

ARTICLE 19



A Healthy knowledge

Right to information and the right to health

ARTICLE 19
Free Word Centre
60 Farringdon Road
London
EC1R 3GA
United Kingdom
T: +44 20 7324 2500
F: +44 20 7490 0566
E: info@article19.org
W: www.article19.org
Tw: [@article19org](https://twitter.com/article19org)
Fb: facebook.com/article19org

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Executive summary

This ARTICLE 19 policy brief examines the policy implications of nations' international human rights obligations on the right to information and the right to health.

It sets out the relationship between the right to information and the right to health, specifically examining how the right to information is relevant to the right to health, and surveys the international legal frameworks on the right to information and the right to health respectively. The core of the paper highlights the nexus between these rights in practice, identifying key features of a legal and policy framework and makes recommendations for the promotion of the right to health through the right to information, which states should adopt. It also highlights particular issues concerning the protection of maternal health.

This policy brief demonstrates how the right to information and the right to health converge in specific legal and policy terms. The brief develops a number of principles that should be the basis of any comprehensive and coherent national health policy which properly protects the right to information, concerning:

- 1 Legal protections for the right to information and the right to health;
- 2 Duties to respect, to protect and to fulfil rights;
- 3 Non-discrimination and protection of vulnerable individuals;
- 4 The provision of information about public health and on specific issues;
- 5 The protection of the right to informed consent;
- 6 The protection of personal health information and medical data;
- 7 The development of health indicators and the dissemination of health information;
- 8 Publicising international reporting obligations of states; and (9) the obligations of the international community, civil society and the media.

The recommendations of this policy brief are focussed on state actors, although non-state actors should also do their part to promote the right to information and the right to health as mutually reinforcing rights. ARTICLE 19 advocates that all states and relevant non-state actors adopt these recommendations, which demonstrate the relationship between these two rights and how they may be realised in practice.

Some of the key recommendations are:

- State authorities should ensure that there is a legal and policy framework for the protection of the right to information and the right to health, including constitutional and legal protections for these rights.
- State authorities – including the judiciary and public administration - should ensure that they are meeting their obligations to safeguard the rights to information and health through laws, policies and practices.
- State authorities should respect the right to health by, among other things, refraining from certain activities – such as withholding, limiting or misrepresenting health related information – which may impede the realisation of the right to health.
- State authorities should protect the right to health by ensuring that third parties do not restrict or limit people’s access to health-related information.
- State authorities should fulfil the right to health through the promotion and provision of health-related information, education, research and statistics.

Additionally, the brief makes a series of recommendations relating to specific issues including non-discrimination, maternal health, HIV/AIDS, children, the right of access and confidentiality of medical information.

1. Introduction

As human rights, the right to information and the right to health are inextricably connected. This ARTICLE 19 policy brief examines the policy implications of states' international human rights obligations relating to the two rights. The brief sets out the relationship between the right to information and the right to health, specifically examining how the right to information is relevant to the right to health; it examines the international legal frameworks on the right to information and the right to health respectively; it highlights the nexus between these rights in practice, identifying key features of a legal and policy framework and recommendations for the promotion of the right to health through the right to information which states should establish; it identifies particular issues concerning the protection of maternal health and, finally, it concludes with a set of recommendations directed at state and non-state actors on the protection of the right to information and the right to health.

This brief builds on ARTICLE 19's previous work related to the relationship between the right to information and the right to health as well as other economic, social and cultural rights¹ This work includes

leading the development of the London Declaration for Transparency, the Free Flow of Information and Development² and reports on empowerment³ and reproductive rights.⁴ This brief is intended to further develop on this previous work by focusing on the precise nature of the legal and policy relationship between the rights to information and health in a more direct and comprehensive way.

At the outset of this policy brief, it is important to identify what we mean by the "right to information" in the context of health policy. We use this term to mean the right of access by private individuals and groups to any information, whether held by public or private bodies, which is relevant to health. This includes information on family planning methods and information relating to sexual health, whether communicated directly by governments, by traditional media or by other means. Governments are under obligations to ensure the effective right of information for all, including on health matters. At the same time, individuals have a right to information held or transmitted by both state and non-state or private actors, such as the media, private health providers and religious organisations.

1 This work has included *The Right to Know: Human Rights and Access to Reproductive Health Information* (London: ARTICLE 19, 1995). This book examines the obstacles to the communication of information about abortion, contraception, AIDS, and other threats to reproductive health in a range of countries. See also Sandra Coliver, "The right to information necessary for reproductive health and choice under international law", 44 *American University Law Review* 1279 (1995).

2 *The London Declaration for Transparency, the Free Flow of Information and Development* <http://www.right2info-mdgs.org/wp-content/uploads/London-Declaration.pdf>

3 ARTICLE 19, *Access to Information: An Instrumental Right for Empowerment* July 2007 <http://www.article19.org/pdfs/publications/ati-empowerment-right.pdf>. See also ARTICLE 19, "Nigeria: Promoting Access to Information and the Right to Health", 30 April 2009 <http://www.article19.org/pdfs/press/nigeria-promoting-access-to-information-and-the-right-to-health.pdf>

4 ARTICLE 19, *Time for Change: Promoting and Protecting Access to Information and Reproductive and Sexual Health Rights in Peru*, January 2006 <http://www.article19.org/pdfs/publications/peru-time-for-change.pdf>

2. The relationship between the right to information and the right to health

The right to health – or, more precisely, the right to the highest attainable standard of health – is intrinsically linked to the realisation of other rights.⁵ The state's failure to protect human rights more generally can have adverse consequences for health. Obviously, human rights abuses such as torture, domestic violence, unsafe working conditions and sexual exploitation of children all affect health. Less dramatically, many other health-related activities and policies may themselves violate human rights. For example, medical records may be kept in a manner inconsistent with the rights to information and privacy.⁶

As indicated above, this policy brief is particularly concerned with examining the precise nature of the relationship between the right to information and the right to health. More specifically, this policy brief focuses on the ways in which the effective exercise of the right to information is critical to the realization of the right to health. As such, this brief extends beyond simply examining the scope of the “right to health information”.

There has been a long-standing recognition of the connections between the right to health and the right information, which has been highlighted by various UN human rights bodies.

The World Health Organisation first enunciated the right to the highest attainable standard of health in its constitution in 1946, identifying “health information system[s]” as one of the “six essential building blocks” which together make up a comprehensive health system:

A well-functioning health information system is one that ensures the production, analysis, dissemination and use of reliable and timely information on health determinants, health systems performance and health status.⁷

Within the UN human rights system, the Committee on Economic, Social and Cultural Rights declared in General Comment No 14 that the right to health is “closely related to and dependent upon the realization of other human rights ... [including]... access to information” which it considers as addressing “integral components of the right to health”. The committee has stated that it “interprets the right to health ... as an inclusive right extending not only to timely and appropriate health care but also to the underlying determinants of health such as ... access to health-related education and information.”⁸

⁵ Susan Marks and Andrew Clapham, *International Human Rights Lexicon* (Oxford: OUP, 2005), p 197. It is important to note that the right to health does not mean the right to be healthy, but rather that state authorities are obliged to put in place policies that will lead to available and accessible health care for all.

⁶ Marks and Clapham also note that “compulsory treatment may also be administered in a manner that cannot be reconciled with rights to physical integrity, privacy and freedom of religion, and possibly even life”, and that “health policies may be elaborated which do not meet obligations of non-discrimination”. See Marks and Clapham *ibid* at p 198.

⁷ World Health Organisation, *Everybody's Business: Strengthening Health Systems to Improve Health Outcomes*, 2007. http://who.int/healthsystems/strategy/everybodys_business.pdf

⁸ General Comment No 14, UN Doc E/C.12/2000/4 Para 3.

Furthermore, the UN Special Rapporteur on the right to the highest attainable standard of physical and mental health has summarised the importance of access to information and transparency as essential features of an effective health system in his report to the seventh session of the Human Rights Council in 2008. He stated:

Access to health information is an essential feature of an effective health system, as well as the right to the highest attainable standard of health. Health information enables individuals and communities to promote their own health, participate effectively, claim quality services, monitor progressive realization, expose corruption, hold those responsible to account, and so on. The requirement of transparency applies to all those working in health-related sectors, including States, international organizations, public private partnerships, business enterprises and civil society organizations.⁹

Thus, the right to health is concerned with both processes and outcomes. As Paul Hunt, the former UN Special Rapporteur on the Right to Health and Gunilla Backman emphasise, “it is not only interested in what a health system does (e.g. providing access to essential medicines and safe drinking water), but also how it does it

(e.g. transparently, in a participatory manner and without discrimination)”.¹⁰

The right to information and its concomitant principle, the free flow of information, are crucial to the right to health in four respects, which are highlighted below.

First, individuals need to have access to information about the content and scope of the right to health itself in order to be able to assess whether their rights are being respected or not and, if not, to claim their rights. Thus, the right to health requires human rights education, especially awareness-raising measures on the right to health itself. For instance, health policy guarantees of free antiretroviral drugs to HIV-positive persons are of little use if individuals are not aware of the right to such medicines in the first place. Similarly, mental health provisions that aim to promote free and informed consent to treatment are unlikely to curb coercive treatment practices if neither mental health professionals nor patients are aware of their rights.

In addition, access to information is crucial for individuals and groups as rights-holders wishing to effectively claim their right to health and ensure that it is enforced, including through litigation. In cases involving the positive obligations of the state with respect to the right to health (i.e. obligations to engage in activity to secure effective enjoyment of the right), relevant

9 A/HRC/7/11, 31 January 2008.

10 Paul Hunt and Gunilla Backman, “Health systems and the Right to the Highest Attainable Standard of Health”, in Andrew Clapham, *Health: A Human Rights Perspective*, Swiss Human Rights Book Vol 3, 40-57 at 43. http://www.swisshumanrightsbook.com/SHRB/shrb_03.html

statistics about the effect of a policy may well be important factors in deciding the case.¹¹ Information is particularly important in health cases involving the environment, when factors such as air and water quality and emissions, and their effects on individuals, can be quantitatively measured.¹²

Second, individuals need to have access to reliable and accurate health information, including about risks to general public health. Public access to information about both dangers from within the health care system such as risks from drugs and procedures and external risks such as from the environment is therefore essential to ensuring the right of individuals to take measures to protect themselves. In this connection, the European Court of Human Rights has ruled that the state must actively inform those affected by toxic emissions from a chemical plant, not merely have a procedure for obtaining information if requested. Where a situation involves an imminent risk to health, simply leaving it up to those who may suffer injury to seek out information about such risks would not discharge the state's duty to protect the public.¹³

Moreover, to achieve transparency and

effective participation in health-decision making, health information should be accurate and easily understandable, including for those in vulnerable groups. For example, in the case of disease outbreaks, the WHO states:

... it is essential that information regarding the disease is permitted to be widely distributed and is in a language understood by the person(s) affected. Similarly, in the case of environmental or natural disasters it is vital that the affected population receives timely information. Moreover, considering a particular group such as migrants, it has been found that one of the reasons they do not make use of health services effectively and do not take action themselves to prevent illness is due to the lack of information about what is available or about health in general.¹⁴

Furthermore, patients receiving or about to receive medical treatment and health professionals need access to reliable information about medicines “so they can make well-informed decisions and use medicines safely”.¹⁵

11 The Centre for Housing Rights and Development, *Litigating Economic, Social and Cultural Rights: Achievements, Challenges and Strategies* (2003), p 25.

12 *Ibid* at 63.

13 *Guerra v Italy* Application No 14967/89 judgment of 19 February 1998.

14 World Health Organisation, *The Right to Health*. http://www.who.int/hhr/Right_to_health.pdf

15 Rajat Khosla and Paul Hunt, “Human Rights Guidelines for Pharmaceutical Companies in relation to Access to Medicines: The Sexual and Reproductive Health Context” 8 (2009). http://www.essex.ac.uk/human_rights_centre/research/rth/docs/Final_pharma_for_website.pdf at 8. See further the Medicines Transparency Alliance Medicines Transparency Alliance (MeTA) which brings together all stakeholders in the medicines market to improve access, availability and affordability of medicines for the one-third of the world's population to whom access is currently denied. The second phase of MeTA began in August 2011, and is being guided by the World Health Organization and Health Action International, who together provide the secretariat to the seven countries in which the pilot took place during 2009-2010: Peru, Kyrgyzstan, Jordan, Ghana, Zambia, Uganda and the Philippines. <http://www.medicines Transparency.org/>

Third, individuals must have access to reliable and accessible information held by health professionals about their own health. International human rights law provides for a strong right of access to one's own records as an aspect of protecting the right to privacy. Access to information about one's own health situation is especially important when facing medical treatment in order to make informed treatment decisions. Related to this is the "right to informed consent" which requires that individuals be given full information about what medical treatment involves, including the benefits and risks, whether there are reasonable alternative treatments, and what will happen if treatment does not go ahead. Procedures undertaken without prior informed consent may violate not only the right to information and the right to health, but also the right to individual autonomy and the right not to be subjected to inhuman treatment, as cases concerning forcible sterilisation have demonstrated.¹⁶

Whilst individuals have a right to information about their own health and the most extensive free-flow of information between themselves and their healthcare providers, they also have the right to ensure that the information is treated confidentially.¹⁷

Access to information about one's health records should not restrict the right to have one's personal health data to be treated confidentially.

