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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. Based on background research prepared after consultation with relevant UN and other intergovernmental and non-governmental actors between October and December 2015, the IBC Working Group, using email exchanges, started preparing a text on this reflection between December 2015 and March 2016. It also met in Kuwait in April 2016 to refine the structure and content of its text. Based on this work, the IBC Working Group prepared a preliminary draft report which was discussed during its 23rd (Ordinary) Session in September 2016. As a follow-up to this discussion, the IBC Working Group started to revise the preliminary draft report between September and December 2016. The IBC Working Group met in Spain in March 2017 to further refine the text. A revised text in the form of a draft report was submitted to the IGBC, the IBC, COMEST, as well as relevant UN and other intergovernmental and non-governmental actors between May and June 2017 for comments. The draft report was then revised based on the comments received. The final draft of the report was further discussed and revised during the 24th (Ordinary) Session of the IBC, and was adopted by the Committee on 15 September 2017.

This document does not pretend to be exhaustive and does not necessarily represent the views of the Member States of UNESCO.

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I. SCOPE OF THE DOCUMENT

1. The terrible suffering of forcibly displaced persons shocks the conscience of humanity and the international community. The refugee crisis of the second decade of the 21st century has justifiably captured global attention, both for humanitarian and for political reasons. Though this is only the latest such episode, due to various factors, including the nature of modern media, global awareness of such troubling events seems greater than ever. Despite all the attention to the various aspects of the immediate crisis, there has been little public discussion of the bioethical issues that face the global community as it confronts not only the contemporary crisis but indeed has confronted humanity in many previous periods of massive forced movements of persons. This report recommends principles that should govern the response of the various parties to the conditions of refugees, now and in the future.

2. All refugees are migrants but not all migrants are refugees. According to the International Organization for Migration (IOM), 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" (IOM, n.d.). Furthermore, IOM also states that 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 educational 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 are forced to 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, 2010a).

4. Human rights and personal security are the critical considerations of refugee status, not economic benefit. They leave their homes, all or most of their possessions, and their 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, whether documented or not, who are not refugees, must be included in moral 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. Many of the problems involving migrants are beyond the scope of this report, though they are also of great humanitarian significance.

6. The terms 'migrant' and 'refugee' do not have neutral meanings and can be used by states for political purposes. Therefore, in accordance with the principles of the Universal Declaration on Bioethics and Human Rights (2005), all states must ensure that these terms are not used to justify discriminatory practices.

II. BACKGROUND STATISTICS AND OVERVIEW OF THE REFUGEE SITUATION

II.1. Magnitude and geographical location of refugees

7. Considering the Universal Declaration of Human Rights (1948) and the Introduction of the Universal Declaration on Bioethics and Human Rights (2005), every person or group in a

situation of forced displacement (internally displaced persons – IDPs – or displaced persons abroad), must be taken into account for the analysis of the magnitude and geographical location of refugees.

8. It is difficult to know the exact magnitude of the refugees' situation, so all statistical data are taken from the 2015 reports of the UNHCR, as the official organ of the United Nations for this purpose. The UNHCR estimates that there are about 60 million forcibly displaced persons around the world. 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. Recognizing that the Universal Declaration on Bioethics and Human Rights (UNESCO, 2005) clearly addresses the duty to future generation, the descendants of refugees are also victims of the circumstances that led to their parents taking refuge in another country or community. For example, when the United Nations Relief and Works Agency for Palestine Refugees (UNRWA) began its operations in the Near East in 1950, it was responding to the needs of about 750,000 Palestinian refugees. Today, some five million Palestinian refugees are eligible for UNRWA services. (If not mentioned otherwise, all subsequent data in this report are from UNHCR, 2015)

9. The statistics do not include returned refugees or former refugees who have returned to their country of origin spontaneously or in an organized fashion but are yet to be fully integrated. These persons deserve respect for their dignity, solidarity and cooperation because of their living conditions.

10. Most refugees are based in developing countries, particularly the Middle East and Africa where there has been recent destabilization through conflicts and wars. There are more than 3 million Syrian refugees in different countries of the Middle East (Jordan, Lebanon, and Turkey) while 6.5 million displaced people still live inside Syria. In addition, about 1.8 million people from Iraq are refugees or IDPs (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 IDPs, mostly from Central Africa Republic, the Democratic Republic of the Congo and South Sudan. 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.

11. In recent years, there has been a massive influx of refugees from the Middle East and Africa into the European Union (EU), a situation that 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. 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; these figures do not include those who have entered the EU illegally as well as undocumented migrants and refugees.

12. Refugees often represent a broad array of social and professional backgrounds and include men, women, the elderly and children who may be unaccompanied. For example, Central America has a great problem of unaccompanied children, adolescents, and women who suffer at the hands of 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.

13. Most refugees end up in camps, especially during mass movements. Although refugee status is supposed 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, many refugees have lived in camps for several decades. An example is the Dabaad camp in Kenya, leading to the concept of the 'forgotten refugees'. Yet attempts to close large 'forgotten' camps and to abruptly repatriate the refugees would represent a

discriminatory measure if the situation in the original country has not yet been resolved and if their safety is not guaranteed.

II.2. Causes of the Refugee Situation

14. The causes of forced displacements are the products of the many complex and interacting factors of the world system, very similar to the dynamics of the determinants of health. In this context, weapons trafficking and wars, great economic disparities and poverty, climate change and hunger represent some of the major causes of forced displacements worldwide.

15. In many developing countries, political instability, which often follows disputed election results, has also contributed to displacements. The flow of refugees 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. It should be noted that insecurity is a multi-dimensional reality that certainly refers to the presence of physical and psychological violence endangering the people confronted with this situation. But insecurity also encompasses the lack of healthy food and drinking water. These are conditions that prevent poor people from meeting their basic needs for survival. Economic insecurity caused by unemployment, limited access to housing and education can also motivate their decisions.

16. 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.

17. Poverty is both a cause and a consequence of the refugee situation. 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. Most of them are living in sub-Saharan Africa (UNDP, 2015). Reports suggest that nearly 80% of the world's population does not have comprehensive social protection (World Bank, 2015). This situation affects access to health care of local populations and the state’s response to the health needs of refugees.

