



NORTHERN
IRELAND
HUMAN
RIGHTS
COMMISSION

**Response of the Northern Ireland Human Rights Commission on the
Health and Social Care (Control of Data Processing)
NIA Bill 52/11-16**

Summary

The Northern Ireland Human Rights Commission (the Commission):

(Paragraph 9) advises the Committee to ask the department to set out the basis for the statement of compatibility. The Commission also advises that departments consider the applicability of the advice given by the Joint Committee on Human Rights. This would assist committees in their scrutiny function.

(Paragraph 18) advises that the Bill could be made clearer on the specific purposes provided by law enabling the collection and processing of medical data. The Committee could consider how to ensure that the powers are used for health and social care purposes envisaged by the Bill and not for other unrelated purposes. For example, clause 1(1)(b) could be amended to specify "in the interests of public safety" rather than "in the public interest". This would make it clear that the provision is tied to health, social care and public safety.

(Paragraph 22) welcomes the proposed enabling power to create offences to ensure protections for rights holders. It notes that clause 1(2)(d) contains a specific indication of a sanction (up to level 5 on the standard scale). The Commission welcomes that the Bill complies with the guidance of the Delegated Powers and Regulatory Reform Committee. However we note that neither the Bill nor the accompanying memorandum indicates the nature of the other procedures. The Commission recommends that the Committee could ask the department to give an indication of the nature of the other

procedures referenced in the Bill.

(Paragraph 25) recommends that, to be an effective safeguard in the processing of confidential information, particularly sensitive health data, clause 1(3) should be amended to specify that regulations "must provide" for authorisation by the committee.

(Paragraph 27) recommends that clause 2(1) be amended to provide that the department "must" establish a committee in order to ensure an effective safeguard in the processing of confidential information. In the alternative, the Committee should gain an unequivocal assurance that a committee will be established within a reasonable timeframe.

(Paragraph 30) recommends that consideration be given to the concerns of the Commissioner for Public Appointments and that the Committee considers how best to ensure diversity on the proposed committee.

(Paragraph 33) advises that the Committee and department should ensure that in fulfilling the "in accordance with the law" requirement, any interference with or restriction of Article 8 rights is clearly provided for in primary or secondary legislation and not left to non-binding codes of practice.

(Paragraph 34) In any event, the Commission also recommends that clause 3 (4) and 3 (5) are amended to specify "must comply with" rather than must "have regard" to the Code of Practice.

(Paragraph 36) welcomes that regulations will be subject to the affirmative resolution procedure as an additional level of protection for article 8 of the ECHR.



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Introduction

1. The Northern Ireland Human Rights Commission (NIHRC or Commission), pursuant to Section 69 (4) of the Northern Ireland Act 1998 is obliged to advise the Assembly whether a Bill is compatible with human rights. Accordingly, the following statutory advice is submitted to the Northern Ireland Assembly Committee for Health, Social Services and Public Safety in relation to the Health and Social Care (Control of Data Processing) Bill (hereinafter the "Bill").
2. The Commission bases its advice on the full range of internationally accepted human rights standards, including the European Convention on Human Rights, as incorporated by the Human Rights Act 1998, and the treaty obligations of the Council of Europe (CoE) and United Nations (UN) systems. The relevant international treaties in this context include:
 - The Council of Europe (COE) European Convention on Human Rights and Fundamental Freedoms (ECHR)¹
 - The International Covenant on Civil and Political Rights (ICCPR)²
 - COE Convention on Data Protection³
 - Charter of Fundamental Rights of the European Union⁴
 - The UN Convention on the Rights of the Child⁵
 - The International Covenant on Economic Social and Cultural Rights⁶

¹ Ratified by the UK in 1951 and given further domestic effect by the Human Rights Act 1998

² Ratified by the UK in 1976

³ The Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data, ETS 108
Ratified by UK in 1997

