

Institute for  
**INFORMATION  
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at New York Law School



Institute for Information Law and Policy  
in cooperation with the Justice Action Center and  
Healthcare Information for All by 2015

White Paper Series 11/12 #01

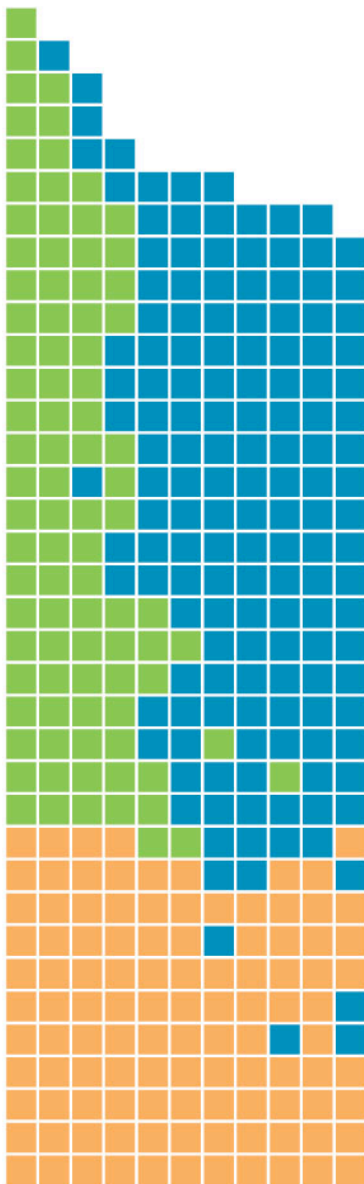
## Access to Health Information Under International Human Rights Law

Project Website: <http://www.hifa2015.org/hifa2015-and-human-rights/>

December 2012

New York Law School's website can be accessed at  
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# Access to Health Information Under International Human Rights Law<sup>1</sup>

## Abstract

This article discusses whether and, if so, to what extent states are obligated under international treaty law to provide individuals, lay healthcare providers, professional healthcare providers, and policymakers with appropriate health information. The article concludes that health information is an essential component of many identified and established human rights. States party to treaties such as the International Covenant on Civil and Political Rights must provide and guarantee access to health information. Appropriate health information fosters meaningful social and political participation and ensures that individuals achieve and enjoy the rights afforded to them by international human rights law. This article provides the international legal foundation for conducting additional, country-specific research on states' compliance with their obligations concerning health information and generating concrete recommendations for what states can do to improve the provision of health information.

## I. Introduction

### *A. Summary*

The purpose of this article is to discuss whether and, if so, to what extent states are obligated under international treaty law to provide individuals, lay healthcare providers, professional healthcare providers, and policymakers with appropriate health information. The article concludes that health information (as defined below) is an essential component of many identified and established human rights. Health information is a determinant of the right to the highest attainable standard of health and access to such information is protected by the right to exchange and impart information. Health information also plays an important role in securing the right to education and the rights of women and children. These rights are protected under the International Covenant on Economic, Social and Cultural Rights (ICESCR), the International Covenant on Civil and Political Rights (ICCPR), and other international and regional human rights treaties. States party to these treaties must provide health information and guarantee access to such information in order to comply with these enumerated obligations. Appropriate health information fosters meaningful social and political participation and ensures that individuals achieve and enjoy the rights afforded to them by international human rights law.

These established human rights impose specific state obligations with respect to access to health information. States must not only refrain from actions that would interfere with

access to health information, but also affirmatively take steps to ensure that individuals are provided with health information. States must ensure that health information is accessible and available to all on a non-discriminatory basis, and particularly to the most vulnerable segments of society. The right to health also requires states to affirmatively provide health information both to individuals and to health professionals. States are also obligated to provide parents with accurate information so as to ensure that their children have appropriate care. They are obligated to ensure that health workers receive adequate training and adequate access to relevant and medically accurate health information and to regulate interference with all of these rights by third parties.

Under the International Covenant on Economic, Social and Cultural Rights, states are obligated to progressively realize the right to health including its underlying determinants. The limitation of progressive realization acknowledges the realities of resource constraints and that the immediate and full realization of rights such as the right to health may not be possible. At the same time, states can immediately realize some aspects of the right, including the obligation not to engage in discrimination with respect to the right and the obligation to take steps towards fulfillment of the right.

Access to health information must be accompanied by parallel efforts to fulfill other basic needs such as the rights to education and to an adequate standard of living. Individuals whose basic needs are not fulfilled will be unable to meaningfully access and process health information. In addition, the right to health and other health-related rights will be greatly advanced if individuals know their rights and the ways in which they can seek to realize them. Educating health workers on the right to health and its various aspects, including the right to health information, can also be a critical step in advancing this right.

The purpose of this paper is to provide a basis for conducting additional, country-specific research on states' compliance with their obligations concerning health information and generating concrete recommendations for what states can do to improve the provision of health information.<sup>2</sup>

## *B. Definitions*

Health information plays a crucial role in the prevention and treatment of disease. Efforts to highlight the importance of health information have tended to focus on the obligation of states to create health information systems or collect disaggregated data about health outcomes and other indicators.<sup>3</sup> These aspects of health information are indeed important. However, there has been comparatively little attention devoted to the importance of providing information to individuals and healthcare providers regarding the prevention and treatment of injury and disease. This article focuses on such information.

“Health information” includes a number of different types of information. This article focuses on four different types of health information:

- 1) health education for the general public concerning the promotion of health and the prevention and treatment of disease and injury, including information about available health services (“health education”),
- 2) information about the treatment of illness and injury when care is provided by a family member or other individual without formal training (“lay healthcare information”),
- 3) information about the treatment of illness and injury when care is provided by a formally trained health worker (“professional healthcare information”),
- 4) information about health policies and laws necessary to enable participation in decision-making about health service provision (“health policy information”).

As used in this paper, “healthcare provider” is broadly defined and includes any individual who is responsible at any time for the healthcare of others, including, for example, family members, traditional healers, and individual members of the public responding to an accident, as well as health workers. The term “health worker” refers specifically to individuals who have formal medical or public health training, including, among others, doctors, nurses, midwives, and community health workers.<sup>4</sup>

## II. Access to Health Information

### *A. Health Information as a Determinant of the Right to Health*

Health information is an essential determinant of the international human right to the highest attainable standard of health, which is protected by several international treaties. Article 12 of the ICESCR protects “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health” and requires that states create “conditions which would assure to all medical service and medical attention in the event of sickness.”<sup>5</sup> The right to health is also protected by Article 16 of the African Charter on Human and Peoples’ Rights, Article 10 of the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights, Article 11 of the European Social Charter, Article 5(e)(iv) of the Convention on the Elimination of Racial Discrimination, Articles 11(1)(f) and 12 of the Convention on the Elimination of All Forms of Discrimination Against Women, and Article 24 of the Convention on the Rights of the Child.<sup>6</sup> The right to health is also “closely related to and dependent upon the realization of other human rights ... , including the right to food, housing, work, education, human dignity, life, non-discrimination, equality, the prohibition against torture, privacy, access to information, freedoms of association, assembly and

movement.”<sup>7</sup>

Health information is an essential determinant of the human right to health. The Committee on Economic, Social and Cultural Rights (ESCR Committee), the international body charged with monitoring state compliance with the ICESCR,<sup>8</sup> has made clear that the right to health extends “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, including on sexual and reproductive health.”<sup>9</sup>

International experts on the right to health have confirmed that health information is a component of the right to health. Paul Hunt, the first United Nations Special Rapporteur on the right to the highest attainable standard of health, stated in his report about a visit to Uganda in March of 2005 that “[a]ccess to health-related information and education is a crucial aspect of the right to health.”<sup>10</sup> In a report to the United Nations Educational, Social and Cultural Organization (UNESCO), Hunt and Gillian MacNaughton, Senior Research Officer for the Human Rights Center at the University of Essex, explain that “access to health *information* is also an essential aspect of the right to health. Health information enables people to promote their own health and to claim quality health facilities, goods and services from the State and others.”<sup>11</sup>

Health policy information is critical in ensuring that individuals are able to participate in political decisions that concern the right to health. The ESCR Committee has explained that the right to health includes the right to participate “in all health-related decision-making at the community, national and international levels.”<sup>12</sup> Detailed information about the state’s national health strategy and plan of action is necessary for individuals to participate in political decisions about the right to health. As Hunt and MacNaughton explain, “essential aspects of the right to health, such as meaningful participation and effective accountability, depend upon having access to information.”<sup>13</sup> In addition, information about the right to health itself, both under international law and as it is protected under domestic law, helps provide individuals with a basis from which they can challenge practices or policies that fall short of that entitlement.<sup>14</sup> Thus, states must provide health policy information and education about the right to health in order to ensure the ability of individuals to participate in political decision-making processes that concern the right to health.<sup>15</sup>

### *B. Health Information and the Rights of the Child*

The Convention on the Rights of the Child (CRC) also requires states party to that treaty to ensure access to health information. Article 17 of the CRC specifically states that “States Parties ... shall ensure that the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health.”<sup>16</sup> Further, Article 24(e) requires states, in pursuing the highest attainable standard of health for children, to “ensure that all segments of society, in particular parents and

children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents.<sup>17</sup> Article 24(e) thus specifically recognizes the importance of providing health information to both children and their parents as lay caregivers.

