obtained from the Scottish Legal Aid Board in relation to applications which demonstrated that in 2008-09 710 applications for Legal Advice and Assistance were made to investigate whether or not evidence exists to support a claim. There were 862 applications for an increase in authorised expenditure (some of which related to applications made in previous years) and of these 770 were granted for the full amount and 33 for a lesser amount. During the same period 65 of the LAA applications resulted in a claim upon the fund. The report suggested that a settlement is more likely where a specialist medical negligence firm of solicitors were instructed.

36 The report also identified one of the key characteristics of the Welsh redress scheme as being that consideration should be given to the combination of different investigation roles, risk management, complaints and claims into a "joined-up" process strongly linked to learning lessons and improving safety.

³⁷ Scottish Government, *Consultation on Recommendations for No Fault Compensation in Scotland for Injuries Resulting from Clinical Treatment*, 19 August 2012, <http://www.scotland.gov.uk/Publications/2012/08/4456>

38 Older people (over 65) were more likely to answer 'don't know' to the first statement (12 per cent, compared with 1 per cent of those aged 45-54).

³⁹ See for example <http://www.scotland.gov.uk/Publications/2012/04/6273/6>

⁴⁰ Davies highlights that different professional groups can have very different views on what constitutes quality or a good outcome of health care. Powell et al note that healthcare users are equally problematic in their varied definitions of quality in health care, whether as patients or relatives, carers or taxpayers. See: POWELL, A. E., RUSHMER, R. K. & DAVIES, H. T. O. 2008. A systematic narrative review of quality improvement models in health care (in support of NHS Quality Improvement Scotland). Dundee, St. Andrews: Social Dimensions of Health Institute at The Universities of Dundee and St Andrews. DAVIES, H. 2005. Measuring and reporting the quality of health care: issues and evidence from the international research literature. Edinburgh: NHS Quality Improvement Scotland.

⁴¹ In England and Wales the detail of NHS reform is being established through the Health and Social Care Bill (Department of Health 2012). In Northern Ireland a review of health and social care has identified twelve major principles for change (Department of Health, Social Services and Public Safety 2011).

⁴² <http://www.scottishhumanrights.com/careaboutrights>

⁴³ This independent evaluation study was carried out by Ekosgen, the social research organisation supported by The University of Bedfordshire and Queen Margaret University. The full report can be accessed here- <http://www.scottishhumanrights.com/news/latestnews/article/careevaluationnews>. The evaluation surveys were carried out in two phases. The first, to establish baseline before participants complete Care About Rights training. Analysis in the Phase 2 report is based on responses of 799 participants (as at June 2011). A follow up survey of training participants was carried out in July 2011 asking respondents about the contribution of Care About Rights to their knowledge, understanding and practice. The online follow up survey generated 82 responses (as at July 2011).

⁴⁴ <http://www.thecourier.co.uk/News/Dundee/article/14454c2/consultant-claims-poor-standard-of-care-at-ninewells-was-not-an-isolated-incident.html>

⁴⁵ <http://www.scotland.gov.uk/News/Releases/2012/07/HAI-figures04072012>

46 Among the initiatives which have been introduced to tackle healthcare associated infections are:

- independent, unannounced inspections from the Healthcare Environment Inspectorate
- public reporting of hospital by hospital performance on key indicators such as MRSA and Clostridium difficile, hand hygiene and cleaning with a single website to give access to national and local information
- tripling funding to tackle Healthcare Associated Infections - to over £50 million over three years - to support a new and more comprehensive HAI Delivery Plan
- providing hundreds of additional cleaning staff across NHS Scotland funded by an extra £5 million a year
- introducing a new staff uniform and dress code
- zero tolerance approach to non-compliance with hand hygiene policies across the NHS.

See <http://www.scotland.gov.uk/News/Releases/2012/07/HAI-figures04072012>

⁴⁷ <http://www.scotland.gov.uk/News/Releases/2012/07/HAI-figures04072012>

⁴⁸ For an overview of policy responses and initiative to tackle delayed discharge in Scotland see: HUBBARD, G., HUBY, G., WYKE, S. & THEMESL-HUBER, M. 2004. Research Review on Tackling Delayed Discharge. Edinburgh: Scottish Executive.

⁴⁹ <http://www.isdscotlandarchive.scot.nhs.uk/isd/1323.html>

⁵⁰ Assessments and treatment places were also to be reduced to specified levels.