II.3. Consequences of movements of refugees in the modern world

18. The situation of refugees is not new. However, the scale and complexity of the phenomenon have increased its emergency, aggravated by economic crisis and exclusionary measures in the supposed host countries. In this context the consequences of the refugee situation can be examined from various angles, both for the refugees themselves; for host countries in relation to health and access to health care, and their intended and unintended consequences for the countries of origin and for the countries through which refugees transit.

II.3.1. Consequences for refugees

19. 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 traditionally known home countries and relatively protective structures of solidarity. Many refugees become victims of trade in persons and other forms of exploitation. This is particularly true for women, children and the elderly.

20. Among other problems, overcrowded longstanding camps experience difficulties in distribution of food and water, provision of basic needs and access to quality 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, and to human trafficking and exploitation. But when camps are closed, the inhabitants run the risk of discrimination, stigmatization, and detention, which may prohibit them from accessing international protection and health services.

21. Regarding access to health care, one of the major challenges of the refugee situation is integrating them into the local health system of the host country. Country profiles vary and some health care systems are at least partly privatized which represents a significant burden to the organizations serving refugees and limits their action.

22. The acceptable standard of health care that should be provided to refugees in transit is still an object of discussion.

23. The difficulties in tracking refugees and, in some instances, lack of cultural awareness among health care personnel are two major causes of the lack of detection, treatment and monitoring of diseases and vaccinations, while increasing the risk of therapeutic non-compliance and mortality. These problems are still greater for displaced persons who are not housed in camps or are in transit.

24. Refugees who were or are still victims of violence, mass destruction, persecution and sexual harassment often suffer from psychological trauma and may also have depression due to the loss of their country, friends and family. Traveling through transit countries and arriving in the host country, they may be exposed to xenophobia, discrimination and racism, insecurity and physical violence.

25. Refugees may suffer from a loss of 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 funeral rites to which they might be entitled.

26. Many unaccompanied minors suffer from loneliness, insecurity and fear during travels or in camps. Their access to social protection and formal education may also be curtailed for several years, which could lead to child trafficking and prostitution.

27. Women, as refugees, may suffer from prostitution, exploitation and sexual violence, also for long periods of time, with both physical and psychological consequences which create a need for specific measures (for instance assisting services related to possible pregnancies and treatment of emotional trauma).

II.3.2. Consequences for countries of origin

28. The refugee situation also has consequences for their countries of origin, which will include the loss of human capital and disruptions in the public health sectors which can contribute to the lack of detection of diseases and of provision of adequate health care to those who need them most.

II.3.3. Consequences for transit countries

29. 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.

30. It is important to address the needs of refugees in transit beyond emergency care, and to take protective measures needed to safeguard their health and to provide for their support and safety. Member states must therefore consider and accept their responsibilities to refugees who are transiting their territory, including the provision of physical security, food, water, health care, and other supportive services, although this places a burden on their resources and their man power. Refugees in transit do not forfeit their human rights merely because they have not yet reached their final destination.

II.3.4. Consequences for host countries

31. The World Bank (2010) reported that "the impacts of refugees on the host country are not invariably negative, and that refugees can make positive contributions to the host society and create opportunities for both the displaced and their hosts."

32. But populations in the host countries may already be confronted with problems of social insecurity, poverty and reduction of social and health programs due to austerity measures. The arrival of a large number of refugees could exacerbate these problems. The refugee situation can be used for xenophobia, discrimination and racism that can enter into a vicious cycle against democracy and complicates the resettlement of refugees.

33. There is a consensus that there is an obligation to provide emergency care, but there is also a clear gap in the provision of management of diseases, which require long term health care such as cancer, HIV/AIDS, and drug addiction, although this places a burden on their resources and their manpower. 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.

34. Massive movements of refugees can also lead to burnout among medical doctors, nurses and other health practitioners who directly provide health care 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 INTERNATIONAL INSTRUMENTS

35. For refugees lawfully staying in the host country, Article 23 of the 1951 Convention Relating to the Status of Refugees, as amended by the 1967 Protocol, 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 (UNHCR, 2010a). 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 hospital and emergency treatments (UNHCR, 2010a). Hence, under the 1951 Convention, refugees are entitled to the same right to medical assistance as nationals of their host countries.

36. 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.

37. One of the earliest normative documents to recognize health as a basic human right is the Constitution of the 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 fundamental right, and (2) the standard of health should be of the ‘highest attainable’.

38. 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 […]” (UN, 1948; Article 25[1]). Furthermore, under the International Convention on the Elimination of All Forms of Racial Discrimination (1965), State 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” (UN, 1965; Article 5[e][iv]). Similarly, refugees have fundamental rights 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” (UN, 1985; Article 8[c]). The Convention relating to the Status of Stateless Persons (1954) requires Contracting States to “accord to stateless persons lawfully staying in their territory the same treatment with respect to public relief and assistance as is accorded to their nationals” (UN, 1954; Article 23).

39. Women, children and persons with disabilities 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 […]" (UN, 1979; Article 12). 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 […]" (UN, 1979; Article 12). With regard 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 […]" (UN, 1989; Article 24). The right of persons with disabilities to health is recognised in the Convention on the Rights of Persons with Disabilities (CRPD) (2006). Article 25 of CRPD calls upon State Parties to "take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation" (UN, 2006). As CEDAW, CRC and CRPD apply to all women, children and persons with disabilities, these instruments grant substantive rights to health care to female and child refugees, and refuges with disabilities.

40. 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), 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 EU, "[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, 2000; 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). In the African Union, Article 14 of the Protocol to the ACHPR on the Rights of Women in Africa (2003) protects the health and reproductive rights of women. State Parties are obligated to "ensure that the right to health of women, including sexual and reproductive health is respected and promoted", which includes providing "adequate, affordable and accessible health services" (Article 2[a]) and to establishing and strengthening existing pre-natal, delivery and post-natal health services to pregnant women and breast-feeding mothers (Article 2[b]) (AU, 2003). This Protocol also speaks to the rights of women a propos the rights of men and which mentions special protection for women in distress or who are handicapped or pregnant and ties this ethically to integrity and justice.