Fourth, access to information is essential for individuals and groups, as well as human rights monitors to be able to scrutinise the state's implementation of its obligations on the right to health. Transparency is an essential characteristic of any effective health care system. Access to information also empowers individuals to be able to participate effectively in political decisions taken at community, national and international levels.¹⁸

For society to monitor if the state is developing appropriate policies to promote access to health, it is necessary for individuals to have access to information about the development and implementation of public health policies. It is also important for the state to provide information about the specific content of such policies, so as to analyse how budgetary commitments are delivered. Provided such health related information is made available, individuals and groups are able to participate more effectively in democratic health-related decision-making at the community, national and international levels.¹⁹ Hunt and Backman point out:

¹⁶ See, for example, *V.C. v Slovakia*, Application No 18968/07, judgment of the European Court of Human Rights of 8 November 2011.

¹⁷ The Hippocratic Oath states, "That whatsoever I shall see or hear of the lives of my patients that is not fitting to be spoken, I will keep in confidence".

¹⁸ General Comment No 14, UN Doc E/C.12/2000/4 Para 11.

¹⁹ *Ibid.* On the relationship between participation and access to health information, see Sam Halibi, "Participation and the Right to Health: Lessons learnt from Indonesia" University of Tulsa Legal Studies Research Paper No 2011-02.

Health information enables individuals and communities to promote their own health, participate effectively, claim quality services, monitor progressive realization, expose corruption, hold those responsible to account, and so on. The requirement of transparency applies to all those working in health-related sectors, including states, international organizations, public private partnerships, business enterprises and civil society organizations.²⁰

The right to information and the free flow of information allow a wide variety of other actors including civil society, the media, donors and international and regional human rights authorities to critically assess a state's implementation of the right to health. The positive impact of scrutiny and monitoring, which is dependent upon the effective exercise of the right to information, is not limited to individuals experiencing a lack of protection for their right to health at a particular moment in time: it extends to preventing further violations of the right by exposing the activities, positions, policies and processes of the state. Scrutiny, therefore, demands greater transparency and improved implementation of the right to health by the state.

The International Covenant on Economic, Social and Cultural Rights requires that states parties periodically report to the Committee on Economic, Social and Cultural Rights on the measures that they have adopted for, and the progress made towards, achieving the obligations assumed in the treaty, including the right to health. This monitoring process is most effective when state reports provide information about the achievements and measures taken. International guidelines indicate that reporting should include not only data, but also meaningful analyses in order to evaluate trends and demonstrate whether the state is fulfilling its obligations under the Covenant.²¹ Information is also vital for monitoring at the local level. For example, to evaluate whether the right to health is realised in any state, it is necessary to have access to information about life expectancy rates, child mortality rates, HIV-AIDS rates, not only in the aggregate, but also disaggregated by gender, social class, geographic centres (whether urban or rural), religion and ethnicity. These factors should be measured over time using trend-analysis of key indicators and benchmarks.²²

²⁰ Paul Hunt and Gunilla Backman *supra* note 10 at p 43

²¹ General Comment 1, Reporting by States Parties UN Doc E/1982/22.

²² In this regard, it is interesting to note that the WHO compiles the main health data and statistics for each country which includes descriptive and analytical summaries of health indicators for major health topic.

3. The international legal framework: the rights to information and health

This part examines international and regional law on the rights to information and health and how they should affect domestic law. It is important to note that the two major international human rights treaties which protect the right to information and the right health, the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR), enjoy a high level of ratification by states: the ICCPR has been ratified by 167 States parties, whilst the ICESCR has been ratified by 160 States parties out of 193 members of the UN. Ratification or accession to a treaty, means that a state has consented to be bound to the treaty and is obliged to give domestic effect to the rights contained within that treaty.²³

It is important to note that the nature of States parties' obligations in relation to the right protected under the ICCPR, including the right to information, is not the same as the nature of State parties' obligations in relation to rights protected by the ICESCR, including the right to health. Whereas Article 2 of the ICCPR requires State parties "to ensure" to all individuals within their jurisdiction the rights recognised in the ICCPR and to adopt legislative, judicial, administrative, educative and other appropriate measures to this end,²⁴ Article 2 of the ICESCR requires States parties

to "take steps ... to the maximum of ... available resources, with a view to achieving progressively the full realisation of the rights" recognised in the ICESCR. The significance of Article 2 of the ICESCR is explained in later parts of this policy brief.

1 The right to information

i International law on the right to information

International human rights law includes the right to information as part of the broader fundamental right to freedom of expression, which includes the right to seek, receive and impart information.

Article 19 of the Universal Declaration on Human Rights (UDHR), adopted as a United Nations General Assembly resolution in 1948,²⁵ states:

Everyone has the right to freedom of opinion and expression; this right includes the right to hold opinions without interference and to seek, receive and impart information and ideas through any media and regardless of frontiers.

²³ Articles 2(1)(b), 14(1) and 16 Vienna Convention on the Law of Treaties 1969.

²⁴ General Comment No 31 of the Human Rights Committee on the Nature of the General Legal Obligation Imposed on States Parties to the Covenant UN Doc. CCPR/C/21/Rev.1/Add.13 26 May 2004.

²⁵ UN General Assembly Resolution 217A (III), adopted 10 December 1948.

While the UDHR is not directly binding on States, parts of it, including Article 19, are widely regarded as having acquired legal force as customary international law.²⁶

Article 19 of the ICCPR guarantees the right to freedom of expression and information in more elaborate terms.²⁷

- 1 Everyone shall have the right to hold opinions without interference.
- 2 Everyone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds, regardless of frontiers, either orally, in writing or in print, in the form of art, or through any other media of his choice.
- 3 The exercise of the rights provided for in paragraph 2 of this article carries with it special duties and responsibilities. It may therefore be subject to certain restrictions, but these shall only be such as are provided by law and are necessary:

- i) For respect of the rights or reputations of others;
- j) For the protection of national security or of public order (ordre public), or of public health or morals.

It is important to note that the right to information as protected by Article 19 of the ICCPR may be restricted to respect certain rights including the right to privacy, which is protected by Article 17(1) of the ICCPR.²⁸ However, the right to privacy also includes a strong right of individuals to be able to access and correct their own personal information held by 3rd parties. The Human Rights Committee in General Comment 16 has said that this means that:

Every individual should also be able to ascertain which public authorities or private individuals or bodies control or may control their files. If such files contain incorrect personal data or have been collected or processed contrary to the provisions of the law, every individual should have the right to request rectification or elimination.²⁹

²⁶ For judicial opinions on human rights guarantees in customary international law, see *Barcelona Traction, Light and Power Company Limited Case (Belgium v. Spain) (Second Phase)*, ICJ Rep. 1970 3 (International Court of Justice); *Namibia Opinion*, ICJ Rep. 1971 16, Separate Opinion, Judge Ammoun (International Court of Justice); *Filartiga v. Pena-Irala*, 630 F. 2d 876 (1980) (US Circuit Court of Appeals, 2nd Circuit). For an academic critique, see M.S. McDougal, H.D. Lasswell and L.C. Chen, *Human Rights and World Public Order*, (Yale University Press: 1980), pp. 273-74, 325-27. See also United Nations General Assembly Resolution 59 (1), 1946.

²⁷ UN General Assembly Resolution 2200A (XXI), adopted 16 December 1966, in force 23 March 1976.

²⁸ See also Article 8(1) of the ECHR which states “Everyone has the right to respect for his private and family life, his home and his correspondence”; Article 11(2) of the ACHR states “No one may be the object of arbitrary or abusive interference with his private life, his family, his home, or his correspondence, or of unlawful attacks on his honor or reputation”; Article 16(1) of the CRC states: No child shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence, nor to unlawful attacks on his or her honour and reputation.

²⁹ Human Rights Committee, General Comment No. 16: The right to respect of privacy, family, home and correspondence, and protection of honour and reputation (Art. 17), CCPR/C/GC/16, 4 August 1988; also see communication No. 726/1996, *Zheludkov v. Ukraine*, Views adopted on 29 October 2002.

The UN General Assembly has further emphasised the right of access in their 1990 “Guidelines for the regulation of computerized personal data files” which states:

Everyone who offers proof of identity has the right to know whether information concerning him is being processed and to obtain it in an intelligible form, without undue delay or expense, and to have appropriate rectifications or erasures made in the case of unlawful, unnecessary or inaccurate entries and, when it is being communicated, addressees. Provision should be made for a remedy, if need be with the supervisory authority specified in principle 8 below. The cost of any rectification shall be borne by the person responsible for the file. It is desirable that the provisions of this principle should apply to everyone, irrespective of nationality or place of residence.³⁰

Thus, the right of individuals to access information in records systems about their own medical conditions and treatments is further enhanced by the right of privacy.

There are also other important international agreements which recognise the right of access to information. Implementation of the right is a key requirement imposed on States parties to the UN Convention Against Corruption (UNCAC). Article 13 of the Convention requires that States should “[ensure] that the public has effective access to information”.

ii Regional law on the right to information

The right to information has also been explicitly recognised in all three regional systems for the protection of human rights.

In the Inter-American human rights system, the right to information is recognised by Article 13 of the American Convention on Human Rights (ACHR).³¹ In 2006, the Inter-American Court of Human Rights ruled in *Claude Reyes et al v Chile* that the general guarantee of freedom of expression contained in Article 13 of the ACHR ensures the right to information held by public bodies.³² The court stated that Article 13 of the ACHR, which is modelled on Article 19 of the ICCPR, “encompasses the right of individuals to receive ... information and the positive obligation of the State to provide it, in such form that the person can have access in order to know the information or

³⁰ General Assembly Resolution 45/95, “Guidelines for the regulation of computerized personal data files”, A/RES/45/95, 14 December 1990., §4.

³¹ Article 13 of the American Convention on Human Rights states: “1. Everyone shall have the right to freedom of thought and expression. This right shall include freedom to seek, receive and impart information of all kinds, regardless of frontiers, either orally, in writing, in print, in the form of art, or through any other medium of one’s choice.”

³² *Claude Reyes et al v Chile* Judgement of the Inter-American Court of Human Rights of 19 September 2006 Series C.

receive a motivated answer when for a reason recognised in the Convention, the State may limit the access to it in the particular case.”³³

Within Europe, the European Court of Human Rights has begun to recognise that when public bodies already hold information that is needed for public debate, the refusal to provide it to those who are seeking it is a violation of the right to freedom of expression and information.³⁴ The Court has also examined issues concerning reproductive rights and information resulting from medical testing. Notably, it has held that there needs to be an adequate legal and procedural framework to guarantee that relevant, full and reliable information on the foetus’ health is made available to pregnant women.³⁵

It has also adopted extensive case law on access to medical records and protection of confidentiality.³⁶

The Convention on Access to Official Documents was adopted in November 2009 and to date has been signed by eleven states and ratified by three.³⁷ The convention builds on the Committee of Ministers of the Council of Europe (CoE) Recommendation on Access to Official Documents of 2002 which sets out

broad principles calling on all CoE Member states to guarantee the right of access to all persons.³⁸

There are other important treaties within the Council of Europe. The European Convention on Human Rights and Biomedicine is especially important as it affirms the principles that individuals are entitled to have their personal health information kept private and that individuals should have the right to know information about their own health.³⁹ Article 10 states:

- 1 Everyone has the right to respect for private life in relation to information about his or her health.
- 2 Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.
- 3 In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraph 2 in the interests of the patient.

³³ Ibid at para 77.

³⁴ *Társaság a Szabadságjogokért v. Hungary*, Application No 37374/05 14 April 2009; *Kenedi v Hungary* (App No 31475/05) 26 May 2009.

³⁵ *R v Poland*, Application No 27617/04 26 May 2011.

³⁶ *I v Finland*, Application No 20511/03 17 July 2008

³⁷ See <http://conventions.coe.int/Treaty/Commun/ChercheSig.asp?NT=205&CM=8&DF=19/11/2010&CL=ENG> The convention will come into effect after ten states have ratified it.