⁵¹ See thematic section on safety & security which explores other aspects of care of older people in relation to abuse.

⁵² Witnesses told the Committee of older people: Having no choice on discharge; Being put into placements that do not meet their needs; Having no chance to come to terms with a momentous life changing event (i.e. the possible move for the first time from independent living to residential care); Being discharged to care homes instead of receiving rehabilitation or returning to their homes with community support; Being discharged to care that is miles away from friends and family and Being discharged without adequate care in place or when they are still unwell, JOINT COMMITTEE ON HUMAN RIGHTS 2007. The Human Rights of Older People in Healthcare: 18th Report of Session 2006-7. London: UK Parliament.

⁵³ Pretty v UK, (application no. 2346/02), judgment 29 April 2002, para 62.

⁵⁴ Article 8(2), ECHR.

⁵⁵ Article 5, UN CRC.

56 For example the prevalence of limiting long-term conditions in women was higher in Scotland (28 per cent) than in England (25 per cent). The prevalence of any cardio vascular condition or diabetes among women in Scotland (15.5 per cent) was higher than the comparable rates for women in England (13.0 per cent) or Northern Ireland (12.8 per cent). Ischemic Heart Disease was also slightly higher among women in Scotland (6.2 per cent) than in England (4.0 per cent), as was the rate of IHD or stroke combined. However incidence of possible psychiatric disorder was broadly similar throughout the UK but having a GHQ12 score of zero (indicating psychological wellbeing) was significantly more likely in Scotland (64 per cent of men and 58 per cent of women) than in Northern Ireland (60 per cent of men and 51 per cent of women) BROMLEY, C. & SHELTON, S. 2010. The Scottish Health Survey, UK comparisons 2010. Edinburgh: Scottish Government.

57 This has involved employing of a number of different strategies including: media campaigns; tobacco education in schools; smoking cessation services; and Scotland's first National Action Plan on Tobacco: A breath of Fresh Air SCOTTISH EXECUTIVE 2004. A Breath of Fresh Air For Scotland – Improving Scotland's Health: The Challenge – Tobacco Control Action Plan. Edinburgh Scottish Executive.

58 Smoking, Health and Social Care (Scotland) Act 2005. The Act created offences for a person in charge of no-smoking premises to knowingly permit others to smoke there, and for a person to smoke in no-smoking premises. 58 No-smoking premises are now extensive, as prescribed by the Prohibition of Smoking in Certain Premises (Scotland) Regulations 2006.

⁵⁹ In 2007 the Scottish Government brought in legislation to amend the Children and Young Persons (Scotland) Act 1937 so that it became unlawful to sell tobacco to under eighteens.

⁶⁰ [The Tobacco and Primary Medical Services \(Scotland\) Act 2010](#).

61 Among young people (aged 12-15), regular smoking among 15 year olds had decreased from 30 per cent in 1996 to 19 per cent in 2004 with the improvement rate among boys (14 per cent) much greater than among girls (24 per cent). Among women who smoke during pregnancy, rates have reduced from 29 per cent in 2003 to 22.7 per cent by 2005 (35.8 per cent in the most deprived areas in 2003). Among adults (aged 16-64), smoking has fallen to 26 per cent by 2005 among both men and women (42 per cent in the most deprived areas) WIMBUSH, E., YOUNG, I. & ROBERTSON, G. 2007. Developing effective policy and practice for health promotion in Scotland. *Promotion & Education*, 14, 228-232.

62 With 40 per cent smoking and almost 30 per cent smoking heavily.

63 Warner argues that there is evidence to suggest that the effects of sudden and enforced tobacco withdrawal might be physiologically harmful for patients who smoke, particularly in terms of the possible effects on psychotic symptoms and/or the absorption of antipsychotic medication.