41. 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). The specific obligations are set out in the Appendix. The Charter also protects equitable access to health care, requiring that Party 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). The relevant provisions of the regional human rights instruments that protect the right to health are set out in the Appendix.

42. Since people have a right to the 'highest attainable' standard of health, they should have access to the highest standard of care. 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) (1966), which "recognize[s] the right of everyone to the enjoyment of the highest attainable standard of physical and mental

health" (UN, 1966; 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 ensure access to all medical service and medical attention in the event of sickness.

43. The 'highest attainable' standard of health is similarly echoed in the Universal Declaration on Bioethics and Human Rights (UNESCO, 2005; Article 14[2]), the ESC, the CRC, the CRPD, 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 State Parties 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" (ASEAN, 2012; Article 29).

44. The Committee on Economic, Social and Cultural Rights of the UN (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" (paragraph 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" (paragraph 9). The CESCR had also interpreted the right to health "as an 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 […]" (paragraph 11).

45. 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 care services, but also basic needs that contribute to the overall well-being of refugees, particularly persons in vulnerable situations such as women, the elderly, persons with disabilities, and child refugees.

IV. WHAT DOES THE RIGHT TO HEALTH CARE IMPLY IN THE CONTEXT OF REFUGEES?

46. The right to health – or, as specified in this document, health care – has conventionally been considered as a merely contingent social right instead of an inherent human right. However, from the perspective of democratic principles, including justice, equality, equity and the rule of law, this approach falls short and contradicts the International Covenant on Economic, Social and Cultural Rights, enshrined in Article 12: "1. The States Parties to the present Covenant recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" (UN, 1966). Similarly, the Preamble to the WHO

Constitution states that “the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being […]” (WHO, 1948). Understood as a merely contingent social right conferred by states, the right to health care ends up being interpreted and implemented by legislative and executive powers, not mainly by the courts. Even when considered as an authentic human right, the position of the court might be in some ways restricted, because of its limited powers to require public expenditures. In any case, there must be some legal rules for judicial control of the decision about the right to health. Leaving the right to health merely in the hands of the legislative and executive powers is not compatible with its nature of a fundamental right, whether understood as social or human.

47. The realization of the right to health care requires balancing factors within the practical constraints of the specific country’s resources and capacities as suggested by the World Medical Association (WMA, 2006). However, balancing in this regard does not imply that the right to health should be relegated to a programmatic goal to be attained in the long term (OHCHR and WHO, 2008). Consequently, “no State can justify a failure to respect its obligations because of a lack of resources” (OHCHR and WHO, 2008). 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.

48. 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 personal integrity and quality of life. In this sense, there is as well a link between the right to health care and the rule of law.

49. The attainment and improvement of democratic processes is a key human aspiration. Article 29 of the Universal Declaration of Human Rights states that “[i]n the exercise of his rights and freedoms, everyone shall be subject only to such limitations as are determined by law solely for the purpose of securing due recognition and respect for the rights and freedoms of others and of meeting the just requirements of morality, public order and the general welfare in a democratic society” (UN, 1948). If 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.

50. 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. 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.

51. Refugees and IDPs cannot be taken 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 losses associated with displacement, the adaptation to a new environment and new customs, and the physical and mental consequences of war injuries and persecution. 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 provide them to their own population either, the United Nations has a clear mandate through its specialized agencies and programmes to act in order to uphold the realization of their human rights.

52. 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.

53. In addition, funding mechanisms for health care should not be different for refugees (and IDPs) 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. The intercultural character of bioethics highlights the fact that it is essential to broaden our vision beyond political and cultural boundaries in order to guarantee access to health care for everyone regardless of cultural identification and legal status. The goal can only be a common intercultural one: guaranteeing equity in health on a global scale. Health is essential to life itself and must be considered to be a social and human good. It should not be a condition that causes the marginalization or exclusion of persons on any grounds. From this perspective, access to health resources should not depend on the free market or the calculation of social productivity, but be guaranteed to everyone with a view to intercultural, international and global justice.

V. ETHICAL CHALLENGES[1]

V.1. Decision Making

54. In principle, the same ethical standards apply to medical decision-making for migrants and refugees as for any other persons receiving health care. However, the extreme circumstances in which refugees find themselves may result in more frequent appeal to standards such as best interests of the person concerned in the absence of detailed knowledge of a patient's preferences, especially if they are traveling without close relatives or friends and are unable to communicate with the health personnel.

55. 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. In the decision-making process, understanding the information provided is crucial and may become a challenge when the patient and the health care providers speak different languages and have different cultural values, also with respect to decision-making itself, as will be discussed in paragraph 87. In this context, it becomes essential to benefit from the services of a professional interpreter who should be a member of the heath care team. A professional interpreter may also act as a health mediator who provides clarification concerning the patient's cultural values to the health care team, and vice-versa

56. But what of those who lack decision making capacity? 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 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 who expresses their values and preferences in advance are the first reference point and should be respected. Although those written or verbal statements may not be precise with respect to the current situation, 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 availability of any medical records at all, including advance medical directives. Yet medical

[1] Topics ordered in accord with the Universal Declaration on Bioethics and Human Rights (2005)

ethics makes no exceptions about refugees; their autonomy must be respected so far as is possible under the difficult conditions in which health care workers must function.

58. 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, including for adults who have never achieved decision making capacity, i.e., the severely cognitively impaired, 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.

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 what is thought to be the patient's best interests. In too many instances, children and other persons who have never achieved decision-making capacity travel 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. Persons with intellectual disabilities often face several challenges that threaten to undermine their capacity to make decisions about medical treatments. They may be excluded from decision-making processes because others make incorrect assumptions about their capacity to understand issues or consequences of alternative treatments, or because others believe that they know what is best for them. There is a common misconception that considers individuals with intellectual disability to lack the capacity to make their own health care decisions or to participate in any medical decision-making. Nevertheless, many of these persons have sufficient cognitive capacity to engage in some of the decision-making process or, at least, should be heard concerning their preferences or interests. They may be able to make their own health care decisions if given the right support. Only a small percentage of persons with intellectual disability are severely or profoundly affected, so they should be included in the decision making process as much as their capacity allows, with a full respect for their inherent dignity and personal autonomy, including the freedom to make their own choices. Such support might include access to communication aids or translators, information in different formats, and longer time frames or different environments in which to make decisions. Some persons could need more specific support to make decisions, including reminders of previous decisions and more explanation of the implications of their decisions.