⁴ Ratified by UK in 2000

⁵ Ratified by UK in 1990

⁶ Ratified by UK in 1976,

- The UN Convention on the Elimination of Discrimination against Women⁷
 - UN Convention on the Elimination of Racial Discrimination⁸
 - UN Convention on the Rights of Persons with Disabilities⁹
 - EU Directive 95/46/EC¹⁰
3. The NI Executive is subject to the obligations contained within these international treaties by virtue of the United Kingdom's (UK) ratification or by virtue of their status as European Union law. In addition, Section 26(1) of the Northern Ireland Act 1998 provides that *"If the Secretary of State considers that any action proposed to be taken by a Minister or Northern Ireland department would be incompatible with any international obligations... he may by order direct that the proposed action shall not be taken."*
 4. Further, Section 26(2) states that *"the Secretary of State may, by order, direct that an action be taken on a matter within the legislative competency of the Assembly as required for the purpose of giving effect to international obligations. Such action can include the introduction of a Bill into the Assembly."*
 5. Section 24 (1) of the Northern Ireland Act 1998 provides that *"A Minister or Northern Ireland department has no power to make, confirm or approve any subordinate legislation, or to do any act, so far as the legislation or act – (a) is incompatible with any of the Convention [ECHR] rights"*.
 6. Section 6(2) provides that it is outside the legislative competence of the Northern Ireland Assembly to enact laws that are incompatible with any of the ECHR rights.
 7. In addition to these treaties, there are soft law principles, which have been developed by the human rights organs of the United Nations and Council of Europe. These declarations and principles are non-binding but provide further guidance in this area. They include:
 - UN General Assembly Guidelines for the Regulation of computerized personal data files 1990

⁷ Ratified by UK in 1981.

⁸ Ratified by the UK in 1969

⁹ Ratified by the UK in 2009

¹⁰ Directive 95/46/EC of the European Parliament and of the Council of 24 October 1995, with regard to the processing of personal data and on the free movement of data

- Committee of Ministers Recommendation No R (97) 5 on the Protection of Medical Data
- General Comment No.14 of the Committee on Economic, Social and Cultural Rights on the right to the Highest Attainable Standard of Health
- General Recommendation 24 of the Committee on the Elimination of Discrimination against Women on women and health.

Compatibility

8. The Commission notes that paragraph 19 of the Explanatory and Financial Memorandum accompanying the Bill states that the provisions of the Bill are compatible with the ECHR. The Commission notes guidance from the Westminster government to departments about disclosure of views regarding Convention compatibility in the Explanatory Notes that accompany a Bill. In order to discharge the government's commitment to provide a human rights assessment, departments should do one of the following:¹¹

- state that the department does not consider that the provisions of the Bill engage convention rights;
- in a case where any ECHR issues arise but are not significant, deal with the issues in a short paragraph or paragraphs in the explanatory notes;
- or where significant issues arise, state that issues arising as to the compatibility of the bill with convention rights are dealt with in a separate memorandum and provide a web address at which the memorandum can be accessed.

The Commission also notes the view of the Joint Committee on Human Rights (JCHR) which highlighted the good practice of departments in supplying a detailed human rights memorandum, giving a full explanation of the view that a Bill is compatible with human rights. The JCHR emphasised:¹²

The provision of detailed human rights memoranda to Parliament is an important means of demonstrating the Government's fulfilment of that responsibility. It also facilitates Parliament in fulfilling its responsibility in that regard.

¹¹ Cabinet Office "Guide to Making Legislation" July 2015, https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/450239/Guide_to_Making_Legislation.pdf, pg 86

¹² JCHR "Legislative Scrutiny: Welfare Reform Bill", para 1.11 <http://www.publications.parliament.uk/pa/jt201012/jtselect/jtrights/233/23305.htm#a4>

9. **The Commission advises the Committee to ask the department to set out the basis for the statement of compatibility. The Commission also advises that departments consider the applicability of the advice given by the Joint Committee on Human Rights. This would assist committees in their scrutiny function.**

