



HUMAN
RIGHTS
INQUIRY

Emergency Health Care

Summary Report



NORTHERN
IRELAND
HUMAN
RIGHTS
COMMISSION



HUMAN
RIGHTS
INQUIRY

Emergency Health Care

SUMMARY REPORT

Contents

| | Page |
|---|-------------|
| 1. Overview | 3 |
| What is a human rights inquiry? | 3 |
| Why investigate emergency healthcare? | 3 |
| Public participation | 3 |
| How was the Inquiry conducted? | 3 |
| 2. Human rights framework | 6 |
| International, regional and non-binding instruments with relevance to emergency healthcare | 6 |
| The right to health | 7 |
| 3. Quality, Accessibility and Governance | 10 |
| Quality | 10 |
| Richard’s story: An undignified environment | 10 |
| Accessibility | 11 |
| Tony’s story: The impact of a lack of knowledge and compassion shown to a patient with cerebral palsy | 11 |
| Governance | 12 |
| Clare’s story: “Doubt [for] the rest of my life” | 13 |
| 4. Findings | 14 |
| Respect and protection of the right to human dignity | 18 |
| Access to information in terms that the patient can understand is integral to the right to health and to free and informed consent | 19 |
| A sufficient quantity of health facilities, goods and services is essential to ensure timely health care as required by human rights laws and standards | 19 |
| Human rights standards recognise that a good quality health system requires a minimum number of health professionals | 20 |
| Equal treatment and non-discrimination | 20 |
| Meeting international human rights governance standards | 21 |
| Meeting human rights obligations to promote an open culture | 21 |
| 5. Recommendations | 22 |

Overview

The Northern Ireland Human Rights Commission (NIHRC) launched the Human Rights Inquiry into Emergency Health Care on 3 June 2014. We investigated the extent to which the Northern Ireland Executive and other public authorities respect, protect and fulfil the human rights of those seeking emergency care.

What is a human rights inquiry?

An Inquiry is one of the most effective strategies available to National Human Rights Institutions for investigating and drawing attention to pressing human rights issues.

Why investigate emergency healthcare?

With over 700,000 total attendances at Emergency Departments (EDs) each year, almost everyone in Northern Ireland will have visited or known someone who has needed to use accident and emergency services. Having completed a scoping exercise in March 2014, taking into account public concern, as well as the ongoing reviews of the health and social care system, the Commission concluded that a human rights examination of emergency healthcare was necessary.

Public participation

The Inquiry was wide-ranging taking evidence from ministers, the Department of Health, Social Services and Public Safety (DHSSPS), the Health and Social Care Board, health and social care trust managers, the regulator, clinicians and trade unions, key voluntary organisations dealing with complaints and providing advice alongside patients and families who are at the receiving end of the service. We wanted to hear positive stories as well as negative in order to establish what was working well alongside what needed to improve.

The Inquiry relied on the evidence given to us by the public. We are immensely indebted to everyone who participated in the Inquiry. The evidence at the public hearings can be viewed on the Commission's website www.nihrc.org

How was the Inquiry conducted?

The Inquiry was launched on 3 June 2014. It was the first time anywhere in the world that emergency health care had been the subject of a human rights inquiry. Over 900 posters were distributed across Northern Ireland to public and community spaces such as supermarkets, bus and train stations, town centre notice boards, libraries, leisure centres, community centres and EDs.

Electronic posters and publicity material was distributed to over 600 contacts in the community and voluntary sector, education and training providers, trade unions, health centres and elected representatives. A leaflet distribution exercise was undertaken in ED car parks and extensive use was made of the regional and local print media with advertisements placed in both. Opportunities were also taken to promote the Inquiry on regional and local radio and representatives of the NIHRC took every opportunity to address community sectoral meetings.

A Freephone telephone number was established from 3 June 2014 to 31 July 2014 and arrangements were made to take evidence through a Freepost address and online. A discussion pack for community groups was developed to encourage group submissions through community facilitators. 185 submissions were made through the Freephone, written and online arrangements alongside six contributions from focus groups.

The Inquiry undertook a review of literature, relevant human rights standards, case law, legislation and policy. It also analysed statistical and qualitative material on emergency care; and information received from the DHSSPS, statutory bodies, agencies and community and professional groups. An analysis of recent expenditure on EDs was also commissioned in order to assess the trends in financing care in hospital EDs.

The NIHRC also undertook guided visits of observation to EDs to assist understanding of how departments operated and the challenges they face. These were selected randomly. The following guided visits of observation took place:

| | |
|-------------------------------|---|
| Tuesday 1 July 2014 | Royal Victoria Hospital, Belfast |
| Friday 4 July 2014 | Causeway Hospital, Coleraine |
| Monday 7 July 2014 | Ulster Hospital, Dundonald |
| Saturday 19 July 2014 | Altnagelvin Hospital, Derry/Londonderry |
| Wednesday 30 July 2014 | Craigavon Area Hospital, Portadown |
| Monday 4 August 2014 | Lagan Valley Hospital, Lisburn |
| Friday 8 August 2014 | Bangor Minor Injuries Unit |

All of the visits took place during the day except to Causeway and Altnagelvin hospitals which took place in the evening.