³⁸ Recommendation No. R(2002)2, adopted 21 February 2002.

³⁹ 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, Adopted on 4 April 1997. ETS No. 164.

The right to have personal health data treated with confidentiality is also generally protected through the Council of Europe Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data (“Convention on Data Protection”)⁴⁰ and the EU Data Protection Directive.⁴¹ These measures oblige states to enact provisions into law to allow individuals access to their own health records held by public or private bodies and to limit access by other persons unless they have legal authorisation. In some cases, access to these records can be restricted to access by medical personnel acting on behalf of the individual.⁴²

With respect to the EU’s emerging system of human rights, Article 11(1) of the EU Charter of Fundamental Rights states that “the right to freedom of expression ... [includes] the freedom to ... receive and impart information and ideas without interference by public authority and regardless of frontiers.”⁴³ Article 42 gives all EU citizens and residents a right of access to documents held by EU bodies.

Finally, Article 9(1) of the African Charter on Human and Peoples’ Rights states that “every individual shall have the right to receive information.” In 2002, the African Commission on Human and Peoples’ Rights adopted a Declaration of Principles on Freedom of Expression in Africa⁴⁴ which establish principles on access to information both in the public and private sphere:

- 1 Public bodies hold information not for themselves but as custodians of the public good and everyone has a right to access this information, subject only to clearly defined rules established by law.
- 2 The right to information shall be guaranteed by law in accordance with the following principles:
 - everyone has the right to access information held by public bodies;
 - everyone has the right to access information held by private bodies which is necessary for the exercise or protection of any right;
 - any refusal to disclose information shall be subject to appeal to an independent body and/or the courts;

40 Convention for the Protection of Individuals with regard to Automatic Processing of Personal Data. Adopted on 28 January 1981, ETS No. 108.

41 Directive 95/46/EC of the European Parliament and of the 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; see also Directive 2002/58/EC of the European Parliament and of the Council of 12 July 2002 concerning the processing of personal data and the protection of privacy in the electronic communications sector (EU Directive on privacy and electronic communications).

42 See EU Directive, declaration 42 “Whereas Member States may, in the interest of the data subject or so as to protect the rights and freedoms of others, restrict rights of access and information; whereas they may, for example, specify that access to medical data may be obtained only through a health professional”

43 The Charter on Fundamental Rights of the European Union has had legal effect since 9 December 2009.

44 Adopted at the 32nd Session, 17-23 October 2002.

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- public bodies shall be required, even in the absence of a request, actively to publish important information of significant public interest;
 - no one shall be subject to any sanction for releasing in good faith information on wrongdoing, or that which would disclose a serious threat to health, safety or the environment save where the imposition of sanctions serves a legitimate interest and is necessary in a democratic society; and
 - secrecy laws shall be amended as necessary to comply with freedom of information principles.
- 3 Everyone has the right to access and update or otherwise correct their personal information, whether it is held by public or by private bodies.

The African Special Rapporteur has commented on freedom of information on multiple occasions, making the adoption of bills on access to information one of the key priorities for the continent. She particularly stated with reference to the role of freedom of information vis a vis accountability that “While Freedom of Information derives its origins from and is interrelated with Freedom of Expression, it occupies a special place in the human rights family, in that without the

transparency and accountability of public institutions which constitute a fundamental part of its core elements, the right to express and disseminate opinions for the purpose of ensuring good governance and strengthening democracy cannot be enjoyed in its totality.”⁴⁵

In addition to the growing international and regional recognition of a general right to information, there is greater acknowledgement at the national level that legislative and other measures are necessary to make this right effective. In terms of national laws on the right to information, nearly 100 countries have adopted legislation or national regulation on the right to date, with over 80 countries recognising the right to information as a constitutional right. The collection of states that has adopted legislation on the right to information encompasses states as diverse as Angola (2002),⁴⁶ Chile (2008),⁴⁷ Indonesia (2010) and Sweden (1766).⁴⁸

⁴⁵ African Special Rapporteur on Freedom of Expression, Activity report, presented to the 44th Ordinary Session of the African Commission on Human and Peoples’ Rights.

⁴⁶ Law on Access to Administrative Documents, No. 11/02, 2002.

⁴⁷ Law No 20.285 on Access to Information published in Official Gazette on 20 August 2008.

⁴⁸ The principle of public access to information has been established in Sweden since the 1766 Freedom of Press Act.

iii Interpretation of states' obligations on the right to information

The Human Rights Committee and the Special Rapporteur on Freedom of Opinion and Expression have developed a growing body of guidance on the right to information which is relevant to the right to health.

In General Comment No 34 adopted in 2011, the Human Rights Committee offered authoritative interpretation on the scope and limits of Article 19 of the ICCPR with respect to the right to information. The Comment affirmed that Article 19 of the ICCPR protects the right to information held by public bodies and requires the proactive dissemination of information in the public interest, specifically mentioning access to individuals' personal information and, specifically, medical records. The Comment also states that Article 19 of the ICCPR requires the enactment of the "necessary procedures" such as legislation to give effect to the right to information:

18 Article 19, paragraph 2 embraces a right of access to information held by public bodies. Such information includes records held by a public body, regardless of the form in which the information is stored, its source and the date of production. Public bodies are as indicated in paragraph 7 of this general comment. The designation of such bodies may also include other entities when such entities are carrying out public functions. As has already been noted, taken together with article 25 of the Covenant, the right of access to information includes a right whereby the media has access to information on public affairs⁴⁹ and the right of the general public to receive media output.⁵⁰ Elements of the right of access to information are also addressed elsewhere in the Covenant. As the Committee observed in its general comment No. 16, regarding article 17 of the Covenant, every individual should have the right to ascertain in an intelligible form, whether, and if so, what personal data is stored in automatic data files, and for what purposes. Every individual should also be able to ascertain which public authorities or private individuals or bodies control or may control his or her files. If such files contain incorrect personal data or have been collected

⁴⁹ See communication No. 633/95, *Gauthier v. Canada*.

⁵⁰ See communication No. 1334/2004, *Mavlonov and Sa'di v. Uzbekistan*.

or processed contrary to the provisions of the law, every individual should have the right to have his or her records rectified. Pursuant to article 10 of the Covenant, a prisoner does not lose the entitlement to access to his medical records.⁵¹ The Committee, in general comment No. 32 on article 14, set out the various entitlements to information that are held by those accused of a criminal offence.⁵² Pursuant to the provisions of article 2, persons should be in receipt of information regarding their Covenant rights in general.⁵³ Under article 27, a State party's decision-making that may substantively compromise the way of life and culture of a minority group should be undertaken in a process of information-sharing and consultation with affected communities.⁵⁴

19 To give effect to the right of access to information, States parties should proactively put in the public domain Government information of public interest. States parties should make every effort to ensure easy, prompt, effective and practical access to such information. States parties should also enact the necessary procedures, whereby one may gain access to information, such as by means of freedom of information legislation.⁵⁵ The procedures should provide for the timely processing of requests for information according to clear rules that are compatible with the Covenant. Fees for requests for information should not be such as to constitute an unreasonable impediment to access to information. Authorities should provide reasons for any refusal to provide access to information. Arrangements should be put in place for appeals from refusals to provide access to information as well as in cases of failure to respond to requests.

⁵¹ See communication No. 726/1996, *Zheludkov v. Ukraine*, Views adopted on 29 October 2002.

⁵² See the Committee's general comment No. 32 (2007) on the right to equality before courts and tribunals and to a fair trial, para. 33, Official Records of the General Assembly, Sixty-second Session, Supplement No. 40, vol. I (A/62/40 (Vol. I)), annex VI.

⁵³ General comment No. 31.

⁵⁴ See communication No. 1457/2006, *Poma v. Peru*, Views adopted on 27 March 2009.

⁵⁵ Concluding observations on Azerbaijan (CCPR/C/79/Add.38 (1994)).

The Special Rapporteur on Freedom of Opinion and Expression⁵⁶ has repeatedly called on all States to adopt and implement right to information legislation.⁵⁷

The mandate-holder has reaffirmed that the right to information “imposes a positive obligation on States to ensure access to information, particularly with regard to information held by Government in all types of storage and retrieval systems...”⁵⁸ Together with the Representative on Freedom of the Media of the Organisation for Security and Cooperation in Europe and the Special Rapporteur on Freedom of Expression of the Organisation of American States, the UN Special Rapporteur stated in a Joint Declaration in December 2004 that:

The right to access information held by public authorities is a fundamental human right which should be given effect at the national level through comprehensive legislation (for example Freedom of Information Acts) based on the principle of maximum disclosure, establishing a presumption that all information is accessible subject only to a narrow system of exceptions.⁵⁹

Thus, states’ obligations with respect to the right to information include, most notably, the implementation of that right into domestic law, through legislation on the right to information. Such legislation should:

- reflect the principle of “maximum disclosure” (i.e. any information held by a public body should in principle be openly accessible, in recognition of the fact that public bodies hold information not for themselves but for the public good);
- ensure that access to information may be refused only when it is necessary to protect a legitimate interest and in the overall public interest (i.e. blanket exclusions, class exceptions and provisions whose real aim is to protect the government from embarrassment or exposure are not permissible).

2 The right to health

This section highlights the right to health as protected by numerous international treaties and other instruments. In doing so, it emphasises the particular role that the right to information plays in the normative expression and interpretation of the right to health.

⁵⁶ The Office of the Special Rapporteur on Freedom of Opinion and Expression was established by the UN Commission on Human Rights, the most authoritative UN human rights body, in 1993: Resolution 1993/45, 5 March 1993.

⁵⁷ See, for example, the Concluding Observations of the Human Rights Committee in relation to Trinidad and Tobago, UN Doc. No. CCPR/CO/70/TT0/Add.1, 15 January 2001. 14. The comments of the UN Special Rapporteur on freedom of Opinion and Expression are discussed at length below.

⁵⁸ Report of the Special Rapporteur, 28 January 1998, Promotion and protection of the right to freedom of opinion and expression, UN Doc. E/CN.4/1998/40. 14.

⁵⁹ 6 December 2004. Available at: <http://www.cidh.org/Relatoria/showarticle.asp?artID=319&IID=1>.

i. International law on the right to health

The right to health has been part of the international human rights framework since the Universal Declaration of Human Rights. Article 25(1) states:

Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control.

The most important provision, however, is Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which states:

- 1 The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.
- 2 The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for:
 - a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;

- b) The improvement of all aspects of environmental and industrial hygiene;
- c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
- d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

Article 12 of the ICESCR should be read in conjunction with Article 2 which sets out the general legal obligations undertaken by States parties to the Covenant. It requires parties to take steps to progressively achieve the realization of the rights in a non-discriminatory manner.

The ICCPR also contains an important provision relevant to the right to health in Article 7 of the ICCPR, which concerns the principle of informed consent.

That provision states:

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. In particular, no one shall be subjected without his free consent to medical or scientific experimentation.

Other international human rights treaties concerning certain groups or issues contain provisions on the right to health also.

- Women: The Convention on the Elimination of Discrimination Against Women (CEDAW), which has 187 States parties, recognises the right of women to exercise their human rights on a basis of equality with men and requires that women have access to education and information necessary to promote and protect their reproductive health. Article 12(1) of CEDAW requires States Parties to “eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.”

The CEDAW Committee has stated that implementation of this right is “central to the health and well-being of women.”⁶⁰ It has also pointed out that an approach is required that incorporates information campaigns with education, and that particular attention should be paid to ensuring access to adequate health care facilities and information for rural women.

The Committee has made a number of specific recommendations for government action:

women’s health services and issues should receive a share of the overall health budget comparable with that for men’s health, taking into account their different needs;

all barriers to women’s access to health services, education and information, including in the area of sexual and reproductive health, should be removed;

States should allocate resources for programmes directed at adolescents for the prevention and treatment of sexually transmitted diseases, including HIV/AIDS;

the provision of health services to women by public, non-governmental and private organisations should be monitored to ensure equal access and quality of care;

specific health education for adolescents should address issues of gender equality, violence, prevention of sexually transmitted diseases and reproductive and sexual health rights.⁶¹

⁶⁰ Committee on the Elimination of Discrimination Against Women, General Comment 24, A/54/38 paras 29-31.

⁶¹ Ibid paras 29-31.