V.2. Vulnerability

61. 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 exceptional susceptibility to injury or conditions of limited autonomy to make decisions. Vulnerability should not become an excuse to limit respect for autonomy. On the contrary, it can be an element that helps to contextualize and carefully assess the decision made by the subject. Protections against vulnerability should help to differentiate situations in which there is uncertainty about how autonomous a decision really is.

62. The first document to correlate vulnerability and autonomy was the Belmont Report (USA, 1978), 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 respect for autonomy. This occurs, for example, when there is reference to certain groups that are vulnerable, such as children, prisoners and those who are institutionalized as mentally impaired. Refugees should now be added to this list.

63. Vulnerability, as elaborated in the IBC Report on the Principle of Respect of Human Vulnerability and Personal Integrity of 2011, also encompasses the need to avoid various forms of exclusion 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, which can also be referred to as 'social vulnerability'.

64. Article 8 of the 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" (UNESCO, 2005). 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. The Universal Declaration on Bioethics and Human Rights 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.

65. Because Article 8 of the Declaration is intentionally generic, it must be understood 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. For this reason, governments must ensure quality medical care to those who face discrimination based on their status as refugees.

66. Concerns have been raised about the risk that refugees, as one of the most vulnerable groups, might be exploited in a circle of organ trafficking and become organ providers against their own autonomous choices. As stated by the Report of the IBC on the Principle of Non-discrimination and Non-stigmatization (UNESCO, 2014), vulnerable members of society, such as the illiterate and poor, undocumented immigrants, prisoners and political or economic refugees from poor countries constitute the organ pool in certain parts of the world. Protective measures should be taken to prevent exploitation of refugees as organ providers in receiving countries and in countries of transit. Especially in countries with presumed consent policies in place, refugees need to be protected as long as they retain refugee status and are not citizens of those countries.

67. In some cases, refugees are persons with disabilities, forced to flee despite their limitations, or disabled in the course of leaving their home country. Their situation may be all the more difficult. Consistent with the Convention on the Rights of Persons with Disabilities (UN, 2006), among other obligations, they are not to be treated in a discriminatory fashion and they must be fully included in an accessible manner in efforts to ensure their safety, security and well-being.

V.3. Equality, Justice, Equity, including Resource Allocation

68. 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" (UNESCO, 2005). Human dignity is presupposed as the foundation of human equality 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 emphasized 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.

69. 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 8, for example, states that "individuals and groups of special vulnerability should be protected and personal integrity of such individuals respected" and Article 14 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. (UNESCO, 2005)

70. Justice is a general principle that guides our individual and collective ethical behaviour. Equity is the adaptation of the law to the singularities of justice in a specific case. Therefore, 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.

71. The three principles also constitute part of the general framework of respect for human dignity. Without considering the principles of equality, justice and equity, human dignity cannot be protected. Refugees, as fellow human beings, deserve respect and have dignity that must not be ignored because of their distressing and dire situation. Indeed, their particular form of vulnerability requires that they receive special attention and protection. 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 human dignity for some is a failure to respect it for all. Thus, it is essential that all nations demonstrate solidarity in accommodating the needs of refugees.

72. Justice is also at stake in decisions on allocating scarce resources. These decisions 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.

73. 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 (triage) to a certain extent. Triage is used in disaster situations and even in emergency rooms where injured patients are sorted for medical attention according to their medical needs and prospects with those requiring more immediate care receiving it first. Also, decisions to admit or discharge patients from intensive care units often involve some form of triage.

74. In the context of refugees living in camps, triage 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. Due to restricted budgets these procedures may be very strict (cf. UNHCR) and do not include long-term and costly treatments such as cancer therapies.

75. 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.

76. At first sight there are no moral problems with triage understood as medical screening. However, moral problems may surface when screenings as routine procedure have unintended consequences and/or when the results of screening are used for other than medical purposes.

77. Therefore the IBC, in accordance with the WHO, provides the following guidance:

a. Mandatory testing may deter migrants from seeking a medical examination and compromises the identification of high risk patients; therefore there should be no mandatory testing for diseases among refugees or migrants unless there are clear epidemiological reasons to suspect a high incidence of a certain disease among the refugees. In all other cases mandatory testing is not warranted because there is no tangible evidence on the benefits (or cost / effectiveness balance) of this intervention, which could also be a source of anxiety for refugees and generally for the community.
b. Medical assessments should be carried out to the benefit of the individual and the public and the results communicated to refugees to ensure that all of them have access to health care. These medical assessment should be made for transmissible and non-communicable diseases (NCDs), respecting the human rights of migrants and their dignity.
c. Medical assessments should never be used as a reason or justification for the expulsion of a refugee or migrant.

78. Whereas primary health care for refugees may be guaranteed, it may be difficult to provide long-term care to refugees while on the move or in camps, 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 status, and irrespective of whether they are in transit or not, as part of universal health coverage.

V.4. Identity, Non-Discrimination and Non-Stigmatization

79. Refugees are at grave risk for suffering discrimination and stigmatization. It is therefore important to examine the key factors that make them more vulnerable to these risks. 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.

80. Article 11 of the Universal Declaration on Bioethics and Human Rights 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” (UNESCO, 2005). This suggests that stigma and human dignity are intrinsically associated; human dignity can only be respected when stigma 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. If an individual is labelled as a ‘refugee’, there is a risk for that individual to be denied fundamental human rights, including health care. 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.

81. Refugees have been 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 culturally different from their original communities. This has negative implications when people are forced to adopt customs 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.

82. 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 others. 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.

83. The label 'refugee' itself often has derogatory connotations and can also lead to discrimination and stigmatization. This labelling often affects the type and quality of health care that refugees are given in comparison to locals.