64 This included: three hospital wide consultations and different stages of the journey; a phasing out of tobacco products available at the hospital; the offer of Patient Nicotine Replacement Therapy for all 73 patients that smoked; supporting the 'Cut Down To Quit' (CDTQ) method; the removal of visual smoking cues (e.g. ashtrays and lighters); the provision of a smoking resource pack (provided to all patients in a variety of formats (including 'easy read' for patients with a learning disability) essential information on how to stop smoking, healthy eating, weight management, medication and other useful materials); engagement of smoking Cessation staff with every patient that smoked; an easy-read leaflet for patients on clozapine medication to support their understanding of the interactions smoking had on this medication; no smoking days to raise awareness; and a phased approach including a partial smoke-free ban (allowing smoking to continue within the grounds of the hospital) building up to the comprehensive smoke-free ban

65 The Scottish Government's plans to introduce minimum pricing for alcohol sales in the Alcohol Bill were defeated in September 2010 on the basis that a blanket policy would also affect responsible drinkers BARNES, E. 2011. SNP eyes tougher law on alcohol pricing. *The Scotsman*, 4th September 2011. The SNP victory in May 2011 provided a majority government, which has allowed the issue to be reintroduced as part of the Government's new legislative programme and the issue of minimum pricing has been raised once again.

⁶⁶ See <http://www.healthscotland.com/topics/health/alcohol/MinimumPricing.aspx>

⁶⁷ <http://www.scotch-whisky.org.uk/what-we-do/policy,-parliament-promotion/minimum-pricing/>

⁶⁸ Evaluating *Scottish Diet Action Plan (SDAP)* from 1996 SCOTTISH OFFICE. 1996. Eating for Health: a Diet Action Plan for Scotland. Available:

<http://www.scotland.gov.uk/Topics/Health/health/Health/ActionPlan#a2> [Accessed 29th March 2012].

WIMBUSH, E., YOUNG, I. & ROBERTSON, G. 2007. Developing effective policy and practice for health promotion in Scotland. *Promotion & Education*, 14, 228-232. found that "The direction, intensity and duration of action required to achieve the level of change defined by the dietary targets was

underestimated; resources and initiatives were allocated too thinly across a broad range of actions rather than focusing on achieving population level impact within a few priority areas. The broad range of actions recommended were not transparently or consistently linked to the narrow range of food and nutrient targets identified”.

69 See <http://www.scotland.gov.uk/News/Releases/2002/05/1674> for further details.

70 See www.scotland.gov.uk for further details.

71 This survey had a response rate of 81 per cent. However, it is worth acknowledging the limitations of this research, in that only mothers were surveyed. This portrays an assumption that the responsibility for encouraging a good diet lies with the mother alone and that a father's input has no impact on their child's dietary habits.

72 This was to be done by stopping visitors from bringing in food parcels, no longer allowing patients to order food from outside sources, with the exception of one takeaway per month and adjusting the pricing in the hospital shop to make purchases of low fat and low sugar foodstuffs and drinks a more financially attractive option than the full fat, high sugar versions.

73 Clifford Lyons v The Board of the State Hospital, [2011] CSOH 21. In her judgment Lady Dorrian stated that the right of a person to choose what they eat or drink is a matter in respect of which the right to private and family life (Article 8, ECHR) is engaged but that the promotion of the health of patients by reference to dietary needs, especially patients likely to be in The State Hospital for a long period, may be a sufficiently important objective to justify interference with that right. The possibility of an increase in obesity/diabetes in the context of a prison population or that of a secure hospital gives rise to operational considerations for the institution as a whole and the responsibility of the respondent for the care of those within the institution. However she based her decision on failings in the consultation and involvement process leading to the new food and drink policy. She found that the consultation did not enable patients to effectively consider the option eventually selected, of an outright ban.

74 Everyone lawfully within the UK (i.e. including those on appropriate visas or refugees or asylum seekers) has a right to be registered with a GP. NHS registration is based primarily on residence: <http://www.psd.scot.nhs.uk/doctors/registration-with-a-practice.html> There are approximately 16.7 million GP consultations and 7.5 million practice nurse consultations in Scotland every year. Some services provided by other practitioners such as dentists and opticians are chargeable although check-ups were made free in 2006 ROBSON, K. 2011. The National Health Service in Scotland: SPICe briefing. Edinburgh: Scottish Parliament Information Centre. Nicola Sturgeon has described prescription charges as “a tax on ill health that Scotland's poorest families can ill afford” SCOTTISH GOVERNMENT 2010c. Prescription charge axe: press release. Edinburgh: Scottish Government. and prescription charges were abolished for all as of April 2011 [National Health Services (free prescriptions and charges for drugs and appliances) (Scotland) Regulations 2011]. Asylum seekers, refugees and failed asylum seekers are still entitled to health care in Scotland and any course of treatment commenced will continue until completion or until the person leaves the country NHS SCOTLAND 2011. Health Care for asylum seekers and refugees in Scotland. Edinburgh: Health Rights Information Scotland..

