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MEETING REPORT

Roles and Responsibilities in Realizing Health and Human Rights in the Prevention and Control of Non Communicable Diseases

May 30, 2013 – June 1, 2013

Organized and Hosted by:
Program on Global Health and Human Rights, Institute for Global Health, University of Southern California

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1. Introduction

Globally, non-communicable diseases (NCDs) constitute the leading cause of mortality. In 2008, sixty-three percent of all deaths – 36 million people – were caused by NCDs. Low- and middle-income countries, where the proportion of deaths under the age of 70 from NCDs is highest, accounted for eighty percent of global mortality attributable to NCDs. Yet, even as the links between health and human rights (H&HR) have been well established in a number of areas of health, the extent to which human rights norms and standards can contribute to NCD prevention and control has to date remained largely unexamined.

To begin to determine the role that human rights can play in NCD prevention and control, a two and a half-day conference, entitled "Roles and Responsibilities in Realizing Health and Human Rights in the Prevention and Control of Non Communicable Diseases," was convened at the University of Southern California in Los Angeles in the United States of America from May 30th to June 1st, 2013.

1.1 Meeting Objectives

The conference aimed to bring together people working on NCD prevention and/or control with people working on H&HR in order to:

- Exchange a range of interdisciplinary and experiential perspectives;
- Debate the larger cross-cutting issues bridging these perspectives and approaches;
- Determine existing gaps and avenues for research;
- Determine next steps including: partnerships; potential research collaborations; future publications; and support to national and international policy agenda setting.

1.2 Conference Participants

Conference participants included individuals engaged in work at the intersection of NCDs and H&HR, altogether representing a wide range of disciplinary backgrounds including: anthropology, clinical medicine, demography, epidemiology, law, public health, public policy, and the social sciences (See Annex A for participants list). This mix of participants was purposeful, as the challenge remains for both the research and the political agenda, both in NCDs and in H&HR, to address relevant issues from multidisciplinary perspectives. It was anticipated that coming together in this way would result in a review of conference topics from new vantage points and facilitate collaboration, collective research, and policy agenda setting to improve NCD prevention and control and to link H&HR appropriately.

1.3 Purpose of the Report

The purpose of this report is to introduce potential synergies that exist between NCDs and H&HR approaches. The report aims to synthesize the discussions that took place over two and a half days and provide an overview the major themes that emerged. Finally, the report highlights potential avenues for discipline-specific and collaborative work at the intersection of NCDs and human rights.

1.4 Structure of the Report

Section 2 of this report provides some basic background on NCDs, H&HR, and the intersection of these fields. It draws heavily on materials shared with participants prior to the conference and the plenary discussions of these issues which took place at the conference. Section 3 summarizes the second day of the conference where participants were divided into groups to discuss more specific aspects of the intersection of NCDs and H&HR, spanning the conceptual to the operational. Building on areas of interest that emerged from these discussions, Section 4 outlines recommendations for research and political action that might help capitalize on the synergies identified. A short conclusion ties together some of the overarching issues that emerged over the course of the conference and highlights some immediate next steps (See Annex B for the full conference agenda).

2 Background

2.1 Introduction

This section seeks to provide relevant background information on NCDs and on H&HR, and to introduce general reflections on how these concepts can be brought together as discussed in the initial plenary sessions of the conference.

2.2 NCDs and Health

NCDs cause greater mortality than communicable diseases in all regions of the world with the exception of Africa. Current projections indicate that between now and 2020 the largest increases in NCD prevalence and mortality will occur in low- and middle-income countries (LMICs) in Africa and elsewhere.[i]

The majority of NCD-related illness and death are attributable to: cardiovascular diseases, cancers, diabetes, and chronic respiratory diseases. Along with mental illness, it is estimated that these diseases will cost the developing world $21 trillion over the next two decades. The enormity of the human and financial burden of chronic disease is being increasingly recognized by the international community, most especially since the 2011 high-level meeting on NCDs held under the auspices of the United Nations.

