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PRELIMINARY DRAFT REPORT OF THE IBC ON THE BIOETHICAL RESPONSE TO THE SITUATION OF REFUGEES

Within the framework of its work programme for 2016-2017, the International Bioethics Committee of UNESCO (IBC) decided to reflect on potential bioethical questions arising from the situation of refugees, with a specific focus on health care, and as related to the relevant principles of the Universal Declaration on Bioethics and Human Rights.

At the 22nd (Ordinary) Session of the IBC in September 2015, the Committee established a Working Group to develop an initial reflection on this topic. The IBC Working Group, using email exchanges, started preparing a text on this reflection between October 2015 and March 2016. It also met in Kuwait in April 2016 to refine the structure and content of its text. Based on the work completed so far, this document contains the preliminary draft report prepared by the IBC Working Group.

As it stands, this preliminary draft report does not necessarily represent the final opinion of the IBC and it is subject to further discussion within the Committee in 2016 and 2017. This document also does not pretend to be exhaustive and does not necessarily represent the views of the Member States of UNESCO.

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PRELIMINARY DRAFT REPORT OF THE IBC ON THE BIOETHICAL RESPONSE TO THE SITUATION OF REFUGEES

I. SCOPE OF THE DOCUMENT

1. The movement of large numbers of people under desperate circumstances is not a new phenomenon. Yet the current refugee crisis has justifiably caught the world's attention, both for humanitarian and for political reasons. Due to various factors, including the nature of modern media, global awareness of such troubling events seems greater than ever. For all the attention to the various aspects of the crisis, there has been little public discussion of the bioethical issues that face the global community as it confronts the challenges of this crisis. This report considers what laws and norms should govern the response of the various parties.

2. All refugees are migrants but not all migrants are refugees. According to the World Health Organization (WHO), a migrant is 'any person who is moving or has moved across an international border or within a State away from his/her habitual place of residence'. According to the International Organization for Migration (IOM), 232 million individuals become international migrants each year and another 740 million move inside their own countries (IOM, 2015). There are several reasons that individuals become migrants. People who move to work or in search of an improved life are typically termed economic migrants. International students are migrants who seek new study opportunities. Ecological migrants find their environment disrupted and unliveable. Other migrants move for family reasons, perhaps to care for an ill relative.

3. People who migrate in order to flee war and maltreatment are commonly considered to be refugees. The 1951 United Nations Convention Relating to the Status of Refugees defines a refugee as 'someone who is unable or unwilling to return to their country of origin owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion' (UNHCR, 2010). The United Nations High Commissioner for Refugees (UNHCR) estimates that there are nearly sixty million forcibly displaced individuals around the world, as well as those displaced inside their own countries, known as internally displaced persons or IDPs.

4. The considerations of refugees are human rights and safety, not economic benefit. They leave their homes, most or all of their belongings, relatives and friends. Some are forced to escape with little or no preparation and may have experienced major trauma or been tortured or otherwise maltreated. The journey to safety itself is full of hazards, even risking mortal peril, often without realistic hope of ever returning home.

5. However, migrants who are not refugees are not automatically excluded from ethical or bioethical consideration. They may confront circumstances in the course of their transit to or residence in a host country that raise similar issues to those considered refugees, such as abusive treatment at the hands of an employer or limited access to the local health care system. In accord with the principles of the Universal Declaration on Bioethics and Human Rights (2005), this report will address the situations of both groups in a comprehensive manner insofar as they relate to bioethics. Many of the problems involving migrants are beyond the scope of this report, though they are also of great humanitarian significance.

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II. BACKGROUND STATISTICS AND OVERVIEW OF THE REFUGEE SITUATION

II.1. Magnitude and geographical location of refugees

6. The UNHCR estimates that there are about 60 million forcibly displaced persons around the world. This figure includes internally displaced persons who are forced to leave their homes and communities but still remain in their own country. They have been described as the world's most vulnerable people by the UNHCR with Colombia, Iraq and South Sudan having the largest number of IDPs. Most refugees are based in developing countries, particularly the Middle East and Africa where there has been recent destabilisation through

internal conflicts and wars (UNHCR, 2015). More than 25 per cent of the world's refugee population live in Sub-Saharan Africa and represent 14.9 million refugees and internally displaced persons mostly from Central Africa Republic, the Democratic Republic of the Congo and South Sudan.

7. Although the recent refugee crisis in Europe has attracted global attention, Amnesty International estimates that about 240 million people live outside their country of birth and more than 1500 million people (20% of the world's population) live in countries affected by conflict with 34.3 million people who are internally displaced. It is important that global actors also take into consideration the millions of IDPs and refugees living in their own countries and other parts of the world who equally deserve attention. In Asia and the Pacific region, UNHCR is attending to 3.5 million refugees, 1.9 million IDPs and 1.4 million stateless people. Most of the refugees in Asia are from Afghanistan and Myanmar and two thirds live in camps.

8. In recent years there has been a dramatic influx of refugees from the Middle East and Africa into the European Union (EU), which has been described as the refugee crisis. According to a report by Eurostat, about one million migrants and refugees crossed over to the EU within the year 2015 alone. There are however some inconsistencies in available figures on the magnitude of the refugee crisis in Europe. The European Asylum Support Office (EASO) estimates that between January and June 2015, about 600,000 people applied for asylum within the EU. This figure rose by 106,490 in February 2016. The 2015 Eurostat Demography report also estimates that the number of asylum seekers within the EU shot up to 626,000 in 2015 following the Syrian conflicts. There are more than 3 million Syrian refugees in different countries of the Middle East (Jordan, Lebanon) while 6.5 million displaced people still live inside Syria. In addition, about 1.8 million people from Iraq are refugees or IDPs. These figures do not include those who have entered the EU illegally as well as undocumented migrants and refugees.

9. Refugees often represent a broad array of social and professional backgrounds and include men, women, the elderly and children who may be unaccompanied. Latin America has a great problem of unaccompanied children, adolescents and women who suffer from transnational organized criminal groups. With the war in the Middle East, it is estimated that the number of unaccompanied minors entering the EU rose from 2,000 in January 2015 to 16,000 in November 2015.

10. Most refugees end up in camps especially during mass movements of refugees. Although being a refugee is expected to be a temporary situation with the possibility of being fully integrated into the socio-economic life of the host country or the possibility of returning to their home countries in better conditions, there is evidence that many refugees have lived in camps for several decades leading to the concept of the 'forgotten refugees'. For example, the world's largest refugee camp is found in Kenya. The UNHCR reports that the Dadaab refugee complex is the largest in the world and is estimated to host about 329,811 refugees from Somalia since the Somalia war in 1992. The Kenyan government has announced its plans to close down the Dadaab refugee camp. While this is welcome news to integrate these refugees back into society, questions have been raised about the social, psychological and economic implications of relocating over 600,000 people who have called the Dadaab camp their home for several decades.

II.2. Causes of the refugee situation

11. Existing data suggest that internal wars, conflicts, poverty and climate change represent the major causes of forced migration and displacements worldwide. However, in relation to refugees more specifically, the major cause is internal armed violence and conflicts. Weapons trade and trafficking is also an important cause of violence which often destabilises countries and contributes to the refugee situation.

12. In many developing countries, political instability, which often follows disputed election results, has also contributed to both internal and external displacements. The flow of refugees

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and displaced persons within their country occurs due to persecution, insecurity and conflict, and is frequently compounded by a lack of access to services and means of sustenance.

13. Ethnic and religious conflicts also result in minority groups suffering discriminatory practices, xenophobia, repression and prejudice, with feelings of insecurity and limited access to official justice systems. Such persecution contributes to people fleeing their homes and countries in search of security. Examples are the Rwandan ethnic conflicts and countries with anti-gay laws which have forced some to seek refuge in other countries.

14. Poverty is another major cause of the refugee situation, particularly in sub-Saharan Africa. More than 2.2 billion people (more than 15% of the world's population) are in multidimensional poverty or close to it despite some recent progress. 75% of the world's poor live in rural areas, where they are trapped in insoluble cycles of low productivity, seasonal unemployment and low wages, and changes in weather patterns (UNDP, 2015). Reports suggest that nearly 80% of the world's population does not have comprehensive social protection: from 37% in Europe to 81% in Sub-Saharan Africa, the poverty headcount reduction from social protection varies between 53% (Europe) to 9% (South Asia) and the Gini coefficient (a reliable measure of inequality) varies between 23% (Europe) and 1-2% in all other regions (World Bank, 2015). This situation affects access to health care and the state’s response to the health needs of refugees.