Control of Information of a Relevant Person- Clause 1

10. Clause 1(1) provides the Department of Health, Social Services and Public Safety with regulation making powers in connection with the processing of prescribed information of a relevant person for medical or social care purposes as it considers necessary or expedient in the interests of improving health or social care or in the public interest.
11. The ECHR, Article 8 provides for the right to respect for private and family life and provides that interference must be in accordance with the law and necessary in a democratic society.¹³
12. The European Court of Human Rights (ECtHR) has held that protection of medical data falls within the ambit of the right to private and family life, protected by Article 8 of the ECHR.¹⁴
13. In the case of *L.H. v Latvia*, the ECtHR reiterated that the protection of personal data, not least medical data, is of fundamental importance to the enjoyment of a person's right to respect for private life in Article 8 of the ECHR.¹⁵

¹³ Article 8 states "1. Everyone has the right to respect for his private and family life, his home and his correspondence. 2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic wellbeing of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others."

¹⁴ *M.S v Sweden*, 20837/92.

¹⁵ *L.H v Latvia*, 52019/07, 29 April 2014, para 56 "It particularly noted that legal rules in this area must be drafted with "sufficient clarity" to indicate the scope of the discretion and the manner of its exercise. The Court stated: Of particular relevance in the present case is the requirement for the impugned measure to have some basis in domestic law, which should be compatible with the rule of law, which in turn means that the domestic law must be formulated with such precision and must afford adequate legal protection against arbitrariness. Accordingly the domestic law must indicate with sufficient clarity the scope of discretion conferred on the competent authorities and the manner of its exercise."

14. The court in holding a violation of Article 8 concluded in this case that the applicable law was not formulated with sufficient precision to afford adequate legal protection against arbitrariness, nor did it indicate with sufficient clarity the scope of discretion conferred on the competent authorities.¹⁶
15. The EU Directive on the Processing of Personal Data provides that member states, may, for reasons of substantial public interest, lay down exemptions in addition to those set out in the directive.¹⁷
16. The Council of Europe Committee of Ministers Recommendation on the protection of medical data provides that medical data may be collected and processed for specified purposes and if provided by law:¹⁸
- for public health reasons; or
 - subject to principle 4.8, the prevention of a real danger or the suppression of a specific criminal offence: or
 - another important public interest.
17. However Clause (1)(1) of the Bill states that regulations may be made providing for the processing of information for the purpose of “improving health and social care” or “in the public interest.” The Commission considers that this latter phrase is too broad and does not meet the requirements to be specific on the other “important public interest” being covered.
18. **The Commission advises that the Bill could be made clearer on the specific purposes provided by law enabling the collection and processing of medical data. The Committee could consider how to ensure that the powers are used for health and social care purposes envisaged by the Bill and not for other unrelated purposes. For example, clause 1(1)(b) could be amended to specify “in the interests of public safety” rather than “in the public interest”. This would make it clear that the provision is tied to health, social care and public safety.**
19. Clause 1(2)(d) of the Bill allows the department to make regulations for the creation of offences punishable on summary conviction by a fine not exceeding level 5 on the standard scale or such other level as is

¹⁶ *L.H v Latvia*, 52019/07, 29 April 2014, paras 59 and 60

¹⁷ Article 8(4) of Directive 95/46/EC of the European Parliament and the European Council of 24 October 1995 on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

¹⁸ Council of Europe Committee of Ministers Recommendation No R (97)5 of the Committee of Ministers on the Protection of Medical Data, para 4.3

prescribed or for the creation of other procedures for enforcing any provision of the regulations. Level 5 is the highest level on the standard scale for summary offences.