Long regarded as causes of morbidity and mortality associated with ageing, NCDs are now recognized to also be of concern for children, adolescents and young adults given the ways in which their behaviors, lifestyles and exposure to risk factors may impact their vulnerability to NCDs. Four behavioural risk factors, all of which will likely escalate in LMICs, underlie much of the increase in NCD prevalence: tobacco use, harmful use of alcohol, insufficient physical activity, and unhealthy diet/obesity. According to the World Bank, more than half of the NCD burden could be avoided through health promotion and prevention initiatives.[ii] There is growing recognition of the need for earlier investment in prevention, increased attention to structural factors, and the strengthening of protective factors in particular through investing in avoidance of risk factors and prevention of NCDs among young people.[iii] Reliance on treatment options to combat NCDs is both costly and challenging, particularly in developing countries where few health systems are designed to deliver chronic care.

2.3 Human Rights and Health

Human rights, as articulated in the Universal Declaration on Human Rights in 1948 and reiterated and expanded upon in numerous international human rights documents since, are rights inherent to all human beings. Often expressed and guaranteed in national law, international human rights law establishes the

obligations of states to undertake or refrain from certain acts in order to promote and protect human rights and fundamental freedoms.

Beginning in the 1970s, human rights defenders documented that people living in mental health institutions were often subjected to abuses, amounting to violations of their civil and political rights. In countries around the world women's health advocates used the language of rights to make claims against the state. In the 1980s, many of those engaged in the response to HIV argued that the violations of not only civil and political rights, but of economic, social and cultural rights were fuelling the spread of HIV and exacerbating its impacts. This understanding of the reciprocal interaction between progress in health and the realization of human rights gave rise to new synergies between health and human rights. While most clearly articulated in the early responses to HIV, the links between health and human rights have been increasingly well established with respect to both prevention and care in a number of areas ranging from child health, to infectious disease, sexual and reproductive health, occupational health, women's health, the health of marginalized groups, and health systems strengthening.

2.4 NCDs, Human Rights and Health

2.4.1 Introduction

As noted earlier, the links between NCDs and human rights have not been well established. Significantly, NCDs are not explicitly mentioned in any human rights treaty. However, the right to health as it appears in the International Covenant on Economic, Social, and Cultural Rights (ICESCR) refers to "[t]he prevention, treatment and control of epidemic, endemic, occupational and other diseases", which can, of course, be understood to encompass NCDs. Furthermore, since 2000, human rights mechanisms have paid increasing attention to the main NCDs and their risk factors, but with little sustained commitment to holding governments, let alone industry, accountable under international human rights law for what they do and don't do in relation to NCD prevention and control (See Annex C for Background Paper providing more detail).

Within the global policy environment for NCDs attention to human rights has grown, with more significant interest directed to the articulation of rights, such as in the Global Action Plan 2013-2020. However, mention of human rights is often fleeting and rhetorical with little detail provided on what this might mean in the context of a policy or strategy, nor importantly for programmatic work (See Annex D for more detail).

Participants noted that at a programmatic level there was an opportunity to use human rights norms and standards to do a better job in several areas of NCD prevention and control: (1) the reduction of individual and collective vulnerability to NCDs as related to structural and social factors; (2) the reduction of risk factors related to lifestyle as a consequence of exposure to adverse environments, including advertisement pressures; and (3) the reduction of physical and mental manifestations of NCDs. Despite minimal attention to human rights in relation to NCDs to date, it was agreed that human rights have the potential elements necessary to offer both a conceptual framework and pragmatic approaches to addressing these aspects of NCDs effectively. For example, the principles of equality and non-discrimination can provide NCD interventions with a legal basis for addressing vulnerable groups, such as disenfranchised communities or people who lack capacity and power to claim their entitlements. Governmental obligations under the right to health can be used to ensure the availability, accessibility, and acceptability of quality medical services for affected populations. Other important human rights principles discussed as potentially relevant for NCD prevention and control included transparency, participation, and accountability, with attention also needed as to how the articulation of other rights such as privacy and bodily integrity may be of use.