During the guided visits the NIHRC was taken through the “patient journey” from presenting at EDs through to discharge. The NIHRC had physical access to all areas of each of the EDs and also had the opportunity to speak with a number of nursing and medical staff.

A panel was set up to listen to evidence presented at public hearings. This was chaired by the Chief Commissioner Les Allamby alongside Marion Reynolds, a Human Rights Commissioner and former social services inspector and Professor Paul Hunt, a former

UN Special Rapporteur on the Right to Health and professor at the School of Law at the University of Essex and former professor of Waikato University in New Zealand.

Eleven public hearings were held from 4 September 2014 to December 2014. The opening and closing hearings and a further hearing were held in Belfast. The opening hearing commenced with evidence from the then Minister for Health, Social Services and Public Safety Edwin Poots MLA and the closing hearing with evidence from his successor Jim Wells MLA. Other public hearings were held in Armagh, Bangor, Ballymena, Coleraine, Downpatrick, Derry/Londonderry, Newry and Omagh.

The Inquiry heard from 139 witnesses: of these were in public and three individuals gave evidence in private as they did not want to discuss their personal experiences in a public hearing. The public hearings were recorded and are available on the NIHRC's website www.nihrc.org

The Inquiry also met Sir Liam Donaldson and his team who were commissioned by the DHSSPS to review governance and accountability arrangements during a period which overlapped with the Inquiry.

Those who wished to submit evidence confidentially were enabled to do so. This strengthened the willingness to engage in the call for evidence and in the Inquiry generally. Except for those witnesses who agreed to do so in open forum at public hearing, Inquiry participants have not been named in this report.

Human rights framework

The principal sources of human rights laws are international treaties. Treaties are written agreements to which the participating States are legally bound. Typically, the implementation of a human rights treaty is overseen by a Committee. The International Covenant on Economic Social and Cultural Rights (ICESCR), for example, is monitored by the United Nations (UN) Committee on Economic, Social and Cultural Rights.

In addition to the treaties and their respective Committees, the Human Rights Council of the United Nations can appoint special rapporteurs who are independent experts appointed to examine particular human rights or themes. There is a Special Rapporteur on the right to highest attainable standard of physical and mental health. Within Europe, both the Council of Europe (CoE) and the European Union (EU) have addressed the issue of health. The most relevant European treaties are the European Convention on Human Rights (ECHR) and the Charter of Fundamental Rights of the European Union.

Through the Human Rights Act 1998 (HRA), a majority of the rights and freedoms contained in the ECHR have been given domestic effect. This is the only human rights instrument incorporated directly into UK law.

In addition to the international treaties there exist a number of instruments that are collectively referred to as 'soft law'. These documents are not legally binding but they are of strong persuasive value, especially when issued by the treaty monitoring bodies. They assist with interpreting the treaty obligations, and they often serve as precursors to more binding legal obligations.

The human rights treaties and soft law standards that speak most directly to the topic of emergency health care are listed in the table below.

International, regional and non-binding instruments with relevance to emergency healthcare

| International |
|--|
| United Nations (UN) International Covenant on Economic, Social and Cultural Rights (ICESCR) [UK ratification 1976] |
| UN International Covenant on Civil and Political Rights (ICCPR) [UK ratification 1976] |
| UN International Convention on the Elimination of All Forms of Racial Discrimination (CERD) [UK ratification 1969] |
| UN Convention on the Elimination of Discrimination Against Women (CEDAW) [UK ratification 1986] |
| UN Convention on the Rights of the Child (CRC) [UK ratification 1991] |
| UN Convention on the Rights of Persons with Disabilities (UNCRPD) [UK ratification 2009] |

| Regional |
|--|
| Council of Europe (CoE), European Convention on Human Rights (ECHR) [UK ratification 1951] |
| Charter of Fundamental Rights of the European Union [UK ratification 2000] |
| EU Directive 2000/43/EC implementing the principle of equal treatment between persons irrespective of racial or ethnic origin |
| Non-binding International instruments |
| Universal Declaration on Human Rights (UDHR), 1948 |
| Vienna Declaration and Programme of Action, 1993 |
| Vienna International Plan of Action on Ageing, 1983 |
| UN Declaration on the right to development, 1986 |
| UN Principles for Older Persons, 1991 |
| UN Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care, 1991 |
| UN Human Rights Council Resolution 19/20 'the role of good governance in the promotion and protection of human rights', 2012 |
| CoE, Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine (Convention on Human Rights and Biomedicine) |
| WHO Declaration of Alma-Ata, 1978 |
| Non-binding Regional instruments |
| CoE, Committee of Ministers Recommendation No. R (80) 4 concerning the patient as an active participant in his own treatment, 1980 |
| CoE, Committee of Ministers Recommendation R (97) 17 on the development and implementation of quality improvement systems (QIS) in health care, 1997 |
| CoE, Committee of Ministers Recommendation R (99) 21 on the criteria for the management of waiting lists and waiting times in health care, 1999 |
| CoE, Committee of Ministers Recommendation R (2000) 5 on the development of structures for citizen and patient participation in the decision-making process affecting health care, 2000 |
| CoE, Committee of Ministers Recommendation Rec (2001) 12 on the adaptation of health care services to the demand for health care and health care services of people in marginal situations, 2001 |
| CoE, Committee of Ministers Recommendation (2004) 10 concerning the protection of the human rights and dignity of persons with mental disorder, 2004 |
| CoE, Committee of Ministers Recommendation Rec (2006) 7 on management of patient safety and prevention of adverse events in health care, 2006 |
| CoE, Committee of Ministers Recommendation Rec (2006) 10 on better access to health care for Roma and Travellers in Europe, 2006 |
| CoE, Committee of Ministers Recommendation CM/Rec (2011) 13 on mobility, migration and access to health care, 2011 |
| CoE, Committee of Ministers Recommendation CM/Rec (2012) 8 on the implementation of good governance principles in health systems, 2012 |
| CoE, Parliamentary Assembly Recommendation 1418 (1999) 'Protection of the human rights and dignity of the terminally ill and the dying' |
| ECRI, General Policy Recommendation 13: on combating anti-gypsyism and discrimination against Roma, 2011 |
| WHO, Declaration on the Promotion of Patients' Rights in Europe, 1994 |