II.3. Consequences of the refugee situation

15. The consequences of the refugee situation can be examined from three different angles; namely for the refugees themselves, on host countries and for affected countries. Although these consequences can be multidimensional, the focus of this report is on the situation of refugees in relation to access to healthcare, rights to health and their intended and unintended consequences.

16. Increase in the vulnerability of refugees is one of the major consequences of the refugee situation. Displacements often make people more vulnerable because they are removed from their comfort zones. Children for example are considered vulnerable in many situations; however, when they become refugees their vulnerability is increased, particularly in the case of unaccompanied minors who are removed from protective structures such as parental care. Other groups whose vulnerability increases with their refugee status include women (whose vulnerability may be exacerbated when they are pregnant), and the elderly.

17. The refugee situation also leads to overcrowded longstanding camps with difficulties in distribution of food and water, provision of basic needs and access to qualified health services and education, as well as criminalization of their inhabitants (UNHCR, 2015). These problems also contribute to the spread of infectious, gastrointestinal and respiratory diseases, human trafficking and exploitation. Refugees also run the risk of detention which may prohibit them from accessing international protection and health services.

18. Regarding access to healthcare, one of the major challenges of the refugee situation is integrating them into the local health system of the host country. Although refugees have the right to primary health care, their integration into the local health system is far from guaranteed, and there is lack of consensus on whether health care should be provided for free or requires a contribution from the refugees. Country profiles vary and some health care systems are entirely privatised which represents a significant burden to the organisations on the ground and limits their action.

19. There is little consensus on the acceptable standard of health care that should be provided to refugees. If there seems to be a consensus on the content and definition of the package of primary health care, there is a clear gap in the provision of secondary and tertiary health care such as management of cancer, HIV, drug addiction and other ailments which require long term healthcare. In many cases, refugees do not have access to such treatments, which is a considerable limitation of their right to health and presents major ethical issues.

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20. Constant mobility of refugees also hampers the detection, treatment and monitoring of diseases and vaccinations, while increasing the risk of therapeutic non-compliance. Misuse and lack of control of medical protocols can lead to drug resistance. The often precarious habitat of people during their movement also impacts on their health. The gross mortality rate of displaced people would be significantly higher than that of the people left behind. Reasons include reduced access to health services, drinking water, sanitation and inadequate shelter, the lack of information about their new environment, and the loss of property and social networks.

21. Because many refugees often end up in camps or in circumstances with little nor no governing authority, they are often exposed to very challenging situations. Despite the efforts of international and local organizations, they may have limited or no access to healthcare. Inadequate sanitation in camps or old houses for refugees, overcrowded clinics and hospitals, irregular provision of medical equipment and medicines, challenges in storing medicines, distribution and supervision of medical aid are some of the major challenges confronting refugees. These problems are still greater for displaced persons who are not housed in camps or are in transit.

22. Refugees who are victims of violence, mass destruction, persecution and sexual harassment often suffer from emotional trauma. They may also experience depression due to the loss of their country, friends and family. In addition, the insecurity that arises from living in unfamiliar conditions, such as different languages and cultures, could exacerbate these mental health problems. They may experience humiliation from being newly dependent and feel incapable of finding a solution. There may be little hope of ever returning to their home country and fear for the future of their children and family. The elderly and critically ill may deal with not only the fear of dying in a foreign country but also little expectation of the traditional burial rites to which they might be entitled.

23. For many minors, particularly those that are unaccompanied, their refugee status can often lead to loneliness, insecurity and fear during travels or in camps. Access to social protection and formal education may also be curtailed for several years which could lead to child trafficking and prostitution.

24. Populations in the host countries are also confronted with problems due to the arrival of large numbers of refugees. These include economic insecurity, discomfort with those from other cultures and challenges to safety and their daily way of life. The xenophobia, discrimination and racism that can be stimulated enters into a vicious cycle and complicates the resettlement of refugees.

25. Massive movements of refugees can also lead to burnout among medical doctors, nurses and other health practitioners who directly provide healthcare services. Support should therefore be extended to these practitioners who must ensure the provision of adequate and professional health care to refugees under difficult conditions.

III. REFUGEE HEALTH CARE AND THE LAW

26. According to the United Nations 1951 Convention Relating to the Status of Refugees, as amended by the 1967 Protocol, a refugee refers to a person who 'owing to well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality and is unable or, owing to such fear, is unwilling to avail himself of the protection of that country; or who, not having a nationality and being outside the country of his former habitual residence as a result of such events, is unable or, owing to such fear, is unwilling to return to it' [Article 1]. For refugees lawfully staying in the host country, Article 23 of the Convention mandates that States accord to them 'the same treatment with respect to public relief and assistance' as enjoyed by nationals, even if they do not meet any conditions of local residence or affiliations which may be required of nationals. This article is to be interpreted broadly, and extends to public relief and assistance provided to persons in need 'because of infirmity, illness or age', which include

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hospital and emergency treatments. Hence, under the 1951 Convention, refugees are entitled to the same right to medical assistance as nationals of their host countries.

27. While the 1951 Convention is the basic instrument of reference on the treatment of refugees, health care for refugees is also provided for in other international and regional human rights instruments. Thus, even for countries that have not ratified the 1951 Convention, there remains a legal duty to provide health care to refugees as the human rights framework applies to all human beings without distinction. One of the earliest normative documents to recognize health as a basic human right is the Constitution of the World Health Organization (WHO) (1946), which proclaimed that '[t]he 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'. There are two underlying claims in the WHO's proclamation, namely that: (1) health is a universal right, and (2) the standard of health should be of the 'highest attainable'.

28. The universality of the right to health was subsequently reaffirmed by the Universal Declaration of Human Rights (1948), which declared that: 'Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including …medical care …' [Article 25 (1)]. Furthermore, under the International Convention on the Elimination of All Forms of Racial Discrimination (1965), States Parties are obligated 'to guarantee the right of everyone, without distinction as to … national or ethnic origin, to equality before the law, notably in the enjoyment of… the right to public health [and] medical care' [Article 5(iv)]. Similarly, refugees have a prima facie right to 'health protection [and] medical care' under the Declaration on the Human Rights of Individuals who are not Nationals of the Country in which They Live (1985), 'provided that they fulfil the requirements under the relevant regulations for participation and that undue strain is not placed on the resources of the State' [Article 8].

29. Women and children are offered special protection in the international human rights framework. In relation to health, Article 12 of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) (1979) calls on State Parties to '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…'. In particular, State Parties are to 'ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary…'. With regards to children, State Parties to the Convention on the Rights of the Child (CRC) (1989) are required to protect a child's right of access to health care services for the treatment of illness and rehabilitation of health [Article 24]. State Parties have to take appropriate measures '(b) [t]o ensure the provision of necessary medical assistance and health care to all children with emphasis on the development of primary health care; … (d) [t]o ensure appropriate pre-natal and post-natal health care for mothers; …[and] (f) [t]o develop preventive health care…'. As CEDAW and CRC apply to all women and children, these instruments grant substantive rights to health care to women and children refugees.

30. The right to health is also protected through regional human rights instruments, including the African Charter on Human and Peoples' Rights (ACHPR) (1981) [Article 16], and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (1988; 'The Protocol of San Salvador') [Article 10] and the ASEAN Human Rights Declaration (2012) [Article 28]. In the European Union, '[e]veryone has the right of access to preventive health care and the right to benefit from medical treatment under the conditions established by national laws and practices' (Charter of Fundamental Rights of the European Union, 2012) [Article 35]. Equitable access to health care 'of an appropriate quality' is also an obligation of State Parties to the Council of Europe Convention on Human Rights and Biomedicines (1997) [Article 3].