Participants also discussed the "naming and shaming" approach to addressing human rights violations and noted that encouraging human rights groups to more actively engage with violations of health related rights that have direct repercussions for NCD prevention and control should be considered. For example, the banning of women and girls from participating in physical education and from exercising in public that has occurred in some countries was recognized not only to have violated their rights but to have fueled a chronic disease epidemic. It was agreed that the sort of documentation work done by Human Rights Watch in this area could be taken on by others, and that these links could be better explored in relation to the range of NCDs.

Discussion also focused on the opportunities that engagement with human rights norms and standards might offer to the various actors involved in NCD prevention and control. In addition to the implications for programming noted above, a government's obligations under international human rights law could provide legal channels for focusing attention on how they address NCDs at national, provincial and local levels. Significantly, as has been demonstrated in other areas, if countries have ratified certain agreements and incorporated them into domestic law, these legal obligations may provide civil society actors as rights holders with powerful tools for demanding and championing policy change through legislative reform and use of the courts.

Conference participants identified a range of areas where the synergies between NCDs and human rights might usefully be further explored. Existing human rights mechanisms should be better and more systematically utilized to ensure accountability as to what countries and the private sector do with respect to relevant risk factors. With regard to tobacco use, despite the existence of the Framework Convention on Tobacco Control (FCTC) and clarity regarding the obligations of ratifying parties, the FCTC has no accountability mechanism. [Notably, such a mechanism was proposed by human rights advocates but they had been brought into the discussions too late for this idea to be taken forward]. The human rights framework was also noted as potentially useful for increasing attention to NCDs in the global development arena, particularly in relation to the post-2015 agenda. Participants agreed that human rights-based arguments should also be more usefully employed in the ongoing debates around universal health coverage, importantly including in relation to access to medicines.

Several questions of importance to advancing these linkages within country-based work emerged from this initial discussion. These included: How can national level human rights commitments be used to strengthen NCD prevention and control efforts, and to what effect in places where, for example, the Constitution does not include the right to health? Given differing sociocultural and geopolitical contexts, including settings in which governments oppose the language of human rights, how can human rights norms and standards be most effectively utilized to improve NCD prevention and control? In addition, certain rights are less legally entrenched in different geopolitical contexts, which needs to be taken into account in the approach taken by rights holders, researchers, advocates, and policymakers. Participants agreed to keep attention to these issues in their further discussions.

2.5 Conclusion

The first day concluded with agreement that there are important linkages to be explored, and useful lessons to be drawn on the value of attention to rights for NCD prevention and control from HIV and other health topics, where the connections have been more clearly elaborated. Along these lines, conference participants recognized the need for greater clarity around definitional issues pertaining to certain phrases or terminology, and the potential implications of these definitions for working across disciplines in this area. A few examples of commonly used terms with potentially divergent definitions were discussed. These included the specificity of what is meant by "rights" and a "rights-based approach," as well as the language of "equity" and "equality" and "stigma" and "discrimination." Without trying to privilege one disciplinary perspective over another, participants agreed that clarity and specificity on the use of terminology is a first step for any further discussions intended to apply human rights to NCD work.

3 NCDs, health and human rights – from conceptual linkages to operationalisation

Building on the basic linkages between human rights and NCDs recognized at the end of the first day, four conference themes were agreed upon, that span from conceptual to operational. Working groups met to establish the current state of knowledge in each of the chosen areas, followed by plenary discussion on how best to take the work forward. Each theme built on the next, offering distinct but complementary entry points to support research, advocacy, programming and policy efforts. The first theme focused on establishing a shared conceptual understanding of the linkages between NCDs and human rights. The second sought to uncover what this could mean for programmatic work. The third considered the role of national and international law, and its potential impacts on programmatic work to address NCDs with a human rights lens. The final theme focused on national and global accountability mechanisms and approaches for work in the given area.