The right to health

The right to the highest attainable standard of health is to be realised progressively over time and the State must use the maximum available resources to fulfil the right. The UN Committee on Economic, Social and Cultural Rights has made clear that the concept of progressive realisation "should not be misinterpreted as depriving the obligation

of all meaningful content” but imposes an obligation on States to “move as expeditiously and effectively as possible towards that goal”. Any deliberately retrogressive measures taken by the State and concerning the enjoyment of the right to health must be justified by reference to the totality of rights provided for in the ICESCR and in the context of the maximum available resources.

Progressive realisation towards the full enjoyment of the right to health also exists alongside a number of minimum core obligations. These latter obligations refer to minimum essential levels of the right to health that must be ensured and include for example, the adoption and implementation of a national public health strategy and plan of action, devised on the basis of a participatory and transparent process; appropriate training for health personnel, including education on health and human rights; and monitoring of the extent to which the right is realised.

A further minimum core obligation is the duty to ensure that health facilities, goods and services are accessible on a non-discriminatory basis, especially for vulnerable or marginalised groups. The obligation on States to guarantee the enjoyment of the ICESCR rights without discrimination is also commonly referred to as an immediate obligation.

The UN Committee on Economic, Social and Cultural Rights has stated that “even in times of severe resource constraints, the vulnerable members of society must be protected by the adoption of relatively low-cost targeted programmes.” The Council of Europe Commissioner for Human Rights has also outlined that, “[e]conomic policy is not exempt from the duty of member states to implement human rights norms and procedural principles. As embodied in international human rights law, civil, political, economic, social and cultural rights are not expendable in times of economic hardship but are essential to a sustained and inclusive recovery.”

In practice, the right to the highest attainable standard of health is not an absolute right to be healthy. Instead, it is “an inclusive right extending not only to timely and appropriate health care but, also to the underlying determinants of health” such as adequate food and water.

The UN Committee on Economic, Social and Cultural Rights has stated that health facilities, goods and services should be available, accessible, adequate and of good quality. For emergency care this means sufficient quantity of properly trained skilled medical and other staff with care being accessible to all without discrimination, sensitive to cultural, life cycle and gender requirements.

The CESCR has also recognised the importance of people's involvement and participation in their own health-related decision-making and also wider planning of policies and services. This includes those groups who face barriers to effectively engage in consultation processes.

Quality, Accessibility and Governance

The full Inquiry report, www.nihrc.org, examines many of the human rights laws and standards relevant to the provision of ED care in three chapters dealing with quality, accessibility and governance. The Chapters assess in detail the arrangements put in place by the DHSSPS, the HSC Board and the HSC trusts to deliver emergency health care, including issues such as gathering and providing feedback on services, ensuring accountability and redress. Case studies throughout the report illustrate the issues identified during the course of the Inquiry, examples of which are set out below.

Quality

The right to the highest attainable standard of health includes a duty to provide facilities, goods and services that are of good quality. It also requires a respectful treatment of patients, family members and carers. The manner in which people are treated in Emergency Departments (EDs) is fundamental to maintaining the right to human dignity and related aspects of the right to health, such as information and participation (including consent), and timeliness. Quality also refers to the conditions in which staff work. Human rights standards require, inter alia, the numbers of appropriately skilled health professionals to be commensurate with the health needs of the population.

Richard's story: An undignified environment

During May and June 2014, Richard Watson visited Causeway Hospital ED three times, due to chest pains and breathlessness. On each occasion, Richard sensed that staff were "run off their feet." He described a crowded environment with people waiting on trolleys and chairs. Recalling his second attendance, Richard said there was no access to pillows or painkillers:

"I requested a pillow because I suffer from arthritis and I'm on medication for it. I found it extremely uncomfortable. I had to keep getting off the bed because I couldn't get comfortable and eventually Janet [Richard's partner] made me a pillow out of her coat and a towel she had with her, you know, something to just try, but nothing was done"

"I requested painkillers and other stuff, the doctor did say he would get the nurse to get some [...] but [...] I didn't get it [...]."