The Committee on the Rights of the Child (CRC Committee), the body created by the CRC to monitor state compliance with its provisions, has also recognized the importance of health information for the rights of the child. In its General Comment No. 7, the CRC Committee emphasized that the provision of health education is critical to children's right to health, noting that "States parties have a responsibility to implement children's right to health by encouraging education in child health and development, including about the advantages of breastfeeding, nutrition, hygiene and sanitation."<sup>18</sup>

The CRC Committee also observed that health education empowers children to take part in maintaining their own health, explaining that "[y]oung children are themselves able to contribute to ensuring their personal health and encouraging healthy lifestyles among their peers, for example through participation in appropriate, child-centred health education programmes."<sup>19</sup> UNICEF has also emphasized the importance of health education in empowering children to make decisions about their health, noting that it is critical for children to be "provided with the necessary information about options that exist and the consequences of those options so that they can make informed and free decisions."<sup>20</sup>

### *C. Health Information and the Rights of Women*

Access to health information also plays an important role in realizing women's rights. Article 10(h) of the Convention on the Elimination of All Forms of Discrimination Against Women (Women's Convention) explicitly requires states to provide "[a]ccess to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning."<sup>21</sup> Article 16(1)(e) provides that states shall ensure that men and women enjoy "[t]he same rights to decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights."<sup>22</sup> Article 14(2)(b) calls on states to pay particular attention to the needs of rural women and to ensure such women have "access to adequate health care facilities, including information, counselling and services in family planning."<sup>23</sup> Article 14 of the Protocol to the African Charter on the Rights of Women in Africa (the Maputo Protocol) similarly calls on states to take "all appropriate measures to provide adequate, affordable and accessible health services, including information, education and communication programmes to women especially those in rural areas."<sup>24</sup>

Health information plays a critical role in ensuring women's right to health.<sup>25</sup> Article 12 of the Women's Convention provides that "States Parties shall take all appropriate measures

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.”<sup>26</sup> Guidance issued by the Committee on the Elimination of Discrimination Against Women (CEDAW Committee), the committee charged with receiving state reports on compliance with the Women’s Convention, makes clear that these services must include health information, particularly information about family planning. In interpreting the requirements imposed by Article 12 of the Women’s Convention, for example, the CEDAW Committee stated that “[w]omen have the right to be fully informed, by properly trained personnel, of their options in agreeing to treatment or research, including likely benefits and potential adverse effects of proposed procedures and available alternatives.”<sup>27</sup> The Committee has also placed a priority on the provision of information about family planning, calling on states to “[e]nsure the removal of all barriers to women’s access to health services, education and information, including in the area of sexual and reproductive health, and, in particular, [to] allocate resources for programmes directed at adolescents for the prevention and treatment of sexually transmitted diseases, including HIV/AIDS.”<sup>28</sup> Article 14 of the Maputo Protocol recognizes a “right to have family planning education.”<sup>29</sup> States must also provide sexual health information without discrimination to all women regardless of age or status.<sup>30</sup>

The ESCR Committee has also affirmed the importance of information in ensuring women’s right to health. In interpreting Article 12 of the ICESCR, the ESCR Committee has emphasized that “[t]he realization of women’s right to health requires the removal of all barriers interfering with access to health services, education and information, including in the area of sexual and reproductive health.”<sup>31</sup>

#### *D. Health Information and the Right to Education*

The right to education also requires access to health information. Article 13 of the ICESCR recognizes “the right of everyone to education.”<sup>32</sup> In interpreting the right to education under the ICESCR, the ESCR Committee has stated that “fundamental education corresponds to basic education as set out in the World Declaration on Education For All.”<sup>33</sup> Article V of the World Declaration on Education for All explains that the basic learning needs of youth and adults can be met through, among other things, “formal and non-formal education programmes in health, nutrition, population, agricultural techniques, the environment, science, technology, family life, including fertility awareness, and other societal issues.”<sup>34</sup> Basic learning needs thus include health education.

The right to education also includes the right to education about occupational health and safety. In General Comment No. 13, the ESCR Committee notes that technical and vocational education are part of the right to education and that such training must “take[] account of ... occupational health, safety and welfare.”<sup>35</sup> Among other things, such training could include both health education that individuals need to protect their occupational health, safety, and welfare and lay healthcare information needed by

individuals to care for others injured on the job.

The CEDAW Committee has also recognized the connection between the rights of women to education and to health services, noting that Article 10 of the Women's Convention, which protects the right to education, "enabl[es] women to access health care more readily and reduc[es] female students' drop-out rates, which are often due to premature pregnancy."<sup>36</sup>

### *E. The Right to Receive and Impart Health Information*

The right to receive and impart information also requires the state to protect the right to receive and impart health information. Article 19 of the ICCPR states that "[e]veryone shall have the right to freedom of expression; this right shall include freedom to seek, receive and impart information and ideas of all kinds."<sup>37</sup> Article 9 of the African Charter on Human and Peoples' Rights similarly provides that "[e]very individual shall have the right to receive information."<sup>38</sup> The European Court of Human Rights has found that Article 10 of the European Convention on Human Rights, which protects freedom of expression and information, prohibited Ireland from barring pregnancy counseling services from providing information about abortion facilities outside the country.<sup>39</sup>

Information and ideas "of all kinds" described in Article 19 necessarily include information about health. The Human Rights Council, for example, has recently reaffirmed the importance of the right to receive and impart information in combating maternal mortality and morbidity.<sup>40</sup> In interpreting the right to health, the ESCR Committee has used language similar to Article 19 in describing the nature of the obligation to ensure accessibility of health facilities, goods, and services, explaining that this includes, among other things, the "right to seek, receive and impart information and ideas concerning health issues."<sup>41</sup>

## III. State Obligations Regarding Health Information

The duty to ensure access to health information as protected under these established international human rights is associated with a variety of state obligations. States must refrain from conduct that would interfere with access to reliable health information and affirmatively provide reliable health information under some circumstances. Among other things, states are required to ensure that individuals are provided with health education and must ensure that health workers, both in training and in service, have access to appropriate information for learning, prevention, and treatment. States must also refrain from discrimination and protect the rights of women, children, and vulnerable populations.

### *A. Respect, Protect, and Fulfill*



State obligations toward health information encompass both freedoms and entitlements.<sup>42</sup> States are obligated not only to refrain from conduct that negatively interferes with rights, but also to protect rights from violations by others and to take affirmative steps to fulfill those rights.<sup>43</sup>

First, as articulated by the ESCR Committee, “the obligation to *respect* requires States to refrain from interfering directly or indirectly with the enjoyment of the right to health.”<sup>44</sup> States must refrain from conduct that would interfere with access to health information, including “censoring, withholding or intentionally misrepresenting health-related information, including sexual education and information” or “the deliberate withholding or misrepresentation of information vital to health protection or treatment.”<sup>45</sup>

Second, states also have an obligation to protect rights from violations by others. The “obligation to protect requires States to take measures that prevent third parties from interfering” with enumerated rights.<sup>46</sup> According to the ESCR Committee, states must “ensure that medical practitioners and other health professionals meet appropriate standards of education, skill and ethical codes of conduct.”<sup>47</sup> States are also obligated to “ensure that third parties do not limit people’s access to health-related information and services” and must protect consumers of health information by controlling “the marketing of medical equipment and medicines by third parties.”<sup>48</sup> Finally, the obligation to protect also requires states to “discourage production, marketing and consumption of tobacco, narcotics and other harmful substances.”<sup>49</sup>

Third, States are obligated to fulfill rights. The obligation to fulfill requires states “to facilitate, provide and promote” the right to all the individuals within their jurisdiction. The obligation to fulfill requires states not only “to take positive measures that enable and assist individuals and communities to enjoy the right to health” but also “to *fulfil (provide)* a specific right contained in the Covenant when individuals or a group are unable, for reasons beyond their control, to realize that right themselves by the means at their disposal.”<sup>50</sup> The obligation to fulfill requires States to adopt appropriate legislative, administrative, budgetary, judicial, promotional, and other measures towards the full realization of the identified right. For example, states are obligated to create a health system that provides protection and equal opportunity to achieve the highest attainable standard of health.<sup>51</sup> Because health information is an underlying determinant of the right to health (see section IIA above), such a health system must also ensure the provision of health information.