3.1 Conceptual and operational linkages between non communicable diseases and human rights

3.1.1 Introduction

Participants discussed the potential opportunities for collaboration among people working in human rights and NCDs to improve public health outcomes. Potential synergies were discussed using human rights as the entry point, and then using NCDs as the starting point of discussion. Ultimately, participants agreed that, although some obvious synergies exist, approaching the linkages from these different entry points raised a complementary but different sets of issues. To fully draw out the benefits of these linkages calls for nuanced research which will in turn affect the ways in which relevant work is conceptualized and carried out.

3.1.2 Using human rights as the entry point

Participants agreed that the right to health was the most obvious right linking NCDs and human rights both conceptually and operationally. Specifically, the human right to health, in supporting the highest attainable standard of health, draws attention to NCDs as a leading cause of premature and preventable morbidity and mortality worldwide, and to governments' actions to address this or the lack thereof. The legal basis for the right to health in international law obliges states to act in ways that will improve health and well-being. State obligations provide explicit operational linkages and pragmatic tools for promoting efforts to combat NCDs using human rights. Some international human rights documents are even explicit about specific obligations State parties have with regard to NCD prevention and control, such as promoting physical activity, regulating the advertisement of tobacco and alcohol products, and making available relevant drugs from the WHO Model Lists of Essential Medicines.

Participants also noted that given the legal obligations that stem from the use of human rights there may be different ways in which rights are useful to NCD prevention on the one and NCD control on the other. While prevention generally focuses primarily on populations or communities, debates over control (e.g., treatment and access to certain medicines) largely focus on the access of individuals or subgroups. Recognition of these differences may ultimately be of importance in identifying different rights-based strategies depending upon the NCD issue at hand.

Although participants agreed that the right to health was a clear starting point, they also agreed that other human rights, such as the rights to information and privacy, were relevant for NCDs. The right to information, for example, if properly used could be critical for promoting the adequate labeling of foods in the effort to combat obesity and cardiovascular diseases. Similarly, as has been shown in other areas, nondiscrimination

could have important implications for guaranteeing all populations access to appropriate medical services such as screening or treatment. Nonetheless, further efforts are needed to spell out the linkages between a range of specific human rights and NCDs. This in turn could be useful not only for advocacy and establishing legal obligations, but for supporting programmatic work.

3.1.3 Using NCDs as the entry point

In reality, NCD prevention and control efforts often make distinctions in the approach to different types of disease and risk factors. One question emerging from these distinctions is: should efforts to combat NCDs from a rights perspective address them collectively, as is increasingly being done at the global level, or are rights more relevant when one considers the approach taken to individual diseases or risk factors? Participants suggested that an individual disease focus would be important in specific contexts such as acquiring adequate treatment; however, given the place of NCDs as a whole on the global political agenda, an emphasis on NCDs collectively may be more useful overall. Participants also agreed that when the term NCD is used, there must be a shared understanding of which NCDs are included, for example, whether or not mental health, chronic kidney failure or degenerative diseases of the nervous system are included.

3.1.4 Current limitations and next steps

Given the limited interactions between the NCD and human rights fields to date, work to systematically establish both conceptual and operational linkages is in its infancy. At a conceptual level, efforts are needed to identify not only how rights violations contribute to a higher incidence of NCDs but also to what extent uncontrolled NCD rates may lead to rights violations. Further work is also needed to demonstrate that inclusion of human rights concepts and methods in NCD programming makes a difference. The engagement of both the NCD and human rights communities will be useful for establishing the evidence base, and it was recognized that this is also a necessary step to motivate policymakers and attract acutely needed resources. The aim should be to create a virtuous cycle whereby improved realization of human rights can reduce the burden of NCDs, which in turn can advance the realization of rights.

Participants agreed that new educational opportunities and tools are needed which focus specifically on the linkages between NCDs and human rights. These could be used by advocacy groups to build their own capacity or to train decision-makers. Ideally, they would be offered on-line or through other forms of distance learning and become a part of university offerings as well as academic in-service training. Academic institutions could consider sharing curricula so as to facilitate the spread of ideas and materials as well as course development and delivery. A more general, but related, role for academic institutions interested in strengthening the linkages between NCDs and human rights would be to build capacity in health law more generally as this is lacking in many countries. In particular, the development of cross-disciplinary studies in public health, law and human rights -- whether through the establishment of new, innovative courses or offered through joint graduate degrees such as J.D.-M.P.H. programs or focused LL.M. programs -- was seen as a potentially important contribution.