20. A number of human rights instruments require states to impose sanctions for violations of law. Article 10 of the Council of Europe Convention on Data Protection provides that each party shall undertake to establish appropriate sanctions for violation of domestic law giving effect to the basic principles of data protection. The UN General Assembly Guidelines also provides that criminal or other penalties should be envisaged together with the appropriate individual remedies.¹⁹ The EU Directive on personal data processing requires member states to impose sanctions for infringement of the provisions contained within the directive.²⁰

21. The Westminster Delegated Powers and Regulatory Reform (DPRR) Committee produced guidance to departments on provision of penalties set by delegated legislation. It stated:

*Where a Bill creates a criminal offence with provision for the penalty to be set by delegated legislation, the Committee would expect, save in exceptional circumstances for the maximum penalty on conviction to be included on the face of the bill. Therefore where this is not the case, the memorandum should explain why not.*²¹

22. The Commission welcomes the proposed enabling power to create offences to ensure protections for rights holders. It notes that clause 1(2)(d) contains a specific indication of a sanction (up to level 5 on the standard scale). We welcome that the Bill complies with the guidance of the Delegated Powers and Regulatory Reform Committee. However we note that neither the Bill nor the accompanying memorandum indicates the nature of the other procedures. The Commission recommends that the Committee could ask the department to give an indication of the nature of the other procedures referenced in the Bill.

¹⁹ Principle 8 of UN General Assembly Guidelines for the Regulation of computerized personal data files 1990, available at <http://www.worldlii.org/int/other/PrivLRes/1990/1.htm>

²⁰ Article 24

²¹ Delegated Powers and Regulatory Reform Committee "Guidance for Departments" April 2005 <http://www.parliament.uk/documents/upload/DPRRguide.pdf>

23. The ECtHR has ruled that states must include “appropriate safeguards” to ensure information is not disclosed in a manner that breaches Article 8:

The Court reiterates that the protection of personal data, particularly medical data, is of fundamental importance to a person’s enjoyment of his or her right to respect for private and family life as guaranteed by Article 8 of the Convention. Respecting the confidentiality of health data is a vital principle in the legal systems of all the Contracting Parties to the Convention. It is crucial not only to respect the sense of privacy of a patient but also to preserve his or her confidence in the medical profession and in the health services in general. The domestic law must afford appropriate safeguards to prevent any such communication or disclosure of personal health data as may be inconsistent with the guarantees in Article 8 of the Convention.²²

24. The Commission welcomes the proposed enabling power to make regulations in relation to processing of confidential information involving a committee to authorise processing of confidential information as a safeguard. However we note that clause 1(3) states that regulations “may provide” that such information may only be processed if authorisation is granted by the committee.
25. **The Commission recommends that, to be an effective safeguard in the processing of confidential information, particularly sensitive health data, clause 1(3) should be amended to specify that regulations “must provide” for authorisation by the committee.**

Establishment of a Committee to authorize the processing of confidential information- Clause 2

26. Clause 2 of the Bill provides that the department may make regulations for the establishment of a committee to authorize processing of confidential information of a relevant person in prescribed circumstances and compliance with prescribed conditions. This is intended as a safeguard but it would seem that the approval of this committee is not required (clause 1(3) uses the term “may”). The COE Convention on Data Protection provides that personal data concerning health may not be processed automatically unless domestic law provides

²² *M.S. v Sweden*, 20837/92, 27 August 1997, para 41. See also *Z v Finland*, 22009/93, 25 February 1997 para 95

appropriate safeguards.²³ The UN General Assembly Guidelines also requires states to provide for appropriate safeguards in instances where there is a departure from certain principles.²⁴

27. **To ensure this is an effective safeguard in the processing of confidential information, the Commission recommends that clause 2(1) be amended to provide that the department “must” establish a committee. In the alternative, the Committee should gain an unequivocal assurance that a committee will be established within a reasonable timeframe.**
28. Clause 2(3) provides for regulations on the persons or bodies to be represented on the committee. There is no requirement as to any form of community balance or gender representativeness on this committee. The Commission also notes that the Commissioner for Public Appointments has expressed concern about the lack of diversity and specifically the underrepresentation of women, young people, persons with disabilities and ethnic minorities in public appointments in Northern Ireland.²⁵ The Commission recalls General Comment 14 of the Committee on Economic, Social and Cultural Rights which calls on State parties to integrate a gender perspective in their health policies, planning and programmes to produce better outcomes for men and women.²⁶ Similarly, the Commission notes that General Recommendation 24 of the Committee on the Elimination of Discrimination against Women requires state parties to place a gender perspective in policies and programmes affecting women’s health, and in particular to involve women in the planning, implementation and monitoring of such policies and programmes.²⁷
29. Moreover, Article 29 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) which obliges State parties to ensure the participation of persons with disabilities in political and public life. This is