Richard's partner Janet also recalled relying on other patients and relatives to get water: "during the night I went to the vending machine and it wasn't working; I looked around but some of the patients and relatives told me where there was a water machine."

When asked how he felt treated by the Doctors and nurses, Richard replied: “very good, [...] you could actually see they did what they could; they spent as much time as they could because they had to rush off to do somebody else [...], there was compassion I felt from the nurses, definitely”

In his ‘Statement of Experience’ to the Inquiry, Richard recommended: “More beds in the hospitals. The ED can’t cope and they cannot materialize beds that aren’t there.”

Accessibility

The right to the highest attainable standard of health includes a duty to provide facilities, goods and services that are accessible. Maintaining the principle of equality and ensuring non-discrimination is of fundamental importance to guaranteeing that Emergency Departments (EDs) are accessible. This requires refraining from practices that may distinguish, exclude, restrict or preference patients on the basis that they are members of a particular group, where there is no reasonable and objective justification. It also means that when such practices are identified, positive steps must be taken to eliminate them. In addition, accessibility is dependent upon preventing the conditions within EDs and staff attitudes, which may have the effect of causing or perpetuating the marginalisation of patients belonging to groups that are at risk of experiencing inequalities. It is vital that EDs monitoring processes seek to gather data on accessibility and use of service, in particular by including the views of such groups and ensuring that the collected data is disaggregated. Finally, human rights standards also require that health professionals be trained to both recognise and respond to the specific needs of such patients.

Tony’s story: The impact of a lack of knowledge and compassion shown to a patient with cerebral palsy

Tony O’Reilly, who has cerebral palsy, was taken to Altnagelvin Hospital by ambulance in June 2007 experiencing severe pain. The following account is based on Tony’s evidence to the Inquiry and ‘Statement of Experience’.

Arriving around 3am on a Saturday night, he was taken to a room to be interviewed:

“I was asked had I taken any alcohol, was I on drugs. I explained to the nurse that I hadn’t taken any alcohol and that as a general rule I don’t drink and that I wasn’t on any drugs. Then she asked me, ‘yes, but what drugs have you taken and what alcohol have you been taking’. I explained that I have cerebral palsy and I again explained I had taken no drugs or alcohol. ‘So you have taken

nothing' she questioned me."

"I knew for a fact that the nurse did not believe me. I also knew that the person with her in white looked at me disbelieving ... I was rather dishevelled, I accept that, but I had been in bed. It wasn't as if I was out on a pub crawl. I had taken no drink."

A male nurse who Tony described as kind gave him two slices of toast and a cup of tea. When the doctor arrived, he told Tony that spasms associated with his condition could be more severe with age. He was given painkillers and told after a couple of days he would be fine. Tony went home.

"My issue is not that they didn't ... give me the right treatment... My issue is that in my experience there was a lack of compassion, a lack of understanding that when you go to an A&E situation at 3am in the morning from your own bed ... you're vulnerable, at your most weakest point... At the time I actually thought I was going to die ... because the pain was so severe. Bar one male nurse, nobody showed any compassion, any understanding. They never even asked me about my pain, where it was located. I know they were all convinced I was on drugs or drinking alcohol."

When asked by the Inquiry, Tony recommended to staff:

"Talk to me, ask me at least where the pain is... When I say I have cerebral palsy, believe me. Why would I lie? ... I still have cerebral palsy today because I've had it since I was born... Do your best to believe the patient and if the patient gives guidance and says, 'oh, I'd like this' but maybe the doctor knows best in the sense of 'no this is the treatment', that's fine but listen, listen to the patient."

Governance

The good governance of health systems is an essential component of the right to health. Its requirements include the right to health recognised in law and a national health strategy and action plan. More detailed provisions establishing what people can expect from various health services and facilities should also exist, as well as quality improvement and patient safety policies. People have a right to participate in health decision-making and, to enable this, a health information system and a culture of transparency should be ensured. Accountability is a crucial health governance component. It requires, at least, a system by which realisation of the right to health can be monitored, internally and independently reviewed, and findings actioned. Where violations of the right to health have occurred, access to independent judicial or other effective remedies are required.

Clare's story: "Doubt [for] the rest of my life"

Clare Law talked about a number of experiences attending ED with her mother, including Antrim Area ED in March 2012 when her mother was diagnosed with pneumonia. Clare's mother was placed on an "admissions ward" from the ED despite an indication from her mother's cardiologist that a specialist bed was available.

Clare's mother remained on the admissions ward for four days until moved to the specialist area. In that time, Clare said she was asked if she would consider a "no resuscitation order." She explained: "my religious beliefs tell me God makes that decision [...]" and said "no." On meeting the "health board" Clare said: I requested her notes and I discovered the doctor in the A&E had on one of the forms circled "not for CPR."

Clare explained: "I have been trying to query this for two years as to why a junior doctor took it upon himself to end my mother's life and not discuss it with me [...]. All [the hospital] seem to be able to do is say, 'oh, we're sorry you had a distressing time' [...]. Clare said that she is not "getting at the nurses, they need all the help they can get" but, despite reassurances from two staff members that the instruction would not have been carried out: "that doubt will be with me the rest of my life." She explained: "All I wanted [the doctor] to tell me was 'I decided this because', I don't think I was asking for too much."