84. Refugees' cultural differences from the societies in which they seek refuge should not undermine respect for 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, according to national regulations, refugees with professional backgrounds in health care should be enabled to use their expertise to contribute to the provision of health care.

85. Health systems should have the capacity to accommodate the cultural identities of refugees and eliminate practices that could contribute to discrimination and stigma.

V.5. Culturally Sensitive Institutions of Health Care

86. 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, the UNESCO's Director-General stated that: "[c]ultural 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" (UNESCO, 2016).

87. The Universal Declaration on Bioethics and Human Rights 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" (UNESCO, 2005). 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" (UNESCO, 2005). Article 3 recognizes human dignity and fundamental freedoms as human rights that are to be fully respected. In the context of health care this refers to respect for autonomy and cultural diversity without discrimination and stigmatization and a valid process of information and consent to health interventions.

88. If cultures can agree beyond their differences and divergences, it is insofar as they bear universal values which concern human beings as such, regardless of the circumstances in which individuals and peoples live. This universal dimension points to essential values: respect for life, integrity, equality, and therefore, right to health services.

89. In order to best achieve the requirement for the highest attainable standard of health institutions must be competent. Health facilities, goods and services must be “scientifically and medically appropriate and of good quality. This requires, inter alia, skilled medical personnel, scientifically approved and unexpired drugs and hospital equipment, safe and potable water, and adequate sanitation” (CESCR, 2000; Article 12[d]). And “all health facilities, goods and services must be respectful of medical ethics and culturally appropriate, i.e. respectful of the culture of individuals, minorities, peoples and communities, sensitive to gender and life-cycle requirements, as well as being designed to respect confidentiality and improve the health status of those concerned” (CESCR, 2000; Article 12[c]).

90. An essential condition for the proper implementation of these provisions is linguistic competence. On the one hand, if patients are not understood, the health care team cannot ensure the quality of a good diagnosis (especially in the sensitive field of psychiatric medicine). On the other hand, good compliance from the patient cannot be ensured, if he/she does not understand the information and indications provided for a treatment. In addition, poor mutual understandings, preventing proper treatment, add costs to the usual health care. Consequently, competent services can only carry out their activities by respecting these universal needs, for instance by providing adequate translation and mediation services, respecting the usual confidentiality in the exercise of medical care.

91. Cultural sensitivity must not be used as a justification to accommodate patients’ requests that may be discriminatory toward health personnel or other patients, or that contradict local ethical standards.

92. Health care providers should resist any paternalistic tendency to change the patient's perspective instead of being aware of the patient's needs and values. Education of migrants and refugees concerning local values can promote an effective path towards a dialogical interactive and non-prejudicial attitude. Health care establishments should consider patient preferences and find the most appropriate arrangements. However, reference to the ‘culture of individuals’ in providing ‘culturally sensitive health care’ should not be defined arbitrarily by the patient.

V.6. Global Moral Responsibilities

93. 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 them are: the 1951 Convention Relating to the Status of Refugees; the 1967 Protocol Relating to the Status of Refugee; and recently the Palermo Protocols (2000) and the 2016 New York Declaration for refugees and migrants. 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.

94. All these international documents are meant to ensure the protection of refugees worldwide. However, because many countries 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 displaced persons around the world. This increase has given rise to lessened acceptance of refugee populations and the assistance and protection that was offered to them in the past. Hesitation to accept refugees is partly due to confusion about the differences between migrants and refugees. Fears of terrorism have also undermined public acceptance of refugees in some countries. 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 for citizens. Given these complexities, some countries seem to have undergone a revival of racism and discrimination.

95. The combination of all these factors has led some countries to close their borders, some to show indifference to the problem, and others to make 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.

96. UN Member States have a moral responsibility towards refugees. This obligates them 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.

97. The protection of the rights of refugees is not only an obligation of humanity. It is in the interest of all countries and requires solidarity among all UN Member States. Today only some nations contribute their fair share in accepting large numbers of refugees, but all countries should do their part in protecting and improving the situation of refugees.

98. The causes of the forced displacement of populations (civil wars, ethnic conflicts, religious or others, poverty, the effects of climate change), may at first seem internal to a country or a region, but sometimes they are consequences of other causes which are remote in time or space. Rather, they are part of complex interactions between the different factors constituting the global system. This appears more and more clearly as a global system where a merely sectorial management of problems is no longer sufficient. It is therefore necessary that the international community shows a greater solidarity for the purpose of reducing poverty and social inequalities towards inclusive economic growth, that it commits to a greater cooperation in preventing civil wars which are sometimes predictable, in solving conflicts by peaceful means, and in promoting a reasonable and less exploitation of natural resources and ecosystems.

99. In particular, the following responsibilities of Member States can be highlighted:

a. To prevent and solve, to the extent of their capacities, the causes underlying the creation of refugees and mass migrations.
b. To encourage international cooperation between Member States and relevant international organizations such as the UNHCR and WHO.
c. To pay particular attention to the health needs and the consequences of becoming stateless.
d. To help refugees for their active integration into the host country to regain self-sufficiency and full exercise of their capabilities.
e. To seek appropriate mechanisms to ensure the recognition and respect the dignity and freedom of the refugees.
f. To urge the relevant organizations and professional associations involved in seeking more comfortable and humane conditions for refugees to join the host society and prevent their suffering.
g. To help refugees to achieve self-reliance in host 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.
h. To have measures in place to prevent racial and ethnic discrimination.
i. To consider their responsibilities to refugees who are transiting their territory, including the provision of security, food, water, health care, and other supportive

services. Refugees in transit do not forfeit their human rights merely because they have not yet reached their final destination.

100. The moral 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 how to see in the 'foreigner', in the stranger, a part of ourselves, because there is an inescapable inter-human brotherhood.

V.7. Research

101. It is important to gain new knowledge about the health challenges associated with the extreme conditions of refugees, as well as other needs of refugee populations, in order to develop successful policies and programmes for humanitarian aid.

102. All the usual requirements for ethically designed and executed research must be respected in research in refugee populations. These requirements include a guarantee of the relevance of the research study to the health needs of refugees or similar future populations, risk-benefit assessment, the informed consent of the research participant, the avoidance of double-standards, and the equitable sharing of benefits.