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31. Under the European Social Charter (ESC) (1961, Revised 1996; CETS No.163), individuals enjoy a right to protection of health [Article 11], and a right to social and medical assistance [Article 13]. Accordingly, State Parties have the obligation:

a. to remove as far as possible the causes of ill-health (…);

b. to prevent as far as possible epidemic, endemic and other diseases, as well as accidents (…) [and]

c. to ensure that any person who is without adequate resources and who is unable to secure such resources either by his own efforts or from other sources, in particular by benefits under a social security scheme, be granted adequate assistance, and, in case of sickness, the care necessitated by his condition (…)

32. The Charter also protects equitable access to healthcare, requiring that States apply the provisions (of Article 13) 'on an equal footing with their nationals to nationals of other Parties lawfully within their territories', in accordance with the European Convention on Social and Medical Assistance (1953).

33. Having established that refugees do have a (prima facie) right to health and health care services, the question follows: to what extent is that right? As mentioned earlier, the WHO Constitution proclaims that every human being ought to have a claim to the 'highest attainable' standard of health. This right has been reaffirmed by the Commission on Human Rights (in its resolution 1989/11), and was further elaborated in the International Covenant on Economic, Social and Cultural Rights (ICESCR) (1996), which 'recognize[s] the right of everyone to the enjoyment of the highest attainable standard of physical and mental health' [Article 12]. Pertinent to the context of the health of refugees, the Covenant requires that State Parties take steps 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 prevention, treatment and control of epidemic, endemic, occupational and other diseases; [and]

c. The creation of conditions which would assure to all medical service and medical attention in the event of sickness.

34. The 'highest attainable' (or equivalent) standard of health is similarly echoed in the ESC, the CRC, the San Salvador Protocol, the ACPHR and the ASEAN Human Rights Declaration. Noteworthy of the ICESCR is its elaboration of the extent of health care services that States have an obligation to provide, which include (aside from acute medical treatment) primary and secondary care services, preventive health care, and especially important to the well-being of refugees, mental health care. Recently, the ASEAN Human Rights Declaration raised that bar higher by including reproductive health, and proclaiming that every person has a right 'to basic and affordable health-care services, and to have access to medical facilities' [Article 29] (emphasis added).

35. The Committee on Economic, Social and Cultural Rights (CESCR) has issued a comprehensive interpretation of the normative content of 'The Right to the Highest Attainable Standard of Health' (CESCR, 2000). The CESCR identified the right to health as consisting of freedoms, which 'include the right to control one's health and body … and the right to be free from interference'; and entitlements that 'include the right to a system of health protection which provides equality of opportunity for people to enjoy the highest attainable level of health'. Notably, the CESCR explained that the notion of the 'highest attainable' standard 'takes into account both the individual's biological and socio-economic preconditions and a State's available resources', and pointed out that 'good health cannot be ensured by a State, nor can States provide protection against every possible cause of human ill health' (para 9). As such, the right to health is not a right to be healthy, but 'a right to the enjoyment of a variety of facilities, goods, services and conditions necessary for the realization of the highest attainable standard of health' (para 9). The CESCR had also interpreted the right to health 'as an

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inclusive right extending not only to the timely and appropriate health care but also to the underlying determinants of health, such as access to safe and potable water and adequate sanitation, an adequate supply of safe food, nutrition and housing…' (para 11).

36. The right to health under national constitutional and domestic national laws has also been adjudicated in twenty cases in seven developing jurisdictions. These cases do not concern refugees. They involve nationals in the respective countries. The judicial decisions turn on the interpretation of the respective constitutions and domestic national laws and not on the international conventions or treaties outlined in this chapter. However, they can be instructive for two reasons: first, that the decisions of national courts define, and sometimes limit and proscribe the normative right to health in the respective countries; and second, that such right to health granted to a national in that country cannot be greater than the right to health of a refugee. The WHO's Ruling for Access document which examined these twenty cases and correctly concluded as follows: 'Although each case must be judged on its individual circumstances and merits, the following conclusions can be drawn from the group of rulings as a whole:

a. Most rulings have led to better access to life-saving medicines (17/20 cases).

b. International treaties create state obligations and support individual rights at the national level (8/20).

c. Individual cases can create group rights (7/20).

d. The right to health is not restricted by limitations in social security coverage, including the national list of essential medicines (4/20).

e. Government policies can be challenged in court (2/20).

f. The state has special obligations towards the poor and disadvantaged (2/20).

g. Progressive realization of the right to health is rarely used to restrict access (1/20).'

37. Analysis of the 20 cases identified a number of success factors. These can be either constitutional provisions present in the country, certain aspects of the case, or certain principles being quoted either by the plaintiff or the court:

a. Constitutional provisions: that international treaties rank higher than national laws (7 cases); on the right to health (6/7); or with defined state obligations with regard to health care services and social welfare (3/7).

b. Constitutional provision that human rights treaties enjoy constitutional rank even though the right to health itself is not included in the constitution (1 case).

c. Linking the right to health to the right to life, in the case of life-threatening disease (13 cases).

d. Legal, financial and moral support by public-interest nongovernmental organizations (8 cases).

e. Acquired rights and demanding non-interruption of treatment in the case of time-limited social security rights (4 cases).

f. Non-discrimination implying the right to equitable availability of medical care (3 cases).

g. Non-discrimination on economic grounds implying special state obligations to the poor (2 cases).

Several cases illustrating the ways that various national legal systems have addressed these issues are included in the appendix.

38. Through various international and regional human rights instruments, refugees are able to claim a right to the highest attainable standard of health, and are entitled to the same quality of health care as nationals of their host countries. The right to health extends to both physical, as well as mental, health. As such, States are obligated to provide not only health

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care services, but also basic needs that contribute to the overall well-being of refugees, particularly vulnerable groups such as women and children refugees.

IV. WHAT DOES THE RIGHT TO HEALTH CARE IMPLY?

39. The right to health -- or, as we prefer to specify it, health care -- has been usually considered as a merely contingent social right instead of an inherent human right. However, from the perspective of democratic principles, including justice and equality, the rule of law and democracy, this approach falls short. In particular, understood as a merely contingent social right conferred by states, the right to health care must be interpreted and implemented by the courts, which are not in a position to determine expenditures. In order to have practical efficacy, therefore, the right to health care must be considered as an inherent human right.

40. The rights to life, personal integrity and health care are linked because the implementation of the right to health care directly affects life and personal integrity. Considering this link, the right to health care as an inherent human right must be ensured in order to protect life and personal integrity. Because of the many variables beyond its control, the state does not have a duty to guarantee life or personal integrity, but the state does have the duty to provide health care to help individuals in their struggle against diseases that may compromise quality of life and personal integrity. In this sense, there is as well a link between the right to health care and the rule of law.

41. Democracies are defined by the participation of their members. Such participation requires that the citizens of a democracy have a level of intellectual and physical well-being so that they can play a meaningful role in democratic deliberation and decision making. Ensuring health care is critical to enabling the political participation required in a democracy.

42. The notion of a minimum content or core of health care services does not solve the problem of guaranteeing the right to health. The expression 'the highest attainable standard of health' that appears in almost all international treaties and covenants does not allow states to limit health care for certain groups, such as refugees. The notion of a minimum core of health care services suggests that states may set limits due to economic or other considerations, and may do so in a discriminatory manner. Differences may be acceptable between States in light of their economic situation, but not with regard to the people within their territories, all of whom must have recognition of their right to the highest attainable level of health, independent of their status as citizens or refugees.

43. Refugees and internally displaced persons cannot be lumped together as a single unit, since they are very heterogeneous regarding individual assets, such as previous education and health status, and sometimes wealth. However, both groups suffer from common problems: the psychological trauma of (forced) displacement, the adaptation to a new environment and new customs, and sometimes the sequel of torture or war wounds. Thus, special health services are required, but the availability of these services varies depending on the host country. In cases where States cannot provide suitable care to these populations, because they cannot cater them to their own population either, the United Nations has a clear mandate through its specialized agencies to act in order to uphold the realization of their human rights.

44. Setting up health facilities exclusively for refugees when the local population lacks access to them may become a cause for rejection of these groups, so services should be open to the local population as well. This would serve the additional purpose of facilitating integration with the local communities.