²³ Article 6 of the Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data, ETS 108

²⁴ Principle 3 of the UN General Assembly Guidelines sets out the principles of purpose including is used or disclosed without the consent of the person that all personal data collected and recorded remains relevant and adequate to the purposes so specified; none of the data can be disclosed without the consent of the person concerned; and the period for which the personal data are kept does not exceed that which would enable the achievement of the purpose so specified. See principle 6 of UN General Assembly Guidelines for the Regulation of computerized personal data files 1990, available at <http://www.worldlii.org/int/other/PrivLRes/1990/1.htm>

²⁵ The Commissioner for Public Appointments Northern Ireland “Underrepresentation and Lack of Diversity in Public Appointments in Northern Ireland” available at <http://www.publicappointmentsni.org/index/publications.htm>

²⁶ ComESCR General Comment No.14 “Right to Highest Attainable Standard of Health” E/CN.4/2000/4, para 20

²⁷ ComEDAW General Recommendation No 24 “Women and Health”, para 31(a)

particularly important given that article 31 of the UNCRPD requires states to comply with legally established safeguards, including legislation on data protection, to ensure confidentiality and respect for the privacy of persons with disabilities. Article 5 of the UN Convention on the Elimination of Racial Discrimination (UNCERD) also obliges State parties to guarantee the right of everyone without distinction as to race, colour, or national or ethnic origin to participate in public life.

30. The Commission recommends that consideration be given to the concerns of the Commissioner for Public Appointments and that the Committee considers how best to ensure diversity on the proposed committee.

Code of Practice- Clause 3

31. Clause 3 (1) of the Bill provides that the department must as soon as reasonably practicable, prepare and publish a Code of Practice on the processing of information. Clause 3 (4) provides that Health and Social Care bodies must “have regard” to the Code of Practice in exercising their functions in relation to the provision of health and social care.

32. The Commission notes that when Article 8 rights are being restricted or interfered with, any restriction must be “in accordance with the law”; this is the “legality” requirement. A rule only satisfies the legality requirement if it is legally binding. In the case of *Khan v the UK*, the ECtHR ruled that guidelines that were neither legally binding nor publicly accessible could not satisfy the “accordance with the law” requirement in article 8.²⁸ The Commission notes that the Human Rights Act requires that public authorities and hybrid bodies must act compatibly with Convention rights; it would provide stronger guarantees for rights if the obligation were “to comply with” the Code of Practice and not merely to “have regard” to the Code of Practice.²⁹ Cabinet Office Guidance to making legislation also makes it clear that Codes of Practice are not to be used to define specific legal obligations. Where specific obligations are to be imposed this should be set out in primary or secondary legislation.³⁰

33. Therefore the Commission advises that the Committee and department should ensure that in fulfilling the “in accordance

²⁸ *Khan v the UK*, 35394/97, 12.05.00, paras 27 & 28.

²⁹ Human Rights Act 1998, section 6 (3)

³⁰ Cabinet Office Guide to Making Legislation, July 2015

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/450239/Guide_to_Making_Legislation.pdf, pg 312

with the law” requirement, any interference with or restriction of Article 8 rights is clearly provided for in primary or secondary legislation and not left to non-binding codes of practice.

34. **In any event, the Commission also recommends that clause 3 (4) and 3 (5) are amended to specify “must comply with” rather than must “have regard” to the Code of Practice.**

Regulations- Clause 4

35. Clause 4 (2) provides that regulations made under this Act may not be made unless a draft of the regulations has been laid before and approved by a resolution of the Assembly.
36. **The Commission welcomes this level of scrutiny as an additional protection for article 8 of the ECHR.**