Participants agreed that mobilization efforts should occur as soon as possible. Civil society mobilization as well as priority setting by policymakers and the engagement of academic institutions will be important for strengthening the advocacy base for NCDs and will also assist in informing governments, United Nations treaty bodies, other mechanisms, and agencies, as well as the post-2015 agenda more generally.

3.2 Equality in Access to Quality Medicines, Commodities and Services

3.2.1 Introduction

The work in this area sought to identify the obvious synergies between NCD programming, service delivery and human rights norms and standards. Participants identified objectives for ensuring improvements in equality of access and agreed that a H&HR framework could be used to identify important structural barriers as well as relevant rights holders and duty bearers. The utility of various conceptual principles for ensuring equality of access was debated as well as the specific roles and responsibilities of various actors.

3.2.2 Using human rights as an entry point

Participants determined that medicines, commodities, and services must be considered holistically, given that effective delivery of medicine also requires access to other commodities such as screening tests and additional support services. The group identified three priority linkages for helping to ensure equality in access to medicines, commodities, and services for NCDs: availability, quality, and rational use. Through the discussion, these priorities, although articulated in public health terms, were seen to sit nicely alongside the concepts of availability, accessibility, acceptability and quality of goods and services as described under the right to health as they relate both to goods and services offered through health facilities and those that are related to the underlying determinants of health.

Availability was discussed in the context of sufficient physical supply, geographic proximity, and affordability, thus also encompassing elements of "accessibility" as understood within a human rights approach. Participants also suggested that acceptability of service delivery is important for ensuring legitimate equality of access. Attention to quality would help to ensure the effectiveness of the provision of goods and services, encompassing also the concept of rational usage, which would in turn promote effective and appropriate use of available resources. Particularly important here was ensuring access to affordable medicines, whether through price lowering mechanisms or the promotion of generics. The principle of participation was also recognized in this context to be useful for acceptability, accountability, mobilization efforts, increasing the advocacy base for NCDs, and inspiring locally designed programs. Within country and cross country dimensions of these issues were also explored.

3.2.3 Past experience and strategies for the future

Experience in other areas has shown that it is possible to use rights to promote equal access to medicine including, for example the provision of generic antiretroviral drugs for HIV-positive individuals in many countries. Nonetheless, even if the commitments are there, long-term financing remains a major challenge. Some countries have adopted universal health insurance as a way of improving access to care. Notably, participants disagreed over whether universal coverage guaranteed or even implied equal access and debated the merits of such an approach. In particular, it was noted that even in countries where the national insurance program attempts to provide a universal, minimum package of services, these often fail to cover a wide range of medical conditions including many NCDs. In this respect, the potential use of the human rights principle of "progressive realization" was discussed in that it distinguishes between government unwillingness and government incapacity, and demands that benchmarks and targets be set against which progress can be measured.

In discussion, important questions arose regarding whether it was ethical to initially target NCD prevention and control efforts towards the most easily accessible populations or whether the focus should be on the most vulnerable. Participants agreed that a H&HR approach could help identify the most vulnerable populations and the structural barriers that could impede equal access to medical assistance for populations both within and across States. H&HR could be factored in as priorities are set, as well as offer new approaches for addressing such barriers. Participants noted in this respect that analyzing the range of NCD risk factors from a H&HR perspective would be useful for distinguishing immediate, underlying, and basic causes for lack of access.

Different types of barriers, ranging from proximity to a health post to lack of industry regulation, may be present in different places and with differing implications for different populations. Additional factors, such as stigma and discrimination, may prevent certain groups including racial/ethnic, religious or sexual minorities, among others from accessing NCD service provision. Participants recognized these questions to be the tip of the iceberg but precisely the sorts of issues which would need to be addressed if human rights were to be consciously brought into NCD programming efforts.