Although this framework of respect, protect, and fulfill is primarily used to interpret state obligations under the ICESCR, Article 19 of the ICCPR also requires states to refrain from interfering with the right to receive and impart information and to affirmatively provide some kinds of information. According to the World Health Organization (“WHO”), “[t]he right to receive information [under Article 19] might be shown to have been violated where a maternal death could have been avoided with appropriate dissemination of information regarding what constitutes a complication, means to prevent a complication,

or where to receive care for such a complication.”<sup>52</sup> Thus, an individual’s right to receive information under Article 19 includes an affirmative claim on the state to specific information in some circumstances.

States must also ensure that individuals and healthcare providers are educated about their rights under both domestic and international human rights law in order to allow them to hold the state accountable for failure to respect, protect, or fulfill those rights. Among other things, ensuring accountability requires “empowering health consumers and educating them on the particulars of their entitlements under the health workforce plan” and should be “tied to a broader campaign to educate people on their rights.”<sup>53</sup> As Physicians for Human Rights explains:

Indeed, achieving accountability requires that individuals and communities are aware of both their rights and what they can do if their rights are not being met. Avenues of redress could include using formal reviews of the health workforce plan’s implementation to voice concerns or bringing concerns to other structures, such as health councils, human rights commissions, courts, and administrative bodies. Civil society organizations or other institutions (such as a health ombudsman’s office) may need to facilitate individuals’ participation in these structures, which may otherwise be prohibitively complicated and intimidating, even as these structures should be designed to ease people’s interactions with them.<sup>54</sup>

Efforts to improve accountability should focus not only on creating the structures necessary for accountability but also empowering individuals to use these structures to enforce their rights.

### *B. Progressive Realization*

The obligations of the ICESCR are subject to the limitation of Article 2(1), which provides that each state party to that treaty “undertakes to take steps, ... 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.”<sup>55</sup> The idea of progressive realization “is premised on the recognition that fulfilling [economic and social rights (ESR)] obligations requires economic resources, and the financial constraints faced by many developing countries may make simultaneous and immediate fulfillment of all ESR rights obligations impossible.”<sup>56</sup> Although “each State party must decide for itself which means are the most appropriate under the circumstances with respect to each of the rights,” the ESCR Committee will evaluate whether the methods chosen are appropriate in the circumstances.<sup>57</sup>

Despite the flexibility of progressive realization, the ICESCR nonetheless imposes several obligations that must be realized immediately. First, the ESCR Committee has stated that

“progressive realization means that States parties have a specific and continuing obligation to move as *expeditiously and effectively as possible* towards the full realization of article 12.”<sup>58</sup> Second, “steps towards that goal [of full realization] must be taken within a reasonably short time after the Covenant’s entry into force ... [and] [s]uch steps should be deliberate, concrete and targeted as clearly as possible towards meeting the obligations recognized.”<sup>59</sup> Evidence of such steps would be the creation of legislation or judicial remedies, as well as “administrative, financial, educational and social measures” undertaken by the state.<sup>60</sup> Third, the obligation of non-discrimination is not subject to progressive realization. The “undertaking to guarantee’ that relevant rights ‘will be exercised without discrimination’” is an obligation that is of immediate effect.<sup>61</sup> Fourth, the state is required “to monitor the extent of the realization, or more especially of the non-realization, of economic, social and cultural rights, and to devise strategies and programmes for their promotion,” and this obligation is not affected by resource constraints.<sup>62</sup>

Fifth, the ESCR Committee has explained that states are required “to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights.”<sup>63</sup> This “minimum core” is the minimal essential level of each right that states must protect. As the ESCR Committee explained in General Comment No. 3, if this minimum essential level were not protected, the Covenant would largely be deprived of its purpose.<sup>64</sup> Failure to satisfy this minimum core imposes a fairly strict burden on states to justify their actions. According to the ESCR Committee, “[i]n order for a State party to be able to attribute its failure to meet at least its minimum core obligations to a lack of available resources it must demonstrate that every effort has been made to use all resources that are at its disposition in an effort to satisfy, as a matter of priority, those minimum obligations.”<sup>65</sup> Further, even when the resources available to the state are inadequate, “the obligation remains for a State party to strive to ensure the widest possible enjoyment of the relevant rights under the prevailing circumstances.”<sup>66</sup>

Although the ESCR Committee does not describe health information as a core obligation of the right to the highest attainable standard of health,<sup>67</sup> the Committee has stated that several information-related obligations are of “comparable priority” to the minimum core of this right, including the provision of health education (“education and access to information concerning the main health problems in the community, including methods of preventing and controlling them”) and health worker training (“appropriate training for health personnel, including education on health and human rights”).<sup>68</sup> The ESCR Committee has also confirmed that “reproductive, maternal (pre-natal as well as post-natal) and child health care” are “obligations of comparable priority” as the core obligations that must be ensured immediately.<sup>69</sup> Paul Hunt has also noted that states have “a core obligation to ensure a minimum ‘basket’ of health-related services and facilities” and that this basket includes “sexual and reproductive health services including information [i.e., sexual and reproductive health education], family planning, prenatal and post-natal services, and emergency obstetric care.”<sup>70</sup>

### *C. Health Education and Counseling*

As part of the right to health, states are required to provide individuals with health education. The ESCR Committee has stated that the highest attainable standard of health requires that individuals have access to health education in order to make informed choices about their health, including lifestyle choices.<sup>71</sup> The state must “support[] people in making informed choices about their health,”<sup>72</sup> including by establishing institutions for counseling and mental health services on an equitable basis throughout the country, providing health education, and “establish[ing] prevention and education programmes for behaviour-related health concerns.”<sup>73</sup>

Other international authorities have emphasized the importance of health education. In a report on his mission to Uganda, Paul Hunt, the former Special Rapporteur on the right to health, explained that the right to health includes the right to access information regarding “preventive and health-promoting behaviour, as well as access to health services.”<sup>74</sup> Hunt commended governments for creating public information campaigns to combat illnesses such as HIV/AIDS and measles.<sup>75</sup> Hunt noted that such campaigns were particularly important when dealing with neglected diseases, such as lymphatic filariasis, which some believe is caused by “traditional curses or dark spiritual forces.”<sup>76</sup> International courts have also noted the importance of access to health information in the prevention of disease.<sup>77</sup>

States should consider using multiple channels for delivering health education. In his report on Uganda, for example, Hunt recommended the adoption of public information campaigns directed at both rural and urban communities (including camps for internally displaced persons), and noted that these campaigns should “utilize the mass media, village health teams, health professionals, church and other faith networks, schools, trade unions, and so on so as to raise awareness of neglected diseases and to promote non-discriminatory behaviour towards afflicted persons.”<sup>78</sup>

States have a particular duty to provide health education with respect to certain topics, including “HIV/AIDS, sexual and reproductive health, traditional practices, domestic violence, the abuse of alcohol and the use of cigarettes, drugs and other harmful substances.”<sup>79</sup> The duty to provide health education extends to “disseminat[ing] appropriate information relating to healthy lifestyles and nutrition, harmful traditional practices and the availability of services.”<sup>80</sup> For example, information, such as community education about the importance of skilled birth attendance and health care during pregnancy, can increase the use of health services during pregnancy and labor and thereby reduce maternal mortality.<sup>81</sup>

### *D. Informed Healthcare Providers*

The right to health includes the right to an informed healthcare provider. The ESCR

Committee has explained that health services must be “scientifically and medically appropriate and of good quality.”<sup>82</sup> According to the Committee, quality services require, among other things, “skilled medical personnel.”<sup>83</sup> This statement relates to the training, deployment and support of formal health workers in areas where they are needed. Healthcare is also provided by lay healthcare providers, including family care givers, community health workers, and traditional healers. Where there is a shortage of formal health workers, the demands on lay healthcare providers can be significant. In order to ensure that such care is of the highest possible quality, the state must make information accessible to lay healthcare providers.