45. At the end of the day, the issue revolves around universal health coverage that is truly comprehensive and affordable for all people. Funding mechanisms should not be different for refugees (and internally displaced persons) than they are for locals; ideally they should be either universal health systems funded through general taxes or social security schemes with subsidies for the unemployed and their families.

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V. ETHICAL CHALLENGES

V.1. Equity, justice, equality

46. Article 10 of the Universal Declaration of Bioethics and Human Rights states that '[t]he fundamental equality of all human beings in dignity and rights is to be respected so that they are treated justly and equitably'. Human equality is presupposed as the foundation of human dignity and human rights, with just and equitable treatment as the goal that is to be achieved by global society. These three principles of equality, justice and equity are present in almost every Declaration and are particularly developed in Articles 8 ('Respect for human vulnerability and personal integrity'), 11 ('Non-discrimination and non-stigmatization'), 13 ('Solidarity and cooperation') and 14 ('Social responsibility and health') of the Universal Declaration of Bioethics and Human Rights.

47. In one sense these principles are aspirational ideals but they are also practical standards that the member states are called upon to implement in their policies and practices. Refugees, in particular, are to be considered in the implementation of these principles. Article 14, for example, states that 'individuals and groups of special vulnerability should be protected and personal integrity of such individuals respected' and summarizes the basic needs that must be satisfied in order to ensure the equitable and just treatment of every human as an end in her- or himself.

48. Justice is a general principle that guides our individual and collective ethical behaviour. The concept of justice has been linked to that of equality, often understood as fairness, while equity is associated with fair and impartial treatment. Justice is therefore a general principle while equity is its particular application, a necessary extension of justice. Equity involves and requires the implementation of justice. The equitable implementation of the principle of justice requires us to address the challenges of poverty and exclusion from social opportunities and access to food, water and health care in a non-discriminatory manner. Indeed, health care requires still more, including physical security, shelter, education and a stable source of income.

49. The term justice refers both to a formal legal concept as well as its socio-political interpretation as equity. The two may be distinguished though both are integral in the principle of justice. In bioethics equitable access to health care relates both to broad issues of human life and universal human rights to access certain services. In this sense, equity is one of the indicators that can guide the process of making ethical decisions regarding the commitment of developed countries to the problems encountered by refugees. Deprived of the minimum assets necessary for survival, refugees deserve to be treated justly and as equals, with equity an important practical tool for achieving these goals.

50. The three principles also constitute the general framework of the respect for the human dignity. Refugees, as fellow human beings, deserve respect and dignity that must not be ignored because of their 'distressing and dire' situation. Indeed, their vulnerability requires that they receive special attention and protection. In spite of some recent attempts to replace it with other concepts, the idea of dignity retains a special place in the field of human rights as an intrinsic quality of the human person that demands respect for all people. The failure to respect the quality of human dignity for some is a failure to respect it for all. Thus, it is essential that wealthier nations demonstrate solidarity in welcoming refugees from disadvantaged regions and sites of conflict.

V.2. Culturally sensitive institutions of health care

51. From its formation, UNESCO has focused its work on the intercultural dialogue for peace through education, cultures, science communication and information. At the World Forum on Intercultural Dialogue (2016), the UNESCO's Director-General stated that: 'Cultural diversity is the other name for human dignity and human rights. All cultures are interlinked, and we need to embrace them all, to fully feel ourselves, to fully feel human.'

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52. The Universal Declaration on Bioethics and Human Rights (2005) recognizes that 'health does not depend solely on scientific and technological research developments but also on psychosocial and cultural factors' and 'that a person's identity includes biological, psychological, social, cultural and spiritual dimensions', so 'decisions regarding ethical issues in medicine, life sciences and associated technologies may have an impact on individuals, families, groups or communities and humankind as a whole'. It is necessary that health providers possess a 'moral sensitivity and ethical reflection' to 'promote respect for human dignity and protect human rights, by ensuring respect for the life of human beings, and fundamental freedoms, consistent with international human rights law'. Article 3 recognizes human dignity and fundamental freedoms as human rights that are to be fully respected; in the context of health care, it means the respect for their autonomy and cultural diversity without discrimination and stigmatization for a correct process of information and consent to health interventions.

53. The WHO Constitution enshrines '…the highest attainable standard of health as a fundamental right of every human being' and it states that 'freedoms include the right to control one's health and body and to be free from interference'. Therefore, human rights-based health services must be non-discriminatory, available, accessible, respectful and culturally appropriate, as well as sensitive to gender and life-cycle requirements. States and other duty-bearers are responsible for the observance of human rights which are universal and inalienable. All people everywhere in the world are entitled to them (WHO, 2015). The 61st World Health Assembly called on all Member States to 'promote migrant-sensitive health policies' through integration within health system policies and programs, with consideration given to historical values, contexts and local capacity, such as universal access to basic health care and equity.

54. Refugees may have 'competing interests, ethnic or tribal strife, cultural beliefs such as gender dynamics [that] can limit the participation of migrants [in their new settings] … and they may be apprehensive of authority and data collection procedures or may be afraid to access health care and other services' (Miramontes et al., 2015).

55. In this situation, health care providers need to recognize that they have biases and prejudices both from their own cultural background and their medical education. They are educated to cure and should resist any tendency to change the patient's perspective instead of altering care to accommodate the patient's needs and values. In the context of an emergency involving a great many sick people or people proceeding from countries known to have poor health indicators, this attitude may be reinforced. So the first step to establish a culturally sensitive institution of health care is for health care providers to recognize their own limits about the knowledge of the different cultures of refugees.

V.3. Decision-making

56. The principle of respect for autonomy is pre-supposed in the bioethical literature on medical decision-making: persons who have decision-making capacity are moral agents who have the right to decide about their medical treatment. But what of those who are unable to decide? How are decisions to be made and by whom? In the case of refugees who become ill while in transit and who lack decision-making capacity, these questions may be still more difficult to answer. Problems of decision-making for persons who are unable to decide for themselves are at the heart of modern clinical bioethics.

57. In general, the goal of surrogate decision-making is to approximate the decision that a patient would have made for themselves had they been able to do so. Written documents or statements made by the person that establish their values and preferences in advance are the first reference point and should be respected. Of course, those written or verbal statements may not be precise with respect to the current situation but every effort should be made to establish a plausible approximation of the application of those statements. In fact, documentation of prior values and preferences regarding medical care is rare enough for patients who are well situated, while the circumstances of refugees generally preclude the

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availability of any medical records at all, including advance medical directives. Yet medical ethics makes no exceptions about refugees; every effort must be made to respect their autonomy so far as is possible under the difficult conditions in which health care workers must function.

58. In general, modern medical ethics holds that if there are no advance directives then a plan of action may be derived from what is known about the patient's values, including their religious identification and cultural background. If no one has been designated by the patient in advance to be their surrogate decision-maker, then a spouse, partner, parent, adult sibling or close friend may be in the best position to know the patient's values and preferences. Failing such information, the surrogate may decide based on the patient's best interests. Under some circumstances, legal authorities may identify a guardian to play this role. It is best if the physician does not take the responsibility so as to avoid confusion between his or her caregiving role and the role of the agent of the patient's theorized wishes. All of these procedures may be applied to the case of refugees who lack decision making capacity and for whom there are no advance medical directives.

59. Parents or legally authorized guardians are decision-makers for children unless and until the child has the capacity to be part of the decision-making process, at which point their participation and assent should be sought. For adults who have never achieved that capacity, i.e., the severely cognitively impaired, a surrogate may decide based on the patient's best interests. For those who have lost the capacity to consent, efforts should be made to provide treatment in accordance with what can be known about their likely preferences and values. In too many instances, children and other persons who have never achieved decision-making capacity are traveling alone as refugees. Care must be taken to ensure that they are assigned surrogate decision makers who are sensitive to the special vulnerability of such persons.

60. In principle, the same ethical standards should apply to medical decision-making for migrants and refugees. However, the extreme circumstances in which refugees find themselves may result in more frequent appeal to standards such as best interests in the absence of detailed knowledge of a patient's preferences, especially if they are traveling without close relatives or friends.