103. When performing research in refugee populations special attention should be paid to balancing the need for rigor in the design and conduct of the research and the need to protect research subjects from possible harm from the research itself. Possible harms include psychological distress, overburdening research participants with multiple or repetitive studies, injustice in selection of research subjects, and draining resources or personnel devoted to immediate relief.

104. As stated in the Report of the IBC on the Principle of Respect for Human Vulnerability and Personal Integrity (UNESCO, 2013), particularly vulnerable groups should be recognised and treated with special consideration in research. This includes persons who cannot give consent for themselves and persons who may be vulnerable to coercion or undue inducement. Researchers should avoid creating unrealistic expectations about improvement of the refugees' situation, including their health condition, or offering improper rewards.

105. Informed consent can be challenging especially among refugees living in refugee camps. They could be considered a 'captive' population and a particularly vulnerable group, who may not fully believe that they are free to decline participation, and may be susceptible to coercion if research is sponsored by powerful organizations.

106. When the refugees come from countries that are culturally very different to the host country, the research should be designed and conducted in a culturally sensitive manner and preferably involve researchers familiar with the cultural beliefs and practices of the research participants. In addition, providing information to refugees might be challenging because of language barriers and the crisis situation. To overcome language barriers, it would be necessary to involve an interpreter (a professional one would be desirable).

107. To prevent possible stigmatisation of refugees, researchers should define research objectives that do not lead to discrimination. Confidentiality in research involving refugees should apply not only at the level of individual participants, but also at the community level, e.g. to protect groups fearing persecution in their home countries. To protect research subjects, researchers should avoid collecting data that is not essential for research purposes (e.g. names, addresses), ensure anonymization or pseudo-anonymization, as well as safe storage of research data.

108. Research should not be disguised as treatment (therapeutic misconception) or humanitarian aid. The different roles of the researchers, health care professionals and volunteer workers should always be clear to the refugee population. Possible conflicts of interest on the part of the researchers should be acknowledged and the necessary measures for their resolution should be taken.

109. Organization of ethics review for research in refugee populations is often challenging. Addressing the challenges proactively by developing preparedness plans for researchers, institutions and research ethics committees might be helpful for the organization of ethics review in a crisis situation. The proactive measures may include, e.g. procedures for prioritization of protocols; clear rules for full and expedited review; pre-screening of potential research protocols in advance of a refugee crisis.

110. Members of the refugees' community should be involved in the evaluation of the research proposal. These persons could assess the suitability of the study methodology bearing in mind the characteristics (in terms of cultural values, tradition, etc.) of the participant community, the information to be provided to future participants, etc.

111. In order to avoid duplication of effort and to prevent overburdening of research subjects by repetitive studies, it is necessary to share and make publicly available both positive and negative research results, preferably in open access journals. Special attention should be paid not only to dissemination of the research results among researchers, but also to providing feedback to research participants.

V.8. Challenges to Public Health

112. As previously noted, population density in refugee camps favours the spread of transmissible diseases and poses challenges for hygiene and sanitation. Camp 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 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.

113. Inadequate security in a refugee zone affects health indirectly by compromising the access of humanitarian organizations to populations. Displacement itself causes the interruption of treatment, especially in cases of certain chronic diseases and infections. Problems of malnutrition and of access to drinking water are likely to vary according to migratory status and nature of insertion in the reception area. IDPs 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.

114. Refugees can be victims of many forms of violence: physical, sexual, moral and psychological. For all persons located in conflict areas, including refugees, gender based violations of human rights, violence and persecution increase during wars and armed conflicts. 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. Due to bad living conditions and deprivations suffered during migrations, refugees are especially subject to acute infections and must have to access to appropriate care.

115. Refugees and migrants with non-communicable diseases may be more vulnerable due to the conditions prevailing during their travel (WHO, n.d.). The main non-communicable diseases are cardiovascular diseases, diabetes, cancer and chronic respiratory diseases. Other risks include mental health problems, higher neo-natal mortality, problems of reproductive health, drug use, nutritional disturbances, alcoholism and exposure to violence.

116. Epidemics such as meningitis, yellow fever, viral hepatitis and typhoid occur in these situations. 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. The risks increase as the difficulties accumulated in exile weaken the immune systems of refugees who are already vulnerable to physical and other abuses.

117. Although the notion that there is a link between migration and importation of transmissible diseases is widespread, this association is not well established by the evidence. As described above refugees are exposed mainly to common infectious diseases in host or transit countries, unrelated to migration. The risk that exotic infectious agents are imported into host or transit countries is extremely low, and when it materializes, experience shows that travellers, tourists or health workers are a greater concern than refugees.

V.9. Challenges in Permanent Refugee Camps

118. For host countries, a large group of long-term refugees who may not become part of its citizenry raises concerns of territorial integrity and deployment of services, particularly the closely linked sectors of education and health. Online educational opportunities may have a critical role in compensating for the lack of educational and health care opportunities and should be developed in the refugees' languages.

119. There are many political and social implications for those born in refugee camps that affect access to health care. In some jurisdictions, so long as a person is born in the country they automatically become citizens while in others they do not unless one of the parents is a citizen or permanent resident of the country. Member States must ensure that no children born in these circumstances are rendered stateless.

120. The UN Convention on Refugees clearly states that refugees are entitled to the same social rights as citizens of the host country. But in large camps many people are unemployed or work within the camp. Social security benefits entail rights and duties, including paying taxes. Should work carried out in camps be taxed by the host country in order to provide social security and public services? And if people are taxed, should they not have a say in how their money is spent? In order to do so, they would need to be able to vote at least in local elections.

121. In order to mitigate the health risks to refugees, the countries of origin should make the greatest efforts to ensure their right of return, which is enshrined in international legislation. In many cases these countries have been devastated by wars and their infrastructure severely damaged. This places an extra burden in their efforts to relocate refugees in their previous homes. Sometimes towns have been destroyed, the fields are mined and people are unable to make a living from agriculture any longer. Sometimes homes have been occupied by new inhabitants, for whom a solution must also be found. Sometimes the situation is made even worse because refugees are members of groups or populations that were defeated in civil or international wars, and victors believe it is their right to become permanent occupiers of their territory. Recreating the conditions to return and live in peace is no minor challenge.