The right to health requires that health workers are adequately trained and that they have access to the information they need to deliver effective care. The ESCR Committee has explained that the right to the highest attainable standard of health requires the availability of “trained medical and professional personnel.”<sup>84</sup> In addition, the ESCR Committee has called for the provision of preventive and rehabilitative services, which require health workers with specialized knowledge.<sup>85</sup> Other international documents have also emphasized the importance of trained medical personnel. The Political Declaration on HIV/AIDS, for example, calls on states “to ensure the appropriate training of doctors and other medical personnel.”<sup>86</sup> The importance of improving access to health information for health workers, especially in developing countries, was recently highlighted by the International Council of Nurses, International Pharmaceutical Federation, International Hospital Federation, World Confederation for Physical Therapy, World Dental Federation, and World Medical Association, through their joint Positive Practice Environments campaign.<sup>87</sup>

Pre-service training for health professionals “must be made relevant to country needs.”<sup>88</sup> In resource-poor countries, this means “re-shaping health education so that exposure to providing primary care and working in deprived settings becomes an integral part of pre-service training.”<sup>89</sup> This will help “equip health workers to address common health conditions and to meet the needs of poor and marginalized populations.”<sup>90</sup> Training opportunities for health workers should continue after qualification.<sup>91</sup> Health workers should also be provided with information about human rights so that they can respect and protect the rights of their patients and community members as well as their own human rights.<sup>92</sup>

Health workers also need access to training to ensure that services are “respectful of medical ethics and culturally appropriate.”<sup>93</sup> As Paul Hunt has explained, in order to ensure that a health system respects cultural difference, health workers “should be sensitive to issues of ethnicity and culture.”<sup>94</sup> The health system itself “is required to take into account traditional preventive care, healing practices and medicines” and “training in some traditional medical practices should also be encouraged.”<sup>95</sup> The obligation to educate health workers also includes ensuring that “health care staff are trained to recognize and respond to the specific needs of vulnerable or marginalized groups.”<sup>96</sup>

States should also ensure that health workers are able to effectively communicate with the populations they serve, either by recruiting health workers from the communities to be served or by providing appropriate language training and interpretation. Without the ability to effectively communicate with their patients, health workers will necessarily be limited in their ability to provide health care and information that is accessible,<sup>97</sup> culturally appropriate,<sup>98</sup> of adequate quality,<sup>99</sup> and responsive to the needs of marginalized and vulnerable populations,<sup>100</sup> including indigenous populations.<sup>101</sup> Failure to ensure that health workers are able to effectively communicate with their patients may also have the effect of nullifying or impairing the equal enjoyment or exercise of the right to health on the basis of language, race, or other status.<sup>102</sup>

States can increase access to trained and informed health workers by establishing paraprofessional or community-based health worker programs which offer care and also provide healthcare information to lay providers. For example, Pakistan's National Family Planning and Primary Care Programme, which is aimed at "prevent[ing] and treat[ing] common ailments at the community level in a cost-effective manner," trains and provides information support to salaried community health workers (called "Lady Health Workers" or LHWs) who serve individual communities, predominantly in rural areas.<sup>103</sup> The World Health Organization reports:

Evaluations of this programme have found significant impact on health knowledge and health service utilization, especially in rural areas. For example, in areas with LHWs, there are a higher proportion of births attended by a skilled attendant; more babies exclusively breast-fed; more mothers who know about oral rehydration, and who give it to children with diarrhoea; and more children fully vaccinated, compared with areas without LHWs.<sup>104</sup>

Health worker programs thus increase the level of care available both by performing services themselves and by providing critical healthcare information – such as information about oral rehydration – to lay healthcare providers.

### *E. Access to Research, Reference, and Learning Materials*

The right to health also includes appropriate access to both original medical research and reference and learning materials. According to the ESCR Committee, "health facilities, goods and services must also be scientifically and medically appropriate and of good quality."<sup>105</sup> Healthcare providers need access to both original medical research and reference and learning materials in order to ensure that their services are scientifically and medically appropriate and of good quality. In some contexts, appropriate and quality health care may depend on the accessibility of original medical research, while in others, it may necessitate access to health reference and learning materials.

### i. Original Medical Research

The term ‘original medical research’ here refers to peer-reviewed research papers that describe recently completed research studies. Such papers are generally published in peer-reviewed journals, which may be in print or electronic format. For those with access to the internet, the abstracts (summaries) of papers are usually available to anyone, free of charge, and may be freely reproduced. The electronic full text of original papers may be either (1) accessible to all (free access, with or without permission to reproduce content with appropriate attribution) or (2) accessible only to subscribers.

Where access to original medical research is necessary to ensure appropriate and quality care, states are obligated to ensure that access to this research is affordable. For subscription-based journals, one of the most significant barriers to access is cost. A full text article in a medical journal typically costs about US\$30 to download, while an annual subscription to a journal may cost several hundred dollars.<sup>106</sup> Because of the high costs of obtaining full-text information, healthcare providers may end up relying on abstracts of articles that might not provide a sufficiently reliable basis for making decisions about healthcare.<sup>107</sup> The findings of individual research studies may also be misleading when seen in isolation; wherever possible, all relevant research evidence should be considered, as in systematic reviews.

Whether states have an obligation to make original medical research accessible to everyone free of charge is part of a wider ongoing debate about open-access publishing and subscription-based publishing. Gavin Yamey and many others advocate for “open access,” an alternative to subscription-based publishing that aims to “end the commoditization and privatization of the scientific and medical research literature and make it a truly public resource.”<sup>108</sup> Yamey notes that limited access to medical research means that “health care workers are prevented from accessing the information that they need to practice effective medicine” and “impedes health research capacity and sustainable development in these countries.”<sup>109</sup> In the health arena, one response has been the initiative HINARI (Health Internet Access to Research Initiative). This joint initiative by the WHO and commercial publishers provides free or low-cost access to electronic medical journals to eligible institutions in many low-income countries.

### ii. Reference and Learning Materials

Where necessary in order to ensure appropriate and quality care, states are also obligated to provide access to reference and learning materials. Evidence-based reference and learning materials<sup>110</sup> derive ultimately from original medical research, and such derived materials are the mainstay of direct information support for the vast majority of healthcare providers.

For many health workers, health reference and learning materials that provide reliable, good-quality information about the prevention and treatment of injury and disease

encountered in daily practice are often more useful in practice than original research studies. A review of the information needs of doctors in industrialized countries concluded: “The most useful sources were evidence based textbooks and systematic reviews. Journals were near the bottom along with drug advertising.”<sup>111</sup> Original research articles often discuss advancements or treatments that are not directed to the problems health workers encounter on a daily basis. For village health workers in rural settings with minimal resources, original research articles are even less likely to be relevant. Most original research reflects the priorities of high-income countries. In addition, most research requires high-tech healthcare settings for its application, is written in English, and uses jargon and a technical style inaccessible to all but a small minority.

### *F. Duties Regarding Specific Types of Information*

There are several different types of health information that international instruments and other sources have identified as particularly important. Generally, states should provide information about health services, including their availability and location.<sup>112</sup> States should also provide health education about health risks and healthy behaviors. For example, Article 24(e) of the CRC states that children should be informed about “hygiene and environmental sanitation and the prevention of accidents.”<sup>113</sup> In interpreting the right to health, the ESCR Committee has noted that states should disseminate appropriate information relating to healthy lifestyles and nutrition.<sup>114</sup> The Sphere Project, an international initiative that provides minimum standards for health services in disaster response,<sup>115</sup> recommends that states “provide information on the major endemic health problems, major health risks, ... and behaviors that protect and promote good health.”<sup>116</sup>

In addition, there are several different types of specific information that states should address in providing health education. Health education should include information concerning “HIV/AIDS, sexual and reproductive health, traditional practices, domestic violence, the abuse of alcohol and the use of cigarettes, drugs and other harmful substances.”<sup>117</sup> The CEDAW Committee has also recommended that states ensure the availability and dissemination of information about harmful traditional practices such as female genital mutilation.<sup>118</sup>

Several sources emphasize in particular the importance of sexual and reproductive health education, including information about HIV/AIDS. The United Nations Population Fund has identified lack of information as one of the root causes of a number of sexual and reproductive health problems.<sup>119</sup> In its recommendations about equality in marriage and family relations, the CEDAW Committee stated that “[i]n order to make an informed decision about safe and reliable contraceptive measures, women must have information about contraceptive measures and their use, and guaranteed access to sex education and family planning services, as provided in article 10 (h) of the [Women’s] Convention.”<sup>120</sup> The Committee has also called on states to “[p]rioritize the prevention of unwanted pregnancy through family planning and sex education and reduce maternal mortality rates through safe motherhood services and prenatal assistance.”<sup>121</sup>



Several bodies have also stressed the importance of information about HIV/AIDS. In a report on Angola's compliance with the Women's Convention, the CEDAW Committee recommended the adoption of programs designed to "increase knowledge of and access to affordable contraception methods, so that women and men can make informed choices about the number and spacing of children" and that "sex education be widely promoted and targeted at girls and boys, with special attention to the prevention of early pregnancies and control of sexually transmitted diseases and HIV/AIDS."<sup>122</sup> The Committee has also recommended that states "intensify efforts in disseminating information to increase public awareness of the risk of HIV infection and AIDS, especially in women and children, and of its effects on them."<sup>123</sup> The Political Declaration on HIV/AIDS also emphasizes the need for education about the spread, prevention, and effect of HIV/AIDS.<sup>124</sup>