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- Racial Discrimination: The International Convention on the Elimination of Racial Discrimination (ICERD), which has 175 States parties, indicates that countries should “prohibit and ... eliminate racial discrimination in all its forms and ... guarantee the right of everyone, without distinction as to race, colour, or national or ethnic origin, to equality before the law, notably in the enjoyment of “the right to public health, medical care, social security and social services”.⁶²
 - Children: Article 24 of the Convention on the Rights of the Child, which with 193 States parties is the most widely ratified international human rights treaty, contains particularly detailed provisions obliging states to take extensive measures to protect both the right to health and the right to information.⁶³ Article 17 guarantees explicitly the right to receive information “aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health”.
 - The Committee on the Rights of the Child, which supervises the implementation of the treaty, has frequently criticised the poor information and education programmes of State parties to the Convention, which it considers a violation of children’s rights to health as well as their right to receive information.⁶⁴ In two of its general comments on adolescent health and development⁶⁵ and on HIV/AIDS,⁶⁶ it has emphasised the important role that information programmes play in ensuring a high level of reproductive health.⁶⁷
 - Individuals with disabilities: Article 25 of the Convention on the Rights of Persons With Disabilities obliges states to ensure access to health care to persons with disabilities.
 - Indigenous persons: Articles 21, 23 and 24 of the Declaration on the Rights of Indigenous Peoples contains provisions on the right to health.

⁶² Article 5.

⁶³ Adopted and opened for signature, ratification and accession by General Assembly Resolution 44/25 of 20 November 1989, entered into force 2 September 1990, Articles 13, 17.

⁶⁴ See, for example, its comments in relation to Lithuania (CRC/C/103 (2001)); Saudia Arabia (CRC/C/103 (2001)); Iran (CRC/C/97 (2000)); Djibouti (CRC/C/97 (2000) 96 at para. 555); and Egypt (CRC A/49/41 (1994)).

⁶⁵ Committee on the Rights of the Child, General Comment No. 4, Adolescent health and development in the context of the Convention on the Rights of the Child, CRC/GC/2003/4 (2003).

⁶⁶ Committee on the Rights of the Child, General Comment No. 3, HIV/AIDS and the right of the child, CRC/GC/2003/3 (2003).

⁶⁷ ARTICLE 19, Promoting and Protecting Access to Information and Reproductive and Sexual Health Rights in Peru, January 2006 <http://www.article19.org/data/files/pdfs/publications/peru-time-for-change.pdf>

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- Migrant workers: The International Convention on the Protection of the Rights of All Migrant Workers and Members of their Families of 1990 states that such workers and their families shall have the “right to receive any medical care that is urgently required for the preservation of their life or the avoidance of irreparable harm to their health on the basis of equality of treatment with nationals of the State concerned.”⁶⁸
 - the Vienna Declaration and Programme of Action adopted by the World Conference on Human Rights of 1993 which “recognizes the importance of the enjoyment by women of the highest standard of physical and mental health throughout their life span”;⁷⁰
 - the Millennium Declaration, adopted during the Millennium Summit in 2000, which makes a number of pledges in relation to the health-related dimensions of extreme poverty, especially with respect to maternal health.⁷¹ It also includes a strong demand for access to information.⁷²

In addition to treaty law, there is also a growing body of international declarations and other non-binding agreements which recognise the right to health.⁶⁹ These include, notably:

68 Articles 28 and 45.

69 There are also a range of other international instruments that are relevant to the right to health, including the Constitution of the World Health Organisation of 1946; the Declaration of the Rights of the Child 1959; the Declaration of Alma Ata of 1978; the Principles of Medical Ethics relevant to the Role of Health Personnel, particularly Physicians, in the Protection of Prisoners and Detainees against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment of 1982; the Declaration on the Right to Development of 1986; the Body of Principles for the Protection of All Persons under Any Form of Detention or Imprisonment of 1988; ILO Convention No 169 concerning Indigenous and Tribal Peoples in Independent Countries of 1989; the Basic Principles for the Treatment of Prisoners of 1990; the UN Rules for the Protection of Juveniles Deprived of their Liberty of 1990; the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care of 1991; the UN Principles for Older Persons of 1991; the Standard Rules on the Equalization of Opportunities for Persons with Disabilities of 1993; the Programme of Action of the International Conference on Population and Development of 1994; the Declaration on the Elimination of Violence against Women of 1994; the Programme of Action of the World Summit for Social Development of 1995; the Beijing Platform for Action of 1995; ILO Convention No 182; and the Worst Forms of Child Labour Convention 1999.

70 A/CONF.157/23 para 41.

71 A/RES/55/2.

72 Through the Millennium Declaration, states resolved: “to ensure the freedom of the media to perform their essential role and the right of the public to have access to information.” Ibid para 25.

Although there is currently no international treaty imposing specific obligations on states with respect to HIV/AIDS, the focus on this issue has resulted in the adoption of many declarations as well as the development of a general consensus on HIV/AIDS and the adoption of the International Guidelines on HIV/AIDS and Human Rights of 1996, which contain numerous provisions relevant for the right to information.⁷³ Guideline 6 (as revised in 2002) states:

States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of quality prevention measures and services, adequate prevention, and safe and effective medication at an affordable price.

States should also take measures necessary to ensure for all persons on a sustained and equal basis, the availability and accessibility of quality goods, services and information for HIV prevention, treatment, care and support

The World Health Organisation's Amsterdam Declaration on Patients' Rights of 1994 requires informed consent as a prerequisite for any medical intervention, guaranteeing also the right to refuse or halt medical interventions.⁷⁴

In addition to these international human rights legal provisions and standards, there are numerous provisions of international humanitarian law, specifically the four Geneva Conventions and the First and Second Protocols, which recognize the right to health of various groups of protected persons during international and non-international armed conflicts.⁷⁵

Furthermore, at the international level, the Basel Convention on the Control of Transboundary Movements of Hazardous Wastes and their Disposal, which has 178 States parties,⁷⁶ requires that "information about a proposed transboundary movement of hazardous wastes and other wastes be provided to the States concerned ... to state clearly the effects of the proposed movement on human health and the environment".⁷⁷ States parties are also required to "ensure that, in the case of an accident occurring during the transboundary movement of hazardous wastes or other wastes or their disposal, which are likely to present risks to human health and the environment in other States, those States are immediately informed."⁷⁸

73 Inter-Agency, International Guidelines on HIV/AIDS and Human Rights, July 2006, HR/PUB/06/9, available at: <http://www.unhcr.org/refworld/docid/4694a4a92.html> (2006 consolidated version)

74 Sandra Coliver, "The right to information necessary for reproductive health and choice under international law", 44 American University Law Review 1279 (1995).

75 <http://www.icrc.org/ihl.nsf/CONVPRES?OpenView>

77 Article 4.

78 Article 13.

ii. Regional law on the right to health

There are numerous regional standards on the right to health, notably the Revised European Social Charter⁷⁹ and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (the “Protocol of San Salvador”).⁸⁰

Furthermore, Article 35 of the EU Charter of Fundamental Rights concerns the right of access to health care.

With respect to the African region, Article 16 of the African Charter on Human and Peoples’ Rights states:

- 1 Every individual shall have the right to enjoy the best attainable state of physical and mental health.
- 2 State Parties to the present Charter shall take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.

Significantly, the Protocol to the African Charter on Human and Peoples’ Rights on the Rights of Women in Africa, “the Maputo Protocol” specifically includes the “right to have family planning education” and further obligates governments to “provide adequate, affordable and accessible services, including information, education and communication programmes to women especially those in rural areas”.⁸¹

The African Charter on the Rights and Welfare of the Child also has a provision asserting that “every child shall have the right to enjoy the best attainable state of physical, mental and spiritual health” and that “State Parties to the present Charter shall undertake to pursue the full implementation of this right and in particular shall take measures ... (c) to ensure the provision of adequate nutrition and safe drinking water; (d) to combat disease and malnutrition within the framework of primary health care through the application of appropriate technology; ... (h) to ensure that all sectors of the society, in particular, parents, children, community leaders and community workers are informed and supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of domestic and other accidents.”⁸²

79 Article 11.

80 Article 10.

81 Article 14.

82 Article 14.

A number of regional instruments also protect the specific right to informed consent: the Council of Europe's Convention on Human Rights and Biomedicine (Oviedo Convention) adopted in 1997, and its Additional Protocol concerning Biomedical Research of 2005; Article 3 of the EU Charter of Fundamental Rights (which became part of the EU Treaty in 2009); and the European Council's and Parliament's Clinical Trials Directive of 2001.

iii. Interpretation of states' obligations on the right to health

As indicated above, Article 2 of the ICESCR is relevant to the interpretation of the right to health under the Covenant. That provision states that the rights guaranteed by the Covenant, including the right to health, may be realised progressively. This principle thus acknowledges the constraints due to the limits of available resources.

However, the ICESCR imposes "various obligations which are of immediate effect", as the Committee on Economic, Social and Cultural Rights has emphasised.⁸³ These include the obligation that relevant rights "will be exercised without discrimination..."⁸⁴ They also include the obligation that "steps towards the realization of rights must be taken within a reasonably

short time after the Covenant's entry into force for the States concerned". Such steps should be "deliberate, concrete and targeted as clearly as possible towards meeting the obligations recognized in the Covenant".⁸⁵ Thus, the ICESCR imposes "an obligation to move as expeditiously and effectively" as possible towards the full realisation of rights contained in the Covenant.⁸⁶

In General Comment No 14, which was adopted in 2000, the Committee on Economic, Social and Cultural Rights delivered its authoritative interpretation of states' obligations on the right to the highest attainable standard of health under Article 12 of the ICESCR. In terms of actions to be taken by states pursuant to that provision, the Committee stated that the "non-exhaustive catalogue of examples in article 12.2 provides guidance in defining the action to be taken by States".⁸⁷ In other words, states need to take deliberate, concrete and targeted steps to achieve the full realization of the right to health.

⁸³ General Comment No 3, E/C.12/2000/4 para 1.

⁸⁴ See also General Comment No 20, E/C.12.GC/20. ⁸⁵ General Comment No 3, E/C.12/2000/4 para 2.

⁸⁶ Ibid para 9.

⁸⁷ General Comment No 14, para 13.

The Committee on Economic, Social and Cultural Rights has adopted the tripartite typology of state obligations, which has been applied in the area of social, economic and cultural rights, including the right to health, in particular: the obligations to respect, to protect and to fulfil.⁸⁸ The Maastricht Guidelines on Violations of Economic, Social and Cultural Rights explain these levels of obligations stating:

6 Like civil and political rights, economic, social and cultural rights impose three different types of obligations on States: the obligations to respect, protect and fulfil. Failure to perform any one of these three obligations constitutes a violation of such rights. The obligation to respect requires States to refrain from interfering with the enjoyment of economic, social and cultural rights [...] The obligation to fulfil requires States to take appropriate legislative, administrative, budgetary, judicial and other measures towards the full realization of such rights. Thus, the failure of States to provide essential primary health care to those in need may amount to a violation.

7 The obligations to respect, protect and fulfil each contain elements of obligation of conduct and obligation of result. The obligation of conduct requires action reasonably calculated to realize the enjoyment of a particular right. In the case of the right to health, for example, the obligation of conduct could involve the adoption and implementation of a plan of action to reduce maternal mortality. The obligation of result requires States to achieve specific targets to satisfy a detailed substantive standard. With respect to the right to health, for example, the obligation of result requires the reduction of maternal mortality to levels agreed at the 1994 Cairo International Conference on Population and Development and the 1995 Beijing Fourth World Conference on Women.⁸⁹

⁸⁸ See for example, General Comment No 12, The Right to Adequate Food (Article 11), E/C.12/1999/5, 12 May 1999 paras 14-20; General Comment No 13, The Right to Education (Article 13), E/C.12/1999/10, 8 December 1999 paras 46-48.

⁸⁹ General Comment No 14 above at para 36; Maastricht Guidelines on Violations of Economic, Social and Cultural Rights, adopted by a group of academic experts at a meeting in Maastricht on 22-26 January 1997.

The Committee on Economic, Social and Cultural Rights has provided numerous express examples of how states should meet the requirements to respect, to protect and to fulfil the right to health with respect to the right to information. In particular, States are under the following specific obligations of relevance to the issue of access to information:

- States should refrain from censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information;
- States should adopt legislation or take other measures ensuring equal access to health care and health-related services provided by third parties;
- States should ensure that privatization of the health sector does not constitute a threat to the availability, accessibility, acceptability and quality of health facilities, goods and services;
- States should ensure that harmful social or traditional practices do not interfere with access to pre- and post-natal care and family-planning;
- States should ensure that third parties do not limit people's access to health-related information and services; and
- States should implement sexual and reproductive health information campaigns, in particular with respect to HIV/AIDS.⁹⁰

The Committee has also provided examples of what may constitute a failure of a government to fulfil its obligations with respect to the right to health: a failure to adopt or implement a national health policy designed to ensure the right to health for everyone; insufficient expenditure or misallocation of available public resources which lead to the non-enjoyment of the right to health by individuals or groups, particularly the vulnerable or marginalized; the failure to reduce infant and mortality rates.⁹¹ The Committee also explicitly lists “the deliberate withholding or misrepresentation of information vital to health protection or treatment” as a clear-cut violation of the right to health.⁹²

⁹⁰ Ibid, at paras 34-37.