61. It is often important to gain new knowledge about the health challenges associated with the extreme conditions of refugees. All the usual requirements for ethically designed and executed research studies must be respected in these situations. These requirements include the informed consent of the participant/subject; a guarantee of the relevance of the research study to the health needs of this or similar future populations; the equitable sharing of benefits with the participant/subjects; and post-trial access to the data where practical.

V.4. Resource allocation

62. Decisions on allocated scarce resources are usually located at the macro level of governments and parliamentary bodies. These bodies also respond to refugee situations. It follows that governments should allocate sufficient resources for their response. It is important to keep this in mind in order to prevent a situation where the responsibility for all resource allocation is borne solely by health care workers.

63. However, even with clear decisions at the macro level, there will also be a need to make decisions about resource allocation at the micro level to a certain extent. This is called triage. The word triage is used both outside and within the context of health care. But even within the domain of health care it can have different meanings. The most familiar context in which the word is used is that of healthcare on the battlefield. Priority in health care was to be given first to the slightly injured who can quickly return to the battlefield, then to the more seriously injured and lastly to the 'hopelessly wounded'. But 'triage' is also used in disaster situations and even in emergency rooms where injured patients have been sorted for medical attention according to their medical needs and prospects with those requiring more immediate

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care receiving it first. Also, decisions to admit or discharge patients from intensive care units often involve some form of triage.

64. In the context of refugees living in camps, triage also can have different meanings. (1) In case of a sudden surge in arriving numbers of refugees, triage may mean that choices have to be made about allocating scarce (or at least limited) resources at the place of arrival. (2) Triage may also point at a screening procedure in which refugees (especially the more vulnerable ones among them) are checked to identify health problems. (3) At a further stage, triage may also occur. In camps run by the UNHCR, once access to primary health care has been guaranteed for all, access to further treatments is decided upon by the Standard Operations Procedures. These, due to restricted budgets, may be very strict (cf. UNHCR) and do not imply long-term and costly treatments such as cancer therapies.

65. The ethical principle involved in triage is justice. Distributive justice is a principle which governs how resources should be allocated within a society among individuals with competing needs. Applying the principle of distributive justice, calls for reflection on the nature and extent of what is due. It is important to recognize that the criteria to make triage decisions are never solely medical.

66. For many people triage is associated with a certain feeling of moral uneasiness as its traditional rationale is to do 'the greatest good for the greatest number'. This phrase will be recognized as the classical utilitarian rule. It justifies prioritizing one over another if the first can be saved to contribute to society.

67. In spite of exceptions due to societal needs (e.g. the so-called multiplier effect that justifies prioritizing health care workers over others), generally, only medical criteria should be used in triage, followed by queuing for scarce resources when medical need is roughly equal for eligible patients. Only in case of an epidemic, health care workers among the refugee community could be prioritized, in order for them to be able to help with providing health care to that same community.

68. Triage is recommended (also by WHO) at points of entry to identify health problems in certain refugees (children, pregnant women, and the elderly) soon after their arrival. Proper diagnosis and treatment must follow, and the necessary health care must be ensured to the extent possible. Each and every person on the move must have full access to a hospitable environment, to prevention (such as vaccination) and, when needed, to health care of the highest attainable standard, without discrimination on the basis of gender, age, religion, nationality, race or legal status.

69. At first sight there are no moral problems with triage understood as screening. However, moral problems may surface when:

a. routine screenings have unintended consequences and/or;

b. the results of screening are used for other than medical purposes.

70. According to WHO, simple measures could provide greater health security for migrants:

a. WHO does not recommend mandatory testing for diseases among refugees or migrants because there is no tangible evidence on the benefits (or relation cost / effectiveness) of this intervention, which could also be a source of anxiety for refugees and generally for the community.

b. WHO strongly recommends that medical assessments be carried out to ensure that all refugees in need of protection have access to health care. These medical checks should be made for transmittable and non-transmittable diseases, respecting the human rights of migrants and their dignity.

c. The screening results should never be used as a reason or justification for the expulsion of a refugee or migrant.

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d. Mandatory testing deters migrants from seeking a medical examination and compromises the identification of high risk patients.

71. Whereas primary health care for refugees may be guaranteed, it may be difficult to provide long-term care to refugees, due to further migration but also due to scarcity of resources. In this report a justification is provided for a policy to provide health care services to refugees irrespective of their legal status, and irrespective of whether they are in transit or not as part of universal health coverage.

V.5. Challenges to public health

72. Population density in refugee camps favours the spread of transmissible diseases and poses challenges of hygiene and sanitation. Mortality of children less than five years old seems to be correlated to the size of the population.

73. Camping sites have a significant effect on health. The closer a refugee camp is to conflict areas, the greater the risk of exposure to violence. A study conducted in 51 refugee camps located in seven countries including three in Africa (Ethiopia, Tanzania and Uganda) showed that the gross mortality rate in sites located less than ten kilometres away from the conflict areas was ten times higher than in camps at least fifty kilometres away. The distance between the camp and the health reference structure might also have a significant effect on mortality rate.

74. Inadequate security in a refugee zone affects health indirectly by compromising the access of humanitarian organizations to populations. Problems of malnutrition and of drinking water are likely to vary according to migratory status and nature of insertion in the reception area. Internally displaced persons are often at greater risk of lack of access to supplies, while refugees in camps have easier access to drinking water, to daily food rations and in the long run to food self-sufficiency. The situation of the refugees outside their camps contributes to availability and access to food in the host country, and ultimately to the modalities of insertion in the local economy.

75. Refugees can be victims of many forms of acts of violence, physical, sexual, moral and psychological.

76. Gender based violations of human rights, violence and persecution increase during wars and armed conflicts.

77. Paradoxically, while women take refuge to escape persecution and violence, the risk of transmission of HIV / AIDS is higher during escape and exile. Women are sexually abused by individuals who use their position of power in the conflict areas, on borders and in camps.

78. The exposure of migrants to the risks related to the movements of populations augments their vulnerability to non-transmissible diseases. These risks include psychosocial disturbances, problems of reproductive health, higher neo-natal mortality, drug use, nutritional disturbances, alcoholism and exposure to violence.

79. Factors such as the massive displacement of populations, water shortage, and lack of shelter and adequate sanitation increase disease risk. Epidemics such as meningitis, yellow fever, viral hepatitis and typhoid occur in these situations and also promote the appearance of psychiatric and psychosocial problems. In some refugee camps, diarrheal diseases constitute over 40% of deaths, more than 80% of cases involving children aged less than two years. During their exile and in the camps, refugees are exposed to diseases linked to their precarious living conditions. In these often unhealthy places there is a risk of diseases like gastroenteritis or tuberculosis. The risks increase as the difficulties accumulated in exile weaken the immune systems of refugees who are already vulnerable to physical and other abuses in the street.

80. The lack of access to healthcare for refugees is the main challenge. Displacement causes the interruption of treatment, especially in cases of certain chronic diseases and

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infections. Due to bad living conditions and deprivations suffered during migrations, vulnerable children are subject to acute respiratory infections and must have to access to appropriate care. Lack of hygiene can provoke cutaneous infections.

81. Refugee health is often relegated to second place after other arrangements like shelter and food. However, as pointed out by the regional Head of WHO for Europe: '[a]mong newly arrived migrants, the most frequent health problems are accidental injury, hypothermia, burns, cardiovascular problems, pregnancy complications or delivery, diabetes and hypertension. The main non-transmissible diseases are cardiovascular diseases, diabetes, cancer and chronic respiratory diseases. In some countries with low and average income, diabetes and hypertension in affected adults reached levels of 35 %. Mothers with newborns or young children confront not only sexual and reproductive health problems and acts of violence but also neonatal illnesses.' (WHO Regional Office for Europe, n.d.)

82. Although the idea that there is a link between migration and importation of infectious diseases is widespread, this association is not well-established by the evidence. Refugees are exposed mainly to common infectious diseases in Europe, unrelated to migration. The risk that exotic infectious agents are imported into Europe is extremely low, and when it materializes, experience shows that travellers, tourists or health workers are a greater concern than refugees.

V.6. Identity, Discrimination, Stigmatization

83. As discussed elsewhere in this report, some of the consequences of the refugee situation include the increase in their vulnerability, particularly those related to loss of identity, discrimination and stigmatization. These issues ought to be addressed by responsible authorities, particularly in the context of the refugees' right to healthcare.