Findings

The Inquiry's starting point was the human right of everyone to the highest attainable standard of physical and mental health. The Inquiry examined the extent to which the human rights of patients were respected, protected and fulfilled when receiving care and treatment in emergency care departments. We received evidence that raised breaches of human rights including unnecessarily prolonged waits without medical reason for pain relief, food, or fluids, people placed on trolleys in circumstances that exacerbated existing conditions, patients unsupported and as a result unable to get to the toilet or have their other care needs met, and treatment and care which did not respect dignity or privacy. On the other hand the Inquiry was also told of many examples of kindness, good care and treatment which was much appreciated and of a high standard.

No evidence emerged to suggest that human rights violations were systemic in emergency departments. Where they did occur however, they left a deep and lasting impression on the individuals and families affected.

The emergency care function of our health service is heavily dependent on and influenced by policy and practice elsewhere in the health and social care system. Emergency departments do not control who attends for treatment and rely on other parts of the hospital and social care system to allow patients to be discharged from emergency department care or cared for at home obviating their need to attend hospital. The need to look at the whole hospital and social care system, is, however, beyond the remit of the human rights Inquiry. There has been a number of such reviews in recent times; such as the Transforming Your Care (TYC) review in 2011 and the review of health and social care governance arrangements by Sir Liam Donaldson in December 2014.

The Northern Ireland Executive has committed itself to implementing TYC by allocating funding to enable the transition from hospital to community based services to relieve pressures on emergency departments and other hospital services. During the course of our Inquiry we learned that less funding than was recommended has been provided for the transition to implement TYC. Moreover, while the monies allocated were used for many valuable purposes, much of it was not what the TYC transition funding was designed to achieve. In effect, the TYC proposals have been parked and emergency care departments have continued to struggle to meet the demands placed on them. One of our key recommendations matching that of Sir Liam Donaldson's recent review is that the DHSSPS should urgently revise and implement Transforming Your Care.

The Inquiry examined expenditure on EDs. Over the past five years overall expenditure across Health and Social Care (HSC) Trusts has increased in real terms. In human rights terms, there has, therefore, been no apparent retrogression in funding of EDs. There was, however, limited evidence of long term planning. Annual budgets were constantly exceeded with in-year injections of monies being provided to deal with winter pressures and other demands.

The need for an appropriate skills mix and sufficient medical and nursing staff was a recurring theme. A particular shortage of permanent middle grade clinician posts was identified. As a result, expenditure on locum staff has increased substantially over the last couple of years. Staff in emergency departments work in pressured environments, in accommodation and facilities often not designed to deal with the demands placed on them.

The Inquiry found examples of good practice across all HSC trusts, and between them and the Northern Ireland Ambulance Service Trust. Good practice when effectively applied across the system reduces the risk of human rights violations and helps protect and fulfil the right to health. The South Eastern Health and Social Care Trust's housekeepers regularly check patients to ensure that individuals are not left inappropriately without fluids, or provide support to enable patients to get to the toilet and also provide alerts to medical staff when pain relief issues arise.

The Inquiry found that a number of local positive initiatives and good practice were not generally rolled out across all HSC Trusts. The implementation of positive initiatives in a systematic way is important. For example, the Card before you Leave scheme, to ensure patients with mental health issues, know they will receive a follow up appointment was rightly lauded. Nonetheless, the Belfast Mental Health Rights Group working with the Participation and the Practice of Rights project provided evidence of the difficulties in securing and sustaining a regional wide approach to implementation to ensure the initiative was consistently implemented.

Given that health and social care is organised through a commissioning model with the HSC Board at its apex, with local commissioning groups working on the ground, the problem of implementation across HSC Trusts was somewhat of a surprise to the Inquiry. The need to review the commissioning process should be a priority for the DHSSPS. In the interim, ensuring many of the effective initiatives referred to in this report are considered for implementation across all HSC Trusts should be an immediate task for the HSC Board.

The right to health includes importantly the right to effective public involvement and participation in the planning and delivery of services. The Inquiry received evidence about initiatives to consult

people on service developments (for example, the design of the new emergency department at Antrim Area hospital and gathering service feedback for '10,000 Voices'). Nonetheless, evidence provided to the Inquiry suggests that there was scope for significant improvement in engagement with the public. A similar message emerged in terms of feedback and redress mechanisms. It was telling that one individual told the Inquiry how she had gone online to provide a HSC Trust with positive feedback of the service only to discover that a facility only existed to lodge a complaint.

A similar gap exists within participatory governance. There is a need to strengthen the link between those shaping services and the local communities they serve; this requires consideration of the roles of the Local Commissioning Groups, the Patient Client Council and a more defined role for non-executive directors on HSC Trust boards to act as a conduit between the public, user and representative groups. The volume of evidence we received from user and representative groups enriched the Inquiry and illustrated the value of the feedback that is available. Issues around the need for improved communication with the carers and relatives of patients, with people with rare diseases and how to deal more effectively with patients with mental health problems and other specific groups are an important feature of the report and a number of our recommendations.