⁹¹ General Comment No 14 para 12(b). The UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standards of physical and mental health, Paul Hunt, developed some indicators to measure progress with regard to the realization of the right to health. E/CN.4/2006/48.

⁹² Ibid, at para. 50.

4. A legal and policy framework on the right to information and the right to health

This section presents a legal and policy framework to guide state authorities in properly implementing the right to health and the right to information as indivisible and interdependent rights. It consciously draws and builds on the work of international authorities, including the Committee on Economic, Social and Cultural Rights, to develop this framework.

Principle 1: Legal protection for the right to information and the right to health

In order to guarantee the right to information and the right to health, states should ensure that these rights are protected at a basic level in their domestic systems, through a legal framework. Legislation, however, by itself cannot guarantee that state authorities and public bodies will effectively implement these rights. There should therefore be both a legal as well as a policy framework involving key state organs, including the judiciary and administration, to ensure that these rights are made effective in accordance with international standards.

Recommendations

- State authorities should:
 - ensure that the right to information and the right to health are enshrined in domestic constitutional provisions or their equivalent, in accordance with international human rights law;

- establish clear legal and policy frameworks for the protection of the right to information and the right to health;
- adopt specific legislation on the right to information which includes a strong presumption in favour of disclosure if information, particularly information on health-related matters.

- State authorities – including the judiciary and public administration - should ensure that they are meeting their obligations to safeguard the rights to information and health through laws, policies and practices.⁹³ In doing so state authorities should fully implement the right to information as an interrelated and essential element to the realisation of the right to health.

Principle 2: Duties to respect, to protect and to fulfil rights

Under international law, states need to ensure that they respect, protect and fulfil the right to health, including insofar as this right overlaps with the right to information. General Comment No 14 offers important guidance in this regard and is drawn upon here.

⁹³ Report of Anand Grover, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health A/64/272 10 August 2009 para 94.

Recommendations

- State authorities should respect the right to health by, among other things, refraining from certain activities which may impede the realisation of the right to health. Such activities include:
 - imposing direct restrictions on access to health-related information (e.g. censoring, banning or limiting on certain types of health related information), including sexual and reproductive health;
 - withholding or intentionally misrepresenting health-related information, including sexual and reproductive health information.⁹⁴
- State authorities should protect the right to health by ensuring that third parties do not restrict or limit people's access to health-related information in the ways indicated above.⁹⁵
 - State authorities should fulfil the right to health through the promotion and provision of health-related information, education, research and statistics. The state authorities are specifically required to:
 - promote medical research and health education, as well as disseminate health information, in particular with respect to HIV/AIDS, sexual and reproductive health, traditional practices, domestic violence, the abuse of alcohol and the use of cigarettes, drugs and other harmful substances;⁹⁶
 - formulate, implement and periodically review a coherent national policy to minimize the risk of occupational accidents and diseases, as well as to provide a coherent national policy on occupational safety and health services which includes the provision of health information to workers and the production of annual statistics;⁹⁷
 - promote the recognition of factors favouring positive health results including the provision of information and research;

⁹⁴ General Comment No 14, above at para 34. In the opinion of the Committee on Economic, Social and Cultural Rights, the "deliberate withholding or misrepresentation of information vital to health protection or treatment" would constitute a violation of the obligation to respect. General Comment No 14, above at para 50.

⁹⁵ General Comment No 14, above at para 35.

⁹⁶ In an earlier General Comment on the reporting by States parties, the Committee on Economic, Social and Cultural Rights, states "need to monitor the actual situation with respect to each other of the rights on a regular basis and thus aware of the extent to which the various rights are, or are not, being enjoyed by all individuals within its territory... The fulfilment of this objective cannot be achieved only by the preparation of aggregate national statistics or estimates, but also requires that special attention be given to any worse-off regions or areas and to any specific groups or subgroups which appear to be particularly vulnerable or disadvantaged". In addition, one of the values of the reporting process "is to enable the Government to demonstrate that such principled policy-making has in fact been undertaken". General Comment No 1, E/1989/22 paras 2 and 4.

⁹⁷ See ILO Occupational Safety and Health Convention, 1981 (No. 155) and Occupational Health Services Convention, 1985 (No. 161).

- ensure that authorities meet the state's obligations on the dissemination of appropriate information relating to healthy lifestyles and nutrition, harmful traditional practices and the availability of services;
- support people in making informed choices about their health.⁹⁸

Principle 3: Non-discrimination and protection of vulnerable individuals

As indicated above, under Article 2 of the ICESCR the obligation of non-discrimination in the realisation of the right to health has immediate effect. Yet for many individuals and groups, including most notably women, the realisation of the right to health is often challenged through direct hurdles placed, often by family members, on their ability to access information (eg on women and girls' sexual and reproductive issues), or through factors of societal and structural discrimination (eg the availability of health related information in certain workplaces only, where women would be less likely to be present).

The Special Rapporteur on the right to health has recognised that one of the factors that make women more vulnerable to ill-health is a lack of access to information and education.⁹⁹ The need for human

rights education on the right to health for women has also been specifically recognised by the Committee on the Elimination of Discrimination Against Women, which in its recent concluding observations on Kenya, stated: "while women's access to justice is provide for by legislation, their ability to exercise that right and to bring cases of discrimination before courts is limited by such factors as ... lack of information about their rights".¹⁰⁰

State authorities also have legal obligations to ensure that essential health services for children encompass the provision of child-friendly information about health issues. In this regard, the Committee on Economic, Social and Cultural Rights has noted that the Convention on the Rights of the Child "directs States to ensure access to essential health services for the child and his or her family, including pre- and post-natal care for mothers. [It] links these goals with ensuring access to child-friendly information about preventive and health-promoting behaviour and support to families and communities in implementing these practices" (emphasis added).¹⁰¹

⁹⁸ General Comment No 14, E/C.12/2000/4 paras 36 and 37.

⁹⁹ "Factors that compound the vulnerability of women to ill health include a lack of access to information, education and services necessary to ensure sexual and reproductive health", Report of the Special Rapporteur, Paul Hunt E/CN.4/2003/58, 13 February 2003 para 65. See also Committee on the Elimination of Discrimination Against Women, General Recommendation No 24, para 18.

¹⁰⁰ Concluding Observations of the Committee on the Elimination of Discrimination against Women 2 February 2011 CEDAW/C/KEN/CO/7 para 13.

¹⁰¹ General Comment No 14, E/C.12/2000/4 para 22.

Furthermore, State parties should provide a “safe and supportive environment for adolescents that ensures their opportunity to participate in decisions affecting their health, to build life-skills, to acquire appropriate information, to receive counselling and to negotiate the health-behaviour choices they make.”¹⁰²

Besides women, girls and adolescents, individuals belonging to other vulnerable groups – such as persons with disabilities, sexual minorities, refugees and migrants, and those living with HIV/AIDS - may well face discrimination in accessing health-related information. Therefore, the principle of non-discrimination should form an essential part of any framework on implementing the right to information and the right to health.

Recommendations

- State authorities should ensure access to health information to everyone within the jurisdiction of the state, subject to the principle of confidentiality of personal data.¹⁰³ They should take positive steps to remove all barriers impeding access to health information in the public interest.
- State authorities should ensure the dissemination of health-related information on a non-discriminatory basis.¹⁰⁴ To this end, state authorities should take reasonable positive measures to ensure and enhance access to health information for certain groups including women, children, persons with disabilities, sexual minorities, refugees and migrants and individuals living with HIV/AIDS.¹⁰⁵

¹⁰² General Comment No 14 supra para 23.

¹⁰³ General Comment No 14, supra at note 97 para 21.

¹⁰⁴ Articles 2(2) and 3 of the ICESCR proscribes any discrimination in access to health care as well as the underlying determinants of health, as well as to means and entitlements for their procurement, on the grounds of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth, physical or mental disability, health status (including HIV/AIDS), sexual orientation and civil, political, social or other status, which has the intention or effect of nullifying or impairing the equal enjoyment or exercise of the right to health.

¹⁰⁵ Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt, 17 January 2007 A/HRC/4/28 at para 73. The Special Rapporteur refers to the Canadian case of *Eldridge v. British Columbia*, in which a group of deaf applicants challenged the absence of sign-language interpreters in the publicly funded health-care system. The Supreme Court held that provincial governments had a positive obligation under the Canadian Charter of Rights and Freedoms to address the needs of disadvantaged groups, such as persons with disabilities. The Court decided that the applicants had a right to publicly funded sign-language interpretation in the provision of health care and that the failure of the authorities to ensure that the applicants benefited equally from the provincial medicare scheme amounted to discrimination.

- State authorities have a particular duty to ensure that women in rural areas do not face barriers in accessing family planning information and other types of health-related information.¹⁰⁶
- State authorities should build an environment that allows children and adolescents to acquire health information and to make informed health choices. State authorities should ensure that essential health services for children encompass the provision of child-friendly information about health issues.¹⁰

Principle 4: The provision of information about public health and on specific issues

According to international human rights authorities, notably the Committee on Economic, Social and Cultural Rights, state bodies should disseminate particular types of health information. They place particular emphasis on the provision of information on maternal, reproductive and sexual health.

This should not negate, however, the importance that state authorities should attach to ensuring that the public is properly informed on other matters of general public health such as information about the risk of the spread of diseases, the results of scientific clinical trials or the regulatory approval of medicines. As Lemmens and Telfer argue, “access to critical information about ... drugs, such as the information created through the scientific community’s use of trial registries and results reporting, is ... a key determinant” of the right to health.¹⁰⁸

In this regard, it is recalled that in the seminal case of *The Sunday Times v The United Kingdom (No 1)*,¹⁰⁹ the European Court of Human Rights considered an injunction blocking the publication of an article about the production and regulation of the drug thalidomide as an unjustifiable restriction of Article 10 of the ECHR.¹¹⁰

106 Concluding Observations of the Committee on the Elimination of Discrimination against Women on Kenya, 2 February 2011 CEDAW/C/KEN/CO/7 para 38(d).

107 General Comment No 14, *supra* at note 97 para 22.

108 Trudo Lemmens and Candice Telfer, “Access to Information and the Right to Health: the Human Rights Case for Clinical Trials Transparency”, forthcoming in *American Journal of Law and Medicine* Vol 31, Issue 1 2012. Lemmens and Telfer recognise that “information is created in a complex economic, social, health care and research context” and “many clinical trials data do not have immediate implications for yet”. They continue: “[i]n this process of knowledge creation and interpretation, civil society, medical researchers, patient advocacy groups, industry scientists, government regulators and others all participate in an interactive exchange, often at a global level, in which those involved often have conflicting interests”.

109 *The Sunday Times v The United Kingdom* Application No 6538/74 judgment of the European Court of Human Rights of 26 April 1979.

110 *Ibid* at para 66.

Recommendations

- State authorities should ensure that the public has access to reliable and understandable information about matters of public health and the health system including information about: the risk and spread of diseases; essential, commonly-prescribed or used medicines or drugs; the results of clinical trials; and manufacturing and regulatory approval of medicines.

The Committee has frequently expressed concern about the situation of reproductive and sexual health in states, particularly for women. The Committee defines reproductive health as meaning the following:

that women and men have the freedom to decide if and when to reproduce and the right to be informed and to have access to safe, effective, affordable and acceptable methods of family planning of their choice as well as the right of access to appropriate health-care services that will, for example, enable women to go safely through pregnancy and childbirth.¹¹¹

In the context of reproductive rights, states should provide access to information about sexual and reproductive health, including abortion services. The judgment of the European Court of Human Rights in *Open Door and Dublin Well Women v Ireland* supports this position. In this case, the court found that the government of Ireland's prohibition against pregnancy counselling services providing any information about abortion facilities outside the country violated Article 10 of the ECHR.¹¹²

It is also important that women and girls, but also adults and young people more generally, have comprehensive sex education delivered by trained professionals, including on HIV/AIDS.¹¹³ Such information on sexual and reproductive health issues should be age appropriate in the sense that it is easily comprehensible for the target group.

¹¹¹ General Comment No 14 *supra* at note 97 at footnote12.