⁷⁵ Despite improvements across a range of inequality indicators in comparison with the rest of the UK over the last decade PALMER, G. 2010. The impact of devolution: indicators of poverty and social exclusion. Joseph Rowntree Foundation. Moreover for communities such as Scottish Gypsy/ Traveller, it has been estimated that life expectancy is on average ten years lower than the national average for Traveller men EHRC 2009. Gypsies and Travellers: Simple solutions for living together London: Equality and Human Rights Commission. and can be as low as 55 MECOPP 2012. Hidden Carers, Unheard Voices: Informal caring within the Gypsy/ Traveller community in Scotland. Edinburgh: Minority Ethnic Carers of People Project, LAMBIE, J. 2010. Report of Keep Well Gypsy and Traveller Outreach Service. Edinburgh: NHS Lothian. Gypsy and Traveller mothers are also 20 times more likely than the rest of the population to have experienced the death of a child EHRC 2009. Gypsies and Travellers: Simple solutions for living together London: Equality and Human Rights Commission.

76 These conclusions arose from a study of 92 relevant interviews investigating delivery of responsive and culturally appropriate care in light of barriers such as discrimination at an individual and institutional level and the high risk of inadequate care provision to the most vulnerable with poor English language skills and no family advocate.

77 11 – 20 per cent in Asian Indians, 15 per cent in Afro-Caribbeans and 1-5 per cent in white Caucasians. Type 2 diabetes is four times more common in British South Asians than within the indigenous white population (Baradaran et al. 2006).

78 Further issues of concern raised by this research include a lack of available statistics on a range of issues, namely: only 55 per cent of Local Health Care Cooperatives have access to interpreters; 55 per cent do not record cultural/religious requirements; 24 per cent have no culturally appropriate dietetic counselling; and 33 per cent have no appropriate health information materials available (Baradaran et al. 2006).

79 National Health Service Quality Improvement Scotland is now part of Healthcare Improvement Scotland: http://www.healthcareimprovementscotland.org/welcome_to_healthcare_improvem.aspx

80 Following extensive networking with organizations supporting people with intellectual disabilities, only four people came forward to talk to the researchers.

81 Women Thinking Trans Issues, A Report on Findings of Participatory Action Research on the Inequality of Access to NHS Services by Trans Women, Engender, 2011.

⁸² These Health Boards are now encompassed within NHS Greater Glasgow & Clyde and NHS Highland.

83 HUG is the Highland User Group, which is a collective advocacy group, which represents the interests of users of mental health services across the Highlands. Their key aims include: improve the way people with mental health problems are treated and challenge stigma and discrimination through their Communication Project, of whom the current target focus are school children.

⁸⁴ <http://www.healthscotland.com/equalities/eqia/health-inequalities.aspx>

⁸⁵ SAMH RESPONSE TO CALL FOR COMMENTS ON DRAFT UN REPORT ON DISABILITY, 2011; citing Mental Welfare Commission for Scotland, Our Annual Report 2007-2008.

⁸⁶ SCOTTISH GOVERNMENT 2012. Mental Health Strategy 2012-2015. Edinburgh: Scottish Government.p28: “No other country in the world has set such a wide ranging and comprehensive target within a publicly funded healthcare system.”

⁸⁷ For more information on CBT see:

http://www.mind.org.uk/help/medical_and_alternative_care/making_sense_of_cognitive_behaviour_therapy

⁸⁸ <http://www.voxscotland.org.uk/news/psychological-therapies-heat-access-target-newsletter>

⁸⁹ *Aerts v Belgium* (1998) 29 EHRR 50 para 46. “In principle, the “detention” of a person as a mental health patient will only be “lawful” for the purposes of sub-paragraph (e) of paragraph 1 if effected in a hospital, clinic or other appropriate institution”.

⁹⁰ <http://www.samh.org.uk/our-work/policy-campaigns/mental-health-law>

⁹¹ Limited Review of the Mental Health (Care and Treatment) (Scotland) Act 2003: report, as presented

to Scottish Ministers March 2009

⁹² The MHCTSA introduced advance statements as a means of improve patient participation, in accordance with the Millan principles, which form the backbone of the Act. According to the independent review of the Act completed in 2009, *Limited Review of the Mental Health (Care and Treatment) (Scotland) Act*

2003: report, as presented to Scottish Ministers March 2009, pp 8-9.