Health education is particularly important for adolescents. The CEDAW Committee has noted that "[a]dolescent girls and women in many countries lack adequate access to information and services necessary to ensure sexual health" and that states "should ensure the rights of female and male adolescents to sexual and reproductive health education by properly trained personnel in specially designed programmes that respect their rights to privacy and confidentiality."<sup>125</sup> The outcome document for the Fourth World Conference on Women in Beijing also recognized the importance of providing sexual and reproductive health information to adolescents, noting that programs for adolescents should "raise awareness about, prevent and treat sexually transmitted infections, including HIV/AIDS, and sexual violence and abuse; and counsel adolescents on avoiding unwanted and early pregnancies."<sup>126</sup>

States should also provide information about child health and nutrition, including to lay care providers. The Convention on the Rights of the Child provides that states should take appropriate measures "[t]o ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition, the advantages of breastfeeding, hygiene and environmental sanitation and the prevention of accidents."<sup>127</sup> The Women's Convention explicitly recognizes the importance of providing information to women, who are often the primary caregivers in the family. Article 10(h) of the Women's Convention places an affirmative obligation on the states to provide women "[a]ccess to specific educational information to help to ensure the health and well-being of families, including information and advice on family planning."<sup>128</sup>

States should also provide individuals with information needed to meaningfully participate in the creation of health policy.<sup>129</sup> As Physicians for Human Rights explains, "This may require provision of key documents in advance, directly explaining [the] impact of technical sounding decisions and policies on real life, and encouraging questions through creating an open, non-intimidating, non-judgmental atmosphere that encourages questions and allows time for community members to express their views."<sup>130</sup>

## *G. Availability, Accessibility, Acceptability, and Quality*

The ESCR Committee has identified four essential elements of the right to health. According to the Committee, states must ensure that public health and health-care facilities, goods, and services, which include health-related education and information, are available, accessible, acceptable, and of adequate quality:

*Availability* means that “[f]unctioning public health and health-care facilities, goods and services, as well as programmes, have to be available in sufficient quantity within the State party.” This includes, among other things, adequate “trained medical and professional personnel receiving domestically competitive salaries.”<sup>131</sup>

*Accessibility* is measured along four dimensions: non-discrimination, physical accessibility, economic accessibility, and information accessibility. Non-discriminatory accessibility means that “[h]ealth facilities, goods and services [including health-related education and information] must be accessible to all, especially the most vulnerable or marginalized sections of the population.”<sup>132</sup> Physical accessibility means that “[h]ealth facilities, goods and services [including health-related education and information] must be within safe physical reach for all sections of the population, especially vulnerable or marginalized groups.”<sup>133</sup> Economic accessibility means that “[h]ealth facilities, goods and services [including health-related education and information] must be affordable for all.”<sup>134</sup> (For example, health information might be unaffordable if access to that information requires the use of specific technology.) Information accessibility specifically “includes the right to seek, receive and impart information and ideas concerning health issues.”<sup>135</sup>

*Acceptability* means that “[a]ll health facilities, goods and services [including health-related education and information] must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned.”<sup>136</sup>

*Quality* means that “health facilities, goods and services [including health-related education and information] must also be scientifically and medically appropriate and of good quality.”<sup>137</sup> Although the Committee has not explained what “quality” means in terms of health information, information of good quality can be understood as information that is both *relevant* and *reliable*.<sup>138</sup> Information that is not relevant to the recipient’s particular context or which is not up-to-date, objective, and scientifically based is likely to be ineffective or even harmful.

*Relevant* materials provide information that is appropriate to the language and educational level of the user, as well as his or her geographical, epidemiological, and sociocultural context. Relevant materials are in a presentation and format (e.g. book, CD-

ROM, website, voice) that is appropriate to the needs of the user at that time. Relevant materials are appropriate to the available level of resources (e.g., diagnostic equipment, drug availability). Information must be both objectively and subjectively relevant, reflecting not only an objective assessment of healthcare knowledge, practice, and environment, but also the subjective needs as perceived by the user. States should take steps to ensure that the range of available information is sufficient to meet the diversity of needs of individual users, so that all users can obtain information that is relevant to them.

Health education should also be culturally appropriate. For example, the Sphere Project recommends that states provide information that is locally relevant, initiating health education programs “in consultation with local health authorities and community representatives” and which “take[s] into account health-seeking behaviour and health beliefs of the population.”<sup>139</sup> In addition, “[p]ublic health messages and materials should utilise appropriate language and media, and be culturally sensitive.”<sup>140</sup> In order to be available, accessible, of adequate quality, and responsive to the needs of vulnerable communities, health information must also be provided in a language that can be understood by the relevant communities.<sup>141</sup>

*Reliable* materials are up-to-date, objective, and based on scientific evidence from high-quality research. Objectivity implies the absence of bias (as may occur, for example, with unregulated pharmaceutical advertising) and absence of scientifically unsupported claims. Where possible, and especially with respect to information to guide healthcare decisions, materials should reflect the results of systematic reviews. Systematic reviews are reports which pool and analyze all available data to assess the strength of evidence. They are better at assessing strength of evidence than single studies.<sup>142</sup> Unreliable information is likely to be ineffective and may even cause harm, either at an individual or at a population (public health) level.

Efforts to improve access to relevant, reliable health information should be accompanied by steps to help individuals to find relevant and reliable information, to interpret it, and to apply it in practice. Such capacities include measures to direct users to the information they need, as well as support with basic literacy and information skills.

#### *H. Non-Discrimination and Vulnerable Populations*

Access to health information must be ensured without discrimination of any kind, including on the basis of race, sex, religion, opinion, national origin, or other status. The obligation of non-discrimination is guaranteed by Articles 2(2) and 3 of the ICESCR, Article 2(1) of the ICCPR, and by regional and issue-specific human rights treaties. Although other aspects of the right to access health care may be progressively realized, the obligation of non-discrimination is immediately realizable.<sup>143</sup>

The obligation of non-discrimination may also require specific measures designed to redress inequality. In discussing the equal rights of men and women with respect to

economic, social, and cultural rights, for example, the ESCR Committee has emphasized that the obligation of non-discrimination requires, among other things, “the provision of adequate training for health workers to deal with women’s health issues.”<sup>144</sup>

States must also ensure that health information is accessible to the most vulnerable segments of society. The ESCR Committee, for example, has emphasized that the underlying determinants of health, which include health information, “must be accessible to all, especially the most vulnerable or marginalized sections of the population, in law and in fact, without discrimination on any of the prohibited grounds.”<sup>145</sup> For instance, health information of any type – whether health education or information for lay healthcare providers – must be priced such that it does not become financially inaccessible for the poor, and it must be geographically accessible for those in rural areas.<sup>146</sup> Article 14(2) of the Women’s Convention also requires state parties to take specific measures to eliminate discrimination against women in rural areas by ensuring that they have “access to adequate health facilities, including information, counseling and services in family planning.”<sup>147</sup> The CEDAW Committee has called on states to “ensure that adequate protection and health services, including trauma treatment and counselling, are provided for women in especially difficult circumstances, such as those trapped in situations of armed conflict and women refugees.”<sup>148</sup> The UN Political Declaration on HIV/AIDS states that there is a need to “protect the rights of vulnerable and displaced populations and enable groups to be reached with information, prevention messages and services to limit the spread of HIV.”<sup>149</sup>

In providing health education to children, states should also take steps to ensure that health education is conveyed appropriately. States must “ensur[e] access to child-friendly information about preventive and health-promoting behaviour and support to families and communities in implementing these practices” and “provide a safe and supportive environment for adolescents, that ensures the opportunity ... to acquire appropriate information, [and] to receive counseling.”<sup>150</sup> The Political Declaration on HIV/AIDS emphasizes the need for youth-specific HIV/AIDS education and ensuring that young people have access to correct information about effective prevention, care, and treatment of the disease.<sup>151</sup>

## IV. Conclusion

Health information (as defined in this paper) is an essential component of many identified and established human rights. It plays an important role in securing the rights to health and education, rights of women and children, and the right to exchange and impart information protected under the ICESCR, the ICCPR, and other international and regional human rights treaties. States that are parties to these treaties must ensure the availability, accessibility, acceptability, and quality of relevant and reliable health information. Among other things, states must refrain from interfering with or hindering access to health information, provide health information where necessary, ensure that

information is accessible to the most vulnerable segments of society, and safeguard information from obstruction by third parties. States have obligations along several dimensions of health information, including preventive health education for the general public, care provided by individuals who have no formal training, care provided by formally trained health workers, and information about health policies and laws.

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<sup>1</sup> Molly Land, Associate Professor of Law, New York Law School, New York, USA; Neil Pakenham-Walsh, Coordinator of the Healthcare Information for All by 2015 (HIFA2015) campaign and Co-Director of the Global Healthcare Information Network. Additional contributors include HyoSung Bidol-Lee, Andrea Casillas, Ronete Hikry, and Michael Murphy. Please address correspondence to Molly Land, New York Law School, 185 West Broadway, New York, NY 10013, USA, email: molly.land@nyls.edu. This article is the result of collaboration between the Institute for Information Law and Policy and the Justice Action Center at New York Law School (NYLS) and HIFA2015 ([www.hifa2015.org](http://www.hifa2015.org)), a project administered by the Global Healthcare Information Network, a UK-based non-profit organization. The authors gratefully acknowledge the feedback of HIFA2015 members David Egilman, Eric Friedman, George Kent, Justus Krabshuis, Symphrose Ouma, Richard Marsico, Mona Nasser, R. Prajeesh, and Chris Zielinski. Beulah Chou, Christopher Bruno, Robert Habermann, Dara Mandell, and Juliana Moran provided editorial and research assistance.