122. The international community has a duty to help countries in their efforts to bring back refugees, particularly in the cases of war-torn countries. This may be a costly endeavour and funds should be specially allocated to this task. When this is not possible, and while the situation that gave rise to the existence of refugees remains unchanged, it should try to ensure the integration of refugees to their host countries, in order to facilitate the chances of the most 'normal' possible life for refugees and their families. Only when this is not possible either, should it set up the mechanisms to prolong the refugee status and delivery of services in a 'permanent' camp situation, acknowledging that this has serious negative consequences for the health and physical security rights of those involved.

VI. PUBLIC AWARENESS OF AND ENGAGEMENT WITH THE REFUGEE SITUATION

123. Resistance to refugees is often due to inaccurate information. Public engagement is the process of communicating, creating awareness and involving the general public in a specific setting around an issue relevant and 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 health care, public engagement has particularly been very important in disseminating information about causes of disease, prevention and control in relation to public health and infectious diseases. Creating public awareness is an

essential component of a public engagement process which requires adequate and contextualized communication to the public. There is empirical evidence to suggest that when done effectively, public awareness and engagement can have a great impact in improving and sustaining public health programmes.

124. The current refugee crisis has created a number of challenges both for refugees themselves, and for the countries involved, challenges that necessitate the development of effective public engagement activities that can help disseminate information on the magnitude of the situation to attract the necessary global support to address the many challenges confronting refugees (UNHCR, 2015). This is particularly important in the context of the provision of quality health care to refugees to reduce the burden of diseases prevalent in refugee camps and to improve the overall health of refugees living around the world.

125. Many of our societies, particularly in the developed world, have managed to reach significant levels of well-being through the implementation of social protection mechanisms including, among others, public health care systems managed either directly by the public power or indirectly through the involvement of the private sector. Many of these health care systems are at a stage where there is universal or nearly universal health protection. This has been possible, for the most part, due to the great collaborative effort of the members of the various communities who have come to understand that the best way to develop a fairer and safer society for their citizens is through the necessary implementation of social cohesion mechanisms like this, which at an individual level represent a significant economic effort through taxation or insurance premiums.

126. However, this collaborative feeling seems to have permeated only at an internal level in these societies. It does not extend towards those who do not yet belong to those communities and who need to join those communities as the only way they can escape from a desperate situation, as is often the case with refugees. For example, despite the growing acceptance of the right to health and health care for refugees, it is still uncertain to what extent refugees are able to access quality health care services within refugee camps and foreign settlements where they are currently seeking refuge. Public knowledge on what refugees are entitled to is also limited without adequate information sharing and public awareness. In addition, there is the tendency for some misconceptions about the status of refugees which make the citizens of receiving countries uncomfortable with their presence. This has led to some resistance to accept refugees into well-established societies and contributes to exploitation, discrimination and stigmatization if the appropriate mechanisms are not put in place to keep people informed about the refugee situation and the need for global support and solidarity.

127. In some cases, public awareness on the situation of refugees is different among various groups of the public. The images of refugees offered up by the media do raise awareness of the members of these communities but in many cases not in a way that encourages practical social support. The goal of such public awareness should be to include refugees as active members of the community until the situation that has caused them to flee their country of origin has been resolved.

128. This situation demands that the States and their public powers promote greater public social awareness regarding the situation of refugees allowing for conflict-free integration. Effective measures of education and information for the public regarding the ethical obligation of society towards other humans are required. Those measures should raise the awareness of the population regarding the fact that human rights do not depend on citizenship status and therefore the duties of social protection, including health protection, should be strengthened.

129. Engaging the public on the refugee situation in the context of access to health care can take several forms; activities focused on the refugees (both those in refugee camps and those trying to integrate into host communities), to create awareness on public health, health promotion, available sources of health care, their rights to access to health care and limitations and available support systems such as through the United Nations High Commissioner on

Refugees (UNHCR), WHO, Medicins sans Frontières (MSF) and other stakeholders working in the interest of refugees. A UNHCR report suggests that the agency has utilized the services of community health workers to provide health education and information on accessing health care to many refugees under their care.

130. Public engagement is a two-way process of communication and could provide a great opportunity for mutual education between health care providers and refugees. Many health care workers who attend to refugees in camps and other institutions and facilities in foreign countries may be unfamiliar with the culture, values and beliefs of refugees, particularly in the context of health care. Public engagement thus provides a great opportunity for health care workers to understand refugees better and to be able to tailor health care provision to their needs. An important intrinsic value of public engagement is the expression of respect for refugees and the desire to ensure that their views are incorporated into the development of any social protection and health education programs.

131. Public engagement activities could also aim at creating awareness of the need to avoid unscrupulous individuals and groups who might take undue advantage of the vulnerability of refugees and exploit them. Developing brochures and creating and using the networks available within refugee groups such as community health nurses can be an important way of disseminating this information. For example, the UNHCR has developed a tool kit for teaching young people about migration and asylum in the European Union. It is also important that the public powers draw on the cooperation of professional groups who work closely with refugees regarding the development of strategies, procedures and ways of providing information and education. These engagement efforts ought to be well coordinated to ensure some coherence in the quality of information disseminated.

132. Public engagement can also target communities receiving refugees. As discussed in chapter II, it is clear that there is a lack of understanding about the status of refugees which is contributing to some uneasiness among the general population. It is important to create awareness on the need to address the health needs affecting refugees since these are problems which will end up affecting everyone. Leaving the health of refugees without effective protection does not just contradict the minimum demands of ethics but is also irrational as it may come back to affect those who refuse to share in health services. State actors and the global community must be directly involved in the development of public policy of education and information that can allow their citizens to be aware of the responsibility we all have as human beings towards other human beings and to be aware of the benefit which doing so provides from a public health perspective.