84. Refugees are often forced to leave their local communities that define their identity. The situation worsens in cases where individuals and families either leave behind or lose identification documents in the process of fleeing to safety. They are forced to reconstruct a new identity and take on labels that might contradict their original identities. This is particularly the case with refugees based in settings that are fundamentally different from their original communities. This has negative implications when people are forced to adopt practices that are contradictory to their own beliefs and practices. As a result, they lose their original identity and yet do not feel any sense of belonging to their new society.

85. Although there is no clear consensus on what can be defined as a 'refugee identity', the term itself often has negative connotations. It is associated with people who do not belong and thus contributes to prejudices and social inequalities. The process of constructing identity - be it personal or group identity - is a social construct which depends on inter-subjectivity, i.e. that which happens in relationships established with the other. It is one thing for refugees to construct their own identity and it is another thing for others to construct an identity for them based on the stories surrounding refugees. The challenge is that states and international aid organisations are often ill prepared to handle the refugee situations confronting them.

86. As discussed earlier, the label 'refugee' itself often has derogatory connotations and can also lead to discrimination and stigmatization. For example, as discussed earlier in this report, there is little consensus on a refugee's right to healthcare. This often affects the type and quality of healthcare that refugees are given in comparison to locals. It is understandable that not all host countries can address their healthcare needs due to lack of manpower and medical supplies. Accommodating refugees in these struggling societies could put a lot of pressure on the local healthcare system, unless the global community is willing to provide support. While refugee agencies such as the UNHCR have made tremendous progress in addressing the health needs of refugees, this has often happened within the context of refugees living in camps that are directly under their care. More needs to be done to support countries hosting refugees to meet the growing healthcare needs of refugees. More privileged

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societies with better healthcare systems should also be willing to share in the responsibility of providing appropriate healthcare to refugees.

87. Article 11 of the Universal Declaration on Bioethics and Human Rights (2005) stipulates that ‘no individual or group should be discriminated against or stigmatized on any grounds, in violation of human dignity, human rights and fundamental freedoms’. This suggests that stigma and human dignity are intrinsically associated; one can only exist when the other is absent. Although stigma is conceptualized as a personal mark or attribute, it is essential to recognize that it is a social product, the fruit of structural conditions and power relationships established in societies. When an individual is labelled as a refugee, there is a tendency for that individual to be denied fundamental human rights, including healthcare. Some of the negative consequences of stigma include tense and uncomfortable social interactions, limited social networks, compromised quality of life, low self-esteem, symptoms of depression, unemployment and loss of income. A clearer understanding of the status of refugees in societies hosting them is essential to reduce practices that could be discriminatory and stigmatizing.

88. Refugees are often different from the societies they seek refuge in but that should not undermine their human dignity. Given that the refugee population often includes people with varied social, professional and economic backgrounds, it is important that these different qualities of refugees and the values they bring to their new societies are recognised and strengthened. For example, if they agree, refugees with professional backgrounds in healthcare such as clinicians and nurses should be assisted and integrated into the local healthcare system to enable them to use their expertise to contribute to the provision of healthcare not only to refugees but also to all those in the society in which they live.

89. Refugees should be able to live normal lives and maintain their original cultural identities if the appropriate systems are in place to accommodate them and allow them to flourish and enjoy their fundamental human rights, including a right to appropriate healthcare. Health systems should also have the capacity to recognise and accept the identities of refugees and eliminate structures that could contribute to discrimination and stigma. Failure to recognize someone’s identity is denying their development as humans.

90. There is great potential for refugees to suffer discrimination and stigmatization as a result of their status. It is therefore important to examine the key factors that make them more vulnerable to these practices. In the spirit of solidarity, countries and societies receiving refugees from other contexts should put in place measures that will protect the dignity of refugees and ensure that they are given equal rights and access to health care.

V.7. Vulnerability

91. The word ‘vulnerability’ when applied to different fields or topics has a variety of implications. Despite the differences, the variations in the concept always revolve around an etymological core that correlates vulnerability with conditions of exposure or susceptibility to wounding.

92. The first document to correlate vulnerability and autonomy was the Belmont Report, produced with the objective of establishing ethical principles to guide research involving human subjects. Its text had a strong influence on the concept of vulnerability that would come to be adopted for bioethics in various parts of the world. Although this concept was included among the topics that the report termed some ‘special instances of injustice’, a more attentive analysis reveals the close connections between vulnerability and the principle of autonomy. This occurs, for example, when there is reference to certain groups that are vulnerable, which are identified as racial minorities, the economically disadvantaged, the very sick, and the institutionalized.

93. The main difference between the vision of the Belmont Report and later interpretations about vulnerability is an emphasis on the comprehension of certain broad principles and

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values that are fundamental to the field of bioethics, including human rights, and respect for human dignity.

94. Vulnerability also encompasses various forms of exclusion or side-lining of population groups in relation to events or benefits that may be occurring within the worldwide process of development. The application of the adjective 'vulnerable' to the field of ethics within research on human beings can also mean 'the weaker side of a subject or issue' or 'the point through which someone can be attacked, harmed or wounded,' thus putting the term in a context of frailty, lack of protection, disfavour and even helplessness or abandonment.

95. The role of 'social vulnerability' must be taken into consideration in clinical research. Social vulnerability refers to the ethically acceptable limits of self-determination and increased exposure to risk created by a situation of social exclusion. This concept refers to the need for specific protection measures for participants in research conducted in developing countries as there are certain concealed risks that cannot be identified through the traditional evaluations of research ethics.

96. Article 8 of Universal Declaration on Bioethics and Human Rights states that '[h]uman vulnerability needs to be taken into consideration in applications and advances of scientific knowledge, medical practices and associated technologies. Individuals and groups with specific vulnerability need to be protected and the individual integrity of each person needs to be respected'. 'Vulnerability' thus includes both a descriptive dimension that emphasizes the need to take into consideration human vulnerability in applying knowledge, and a prescriptive dimension that includes the duty to protect individuals and groups with specific vulnerability. This relation between the universal and particular dimensions makes Article 8 suitable for guiding the conflicts and analyses involving vulnerability. Thus, this principle comprises the broadest ethical foundation of the Universal Declaration on Bioethics and Human Rights, which also includes other important principles and values for facing up to the conflicts relating to globalization: equality, justice and equity, non-discrimination and non-stigmatization, solidarity and social responsibility.

97. Because Article 8 of the Declaration is intentionally generic, it is necessary to understand it by taking into consideration not only its universal and contingent aspects but also, and especially, its practical function in identifying and surmounting processes that materially affect different vulnerable individuals and groups around the world. Only through continual linkage between the different regional approaches of bioethics will it be possible to provide legitimate guidance for consolidating the principle of vulnerability, given that no matter how global the conflicts are, their expression always occurs in defined spaces and at defined times.

98. It is for this reason that continual dialogue and linkage should be put in place by institutions involved in international bioethics production, such as UNESCO, and by research centres, universities, researchers and journals involved in the field of bioethics. Although there are important distinctions to be made about the interpretations of the concept of vulnerability, all of them revolve around a minimum core identity centred on the etymology of the word.

V.8. Global Ethical Responsibilities

99. Beyond personal and national responsibilities, over the years the global ethical responsibilities of the UN Member States have gained legal status in various international documents among which are: The 1951 Geneva Convention related to the Status of Refugees, the 1967 Protocol Relating to the Status of Refugee and recently the Palermo Protocols (2000) and the document of the UN High Commissioner for Refugees (UNHCR, 2007). These responsibilities are shared and supported by the office of the UNHCR, which holds global information, advises countries, provides the financial means to assist and protect refugees in their legal status, provides access to health services (physical and mental) and education, advocates for equal treatment and eventually their integration into the host society.