<sup>2</sup> HIFA2015 members suggested such projects might include drafting a set of “good practices” with respect to health information that could be a guide for governments and a tool for civil society to hold their governments accountable (and which addresses who is entitled to what information and how rights should be organized and ensured), or evaluating access to health information in various countries (including by attempting to get relevant questions on health information incorporated into routine datasets such as Country Situational Analyses). Topics for further research might include: lay health education; the importance of, effective approaches to, and the potential impact of educating both health workers as well as individuals and communities on the right to health and their health-related rights more broadly; mental health counseling; connections between health information and stigma and discrimination; the right of individuals to access their own and their family’s health records; the issue of informed consent; fairness in the provision of health-related information in commercial products such as food and pharmaceuticals; links between health information, culture and language; and the concept of “essential information” to which there is a right of access.

<sup>3</sup> See, for example, Gunilla Backman et al., “Health systems and the right to health: an assessment of 194 countries,” *Lancet* 372/9655 (2008), pp. 2078-2082.

<sup>4</sup> The World Health Organization defines “community health workers” as follows: “Community health workers should be members of the communities where they work, should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a part of its organization, and have shorter training than professional workers.” World Health

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Organization, *Community health workers: What do we know about them?* (Geneva: WHO, 2007). Available at

[http://www.who.int/hrh/documents/community\\_health\\_workers\\_brief.pdf](http://www.who.int/hrh/documents/community_health_workers_brief.pdf).

<sup>5</sup> International Covenant on Economic, Social and Cultural Rights (ICESCR), G.A. Res. 2200A (XXI), Arts. 12(1), 12(2)(d) (1966). Available at

<http://www2.ohchr.org/english/law/cescr.htm>. U.N. Doc. A/6316 (Jan. 3, 1976).

<sup>6</sup> Article 25(1) of the 1948 Universal Declaration of Human Rights also provides that “[e]veryone has the right to a standard of living adequate for the health and well-being of himself and of his family, including ... medical care.” Universal Declaration of Human Rights (UDHR), G.A. Res. 217A (III), (1948) Art. 25(1). Available at

<http://www.un.org/Overview/rights.html>. The UDHR is not a treaty, although some of its other provisions have become customary international law. See, for example, Mary Robinson, “High Comm’r for Human Rights, U.N., The Declaration of Human Rights: A Living Document” (presentation at the Symposium on Human Rights in the Asia-Pacific Region, January 27, 1998). Available at

<http://www.unu.edu/unupress/Mrobinson.html#declaration>.

<sup>7</sup> Committee on Economic, Social and Cultural Rights, General Comment No. 14, The Right to the Highest Attainable Standard of Health (General Comment No. 14), UN Doc. No. E/C. 12/2000/4 (2000), para. 3. Numerous other documents also recognize the right to health. The preamble of the World Health Organization’s Constitution states, for example, that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition.” Constitution of the World Health Organization, July 22, 1946, 62 Stat. 2679, 14 U.N.T.S. 185, pmb1.

<sup>8</sup> ECOSOC Resolution 1985/17, Review of the composition, organization and administrative arrangements of the Sessional Working Group of Governmental Experts on the Implementation of the International Covenant on Economic, Social and Cultural Rights (May 28, 1985). Available at

<http://ap.ohchr.org/documents/E/ECOSOC/resolutions/E-RES-1985-17.doc>.

<sup>9</sup> General Comment No. 14 (see note 7), para. 11. The right to health is best understood as the right to enjoy “a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health.” *Ibid.*, para. 9; see also Trudo Lemmens & Candice Telfer, *Access to Information and the Right to Health: The Human Rights Case for Clinical Trials Transparency*, 38 *Am. J.L. & Med.* 63, 99 (2012) (arguing, in making a human rights case for access to information about clinical trials, that “meaningful information is a critical determinant of the right to the highest attainable standard of health and requires a reliable system of knowledge production”).

<sup>10</sup> Paul Hunt, UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Mission to Uganda, UN Doc. E/CN.4/2006/48/Add.2 (2006), para. 33.

<sup>11</sup> Paul Hunt and Gillian MacNaughton, *Impact assessment, poverty and human rights: A case study using the right to the highest attainable standard of health* (UNESCO 2006), p.

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30. Available at <http://physiciansforhumanrights.org/students/hhr-ed/impact-assessments-poverty.pdf>.

<sup>12</sup> General Comment No. 14 (see note 7), para. 11; see also, *ibid.*, para. 17 (“A further important aspect is the improvement and furtherance of participation of the population in the provision of preventive and curative health services, such as the organization of the health sector, the insurance system and, in particular, participation in political decisions relating to the right to health taken at both the community and national levels.”); *ibid.* para. 43(f) (noting that national strategies and plans of action should be “periodically reviewed, on the basis of a participatory and transparent process”).

<sup>13</sup> Hunt and MacNaughton (see note 11), p. 31; see also, Paul Hunt, UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (2008 Hunt Report), UN Doc. A/HRC/7/11 (2008), para. 41 (“Crucially, States have a human rights responsibility to establish institutional arrangements for the active and informed participation of all relevant stakeholders, including disadvantaged communities.”).

<sup>14</sup> Physicians for Human Rights, *The right to health and health workforce planning: A guide for government officials, NGOs, health workers and development partners* (Cambridge, MA / Washington, DC: Physicians for Human Rights, 2008), p. 55. Available at <http://physiciansforhumanrights.org/library/report-2008-08-04.html>.

<sup>15</sup> Because it enables individuals to participate in health-related political decision-making, health policy information can also be understood as a component of the right to development, which is protected under the ICESCR and other international treaties. See ICESCR (see note 5), Art. 1. Article 2 of the United Nations’ Declaration on the Right to Development explains that “development is a comprehensive economic, social, cultural and political process, which aims at the constant improvement of the well-being of the entire population and of all individuals on the basis of their active, free and meaningful participation in development and in the fair distribution of benefits resulting there from.” Declaration on the Right to Development, G.A. Res. 41/128, (1986), Art. 2. Health policy information helps empower individuals to participate in this process.

<sup>16</sup> Convention on the Rights of the Child (CRC), G.A. Res. 44/25 (1989), Art. 17.

<sup>17</sup> *Ibid.*, Art. 24(e).

<sup>18</sup> Committee on the Rights of the Child, General Comment No. 7: Implementing Child Rights in Early Childhood (General Comment No. 7), UN Doc. CRC/C/GC/7/Rev.1 (2006), para. 27(b); see also, UN Comm. on the Rights of a Child et al., *A guide to General Comment No. 7: Implementing child rights in early childhood* (2006), pp. 15-17 (discussing the importance of breastfeeding and adequate nutrition).

<sup>19</sup> General Comment No. 7 (see note 18), para. 27(b).

<sup>20</sup> Fact Sheet: Right to Participation. Available at <http://www.unicef.org/crc/files/Right-to-Participation.pdf>.

<sup>21</sup> International Convention on the Elimination of All Forms of Discrimination against Women (Women’s Convention), G.A. Res. 34/180 (entered into force Sept. 3, 1981) 34 U.N. GAOR Supp. (No. 46), U.N. Doc. A/34/4, Art. 10(h).

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<sup>22</sup> Ibid., Art. 16(1)(e).

<sup>23</sup> Ibid., Art. 14(2)(b).

<sup>24</sup> Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol), adopted by the 2nd Ordinary Session of the Assembly of the Union, Maputo, CAB/LEG/66.6 (Sept. 13, 2000), reprinted in *African Human Rights Law Journal* 1/40; entered into force Nov. 25, 2005, Art. 14(a).

<sup>25</sup> See generally Human Rights Watch, *"I am not dead, but I am not living": barriers to fistula prevention and treatment in Kenya* (New York, NY: Human Rights Watch 2010), p. 31 (noting that "[i]nformation is a key aspect of the right to health and is critical to women's reproductive health").

<sup>26</sup> Women's Convention (see note 21), Art. 12(1).

<sup>27</sup> Committee on the Elimination of Discrimination Against Women, General Recommendation No. 24 (1999), para. 20.

<sup>28</sup> Ibid., para. 31(b).

<sup>29</sup> Maputo Protocol (see note 24), Art. 14(a).