⁹³ <http://www.scotland.gov.uk/Topics/Health/health/mental-health/mhlaw/mhareview>

⁹⁴ See www.scottishhumanrights.com/careaboutrights

⁹⁵ <http://www.scotland.gov.uk/Publications/2010/09/10151751/17>

⁹⁶ www.dementiarights.org

97 Where such interventions do not reach the threshold of inhuman or degrading treatment or punishment, they should be considered as interferences with Article 8 of the ECHR and HRA and must therefore be considered using the three stage tests of legality, necessity and proportionality. However, in certain circumstances they may amount to ill-treatment prohibited under Article 3 ECHR and HRA, which can never be justified. Consideration of human rights must then take into account all relevant circumstances in the particular case. See e.g. the English case of *R (Wilkinson) v Broadmoor Special Hospital Authority* [2002] 1 WLR 419.

98 *Herzcegalvy v. Austria*, Judgment of 24 September 1993, 244 Eur. Ct. H.R. (ser. A), ¶ 82, 15 E.H.R.R. 437

(1993). The Court observed that, “[t]he position of inferiority and powerlessness which is typical of patients confined in psychiatric hospitals calls for increased vigilance in reviewing whether the Convention has been complied with.”

99 *Price v. United Kingdom*, Application No. 3394/96, 10 July 2001

100 The UN Human Rights Committee specifically mentions “prolonged solitary confinement” as a practice that may amount to a violation of Article 7 of the ICCPR, General Comment 20, 1992, para 6.

¹⁰¹ In response to the Scottish Parliament's Health and Sport Committee Inquiry into the Regulation of Social Care for Older people the Scottish Government committed in January 2012 that "*The Care Inspectorate will support the Scottish Government in reviewing and updating the National Care Standards*"

http://www.scottish.parliament.uk/S4_HealthandSportCommittee/Inquiries/20120120_Scot_Govt_Care_Inquiry_resp.pdf

¹⁰² Limited Review of the Mental Health (Care and Treatment) (Scotland) Act 2003: report, as presented to Scottish Ministers March 2009, p 74, "*we recommend that there is a review of this important and complex area of care and treatment before considering whether any legislative changes are required. Such a review could also address the very limited guidance available for Scottish mental health and learning disability hospitals on the use of force in hospital settings.*"

¹⁰³ In 2000, a critical report by the Mental Welfare Commission into the treatment and care of a particular patient, allied with The State Hospital Board's drive to build on the changing culture throughout the 90s, prompted The State Hospital to conduct a fundamental examination of its human rights practice. A decision was taken to use the Human Rights Act as a vehicle for cultural change, to put the human rights of everyone – staff, patients, carers and family members – at the heart of The State Hospital's services SHRC 2009. Human Rights in a Health Care Setting: Making it Work for Everyone. An evaluation of a human rights-based approach at The State Hospital. Glasgow: SHRC..

¹⁰⁴ Ibid, pp63-66.

¹⁰⁵ Under these circumstances certain treatment such as neurosurgery and electroconvulsive therapy cannot be provided but drug treatment for more than two months, medication to reduce sex drive and artificial nutrition can be provided with the written opinion of a Designated Medical Practitioner and medication within the first two months can be given without consent where the Responsible Medical Officer provides written reasons as to why it is in the patient's best interests that such treatment proceeds.

¹⁰⁶ Medication being used as a method of restraint is described by the Mental Welfare Commission (2006) as the use of tranquilising or sedating drugs for purely symptomatic treatment of restlessness or other behaviour. Drug treatments for medical or psychiatric conditions which underlie the disturbance are not included.

¹⁰⁷ This report details what was found on visits to 30 care homes and to individual people with dementia who lived in them.

¹⁰⁸ For example see: http://www.spsso.org.uk/webfm_send/2822;
<http://www.spsso.org.uk/investigation-reports/2010/september/grampian-nhs-board>;
http://www.spsso.org.uk/webfm_send/2663;http://www.spsso.org.uk/webfm_send/2472;
http://www.spsso.org.uk/webfm_send/3449