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100. All these international documents are meant to ensure the protection of refugees worldwide. However, because many countries in Europe, Africa, Asia and Latin America are undergoing internecine wars and because many islands and coastal cities around the world have suffered climatic catastrophes, there has been a huge increase in the number of refugees around the world. This increase has given rise to lessened acceptance of refugee populations and the assistance and protection that was offered to them the past. This is partly due to confusion about the differences between migrants and refugees. Fears of terrorism have also undermined public acceptance of refugees. Globalized commerce has enabled rich countries to become still wealthier and protective of their economic advantages. Some governments and citizens fear that they will be invaded by minorities that will hinder the governance of their countries. They are afraid of losing their cultural and religious identity; and see the refugees as a threat to the sources of employment ofcitizens. Local people may fear that the refugees remove their sources of employment. Given these complexities, some countries have undergone a revival of racism and discrimination.

101. The combination of all these factors has led some countries to close their borders, some have shown indifference to the problem, and others have made the reception of refugees more difficult by increasing administrative requirements. In fact, few nations have opened their doors to those who need asylum. Generally, there has been an unfortunate and growing forgetfulness of the value of every person as included in the protections afforded by universal human rights.

102. U.N. Member States have a moral responsibility towards refugees. This requires a sincere and generous willingness to help the 'others' who are our equals and are in a highly vulnerable condition. It follows that they are owed care for their health and welfare efforts to help them re-establish their autonomy and self-sufficiency.

103. The protection of the rights of refugees is in the interest of all countries and requires solidarity among all U.N. Member States. In fact, both man-made and natural disasters are mostly related directly or indirectly to the satisfaction of the interest of the rich and commercial monopolies, who exploit the poor nations. Therefore, the developed countries have a great debt to those of developing countries. Given the fact that today there are only a few nations that are able to accept large numbers of refugees, those countries should contribute their fair share to improve the situation of refugees.

104. In particular, the following responsibilities can be highlighted:

a. To encourage international cooperation between Member States and relevant global authorities such as the UNHCR should be encouraged.

b. To pay particular attention to the health problems and the consequences of becoming stateless. It is important to help refugees for their active integration into the society, to regain their self-sufficiency and full exercise of their capabilities.

c. To seek appropriate mechanisms to ensure the recognition and respect the dignity and freedom of the refugees.

d. To get the relevant organizations and professional associations such as the World Medical Association and the UNHCR involved in seeking more comfortable and humane conditions for refugees to join the host society and prevent their suffering according to the Article 11 of the Declaration.

e. To help refugees to gain independence in receiving countries, by teaching them the language of the country, and instructing them in practical matters so that they can adapt, and to provide information on sources of work where they can exercise their skills and gradually move from dependence to independence.

f. To have measures in place to prevent racial and ethnic discrimination.

105. Finally, the ethical foundation of the global responsibilities towards refugees is that the cultivation of our own humanity depends on caring for the humanity of others and we know

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how to see in the 'foreigner', in the stranger, a part of ourselves, because there is an inescapable inter-human brotherhood. The 'others' are equal to us. This is the basis of morality and bioethics.

V.9. Refugees in Transit: An Unsafe Journey to Safety

106. In many cases, refugees who begin their journey to find a safe place to live must transit several countries before arriving at their final destination. While international documents and conventions have focused on the refugees' rights in their final destination country in which they try to settle, the refugees' journey from their own country to the destination country is often treacherous. It is important to address the needs of refugees in transit and to take protective measures needed to safeguard their health and to provide for their support and safety. Member states must therefore consider their responsibilities to refugees who are transiting their territory, including the provision of security, food, water, healthcare, and other supportive services. Refugees in transit do not forfeit their human rights merely because they have not yet reached their final destination.

VI. PUBLIC AWARENESS AND ENGAGEMENT ON THE REFUGEE CRISIS

107. Public awareness is the public's level of understanding the importance and implications of a specific problem or situation. In similar terms, public engagement is the process of communicating, creating awareness and involving the general public in a specific setting around a relevant issue affecting the wellbeing of a target population. It involves a myriad of activities such as public education through the media, public meetings and educational programs. In the context of healthcare, public engagement has been particularly important in disseminating information about causes of disease, prevention and control in relation to public health and infectious diseases.

108. The current refugee crisis has created a number of challenges both for refugees themselves, affected countries and receiving countries. This necessitates the development of effective public engagement activities that can help disseminate information on the magnitude of the situation to attract the necessary global support.

109. Many countries have managed to reach significant levels of well-being through the implementation of social protection mechanisms which include public healthcare systems managed either directly by the public power or indirectly through the involvement of the private sector (see the generally traditional Bismarck and Beveridge models). These health care systems are at a stage where there is universal or nearly universal health protection. This has been possible mainly due to the great collaborative effort of the members of the various communities which have come to understand that the best way to develop a fairer and safer society is through the implementation of social cohesion mechanisms like universal health care, which at an individual level represents a significant economic effort through taxation or insurance premiums.

110. However, this collaboration has only permeated at an internal level in these societies; it does not extend towards those who do not yet belong to those communities. For example, despite the growing acceptance of the right to health and healthcare for refugees, it is still uncertain to what extent refugees are able to access quality healthcare services within refugee camps and foreign countries where they are currently seeking refuge. In addition, the misconceptions about refugees in foreign countries make the citizens of these countries uncomfortable with their presence. This could lead to exploitation, discrimination, and stigmatization if appropriate mechanisms are not put in place to keep people well informed.

111. Public media has played a key role in raising awareness on the magnitude of the refugee crisis. This has a led to some global support from government and non-governmental agencies to respond to this crisis.

112. This situation demands that States take positive action towards the promotion of greater public awareness regarding the situation of refugees allowing for conflict-free

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integration. Effective measures of education and information for the public regarding the ethical obligation of society towards other people are required. Among these, those measures which raise the awareness of the population regarding the fact that the status of a human being does not depend on citizenship status and, as such, the duties of social protection, such as health protection, must be strengthened.

113. Engaging the public on the refugee situation in the context of access to health care can take several forms. There should be activities focused on refugees to create awareness of public health, health promotion, available sources of health care, their rights to access to healthcare and limitations, and available support systems such as through the UNHCR and other organizations working in the interest of refugees. Public engagement activities could also aim at creating awareness of the need to avoid unscrupulous individuals and groups who might exploit the vulnerability of refugees.

114. Public authorities should draw on the cooperation of professional groups who work most closely with refugees regarding the development of strategies, to provide information and education. These engagement efforts should be well coordinated to ensure that accurate information is disseminated. The media also have a responsibility to avoid alarmism and convey valid information.

115. State actors and the global community must be directly involved in the development of educational programs that inform their citizens of the responsibility they have towards others individuals and of the benefit which doing so provides from a public health perspective.

VII. RECOMMENDATIONS

116. Some potential recommendations that could be further discussed and developed by the IBC in the next version of the draft report are as follows:

a. To observe human rights in addressing the essential needs of refugees especially in large movement of refugees, a collective response by governmental and non-governmental organizations is required.

b. Refugees have a prima facie right to health and health care services that must be respected by all states.

c. Vulnerable groups such as women and children should be entitled to special health care services.

d. Special intergovernmental arrangements must be made to ensure that these rights apply when refugees are in transit.

e. Refugees retain the right to make their own medical decisions or to have an informed surrogate decide in accordance with their known or likely values and preferences.

f. All ethics regulations in biomedical research should be applied in the situation of refugees to protect their rights, health and safety.

g. Needed health care services must be provided in a non-discriminatory manner.

h. Those services should include consideration of the special needs of traumatized persons.

i. States must make every reasonable attempt to integrate newly arrived refugees into their health care systems.

j. Governmental and non-governmental organizations should work with responsible media to inform the host nations’ publics about the human rights, circumstances, and health care needs of newly arrived refugee populations.

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APPENDIX

Case 1: A South African Case Dealing With the Right to Emergency Medical Care

‘A case, decided by the Constitutional Court of South Africa in November 1997 (Soobramoney v. Minister of Health [Kwazulu-Natal]), dealt with the interpretation of the rights to emergency health care and to life contained in the South African Constitution. Soobramoney, who was suffering from chronic renal failure, sought dialysis treatment from a state hospital in Durban. The hospital had been forced to adopt a set of guidelines for dialysis treatment because of its limited facilities. Only those who could be treated through dialysis had automatic access to the treatment. The patient was suffering from chronic renal failure and his condition was irreversible; his life could be prolonged by regular dialysis, but his condition could not be treated or remedied. In addition, patients who were suffering from chronic renal failure and who were eligible for a kidney transplant also had limited access to the dialysis facilities. However, Soobramoney was not eligible for a transplant because of a heart condition. Thus, he did not come within the hospital's guidelines, and due to the hospital's limited resources his request for treatment was turned down.