<sup>30</sup> General Recommendation No. 24 (see note 27), para. 18 (states "should ensure, without prejudice and discrimination, the right to sexual health information, education and services for all women and girls, including those who have been trafficked, including those who have been trafficked, even if they are not legally resident in the country").

<sup>31</sup> General Comment No. 14 (see note 7), para. 21; see also *ibid.* para. 14 ("noting that state obligations to reduce rates of stillbirth and infant mortality and to improve the healthy development of the child "may be understood as requiring measures to improve child and maternal health, sexual and reproductive health services, including access to family planning, pre- and post-natal care, emergency obstetric services and access to information, as well as to resources necessary to act on that information").

<sup>32</sup> ICESCR (see note 5), Art. 13(1). The right to education is also found in Article 26 of the UDHR, which provides that "[e]veryone has the right to education." UDHR (see note 6), Art. 26.

<sup>33</sup> General Comment No. 7 (see note 18), para. 22.

<sup>34</sup> World Declaration on Education for All: Meeting Basic Learning Needs (Mar. 5-9, 1990), Art. V. Available at [http://www.unesco.org/education/efa/ed\\_for\\_all/background/jomtien\\_declaration.shtml](http://www.unesco.org/education/efa/ed_for_all/background/jomtien_declaration.shtml).

<sup>35</sup> Economic, Social, and Cultural Rights Committee, General Comment No. 13: The Right to Education (Art. 13) (General Comment No. 13), UN Doc. E/CN.12/1999/10 (Dec. 8, 1999), para. 16(b).

<sup>36</sup> General Recommendation No. 24 (see note 27), para. 28.

<sup>37</sup> International Covenant on Civil and Political Rights, G.A. Res. 2200A (XXI) (1976), UN Doc. A/6316, Art. xix.

<sup>38</sup> African [Banjul] Charter on Human and Peoples' Rights, adopted June 27, 1981, OAU Doc. CAB/LEG/67/3 rev. 5, 21 I.L.M. 58 (1982), entered into force Oct. 21, 1986.

<sup>39</sup> Lemmens & Telfer (see note 6), p. 102-03.



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<sup>40</sup> UN Human Rights Council, Preventable maternal mortality and morbidity and human rights, UN Doc. A/HRC/11/L, (2009), para. 2.

<sup>41</sup> General Comment No. 14 (see note 7), para. 12.

<sup>42</sup> *Ibid.*, para. 8.

<sup>43</sup> See, for example, *ibid.*, para. 33 (“The right to health, like all human rights, imposes three types or levels of obligations on States parties: the obligations to *respect, protect and fulfil.*”); see also Human Rights Watch (see note 25), p. 35 (“The right to access health-related information translates into both negative and positive obligations on the part of the state. On the one hand, the state is obligated to refrain from limiting access to information and from providing erroneous information. On the other hand, it must ensure access to full and accurate information.”).

<sup>44</sup> General Comment No. 14 (see note 7), para. 33.

<sup>45</sup> *Ibid.*, paras. 34, 50.

<sup>46</sup> *Ibid.*, para. 33.

<sup>47</sup> *Ibid.*, para. 35.

<sup>48</sup> *Ibid.*; see also *ibid.*, para. 51 (states must “protect consumers and workers from practices detrimental to health, e.g. by employers and manufacturers of medicines or food”).

<sup>49</sup> *Ibid.*

<sup>50</sup> *Ibid.*, para. 37 (emphasis in original).

<sup>51</sup> See *ibid.*, para. 6.

<sup>52</sup> Rebecca J. Cook et al., *Advancing safe motherhood through human rights* (Geneva, Switzerland: WHO, 2001), p. 58.

<sup>53</sup> Physicians for Human Rights (see note 14), p. 55. Establishing mechanisms of accountability may also require the creation of benchmarks to measure progress, the collection of disaggregated data to measure progress in achieving these benchmarks, sharing of this information with the public, the creation of processes by which individuals and groups can seek review of their claims and participate in political decision-making, and the provision of remedies for those whose rights have been violated. See, for example, *ibid.*; Helen Potts, *Accountability and the right to the highest attainable standard of health* (Colchester, Essex: University of Essex, 2008), p. 5.

<sup>54</sup> Physicians for Human Rights (see note 13), p. 56.

<sup>55</sup> ICESCR (see note 5), Art. 2(1).

<sup>56</sup> Sakiko Fukuda-Parr et al., *Measuring the progressive realization of human rights obligations: An index of economic and social rights fulfillment*, University of Connecticut Department of Economics Working Paper (August 2008), p. 6.

<sup>57</sup> Committee on Economic, Social and Cultural Rights, General Comment No. 3: The nature of States parties’ obligations (General Comment No. 3), UN Doc. E/1991/23, annex III at 86 (1991), para. 4.

<sup>58</sup> *Ibid.*, para. 31 (emphasis added).

<sup>59</sup> *Ibid.*, para. 2.

<sup>60</sup> *Ibid.*, para. 7.

<sup>61</sup> *Ibid.*, para. 1.

<sup>62</sup> *Ibid.*, para. 11.

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<sup>63</sup> Ibid., para. 10 (“a minimum core obligation to ensure the satisfaction of, at the very least, minimum essential levels of each of the rights is incumbent upon every State party”). A state in which a significant number of individuals are deprived of this minimum core cannot be considered in compliance with its obligations under the ICESCR. Ibid.

<sup>64</sup> Ibid.

<sup>65</sup> Ibid.

<sup>66</sup> Ibid., para. 11.

<sup>67</sup> The core obligations of the right to the highest attainable standard of health include at least the following: “(a) To ensure the right of access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups; (b) To ensure access to the minimum essential food which is nutritionally adequate and safe, to ensure freedom from hunger to everyone; (c) To ensure access to basic shelter, housing and sanitation, and an adequate supply of safe and potable water; (d) To provide essential drugs, as from time to time defined under the WHO Action Programme on Essential Drugs; (e) To ensure equitable distribution of all health facilities, goods and services; (f) To adopt and implement a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population; the strategy and plan of action shall be devised, and periodically reviewed, on the basis of a participatory and transparent process; they shall include methods, such as right to health indicators and benchmarks, by which progress can be closely monitored; the process by which the strategy and plan of action are devised, as well as their content, shall give particular attention to all vulnerable or marginalized groups.” General Comment No. 14 (see note 7), para. 43(a)-(f).

<sup>68</sup> Ibid., para. 44(d)-(e).

<sup>69</sup> Ibid., para. 44(a).

<sup>70</sup> 2008 Hunt Report (see note 13), para. 52.

<sup>71</sup> General Comment No. 14 (see note 7), para. 37(iv); see also, *ibid.*, paras. 36, 37(iii).

<sup>72</sup> Ibid., para. 37(iv).

<sup>73</sup> Ibid., para. 16.

<sup>74</sup> Mission to Uganda (see note 10), para. 33.

<sup>75</sup> Ibid.

<sup>76</sup> Ibid., para. 34.

<sup>77</sup> *Cruz del Valle Bermúdez y otros v. MSAS s/amparo*, Expediente N° 15.789, Sentencia N° 196, 1999 ESCR-Net (Tribunal Supremo de Venezuela, May 15, 1999), p. 196; Summary of *Cruz del Valle Bermúdez y otros v. MSAS*. Available at [http://www.escr-net.org/caselaw/caselaw\\_show.htm?doc\\_id=406005](http://www.escr-net.org/caselaw/caselaw_show.htm?doc_id=406005). The Court ordered that a preventive health education policy be created to combat HIV/AIDS.

<sup>78</sup> Mission to Uganda (see note 10), para. 35.

<sup>79</sup> General Comment No. 14 (see note 7), para. 36.

<sup>80</sup> Ibid; see also *ibid.*, para. 37(iii).

<sup>81</sup> Cf. World Health Organization, *World health report 2008: Primary health care (now more than ever)* (Geneva, Switzerland: World Health Organization, 2008), p. 54 (noting

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that in Nepal, “the community dynamics of women’s groups led to the better uptake of care, with neonatal and maternal mortality lower than in control communities by 29% and 80%, respectively”).

<sup>82</sup> General Comment No. 14 (see note 7), para. 12(d).

<sup>83</sup> Ibid.

<sup>84</sup> Ibid., para. 12(a)-(b).

<sup>85</sup> Ibid., para. 17; *see also* Committee on Economic, Social and Cultural Rights, General Comment No. 6: The Economic, Social and Cultural Rights of Older Persons, UN Doc. E/1996/22 (1996), para. 34.

<sup>86</sup> Political Declaration on HIV/AIDS (Political Declaration on HIV/AIDS), G.A. Res. 60/45, UN Doc. A/RES/60/262 (2006), para. 36.