Accountability is a further essential component underpinning the right to health. Evidence emerged which commended the Serious Adverse Incident (SAI) and Adverse Incident processes. The Inquiry was told about the challenge associated with marrying the twin aims of publicly getting to the bottom of what had happened in a specific case and ensuring that an effective future learning experience was created. The evidence indicated a need for improved patient and family involvement in the SAI and Adverse Incident processes. In particular, we heard evidence of the need to ensure patients and relatives receive an explanation of what has happened and where applicable how any learning from an incident is being put into practice. The publication of a guide for engagement with service users/family in the SAI process is welcome and the DHSSPS commitment to introduce a duty of candour should be expedited.

A further key human rights element of accountability is a robust, independent regulatory and inspection framework with powers to ensure recommendations from inspections are put into practice. During the Inquiry the Regulation and Quality Improvement Authority (RQIA) played a more prominent oversight role. From the evidence received and developments elsewhere we concluded that there is a need to strengthen regulatory independence and enhance statutory enforcement powers and the inspection framework. An enhanced role for the RQIA will need to be appropriately resourced.

The evidence received on measuring quality was mixed in terms particularly of the value of the four hour waiting time target. There was evidence that the nature and range of indicators to monitor the quality of the patient's experience in emergency departments is progressively improving. The Inquiry found that individual HSC Trusts were developing holistic approaches to measuring the overall quality of care in their EDs.

Currently, according to the DHSSPS, the way the 12-hour targets for treatment and discharge are measured in Northern Ireland does not facilitate a direct comparison with other parts of the United Kingdom. In any event, the Inquiry concludes that it is now appropriate to examine the utility of the four-hour target as part of a wider initiative to introduce more comprehensive measures of quality which should be applied consistently across all the HSC Trusts. The Inquiry found considerable data gaps, including that only the Belfast HSC Trust was publishing whether the target to treat patients with mental health issues within two hours was being met. The current categories for data collection in Northern Ireland also do not meet the recommendations set by the UN Special Rapporteur on the Right to Health.

The Inquiry found that no dedicated ED minimum standards exist. As a result, human rights concepts of dignity, privacy, respect, involvement in decision-making and receiving information in a timely manner were not consolidated into one set of standards or placed within a human rights framework. This does not mean there is an absence of documentation around the quality of care in emergency departments. For example, the DHSSPS Quality Standards are applicable to various HSC settings. But the development of a single, comprehensive set of minimum standards for emergency care departments utilising human rights provides an opportunity to embed human rights values and principles in a practical way setting out the expectations that both patients and staff should have when using and delivering services. Training on human rights standards, including responding to the needs of vulnerable and marginalized groups, also needs strengthening with a focus on the specific context of providing care in emergency departments.

The Inquiry produced evidence on a number of issues that have, to date, largely escaped public attention. We learned that more than one fifth of persons reported as missing in Northern Ireland were individuals who had left an ED. The missing persons are often individuals experiencing mental health difficulties. There is one local initiative between the Police Service of Northern Ireland and a HSC Trust there is not, however, a regional approach to dealing with this issue. This shortcoming needs to be remedied.

The Inquiry also heard about the difficulties posed when EDs are left to deal with end of life care issues. We heard evidence that an ED is not an appropriate place for such care and the distressing impact such situations had on loved ones. In particular, we received evidence that sometimes people were transferred to emergency departments when end-of-life care could have been more appropriately provided in a nursing home or at home. This matter gives rise to a number of human rights issues. A strategy is needed to minimize the number of people being transferred to emergency departments in such circumstances including a specific focus on managing end of life care in nursing homes or at home, wherever possible. This strategy should take into account the 'what I need you to know' patient passport developed by the Royal College of General Practitioners and launched in early 2014.

When the Inquiry asked senior management and clinicians about the role human rights standards and concepts played in underpinning emergency department services, their initial response was at times questioning. Once the human rights concepts of the right to privacy and dignity, responsiveness to need, the role of participation, involvement and access to information, participatory governance and independence, transparent accountability mechanisms was explored further with them, then on several occasions we were told that these implicitly underpinned how care was developed and delivered.

The right to the enjoyment of the highest attainable standard of physical and mental health to be progressively realised was clearly a goal being pursued by the DHSSPS, the Board and each local HSC Trust. Moving human rights standards and concepts from implicit to explicit intent would be a powerful and valuable statement. The final chapter of the report set out a road map about how a human rights based approach to emergency department care could be developed. The Inquiry recommends setting up a pilot project with one or more HSC Trust to develop a human rights based approach. A successful initiative in this area would place Northern Ireland as a pioneer on the global stage.

The Inquiry made over 100 key findings. Some examples are highlighted and summarised below:

Respect and protection of the right to human dignity

- Staff are striving to maintain patient dignity in an often challenging and crowded environment. But evidence to the Inquiry, including reported instances where assistance with personal care needs has not been provided, no pain relief, and no access to food and fluids points to the types of circumstances in which there is a risk of human rights violations occurring.