¹¹² *Open Door and Dublin Well Women v Ireland* Application No 14234/88 [1992] ECHR 68. This case is referenced even though it “does not deal with the broader public notion of human rights as protective of transparency and accountability in questions of public policy and government action” and was decided on the principle of proportionality (ie that the absolute prohibition on information about travelling abroad for an abortion was overly broad and disproportionate). Trudo Lemmens and Candice Telfer, “Access to Information and the Right to Health: the Human Rights Case for Clinical Trials Transparency” above.

¹¹³ The Committee on the Rights of the Child, in its 2007 Concluding Observations on Kenya, recommended that the state should take into account that committee's General Comment No 3 on HIV/AIDS and the rights of children and the International Guidelines on HIV/AIDS and Human Rights. General Comment No 3 of the Committee on the Rights of the Child CRC/GC/2003/3; International Guidelines on HIV/AIDS and Human Rights E/CN.4/1997/37. Committee on the Rights of the Child CRC/C/KEN/CO/2 19 June 2007 para 52(c).

State authorities should also disseminate specific information and promote education on the harmful effects of traditional practices, such as female genital mutilation, and the fact that their continued practice is an abuse of the rights of children and women.¹¹⁴ Such dissemination is particularly important in societies where such harmful practices are prevalent.

Recommendations

- State authorities should provide information on maternal, reproductive and sexual health matters, particularly to women and girls in a timely manner and without delay. This should include information about safe, effective, affordable and acceptable methods of family planning and access to appropriate health-care services,¹¹⁵ including pre- and post-natal care and emergency obstetric services.¹¹⁶

This information should include information about abortion services, even where abortion is legally restricted.¹¹⁷

- State authorities should provide information and education on HIV/AIDS and sexual health to young people, as well as training to medical workers and teachers on HIV/AIDS and sex education.
- State authorities should ensure that women and girls with HIV/AIDS have access to information about antiretroviral medication during pregnancy, labour and after birth, including for their children.¹¹⁸
- State authorities have a duty to ensure that reproductive, contraceptive, family-planning and sex information is age appropriate.¹¹⁹

114 Committee on the Rights of the Child CRC/C/KEN/CO/2 19 June 2007 para 53.

115 For example, in *Andrea Szijjarto v. Hungary*, a Hungarian woman of Roma origin alleged that she had been coercively sterilized. In 2000, she went into labour and was taken to hospital. Upon examination, it was found that the foetus had died and a Caesarean section was urgently needed. On the operating table, she was asked to sign a form consenting to the Caesarean section, as well as a "barely legible note" handwritten by the doctor giving permission for sterilization. The reference to sterilization was in a language that she did not understand. In her application to the Committee on the Elimination of Discrimination against Women, she alleged that this conduct constituted a violation of her right to appropriate health-care services, as well as her right to decide freely and responsibly on the number and spacing of her children. The Committee decided that Hungary had failed to provide Andrea with appropriate information and advice on family planning and ensure that Andrea had given her fully informed consent to the operation and it recommended that the Government provide the applicant with appropriate compensation. Committee on the Elimination of Discrimination Against Women, Communication No. 4/2004, UN Doc. CEDAW/C/36/D/4/2004 (2006).

116 General Comment No 14 supra at note 97 para 14.

117 Sandra Coliver, *ibid.*

118 Concluding Observations of the Committee on Economic, Social and Cultural Rights E/C.12/KEN/CO/1 December 2008, para 32.

119 The Committee on the Elimination of Discrimination Against Women has also called on States parties to take steps under the right to health, in particular to "prioritise the prevention of unwanted pregnancy through family planning and sex education and reduce maternal mortality rates through safe motherhood services and prenatal assistance". Committee on the Elimination of Discrimination Against Women, General Recommendation No 24, para 31. In a similar way the Convention on the Rights of Persons with Disabilities requires States parties to provide "access to age-appropriate information, reproductive and family planning education". Convention on the Rights of Persons with Disabilities Articles 23(b) and 25(a).

- State authorities should:
 - conduct awareness-raising campaigns to combat and eradicate traditional practices harmful to the health, survival and development of women and children, especially girls, such as female genital mutilation;
 - introduce sensitization programmes for practitioners and the general public to encourage change in traditional attitudes, and engage the extended family and the traditional and religious leaders in these actions.

Principle 5: Protection of the right to informed consent

Under the ICESCR, state authorities are required to implement the right to informed consent. This requirement draws together the right to health and the need and right to access information into one specific right.¹²⁰ The Special Rapporteur on the Right to Health, Anand Grover, has identified that this right also “invokes several elements of human rights ... [including] the right to ... freedom of ... expression”.¹²¹ He has stated:

Informed consent is not mere acceptance of a medical intervention, but a voluntary and sufficiently informed decision, protecting the right of the patient to be involved in medical decision-making, and assigning associated duties and obligations to health-care providers. Its ethical and legal normative justifications stem from its promotion of patient autonomy, self-determination, bodily integrity and well being.¹²²

The proper implementation of the right to informed consent therefore depends on the extent to which state authorities ensure that an individual has received the information necessary to be able to give consent. More specifically, the state has a duty to ensure that patients have a right to “disclosure of the associated benefits, risks and alternatives to a medical procedure ... [as well as]... the right to refuse such information in giving consent, providing disclosure of such information has been appropriately offered”.¹²³

¹²⁰ The Special Rapporteur has examined the fundamental role that informed consent plays in respecting, protecting and fulfilling the right to health, discussing specifically the areas of clinical practice, public health and medical research. Report of Anand Grover, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health A/64/272 10 August 2009.

¹²¹ *ibid.*

¹²² Report of Anand Grover, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health A/64/272 10 August 2009, para 9.

¹²³ Para 15. In addition, informed consent requires “legal capacity” (the “ability to comprehend, retain, believe and weigh information provided in arriving at a decision”) and is “valid only when documented prior to a medical procedure and provided voluntarily, meaning without coercion, undue influence or misrepresentation.” Paras 10 and 13. Legal capacity can be presumed amongst adult persons and renders them to the right to consent to, refuse or choose an alternative medical intervention. Children’s legal capacity is approached differently around the world, such as by the use of a competency test to establish the sufficient maturity to provide consent or requirements for parental control.

Recommendations

- State authorities should ensure that individuals have the necessary health-related information to be able to exercise their right to health effectively. To this end, health care providers should be required to disclose the associated benefits, risks and alternatives to the medical procedure offered, as well as the right to refuse such information in giving consent, providing disclosure of such information has been appropriately offered.
- State authorities should ensure that health care providers deliver the following aspects of a health system in order to fulfil the right to health:
 - services and information should be available, acceptable, accessible, and of good quality;
 - health information should be imparted and comprehended by means of supportive and protective measures such as counselling and the involvement of community networks;
 - health information should also be freely available on a non-discriminatory basis, accessible by reference to the individual's particular communication needs (including special physical or cultural circumstances), and presented in a manner culturally and otherwise acceptable to the person consenting;
 - the communication of health information should recognise varying levels of comprehension and should not be too technical, complex, hasty, or presented in a language, manner or context that the patient does not understand.¹²⁴

Principle 6: Protection of personal health information and medical data

Under Article 19 of the ICCPR, the right of access to information clearly includes the right to seek, receive and impart information and ideas concerning health issues. That right clearly encompasses the right to access to information about one's own personal health and medical records. This right should not impair "the right to have personal health data treated with confidentiality"¹²⁵ – an obligation flowing from the right to private life in relation to health which is protected in various international and regional instruments.¹²⁶

¹²⁴ Report of Anand Grover, Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health A/64/272 10 August 2009. Paras 22, 23 and 93.

¹²⁵ General Comment No 14, *supra* at note 97 para 12(b)(iv).

¹²⁶ See Articles 10(1) and (2) of the European Convention on Biomedicine. According to these principles, the following situations would involve a violation of patients' rights to the protection of their personal health data as a part of the right to private life: where patient medical information is open to all hospital staff, including those not involved in patient care; where patients are forced to disclose their medical diagnosis to their employer in order to obtain sick leave from work; where staff of medical/psychiatric institutions routinely open patient mail and review their correspondence. See Open Society Health Program/Equitas, Health and Human Rights, A Resource Guide March 2009 <http://www.equalpartners.info/PDFDocuments/EngCompleteResourceGuide.pdf>

As noted above in section 3.1, Article 17 of the ICCPR provides individuals with a right of access to, and protection of, their own personal information held by any person. The UN General Assembly has issued guidelines for member states on the confidentiality of personal information held in computer systems.

This protection of confidentiality is considered fundamental under European Human Rights laws. In *M.S. v Sweden* the European Court of Human Rights highlighted the fundamental importance of the protection of personal data, not least medical data, to a person's enjoyment of his or her right to private and family life.

Respecting the confidentiality of health data is a vital principle.... It is crucial not only to respect the sense of privacy of the patient but also to preserve his or her confidence in the medical profession and in the health services in general.¹²⁷

The Court has also recognised that the disclosure of health information may also “dramatically affect a person’s private and family life, as well as social and employment situation, by exposing him or her to opprobrium and the risk of ostracism.”¹²⁸

As indicated above, the right to have personal health data treated with confidentiality is further protected by the Council of Europe Convention on Data Protection,¹²⁹ the EU Data Protection Directive as well as a related ECOWAS directive.¹³⁰ The right is also found in the national data protection laws in over 80 states.¹³¹ These instruments and laws provide more guidance on the content of this right. They are reflected to an extent in the recommendations below.

Recommendations

- State authorities should ensure that individuals have full access to information about their own personal health, including their own medical records, held by any party.
- State authorities should ensure that the personal health information of individuals, including their medical records, are kept confidential and are not shared or processed without the informed consent of the individual concerned and the application of appropriate safeguards of domestic law.

¹²⁷ Application Nos 74/1996/693/885 Judgment of the European Court of Human Rights of 27 August 1997.

¹²⁸ *Z v Finland*, Application No 9/1996/627/811, Judgment of the European Court of Human Rights of 25 February 1997.

¹²⁹ Adopted on 28 January 1981, ETS No. 108.

¹³⁰ Directive 95/46/EC of the European Parliament and of the 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; ECOWAS, Supplementary Act A/SA.1/01/10 on Personal Data Protection within ECOWAS, 16 February 2010.

¹³¹ Ser Graham Greenleaf, *Global Data Privacy Laws: 89 Countries, and Accelerating, Privacy Laws & Business International Report*, Issue 115, Special Supplement, February 2012. <http://ssrn.com/abstract=2000034>; See also Banisar, *Data Protection Laws Around the World Map*, November 2011. <http://ssrn.com/abstract=1951416>

- To safeguard the right to the protection of personal health information, including medical records, state authorities should ensure that individuals have the ability to:
 - Establish the existence of a file containing information or data about their personal health, inquire about the reasons for its creation, determine the identity and address of the controller of the file and any parties who have access to the file;
 - Access the file or data in an intelligible form without delay or expense;
 - Obtain the rectification or the erasure of the file or data if they have been processed contrary to appropriate safeguards;
 - Have a remedy if the request for confirmation, communication, rectification or erasure is not complied with.¹³²
- State authorities should ensure that those who have access to information on the health status of persons in public life take appropriate measures to maintain its confidential nature.

Principle 7: Development of health indicators and the dissemination of health information

i. Indicators and benchmarks

Under their obligations to report to the Committee on Economic, Social and Cultural Rights under Article 12(2) of the ICESCR, States parties have a duty to provide information as to the steps taken to achieve the full realisation of the right to health including those necessary for:

- a) The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
- b) The improvement of all aspects of environmental and industrial hygiene;
- c) The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
- d) The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

The development of a range of specific and appropriate health indicators and national benchmarks in relation to each indicator is crucial to enabling any state to properly strategise on the improvement

¹³² Article 9 of the Convention on Data Protection.

of its health system. It is also essential for the purposes of the free flow of information and transparency, and, consequently, governmental accountability for the health system. As the Special Rapporteur on the right to health has stated, “health indicators are needed to measure the degree to which health information is available and accessible to all”.¹³³ Finally, it is also necessary for the government of a state to report on the domestic implementation of the international treaty provisions on the right to health to international treaty monitoring bodies, notably Article 12 of the ICESCR to the Committee on Economic, Social and Cultural Rights.

Health indicators may be developed or improved on the basis of the existing work undertaken by the World Health Organisation (WHO) as well as, in particular, the United Nations Children’s Fund (UNICEF).¹³⁴ A number of health indicators¹³⁵ inform the work of the WHO including the compilation of the World Health Statistics Report, its annual compilation of data from its 193 Member States, which includes a summary of progress towards the health-related Millennium Development Goals and Targets. The report draws on indicators to provide a comprehensive summary of the current status of national health and health

systems in the following nine areas: life expectancy and mortality; cause-specific mortality and morbidity; selected infectious diseases; health service coverage; risk factors; health workforce, infrastructure and essential medicines; health expenditure; health inequities and demographic and socioeconomic statistics.¹³⁶ Due to the requirements of confidentiality regarding personal health data, indicators should also be developed to measure the degree to which such confidentiality is respected.