<sup>87</sup> *Positive Practice Environments: Meeting the information needs of health professionals* (Geneva: Switzerland: Global Health Workforce Alliance, 2010), pp. 1-2. Available at [http://www.ppecampaign.org/sites/ppecampaign.org/files/images/PPE\\_FactSheet\\_Meeting\\_the\\_information\\_needs\\_HIFA2015.pdf](http://www.ppecampaign.org/sites/ppecampaign.org/files/images/PPE_FactSheet_Meeting_the_information_needs_HIFA2015.pdf).

<sup>88</sup> Physicians for Human Rights (see note 14), p. 45.

<sup>89</sup> Ibid.

<sup>90</sup> Ibid.

<sup>91</sup> 2008 Hunt Report (see note 13), para. 83.

<sup>92</sup> Paul Hunt, UN Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, UN Doc. A/HRC/60/348 (Sept. 12, 2005), para. 11 (“Inadequate compliance by health professionals with human rights standards is often the result of complex and interrelated circumstances, including political pressures and societal influences. However, it is often partly attributable to inadequate or non-existent training in human rights. Human rights education is an essential starting point for equipping health professionals with the knowledge and tools to empower them to promote and protect human rights.”).

<sup>93</sup> General Comment No. 14 (see note 7), para. 12(c).

<sup>94</sup> 2008 Hunt Report (see note 13), para. 44.

<sup>95</sup> Ibid.

<sup>96</sup> General Comment No. 14 (see note 7), para. 37(ii).

<sup>97</sup> Ibid., para. ¶ 12(b) (“accessibility includes the right to seek, receive and impart information and ideas concerning health issues”).

<sup>98</sup> Ibid., para. 12(c) (“All health facilities, goods and services must be ... culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-style requirements ...”).

<sup>99</sup> Ibid., para. 12(d) (“health facilities, goods and services must also be scientifically and medically appropriate and of good quality” which “requires, *inter alia*, skilled medical personnel”).

<sup>100</sup> Ibid., para. 37(ii) (noting that the obligation to fulfill includes “ensuring that health services are culturally appropriate and that healthcare staff are trained to recognize and

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respond to the specific needs of vulnerable or marginalized groups”).

<sup>101</sup> Ibid., para. 27.

<sup>102</sup> Ibid., para. 18 (noting that the ICCPR “proscribes any discrimination in access to health care and 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”).

<sup>103</sup> World Health Organization, *Everybody’s business: Strengthening health systems to improve health outcomes* (Geneva, Switzerland: WHO, 2007), p. 18. Available at [http://www.who.int/healthsystems/strategy/everybodys\\_business.pdf](http://www.who.int/healthsystems/strategy/everybodys_business.pdf).

<sup>104</sup> Ibid.

<sup>105</sup> General Comment No. 14 (see note 7), para. 12(d).

<sup>106</sup> Gavin Yamey, “Excluding the poor from accessing biomedical literature: A rights violation that impedes global health,” *Health and Human Rights Journal* 10/1 (2008), p. 1.

<sup>107</sup> Ibid.

<sup>108</sup> Ibid., p. 9.

<sup>109</sup> Ibid., p. 4.

<sup>110</sup> See note 142 and accompanying text.

<sup>111</sup> Fiona Godlee et al., “Improving access to health information in the developing world,” draft paper (Mar. 22, 2004), para. 3.4. Available at [www.who.int/entity/rpc/meetings/en/improving\\_access\\_draft.pdf](http://www.who.int/entity/rpc/meetings/en/improving_access_draft.pdf) (citing Richard Smith, “What clinical information do doctors need?” *British Medical Journal* 313/1062 (1996)).

<sup>112</sup> General Comment No. 14 (see note 7), paras. 36, 37(iii) (“availability of services”); see also, The Sphere Project, *Humanitarian charter and minimum standards in disaster response* (Geneva, Switzerland: The Sphere Project, 2004). Available at <http://www.sphereproject.org/content/view/27/84/lang,English/> (“availability and location of health services”).

<sup>113</sup> CRC (see note 16), Art. 24(e).

<sup>114</sup> General Comment No. 14 (see note 7), paras. 36, 37(iii).

<sup>115</sup> The Sphere Project (see note 112).

<sup>116</sup> Ibid., p. 265.

<sup>117</sup> General Comment No. 14 (see note 7), para. 36.

<sup>118</sup> Committee on the Elimination of Discrimination Against Women, General Recommendation No. 14, (1990), paras. a, b.

<sup>119</sup> United Nations Population Fund, *UNFPA at work: Six human rights case studies* (New York, NY: UNFPA / Harvard School of Public Health Program on International Health and Human Rights, 2008), p. 20. Available at <http://www.unfpa.org/public/home/publications/pid/1975>; see also, Human Rights Watch (see note 25), p. 35 (“Access to health information is a necessary part of women’s and girls’ ability to make informed choices and to access health services needed to ensure healthy pregnancy and delivery and treatment for related complications such as obstetric

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fistula.”); *ibid.*, p. 37 (“Family planning education, information, and services are critical to women’s wellbeing and to their reproductive and maternal health. Adequate information about the advantages of family planning and contraception methods, as well as access to such services, is important for reducing maternal deaths and morbidities such as obstetric fistula because it helps women to have planned pregnancies.”).

<sup>120</sup> Committee on the Elimination of Discrimination Against Women, General Recommendation No. 21, (1994), para. 22.

<sup>121</sup> General Recommendation No. 24 (see note 27), para. 31(c).

<sup>122</sup> Concluding Observations of the Committee on the Elimination of Discrimination Against Women, Angola, UN Doc. A/59/38 (2004), para. 163.

<sup>123</sup> Committee on the Elimination of Discrimination Against Women, General Recommendation No. 15 (1990), para. a.

<sup>124</sup> Political Declaration on HIV/AIDS (see note 86), para. 22.

<sup>125</sup> General Recommendation No. 24 (see note 27), para. 18; see also, *ibid.*, para. 23 (calling on states to report on measures they have taken to ensure access to family planning services and to pay particular attention “to the health education of adolescents, including information and counselling on all methods of family planning”).

<sup>126</sup> Resolution adopted by the General Assembly [on the report of the Ad Hoc Committee of the Whole of the Twenty-third Special Session of the General Assembly (A/S-23/10/Rev.1)]: Further actions and initiatives to implement the Beijing Declaration and Platform for Action, UN Doc. A/RES/S-23/3 (Annex) (Nov. 16, 2000), para. 79(f).

<sup>127</sup> CRC (see note 16), Art. 24(e).

<sup>128</sup> Women’s Convention (see note 147), Art. 10(h).

<sup>129</sup> Physicians for Human Rights (see note 14), p. 15 (“Policymakers have a responsibility to ensure that community participation is informed, that communities have the capacity, the organization, the information and the “language” to effectively engage in health policy and planning discussions.”).

<sup>130</sup> *Ibid.*

<sup>131</sup> General Comment No. 14 (see note 7), para. 12(a).

<sup>132</sup> *Ibid.*, para. 12(b).

<sup>133</sup> *Ibid.*

<sup>134</sup> *Ibid.*

<sup>135</sup> *Ibid.*

<sup>136</sup> *Ibid.*, para. 12(c).

<sup>137</sup> *Ibid.*, para. 12(d).

<sup>138</sup> See Lemmens & Telfer (see note 6), p. 105 (emphasizing the importance of access to *reliable* information).

<sup>139</sup> The Sphere Project (see note 112), p. 265.

<sup>140</sup> *Ibid.*; see also Mission to Uganda (see note 10), para. 35 (recommending that public information campaigns about neglected diseases be in local languages).

<sup>141</sup> See General Comment No. 14 (see note 7), paras. 12(b) (noting that “health facilities, goods and services have to be accessible to everyone without discrimination”), 18 (noting that “the Covenant proscribes any discrimination in access to health care and underlying

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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”).

<sup>142</sup> Síle Lane, *Sense about systematic reviews* (London, UK: Sense About Science, 2009). Available at

<http://www.senseaboutscience.org.uk/PDF/SenseAboutSystematicReviews.pdf>.

<sup>143</sup> General Comment No. 14 (see note 7), para. 30.

<sup>144</sup> Committee on Economic, Social and Cultural Rights, General Comment No. 16, Article 3, The Equal Right of Men and Women to the Enjoyment of All Economic, Social and Cultural Rights, UN Doc. E/C.12/2005/3 (2005), para. 29.

<sup>145</sup> General Comment No. 14 (see note 7), para. 12(b).

<sup>146</sup> *Ibid.*

<sup>147</sup> Women’s Convention (see note 21), Art. 14(2).

<sup>148</sup> General Recommendation No. 24 (see note 27), para. 16.

<sup>149</sup> Follow up to the outcome of 26th special session: Implementation of the Declaration of Commitment on HIV/AIDS, G.A. Res. 59/43, UN Doc. A/59/CRP.3 (2005), para. 24(f).

<sup>150</sup> General Comment No. 14 (see note 7), paras. 22, 23.

<sup>151</sup> Political Declaration on HIV/AIDS (see note 86), para. 26.