- While interactions with staff were often reported to have been positive, person-centred care was, at times, undermined by a perceived disregard, lack of attention or kindness from health professionals.
- 'Dignity in death' should involve, *inter alia*, support for patients' social and spiritual needs and care and support for friends and family. But Inquiry evidence suggests that the provision of care and support to maximise dignity for 'end of life' patients and their friends and family is not always prioritised in EDs.
- Older people receiving 'end of life' care are at times inappropriately transferred from nursing homes, or other community care settings, to EDs. It was generally felt that greater investment in, development of, and training of staff within, community and home services was required to help avoid this occurring.

Access to information in terms that the patient can understand is integral to the right to health and to free and informed consent

- Staff often sought to ensure that information about health conditions and the treatment process was fully explained to patients, family members and carers. But there were occasions when insufficient or no information was communicated. This suggests that the active participation of patients, family members and carers is not always encouraged in EDs.
- Staff reported levels of over-crowding within EDs and the corresponding need to prioritise medical care, compromise their ability to communicate well.
- Screens displaying information about waiting times in EDs are a positive development, but these screens are not utilised consistently or they do not always work.

A sufficient quantity of health facilities, goods and services is essential to ensure timely health care as required by human rights laws and standards

- Delays are often due to the limited availability of 24/7 facilities, inpatient and non-hospital based services outside EDs. Moreover, while various initiatives aimed at improving the situation were identified, these, at times, appeared to be dependent on individual HSC Trust or EDs.
- Evidence points to a lack of consensus on the utility of the waiting time target, particularly the four-hour component. There was also no evidence that the utility of the target (as opposed to outcomes against it) is reviewed. It was therefore not possible to determine if the waiting time target is based on transparent criteria that address the risk of deterioration in clinical and quality of life terms.

Human rights standards recognise that a good quality health system requires a minimum number of health professionals

- There is a general view that EDs are typically understaffed.
- Recruiting and retaining middle grade doctors, and ensuring sufficient skill mix among nursing staff was a concern.
- Evidence of progressive improvement included recruitment of Advanced Nurse Practitioners, the development of the Emergency Nurse Practitioner role, and work on an 'emergency care framework.'

Equal treatment and non-discrimination

- Concerns were expressed by members of the public about dismissive attitudes from staff towards older people, sometimes including a perception of deliberate de-prioritisation.
- Patients presenting with self-harm perceived ED to be a hostile environment, detecting a lack of compassion and annoyance from staff. The Inquiry was informed that these attitudes may at times be reflected in the medical treatment administered.
- Patients with less common conditions reported negative experiences from staff, including feeling laughed at. The core complaint was that staff did not listen to the patient which at times appeared to result in improper medical treatment. This impacted upon the patients' willingness to attend ED in the event of future emergencies.
- Concerns were expressed about residents of nursing homes presenting alone to ED. These related to accessing relevant information and the risk of patients with dementia leaving.
- Concerns were expressed that older persons, particularly those with dementia, are being transferred alone at night in taxis.
- Older persons appear to wait the longest in ED.
- A reported lack of physical provision for blind and partially sighted persons, such as buzzers and braille information, made EDs difficult to navigate.
- While acknowledging ongoing initiatives to address the issue, there is a lack of sign language interpreters across HSC.
- Concerns were expressed at the lack of privacy at reception and during triage for patients presenting in mental health crisis.
- The 'patient passport' initiative to assist persons presenting to ED with communication difficulties was described as being in its formative stages and regarded as a positive development. Concerns were however raised about staff not paying due regard to the passport. An inconsistent approach may have hindered its effective implementation to date.
- Specialist staff regarded a separate children's area as vital. While dedicated children's areas were available in a number of hospital EDs, this did not appear to be the case in all.

Meeting international human rights governance standards

- There are signs that the commissioning process, essential for the effective planning and function of ED services, is not working as it should.
- There is no single, comprehensive set of standards to clarify what people can expect from acute services and facilities within EDs.
- Serious Adverse Incident guidance is weak on guiding responsible persons within EDs on how to detect serious incidents.
- There is no incident reporting mechanism for patients, and, (beyond NIMDTA trainee surveys), no routine anonymous reporting mechanism for staff.
- There is no clear statutory provision compelling the health regulator, RQIA, to undertake routine inspections of statutory acute hospitals; while acknowledging the DHSSPS Quality Standards applicable to various HSC settings, there are no dedicated ED minimum standards to inspect against.
- Increasing overspend by trusts on ED raises questions about whether services are planned to match need, and also long-term planning requirements.

Meeting human rights obligations to promote an open culture

- Perceptions of a closed culture commonly existed among public and some staff participants.
- There was a sense from the public that openness is encouraged within the health profession, but not in relation to patients or family.
- Some staff reported openness among colleagues, but this is not reciprocated by management.
- On the existence of bullying, a disconnect was apparent between staff/ organisations representing staff and Trust representatives with the former commonly stating it was endemic or apparent in most EDs, and the latter that it is not systemic. Some felt bullying was not intended but rather symptomatic of behaviours that can occur in a busy ED.

Recommendations

The Inquiry made 26 recommendations. These are set out below with references to the relevant pages in the full Inquiry report.