Recommendation

- State authorities should develop health indicators that monitor the state’s progress towards the achievement of the right to health. In doing so, states should obtain guidance on appropriate right to health indicators, addressing different aspects of the right to health from relevant global agencies, such as the World Health Organisation (WHO) and the United Nations Children’s Fund (UNICEF) in this field.

ii. Data collection and dissemination

States are required to provide and disseminate information on public health and the health system. The State is under an obligation to proactively disseminate

¹³³ Report to the sixty second session of the Commission on Human Rights, E/CN.4/2006/48, 3 March 2006 at para 49(c)(iii).

¹³⁴ The WHO organisation is the directing and coordinating authority for health within the UN system that is responsible for providing leadership on global health matters, shaping the health research agenda, setting norms and standards, articulating evidence-based policy options, providing technical support to countries and monitoring and assessing health trends.

¹³⁵ For the WHO indicators see WHO Indicator Compendium (2011) http://www.who.int/whosis/indicators/WHS2011_IndicatorCompendium_20110530.pdf

¹³⁶ WHO, World Health Statistics 2011 http://www.who.int/gho/publications/world_health_statistics/EN_WHS2011_Full.pdf

information in the public interest, under Article 19 of the ICCPR, as well as to take deliberate, concrete and targeted steps to realise the right to health under Article 12 of the ICESCR. In view of discrimination against individuals on a number of grounds, it is important that such information on health issues is disaggregated.

Disaggregation of data according to gender is especially important because of the challenges, vulnerabilities and discrimination faced by women and girls in societies across the world. As the Committee on Economic, Social and Cultural Rights states: “the disaggregation of health and socio-economic data according to sex is essential for identifying and remedying inequalities in health”.¹³⁷ State authorities should also ensure the disaggregation according a range of criteria including, most obviously, “the prohibited grounds of discrimination”.¹³⁸ The prohibited grounds of discrimination should be included to encompass sex, racial or ethnic origin, language, religion, national or social group, as well as disability, age and sexual orientation and identity. Finally, in order to assess and address any disparities in health between urban and rural populations or between different socio-economic groups, it is important that data is disaggregated according to geographic situation and income levels.

The collection and provision of such disaggregated data may certainly be costly. However, the “‘opportunity’ far outweighs the ‘cost’, not only in terms of the added value for focusing interventions on key bottlenecks and informing policy-making in the [health sector], but also the very substantial knock-on effects that this would bring for health, education, gender equality, education, nutrition, economic growth and poverty reduction”.¹³⁹ In preparing their reports for international bodies, states, particularly low-income states, should use “the extensive information and advisory services of WHO with regard to data collection [and] disaggregation”.¹⁴⁰

The Special Rapporteur has recognized the value of disaggregated data and indicators. The former mandate holder has stated: “disaggregated indicators, such as the proportion of births attended by skilled health personnel, when used with benchmarks, can help a State identify which policies are working and which are not. Moreover, it can also help to hold a State to account in relation to its responsibilities arising from the right to health.” At the same time, only one indicator, even when disaggregated, “cannot possibly capture all the dimensions that are important from the human rights perspective”.¹⁴¹

137 General Comment 14 (2000) *supra* at note 97 para 20.

138 *Above* at para 57.

139 See the Comments (in relation to water and sanitation) of the Independent Expert on the issue of human rights obligations related to access to safe drinking water and sanitation in Climate Change and Human Rights to Water and Sanitation, Position Paper http://www2.ohchr.org/english/issues/water/lexpert/docs/Climate_Change_Right_Water_Sanitation.pdf p 40.

140 General Comment No 14 *supra* at note 97 at para 63.

141 E/CN.4/2006/48 para 47.

Recommendations

- State authorities should ensure that:
 - Reliable data relating to the realisation of the right to health is collected on a comprehensive and regular basis, and is used to inform public health policy-making as well as periodic reporting under international human rights treaties, including data on the accessibility, adequacy, acceptability and affordability of health services and facilities;
 - Information on the challenges to public health and policy responses is widely available in a range of languages and accessible formats, including non-technical summaries of key documents and descriptions of public health policies;
 - Data on the realisation of the right to health is disaggregated according to excluded individuals and groups with a particular reference to sex, racial or ethnic origin, language, religion, national or social group, disability, age and sexual orientation and identity. Such data should also be disaggregated according to underserved areas, urban and rural disparities and upper and lower income quintiles.

Principle 8: Publicising international reporting obligations

As the Limburg Principles on the Implementation of the ICESCR highlight, information related to health policies is essential for effective decision-making in health-related policy processes.¹⁴² Principle 76 mentions that the process of reporting before the Committee on Economic, Social and Cultural Rights itself should be publicized in order to allow for public debate and participation.

76 States parties should view their reporting obligations as an opportunity for broad public discussion on goals and policies designed to realize economic, social and cultural rights. For this purpose wide publicity should be given to the reports, if possible in draft. The preparation of reports should also be an occasion to review the extent to which relevant national policies adequately reflect the scope and content of each right, and to specify the means by which it is to be realized.

Recommendation

- State authorities should publicise the process of reporting to the UN treaty bodies itself to facilitate and promote public understanding, discussion and participation on the impact of national policies, practices and processes on the realisation of the right to health.

Principle 9: Obligations of the international community, civil society and the media

Coordinated efforts for the realization of the right to health through the provision and promotion of health related information and information about health services also require the involvement of other States parties to the ICESCR, intergovernmental organisations, various components of civil society and the media.

i. States parties to the ICESCR

Whilst a state's authorities and bodies have the primary responsibility to ensure the right to health, other states who are States parties to the ICESCR also have mutual and concurrent obligations under Article 2(1) of the ICESCR. That provision states:

- 1 Each State Party to the present Covenant undertakes to take steps, individually and through international assistance and co-operation, especially economic and technical, to the maximum of its available resources, with a view to achieving progressively the full realization of the rights recognized in the present Covenant by all appropriate means, including particularly the adoption of legislative measures.

In its General Comment No 3, the Committee drew attention to the obligation of all States parties to take steps, individually and through international assistance and cooperation, especially economic and technical, towards the full realization of the rights recognized in the Covenant, such as the right to health.¹⁴³

In General Comment 14, the Committee on Economic Social and Cultural Rights indicated that: "States parties should recognize the essential role of international cooperation and comply with their commitment to take joint and separate action to achieve the full realization of the right to health".¹⁴⁴ In this regard, "States parties are referred to the Alma-Ata Declaration which proclaims that the existing gross inequality in the health status of the people, particularly between developed and developing countries, as well as within countries, is politically, socially and economically unacceptable and is, therefore, of common concern to all countries."¹⁴⁵

Furthermore, donor states should ensure that overseas development assistance (ODA) is fully transparent and there is access to information on the use of ODA and full and meaningful participation of all relevant stakeholders, including affected communities, in the use of ODA.¹⁴⁶

¹⁴³ General Comment No 3 on the "Nature of States Parties' Obligations" 14 December 1990.

¹⁴⁴ General Comment No 14, UN Doc E/C.12/2000/4 at para 38. See also Article 56 of the UN Charter, Articles 12, 2(1), 22 and 23 of the ICESCR and Article II, Alma-Ata Declaration, Report of the International Conference on Primary Health Care, Alma-Ata, 6-12 September 1978, in World Health Organization, "Health for All" Series, No. 1, WHO, Geneva, 1978.

¹⁴⁵ General Comment No 14, *ibid* at para 38.

¹⁴⁶ Independent Expert on the issue of human rights obligations related to access to safe drinking water and sanitation, Climate Change and Human Rights to Water and Sanitation, Position Paper http://www2.ohchr.org/english/issues/water/expert/docs/Climate_Change_Right_Water_Sanitation.pdf p 33. See also the London Declaration on Transparency, the Free Flow of Information and Development 25 August 2010 <http://www.article19.org/data/files/medialibrary/1798/London-Declaration.pdf>

Recommendations

- States parties to the ICESCR are obliged to respect the enjoyment of the right to health in other states and to prevent third parties from violating the right in those other states if they are able to influence these third parties by way of legal or political means. In this regard, States parties to the ICESCR are obliged to facilitate access to health information and information about health services in other states through agreements, discussions and other measures.
- All states should ensure that their overseas development assistance (ODA), particularly where it is being targeted to promote the right to health, is fully transparent and there is access to information on the use of ODA.

ii. Intergovernmental organisations and agencies

Under Articles 22 and 23 of the ICESCR, relevant bodies within the United Nations system should cooperate effectively with a state's authorities, building on its respective expertise, in relation to the implementation of the right to health at the national level, with due respect to their individual mandates. In doing so, these bodies should support states to take steps to realise the right to health, including through the promotion of the right to information.¹⁴⁷

Recommendation

- Intergovernmental organisations working to promote global public health should support states' authorities to take steps to realise the right to health at the national level, including through the promotion of the right to information.

iii. Civil society and the media

Access to health information allows civil society groups as well as the media to ensure public accountability and to facilitate scrutiny of governmental decisions on health related matters.¹⁴⁸ It is recalled that the European Court of Human Rights affirmed the importance of civil society organisations being able to obtain access to government-held information for the purpose of promoting public debate and playing “their vital role as ‘public watchdogs’”.¹⁴⁹

Civil society organizations may also themselves engage in activities to promote access to health information. The role of non-governmental organizations in developing countries has often been characterized by initiatives which enhance transparency and the right to health information.

¹⁴⁷ General Comment No 14 supra note 142 at para 64.

¹⁴⁸ Trudo Lemmens and Candice Telfer above.

¹⁴⁹ Társaság a Szabadságjogokért v. Hungary, Application no. 37374/05 14 April 2009 at para 38.

As the Special Rapporteur on the Right to Health, Paul Hunt, has recognized:

Non-governmental organizations working in low- and middle-income countries have always had a clearer appreciation of health and human rights issues than their counterparts working in high-income countries. In some countries, the Special Rapporteur has been deeply impressed by civil society's commitment to, and familiarity with, the right to health. In Peru, for example, some civil society groups explicitly use human rights language, run right-to-health information campaigns, call for grass-roots participation in health policymaking, take health and human rights cases, and so on. Such health and human rights activism has coincided with the publication of a range of relevant materials in all regions, such as *The Right to Health: A Resource Manual for NGOs*.¹⁵⁰

NGOs should build on their existing roles of promoting the right to health through the scrutiny of state health policies and through the initiation or support of campaigns that promote access to health information specifically.

Recommendations

- State authorities should support the role of civil society organizations and the media in promoting the right to health. In doing so, state authorities should establish and protect an enabling environment for civil society organisations and the media.
- Civil society organisations should develop or enhance their strategies (including litigation strategies) and campaigns to promote access to health information.

¹⁵⁰ J Asher, *The Right to Health: A Resource Manual for NGOs*, 2004. Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt, 17 January 2007 A/HRC/4/28 at para 12.

5. Case-study: Maternal health

This section of the policy highlights one particular issue, that of maternal health. At the outset, it is noted that improvement in maternal health is not only a human rights issue but constitutes one of the eight Millennium Development Goals (MDG 5).

The two targets for this goal are to: (5A) reduce by three quarters, between 1990 and 2015, the maternal mortality ratio; and (5B) achieve, by 2015, universal access to reproductive health. It is clear that accurate and timely information is required to be able to track the respective indicators for each of these targets.¹⁵¹

Progress towards the achievement of this goal has been very slow. The United Nations Development Programme (UNDP) has noted that the international community is a long way from achieving MDG 5 on maternal health.¹⁵² Its website states:

Maternal mortality remains unacceptably high across much of the developing world. In 2005, more than 500,000 women died during pregnancy, childbirth or in the six weeks after delivery. Ninety-nine per cent of these deaths occurred in the developing regions, with sub-Saharan Africa and Southern Asia accounting for 86 per cent of them. In sub-Saharan Africa,

a woman's risk of dying from treatable or preventable complications of pregnancy and childbirth over the course of her lifetime is 1 in 22, compared to 1 in 7,300 in the developed regions.¹⁵³

In 2011, the WHO assessed global progress towards this goal in the following terms:

The number of women dying as a result of complications during pregnancy and childbirth has decreased by 34% – from 546 000 in 1990 to 358 000 in 2008. Although the progress is notable, the annual rate of decline of 2.3% is less than half of the 5.5% needed to achieve the target. Almost all maternal deaths (99%) in 2008 occurred in developing countries.