The discussion highlighted the need for outreach and education, as many individuals may not be aware of their entitlements as rights holders or of what constitutes a violation of their rights. This is true at a general level, but was recognized to be particularly true in relation to NCD prevention and control. Similarly, explicit articulation of the responsibilities of duty bearers in this context was recognized as a step towards underscoring the utility of rights-based approaches for NCD prevention and control.

3.2.4 Current limitations and next steps

Long-term treatment for chronic conditions implies the challenges of maintaining an adequate supply and sufficient financing for medication over the course of a lifetime. The lack of generic medicines for NCDs was identified as a major limitation to improving access. Trade agreements such as Trade Related Aspects of Intellectual Property Rights (TRIPS) and Transpacific Partnership agreements have expanded patent coverage for many medications impeding efforts to make NCD medicines, in particular generics, available to all. Participants recognized a plethora of problems impeding access, and suggested in addition to research and advocacy the need for health and human rights impact assessments in a range of areas including the impacts of certain trade agreements on NCDs. In this respect, clarification of the roles and responsibilities of state and private sector actors in ensuring access was seen as an important next step. Improving access -- and in particular *equality* of access -- to quality medicines, commodities and services was recognized as a key concern going forward, requiring efforts from academia, activists, the private sector, government, and UN agencies alike.

3.3 NCDs, Human Rights and the Law

3.3.1 Introduction

The work in this area sought to explore the impacts of national and international law on NCD prevention and control, as well as particular H&HR issues that emerge at this intersection. The working group identified specific areas of law that have significant implications for NCD efforts, as well as legal mechanisms at both domestic and international levels that could be useful for addressing NCDs more effectively. Anchoring the discussion was agreement that the law is a vital tool for redressing established rights and for creating a policy environment conducive to improving NCD-related health outcomes.

3.3.2 Regulation and the role of law and policy in NCD prevention and control

It was agreed that the law can help mold the socioeconomic or political environment to promote positive health outcomes. The importance of law and policy in regulating entities through restrictions, reprimands, or taxation for certain practices was highlighted. Discussion centered also on law and policies as a mechanisms for enabling, funding, or directly providing goods and services, such as the provision of insulin to individuals with diabetes.

Participants also considered the role of litigation as a potential mechanism for improving efforts to combat NCDs within national contexts. Litigation has been utilized as a strategy to deal with NCDs in the past, most famously against tobacco companies.

Regulation of certain industries related to NCD risk factors, such as the food, beverage, alcohol, and tobacco industries was highlighted as vital at the national level. In some countries, marketing regulations resulted in new mandatory labeling practices designed to curb smoking rates, particularly among youth. There have been numerous tobacco-related laws and policies enacted around the globe that have successfully contributed to decreases in smoking rates, but efforts in relation to other NCD risk factors remain fairly novel. Participants also highlighted the potential to use international law to promote global accountability more effectively in this area. While more evidence may be necessary to select the best approach, participants agreed that governments must strengthen regulation of the private sector contributing to the NCD disease burden. Policy options include the dissemination of factual public information, higher taxes, stricter regulation of advertising, and labeling requirements. In this respect, it was agreed that differences amongst those industries providing some benefits to populations (e.g. food and pharmaceuticals) vs. those that do not (e.g. tobacco) would require specificity not only in national-level regulation but in the articulation of international obligations for regulation in this area.

With respect to work at the international level, participants also noted that to date State obligations under the right to health have been under-utilized for NCD prevention and control. Participants highlighted, in particular, the use which could be made of the framework outlined by General Comment 14 of the ICESCR to address relevant risk factors as well as to ensure that goods and services meet standards of availability, accessibility, acceptability, and quality (3AQ).

3.3.3 Current limitations and next steps

Participants stressed the need for research on and evidence of the role that law plays in supporting or hindering effective NCD prevention and control, and the application of a human rights analysis to such efforts, including the costs of inaction. It was recognized that the positive and negative impacts of law had not yet been systematically analyzed from within a human rights framework, and that this would be an area ripe for action drawing on the strengths of those present at the meeting.