1. The DHSSPS should develop dedicated ED minimum care standards, rooted in human rights and providing a benchmark for patient experience within EDs. The standards should include criterion on, *inter alia*:
 - The promotion of dignity in ED;
 - Participation by individuals, their family members and other carers in the care provided in the ED setting;
 - Measures covering staff behaviour and attitude, adequate facilities;
 - Accessible mechanisms to provide feedback of ED experiences including complaints;
 - The policies and procedures each ED should have including a hospital wide escalation policy to address overcrowding; and,
 - Ways of helping to guarantee equality of access for particular groups of patients including older people, patients with dementia, rare diseases, sensory impairments and those presenting in mental health crisis. (p26, p93, p102)
2. The DHSSPS should expedite its review of the Health and Social Care Board's commissioning process. (p93)
3. The DHSSPS should strengthen the statutory requirement for participatory governance to enhance public and staff representation on key planning and decision-making forums for ED services. A more public-facing defined role should also be developed for non-executive directors on HSC Trust boards. (p94, p108)
4. The DHSSPS should clarify the issue of confidentiality when seeking information about health conditions and the treatment process while highlighting the valuable role of family members and carers in sharing information. (p34)
5. The DHSSPS should urgently develop an implementation plan for Transforming Your Care. (p105, p106)
6. The DHSSPS should enhance the statutory framework requiring the RQIA to routinely inspect EDs, to include consideration of appropriate enforcement powers and provide the resources to facilitate the discharge of RQIA's role. (p94, p112)
7. The DHSSPS should develop a Northern Ireland single Health and Social Care accredited advice and information service. (p108)

8. The DHSSPS should develop a regional policy for the direct admission of older people and those with chronic conditions to wards. The DHSSPS should also consult with the HSC Trusts, GPs, care home providers and relevant community and voluntary organisations, to develop a policy aimed at addressing the inappropriate transfer of older people to EDs for end-of-life care. (p32, p58)
9. The RQIA should ensure through inspection of EDs and nursing homes that nursing home residents are neither inappropriately transferred nor left unaccompanied in EDs. (p93)
10. The DHSSPS should expedite the introduction of a statutory duty of candour on all HSC Trusts and independent health care providers. (p93)
11. The regional data for monitoring health care services, including presentations at EDs should be expanded by the DHSSPS to include all of the categories regarded as a minimum by the Special Rapporteur, namely: sex, race, ethnicity, rural/urban and socio-economic status. (p46, p54, p70)
12. The DHSSPS should review and determine the utility of the four-hour target alongside developing other quality measures of care within EDs for implementation across all HSC Trusts. (p39)
13. The HSCB should ensure that HSC Trusts publish waiting times for persons presenting to EDs in mental health crisis and monitor and report on compliance. (p53)
14. The HSCB and one or more Health and Social Care Trusts should pilot and evaluate a human rights based approach to care in EDs. (p121)
15. The HSCB should ensure that individual HSC Trusts identified good practice initiatives are rolled out on a regional basis. (p25, p26, p97)
16. The HCSB should provide clarity on staffing levels when commissioning services from the HSC Trusts to support long term financial planning. This should include the number and skills mix required in EDs, the need to ensure sufficient numbers at the right grade to manage staff turnover and facilitate attendance at training. (p43)
17. The HSCB should ensure that training on human rights, equality and non-discrimination, are explicitly required for ED staff. (p25, p43, p73)

18. The HSCB should develop a regional protocol to reduce the incidence of, and to deal with, persons who leave EDs untreated and subsequently become treated as missing persons. (p62)
19. The HSC Trusts should review mechanisms for encouraging the reporting of Adverse Incidents and the provision made to ensure staff feedback and dissemination of learning. (p93)
20. The HSCB should ensure that a mechanism is in place for consistent, timely reporting and routine scrutiny of deaths in EDs by developing a regional policy framework. (p112)
21. The HSCB should broaden and deepen feedback and participation from patients and user organisations. This should include securing the long term future of programmes such as the '10,000 Voices' initiative. (p70)
22. HSC Trusts should ensure ongoing improvement in EDs of physical provision for service users with sensory impairments. The HSC Trusts should maximise the use of technology, such as screens displaying information about waiting times in EDs, and do so consistently. This should be undertaken in partnership with representative and user organisations. (p34, p58-59, p63)
23. The expected ratios of sign language interpreters available to EDs across HSC Trusts should be specified by the HSCB. Additionally the HSCB should ensure that the telephone interpreting service includes professional interpreters for the Roma language. (p34, p58, p59, p63)
24. The HSC Trusts should ensure that EDs raise awareness of, and provide accessible information about feedback on, the service provided and complaints procedures. Complainants should receive feedback on the outcome of their complaints. (p115, p116)

Additionally, in order to strengthen the place of international human rights within health care the NIHRC recommends

25. The DHSSPS should engage with the Office of the First Minister and Deputy First Minister to progress a legislative prohibition of discrimination in the provision of health care on grounds of birth, property, or health status. (p54)
26. The DHSSPS should incorporate to greater effect in domestic law the right to the highest attainable standard of physical and mental health. (p93, p95)