VII. RECOMMENDATIONS

133. The large numbers and immense suffering of refugees throughout the world today offend humankind´s sensitivity. The causes of the situation being clearly identified, the international community has a moral responsibility to identify adequate preventive measures, specifically with regard to arms trafficking, wars, internal conflicts, and economic disparities. Recognizing the dignity, rights and well-being of refugees, durable international and local solutions must be instituted and implemented to protect the health and welfare of refugees. Therefore, there is a global moral and legal obligation to meet the health care needs of refugees. Particular attention must be paid to address the health needs of refugees who are stateless persons.

A. Principles

a. Refugees have a right to access health care services according to their needs.

b. Health care services must be provided in a non-discriminatory manner. Health care cannot be limited for certain groups such as refugees only.

c. 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.

d. Refugees who are health care professionals themselves should be enabled to participate in the solutions of the health problems of refugees.

e. There should be no mandatory screening and testing for diseases among refugees unless there are benefits to refugees and the public such as a clear epidemiological reason to suspect a high incidence of a certain disease among the refugees.

f. All internationally recognized ethical guidelines and national regulations in biomedical research must be applied in research on refugees to protect their rights, health and safety.

g. Protective measures must be taken to prevent exploitation of refugees.

B. Recommendations for the International Level

h. Member States should encourage international cooperation between relevant international organizations such as the UNHCR and WHO.

i. Member States should make special intergovernmental arrangements to ensure that the rights stipulated above are also put into practice when refugees are in transit.

j. Member States should create special programs of protection of unaccompanied children, women, disabled persons and the elderly.

C. Recommendations for the National and Local level

k. Member States must make every reasonable attempt to provide refugees with health care in a non-discriminatory manner.

l. Member States should help refugees to become self-reliant in host countries, e.g. by teaching them the language of the country, instructing them in practical matters so that they can adapt, and by providing information on sources of work where they can exercise their skills and gradually move from dependence to independence.

m. The relevant health organizations and health care professionals should join the host society in an effort to prevent the suffering of refugees.

n. National bioethics committees or their equivalents should report on ethical issues arising from local circumstances in dealing with refugees.

o. 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 refugee populations.

p. Governmental and non-governmental organizations should provide refugees with education and preparation for returning home in order for them to be prepared when the cause of forced displacement is over.

q. Governments should provide alternatives to camps according to the legislation and national policies of their countries.

APPENDIX: REGIONAL HUMAN RIGHTS INSTRUMENTS THAT PROTECT THE RIGHT TO HEALTH

African Charter on Human and Peoples' Rights (1981)

Article 16

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

Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (2003; 'The Maputo Protocol')

Article 14

Health and Reproductive Rights

1. States Parties shall ensure that the right to health of women, including sexual and reproductive health is respected and promoted. This includes:
   a) the right to control their fertility;
   b) the right to decide whether to have children, the number of children and the spacing of children;
   c) the right to choose any method of contraception;
   d) the right to self-protection and to be protected against sexually transmitted infections, including HIV/AIDS;
   e) the right to be informed on one's health status and on the health status of one's partner, particularly if affected with sexually transmitted infections, including HIV/AIDS, in accordance with internationally recognised standards and best practices;
   f) the right to have family planning education.
2. States Parties shall take all appropriate measures to:
   a) provide adequate, affordable and accessible health services, including information, education and communication programmes to women especially those in rural areas;
   b) establish and strengthen existing pre-natal, delivery and post-natal health and nutritional services for women during pregnancy and while they are breast-feeding;
   c) protect the reproductive rights of women by authorising medical abortion in cases of sexual assault, rape, incest, and where the continued pregnancy endangers the mental and physical health of the mother or the life of the mother or the foetus.

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

Right to Health

1. Everyone shall have the right to health, understood to mean the enjoyment of the highest level of physical, mental and social well-being.
2. In order to ensure the exercise of the right to health, the States Parties agree to recognize health as a public good and, particularly, to adopt the following measures to ensure that right:
    a. Primary health care, that is, essential health care made available to all individuals and families in the community;
    b. Extension of the benefits of health services to all individuals subject to the State's jurisdiction;
    c. Universal immunization against the principal infectious diseases;
    d. Prevention and treatment of endemic, occupational and other diseases;
    e. Education of the population on the prevention and treatment of health problems, and
    f. Satisfaction of the health needs of the highest risk groups and of those whose poverty makes them the most vulnerable.

ASEAN Human Rights Declaration (2012)

Article 28

Every person has the right to an adequate standard of living for himself or herself and his or her family including:

a. The right to adequate and affordable food, freedom from hunger and access to safe and nutritious food;
b. The right to clothing;
c. The right to adequate and affordable housing;
d. The right to medical care and necessary social services;
e. The right to safe drinking water and sanitation;
f. The right to a safe, clean and sustainable environment.

Charter of Fundamental Rights of the European Union (2012)

Article 35

Health care

Everyone 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. A high level of human health protection shall be ensured in the definition and implementation of all the Union's policies and activities.

Council of Europe Convention on Human Rights and Biomedicines (1997)

Article 3

Equitable access to health care

Parties, taking into account health needs and available resources, shall take appropriate measures with a view to providing, within their jurisdiction, equitable access to health care of appropriate quality.

European Social Charter (ESC) (1961, Revised 1996; CETS No.163)

Article 11

The right to protection of health

With a view to ensuring the effective exercise of the right to protection of health, the Parties undertake, either directly or in cooperation with public or private organisations, to take appropriate measures designed inter alia:

1. to remove as far as possible the causes of ill-health;
2. to provide advisory and educational facilities for the promotion of health and the encouragement of individual responsibility in matters of health;
3. to prevent as far as possible epidemic, endemic and other diseases, as well as accidents.

Article 13

The right to social and medical assistance

With a view to ensuring the effective exercise of the right to social and medical assistance, the Parties undertake:

1. 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;
2. to ensure that persons receiving such assistance shall not, for that reason, suffer from a diminution of their political or social rights;
3. to provide that everyone may receive by appropriate public or private services such advice and personal help as may be required to prevent, to remove, or to alleviate personal or family want;
4. to apply the provisions referred to in paragraphs 1, 2 and 3 of this article on an equal footing with their nationals to nationals of other Parties lawfully within their territories, in accordance with their obligations under the European Convention on Social and Medical Assistance, signed at Paris on 11 December 1953.

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