¹⁵¹ For target 5A, the indicators are: 5.1 Maternal mortality ratio; and 5.2 Proportion of births attended by skilled health personnel. For target 5B, the indicators are: 5.3 Contraceptive prevalence rate; 5.4 Adolescent birth rate; 5.5 Antenatal care coverage (at least one visit and at least four visits); 5.6 Unmet need for family planning

¹⁵² See generally UNDP, The Millennium Development Goals Report 2011 (Progress Report) http://mdgs.un.org/unsd/mdg/Resources/Static/Products/Progress2011/11-31339%20%28E%29%20MDG%20Report%202011_Book%20LR.pdf

¹⁵³ UNDP, How can we track MDG progress? <http://web.undp.org/mdg/progress.shtml>

From 2000 to 2010 just over half of all pregnant women made the WHO-recommended minimum of four antenatal visits. While the global proportion of births attended by a skilled health worker has increased, in the WHO regions of Africa and South-East Asia fewer than half of all births had skilled assistance.

Globally, contraceptive use has been on the rise, annually increasing 0.2% since 2000. From 2000 to 2008 there were 48 births per 1000 adolescent girls aged 15–19 globally.¹⁵⁴

As these statements from the UNDP and WHO suggest, the major challenge to maternal health stems from problems broadly concerning issues of maternal mortality and morbidity.

Maternal mortality is defined by the WHO as: “the death of a woman while pregnant or within 42 days of termination of pregnancy ... from any cause related to or aggravated by the pregnancy or its management, but not from accidental or incidental causes”.¹⁵⁵

Maternal morbidity is defined as a “condition outside of normal pregnancy, labour, and childbirth that negatively affects a woman’s health during those times.”¹⁵⁶

Challenges to maternal health, particularly the factors contributing to maternal mortality, are deeply connected with access to information. ¹⁵⁷ Resolution 11/8 of the Human Rights Council adopted on 17 June 2009 recognises that:

Most instances of maternal mortality and morbidity are preventable and that preventable maternal mortality and morbidity is a health, development and human rights challenge that also requires the effective promotion and protection of the human rights of women and girls, in particular their rights to life, to be equal in dignity, to education, to be free to seek, receive and impart information, to enjoy the benefits of scientific progress, to freedom from discrimination, and to enjoy the highest standard of physical and mental health, including sexual and reproductive health.¹⁵⁸

154 WHO, Progress towards the health-related Millennium Development Goals, May 2011 <http://www.who.int/mediacentre/factsheets/fs290/en/index.html>

155 WHO, International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, vol 2, Instruction Manual, (2nd ed, Geneva, 2004) p 141.

156 S. A. Orshan, *Maternity, Newborn and Women’s Health Nursing: Comprehensive Care across the Life Span* (Philadelphia, Lippincott Williams and Wilkins, 2008) p 15.

157 The UN’s High Commissioner for Human Rights Navi Pillay has also recognised that issues of maternal mortality and morbidity implicate the right to information. She stated: “There are multiple human rights dimensions to maternal mortality and morbidity, ranging from how these compromise the right to life, to be equal in dignity, to education, to be free to seek, receive and impart information, to enjoy the benefits of scientific progress, to freedom from discrimination, and the highest attainable standard of physical and mental health.” Geneva, 14 June 2010 <http://www.ohchr.org/EN/NewsEvents/Pages/MaternalMortality.aspx>

158 Para 2, Resolution 11/8 of 17 June 2009.

The UN Special Rapporteur on the right to health has indicated that the right to health “entitles women to services in connection with pregnancy and the post-natal period, and to other services and information on sexual and reproductive health”.¹⁵⁹

Moreover, the mandate holder has recognised that maternal mortality is overwhelmingly due to delays that ultimately prevent pregnant women from accessing the health care they need. The first of these delays is the delay in seeking appropriate medical help for an obstetric emergency for reasons of lack of access to information as well as for lack of cost, lack of recognition of an emergency, poor education and gender inequality.¹⁶⁰ Therefore, timely access to reliable reproductive and sexual health related information is crucial for the protection of health of women and girls, particularly during and after pregnancy.

Access to such information for women and girls is also about ensuring gender equality and non-discrimination on the basis of sex. States have an obligation to ensure that their laws, policies and practices meaningfully address the specific needs of women because of their ability to become pregnant and give birth, including by providing sexual and reproductive health and services.¹⁶¹

Furthermore, access to information is a necessary part of women’s ability to make informed choices with respect to their sexual and reproductive lives and to access health services necessary to ensure a healthy pregnancy and delivery. It is recalled that CEDAW establishes that states must provide “access to the information, education and means” to enable women to decide freely and responsibly on the number and spacing of their children.

It is also important to emphasise that access to such information should not only be provided to adult women, but also to adolescents and girls. The Committee on the Rights of the Child has emphasised that states “should provide adolescents with access to sexual and reproductive information, including on family planning and contraceptives, the dangers of early pregnancy, the prevention of HIV/AIDS and the prevention and treatment of sexually transmitted diseases.”¹⁶²

¹⁵⁹ Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Paul Hunt, A/61/338, 13 September 2006 para 13.

¹⁶⁰ Ibid at para 21. See also Report of the Office of the High Commissioner for Human Rights on preventable maternal mortality and morbidity and human rights, A/HRC/13/39, 16 April 2010.

¹⁶¹ Report of the Office of the High Commissioner for Human Rights on preventable maternal mortality and morbidity and human rights, A/HRC/13/39, 16 April 2010, para 17.

¹⁶² General Comment No 14: Adolescent health and development in the context of the Convention on the Rights of the Child (2003), para 28.

The following recommendations on the right to information and the right to maternal health have been indicated previously, but deserve emphasis here.

Recommendations

- State authorities should provide information on maternal, reproductive and sexual health matters to women and girls in a timely manner and without delay. This should include information about safe, effective, affordable and acceptable methods of family planning and access to appropriate health-care services, including pre- and post-natal care and emergency obstetric services. This information should include information about abortion services, even where abortion is legally restricted.
- State authorities should ensure that women and girls with HIV/AIDS have access to information about antiretroviral medication during pregnancy, labour and after birth, including for their children.
- State authorities have a duty to ensure that reproductive, contraceptive, family-planning and sex information is age appropriate.

6. Conclusions and recommendations

This policy brief has demonstrated how the right to information and the right to health unite in specific legal and policy terms. The brief develops a number of principles that should form the basis of any comprehensive and coherent national health policy which properly protects the right to information, concerning: (1) the legal protection for the right to information and the right to health; (2) duties to respect, to protect and to fulfil rights; (3) non-discrimination and protection of vulnerable individuals; (4) the provision of information about public health and on specific issues; (5) the protection of the right to informed consent; (6) the protection of personal health information and medical data; (7) the development of health indicators and the dissemination of health information; (8) publicising international reporting obligations of states and (9) the obligations of the international community, civil society and the media.

ARTICLE 19 strongly recommends that all states and relevant non-state actors adopt these recommendations as a crystallisation of the state of the relationship between these two rights and as an indication as to how these rights may be realised simultaneously in practice.

The recommendations of this policy brief are focussed on state actors, although non-state actors should also contribute to promoting the right to information and the right to health as mutually reinforcing rights.

In terms of internal or domestic laws and policies:

- State authorities should ensure that there is a legal and policy framework for the protection of the right to information and the right to health, including constitutional and legal protections for these rights.
- State authorities – including the judiciary and public administration - should ensure that they are meeting their obligations to safeguard the rights to information and health through laws, policies and practices.
- State authorities should respect the right to health by, among other things, refraining from certain activities – such as withholding, limiting or misrepresenting health related information – which may impede the realisation of the right to health.
- State authorities should protect the right to health by ensuring that third parties do not restrict or limit people's access to health-related information.

- State authorities should fulfil the right to health through the promotion and provision of health-related information, education, research and statistics.
- State authorities should ensure access to health information to everyone within the jurisdiction of the state, subject to the principle of the confidentiality of personal data.
- State authorities should ensure the dissemination of health-related information on a non-discriminatory basis. They should take measures to ensure and enhance access to health information for certain groups including women, children, persons with disabilities, sexual minorities, refugees and migrants and individuals living with HIV/AIDS.
- State authorities should ensure that women in rural areas do not face barriers in accessing family planning information and other types of health-related information.
- State authorities should build an environment that allows children and adolescents to acquire health information and to make informed health choices.
- State authorities should ensure that the public has access to reliable and understandable information about matters of public health and the health system including information about: the risk and spread of diseases; essential, commonly-prescribed or used medicines or drugs; the results of clinical trials and the manufacturing and regulatory approval of medicines.
- State authorities should provide reliable information on maternal, reproductive and sexual health matters, particularly to women and girls, including on family planning, health and abortion services. Such information should be provided in a timely manner and without delay.
- State authorities should provide information and education on HIV/AIDS and sexual health to young people, as well as training to medical workers and teachers on HIV/AIDS and sex education.
- State authorities should ensure that women with HIV/AIDS have access to information about antiretroviral medication.
- State authorities have a duty to ensure that reproductive, contraceptive, family-planning and sex information is age appropriate.

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- State authorities should conduct awareness-raising campaigns to combat and eradicate traditional practices (e.g. female genital mutilation) and introduce sensitization programmes to encourage change in traditional attitudes.
 - State authorities should ensure that individuals have the necessary health-related information be able to exercise their right to information effectively (e.g. on the associated benefits, risks and alternatives to the medical procedure offered).
 - State authorities should ensure that health care providers provide information on aspects of a health system that is available, acceptable, accessible, of good quality, freely available on a non-discriminatory basis, and presented in a manner culturally and otherwise acceptable to the person consenting.
 - State authorities should ensure that individuals have full access to information about their own personal health, including their personal medical records.
 - State authorities should ensure that the personal health information of individuals is kept confidential and is not shared or processed without the informed consent of the individual concerned and the application of appropriate safeguards.
 - State authorities should ensure that those who have access to information on the health status of persons of concern take appropriate measures to maintain its confidential nature.
 - State authorities should develop, on the basis of guidance from relevant global agencies such as WHO and UNICEF, health indicators that monitor the state's progress towards the achievement of the right to health.
 - State authorities should ensure that reliable and disaggregated data relating to the realisation of the right to health (e.g. on the accessibility, adequacy, acceptability and affordability of health services and facilities and the challenges to public health) is collected on a comprehensive and regular basis, and is used to inform public health policy-making and reporting to international bodies.
 - State authorities should publicise the process of reporting to the UN treaty bodies to facilitate and promote public understanding and discussion of, and participation in, the impact of national policies, practices and processes on the realisation of the right to health.
 - State authorities should support the role of civil society organizations and the media in promoting the right to health. In doing so, state authorities should establish and protect an enabling environment for civil society organisations and the media.

In terms of external or foreign policies:

- States should respect the enjoyment of the right to health in other states. States should prevent third parties from violating the right to health in those other states if they are able to influence third parties through legal or political means.
- States should ensure that their overseas development assistance (ODA), particularly that which is targeted to promote the right to health, is fully transparent and that access to information is provided on the use of ODA.

Whilst states have obligations under international and regional human rights treaties, non-state actors also have responsibilities to promote the right to information and the right to health. Notably:

- Intergovernmental organisations working to promote global public health should support states' authorities to take steps to realise the right to health at the national level, including through the promotion of the right to information.
- Civil society organisations should develop or enhance their strategies (including litigation strategies) and campaigns to promote access to health information.

About the ARTICLE 19 Law Programme

The ARTICLE 19 Law Programme advocates for the development of progressive standards on freedom of expression and access to information at the international level, and their implementation in domestic legal systems. The Law Programme has produced a number of standard-setting publications outlining international and comparative law and best practice in areas such as defamation, access to information and broadcast regulation.

On the basis of these publications and ARTICLE 19's overall legal expertise, the Law Programme publishes a number of legal analyses each year, comments on legislative proposals, and existing laws that affect the right to freedom of expression, and develops policy papers and other documents. This work, carried out since 1998 as a means of supporting positive law reform efforts worldwide, frequently leads to substantial improvements in proposed or existing domestic legislation. All materials developed by the Law Programme are available at www.article19.org/resources.php/legal

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If you would like to discuss this policy brief further, or If you have a matter you would like to bring to the attention of the ARTICLE 19 Law Programme, please contact us by e-mail at legal@article19.org.

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ARTICLE 19 Free Word Centre 60 Farringdon Road London EC1R 3GA
T +44 20 7324 2500 F +44 20 7490 0566
E info@article19.org W www.article19.org Tw [@article19org](https://twitter.com/article19org) facebook.com/article19org