Soobramoney based his legal challenge on two provisions of the Constitution: section 27(3), which says ‘no one may be refused emergency medical treatment,’ and section 11, which guarantees that ‘everyone has the right to life.’ The Constitutional Court had to decide: Did the right to emergency medical care include a claim to ongoing treatment of chronic illnesses that would prolong life? The court found that the right to emergency medical care did not apply in this particular situation. The plaintiff's situation was not an emergency which called for immediate remedial treatment, and thus it did not come within the scope of the constitutional provision, observed the court. As Justice Sachs noted, the right to emergency care provided reassurance to the public that accident and emergency departments would be available to deal with unforeseeable catastrophes that could befall any person, at any place and at any time.

There were many more patients who were suffering from chronic renal failure than there were dialysis machines to treat them. In this context, the court said, it was legitimate to adopt guidelines to determine who should receive treatment. It agreed that by using the dialysis machines in accordance with the guidelines, more patients benefited than would be the case if they were used to keep persons with chronic renal failure alive. The outcome of the treatment would also be more beneficial, because it was being directed at curing patients and not simply at maintaining them in a chronically ill condition. Even in the most advanced countries, access to life-prolonging treatment is rationed. Providing all persons with chronic renal failure with dialysis treatment would make substantial inroads into the health budget. The provincial administration had to make difficult choices with regard to the resources that should be spent on health care and how they should be spent. Where the decision was rational and taken in good faith, the Court would not intervene. Agonizing decisions have sometimes to be made on how a limited budget could be stretched to benefit the maximum number of patients, the court said.

Health-care rights by their very nature have to be approached from a framework that is based on human interdependence. Where rights are shared, an appropriate balance needs to be struck between equally valid entitlements and competing rights bearers. (Soobramoney died soon after the judgment of the Constitutional Court was issued)’ (Gonzalez, 2000).

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Case 2: A South African Case Dealing With

1) An alleged violation of the right to health care services.

2) **Whether there is an unrestricted right to minimum core medical services.**

‘South Africa is in the midst of an HIV/AIDS epidemic with more than 6 million people infected. In 2,000, with infections of newborns in the range of 80,000 per year, the anti-retroviral drug Nevirapine offered the potential of preventing the infection of 30 – 40,000 children per year.

The drug was offered to the Government for free for five years, but the South African Government announced it would introduce Mother-To-Child-Transmission (MTCT) only in certain pilot sites and would delay setting these up for a year, thereby denying most mothers access to treatment. The Treatment Action Campaign (TAC) launched a constitutional challenge, alleging a violation of the right to access health care services and demanding a program to make the drug available throughout the country. Judge Chris Botha of the High Court ruled in favour of TAC, ordering that Nevirapine be made available to infected mothers giving birth in state institutions and that the government present to the court an outline of how it planned to extend provision of the medication to its birthing facilities, country-wide. The Government appealed the decision to the Constitutional Court. Botha, J. granted interim relief pending the appeal. The Constitutional Court rejected the appeal, finding that the restrictions of Nevirapine to pilot sites excluded those who could reasonably be included in the program. The Court ordered the Government to extend availability of Nevirapine to hospitals and clinics, to provide counsellors; and to take reasonable measures to extend the testing and counselling facilities throughout the public health sector. The Court rejected the argument advanced by one of the interveners for a distinction between a minimum core content of the right to healthcare and the obligations imposed on the state in section 27(2) that are subject to progressive realization and available resources.'[1]

Case 3: A Case Study from Venezuela Dealing With Strategies for Furthering the Right to Health

'Acción Ciudadana Contra el SIDA (ACCSI), an organization addressing issues of HIV/AIDS and human rights in Venezuela, has been developing a legal strategy to make the state adopt a policy regarding the provision of anti-viral drugs and comprehensive drugs to HIV/AIDS patients. To this end, three writ petitions have been brought against the Ministry of Health before the Supreme Court of Justice (CSJ). These petitions allege violations of the rights to life, health, personal liberty and security and non-discrimination, and of the right to benefit from science and technology, all stemming from the systematic failure to provide the persons bringing the action with health care.

Some of the grounds articulated were that the distribution of essential drugs is one of the obligations of the state in relation to the right to health. Access to antiviral treatment is of vital importance, as is the supply of medicines to combat opportunistic diseases. The right to life is a fundamental right, linked to the right to health. The lack of access to treatment violates the right to benefit from scientific progress. Social assistance programs, consistent with the Constitution, should cover those who are outside the social security system.

The first judgment of the CSJ accorded legal recognition to the connection between the rights to life and access to the scientific advances and the right to health. It declared that writ (amparo action) admissible in part, affirming the violation of the rights to the protection of health, to life, and to scientific advances by the entity against which the action was filed. In addition, the right to health (by now partly developed) is conceptualized based on positive obligations of the state beyond prevention and assistance. It is not sufficient to attend to the opportunistic disease, but the virus must be treated, drawing on available advances, until a cure is found. Following this line of argument, the court ordered the Ministry of Health to provide drugs on a regular and periodic basis, to perform or cover the costs of the specialized exams, to supply drugs to treat the opportunistic diseases, and to develop a policy of providing information, treatment, and comprehensive medical care.

Committees of persons filing the writ petition (amparo claims) were formed to follow up on these judicial decisions and have led the constitutional courts to make a pronouncement on the same issues. Through political pressure, these committees have succeeded in having the

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[1] Minister of Health v Treatment Action Campaign (TAC) (2002) 5 SA 721 (CC), (https://www.escr-net.org/caselaw/2006/minister-health-v-treatment-action-campaign-tac-2002-5-sa-721-cc)

judgments implemented swiftly. In addition, they monitor the purchases and deliveries of the drugs, and give workshops to empower persons who may bring such actions in the future.

The persons affected on an individual basis must file the writ petition (amparo action). Where necessary, their names can be kept confidential. The ten persons who filed the first petition remained anonymous. Recently, the strategy has been refined so as to file regional writ petitions (amparo actions), to distribute the budgetary burden and have patients obtain their services and drugs in their localities.

Finally, in an unprecedented decision, the CSJ recognized the complaint on behalf of diffuse interests. It would benefit the entire class of persons affected by HIV/AIDS who do not have the means to obtain treatment. It represents an important step towards the justiciability of ESC rights in the Venezuelan legal order.' (Gonzalez, 2000).

Case 4: A Colombian Case Dealing with the Right to Health as a Fundamental Right

'On July 31, 2008, the Constitutional Court of Colombia (the Court) handed down a decision (T-760/2008) that ordered a dramatic restructuring of the country's health system. The judgment came as the culmination of a wave of litigation to enforce the right to health, with tens of thousands of health rights cases before the Colombian courts each year. Since 1992, the Court has staunchly upheld rights to access and treatment in the context of a highly neoliberal state, and has not shied away from decisions with considerable resource implications.

Colombia is a striking example of how broader regional and global trends can have an impact on judicial enforcement of claims for health goods and services. However, there is a wide-ranging debate in public health circles about the appropriateness and impact of such judicial interventions on health policy and health equity. Critics question, for example, whether judicial activism distorts priority-setting and undermines the role of administrative and legislative bodies.

[In 2008, the Court identified three requirements which would enable plaintiff's *tutela* action against the State's decision to limit one's access to healthcare to be enforceable.

1) There is an identifiable association with "fundamental rights", such as the right to life.
2) The decision must be brought by a person representing a vulnerable group which guaranteed special constitutional protections in order to achieve certain minimum levels of subsistence; and
3) The health service at issue must be part of the national system.]

Although it is too early to judge the implementation of the July 2008 decision, the sweeping 411-page judgment reaffirms that courts can enforce access to health goods and services as a matter of fundamental rights, even when there are substantial resource implications. It further indicates that courts can creatively define their role in health priority-setting.' (Yamin, Parra-Vera, 2009)

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