Research is needed to better understand the implications that particular domestic legal systems, and approaches to regulation, have for the different aspects of NCD prevention and control. It was noted in particular that States with a weak rule of law have little capacity to effectively regulate private entities. Even in countries where the rule of law is stable, regulation of industry may not be sufficiently strong. Government, academic partners and civil society organizations could usefully gather evidence and consider potential approaches to the regulation of NCD-associated industries using a human rights lens to frame their efforts.

One major barrier to studying or addressing the impact of law on NCD prevention and control -- particularly in many low- and middle-income countries -- is a lack of capacity, and limited knowledge of health law and the linkages between law and health. Training in these areas is needed for professionals, including lawyers and public health officials, as well as of civil society groups and students. Excellent modules developed in the context of HIV and infectious disease, highlighting the role of law and the use of human rights to guide analysis, may serve as useful models.

Globally, more attention to the use of existing monitoring mechanisms, such as the human rights treaty monitoring bodies, could help to ensure adequate attention to the law in the context of NCDs. In particular, such bodies could provide feedback and human rights-based recommendations to States for action on NCDs.

3.4 Governance and Accountability for NCD Prevention and Control

3.4.1 Introduction

Discussion around this topic brought attention to practical opportunities for improving governance and accountability for NCD prevention and control at global, regional, national and sub-national levels with due attention to human rights considerations. Participants distinguished between governance of NCD prevention

and control efforts, and the mechanisms of accountability of actors involved in these efforts. While governance and accountability were often discussed together, and do ultimately go hand in hand, participants noted that to improve the linkages between NCDs and human rights in relation to governance and accountability would require quite different strategies that remain to be developed.

3.4.2 Governance and accountability structures

3.4.2.1 Global, regional, national and local levels

As existing global mechanisms are inherently weak yet the subject of growing interest, participants agreed that they might be an opportune venue for concretely strengthening the linkages between rights and NCD prevention and control. While adequate and sustainable financing was noted as key to success in this area, discussion centered on the ways in which existing mechanisms could be strengthened regardless of additional financing. For example, accountability could be advanced at all levels by adding a human rights dimension to the mechanisms being established specifically around NCDs. Further, the existing UN human rights machinery (e.g. Universal Periodic Reporting to the Human Rights Council and UN Human Rights Treaty Bodies) could be encouraged to strengthen their dialogues with States around what is being done in the area of NCD prevention and control. The utilization of Optional Protocols that establish judicial mechanisms might also be fruitfully explored.

In taking the lead in priority setting around NCD work, inter-governmental institutions, such as the World Health Organization and UNDP, should consider the explicit support they can draw from the concrete application of human rights norms and standards to their work as they have done in other areas central to their mandates such as HIV and reproductive health. The role of other actors, however, must also be considered; the World Bank, for example, was instrumental in national tobacco control by recommending state taxation of tobacco products for revenue generation. These powerful actors can play a useful role, but have had much less direct engagement with human rights principles to date.

Regional intergovernmental organizations such as the Organization of American States (OAS), the European Union (EU), the Association of Southeast Asian Nations (ASEAN) or the African Union (AU) may serve as important avenues for discussing and implementing NCD prevention and control efforts generally. Linkages to the existing human rights mechanisms within these organizations could be explored. Regional organizations can be especially important in terms of establishing leadership on the NCD and human rights linkages, given that they can set normative frameworks that aggregate shared cultural values and economic interests.

Governments have the potential to be especially powerful leaders in ensuring that NCD prevention and control efforts utilize a H&HR perspective. States should ensure that these linkages are apparent in national level plans, budgets and campaigns across sectors such as health, trade and development. By including rights-holders in discussions pertaining to such initiatives, governments can help promote acceptability, successful implementation and sustainability. Participants emphasized the importance of recognizing also the diversity of leadership within states as it relates to NCD prevention and control. In addition to ministries of health and national public health centers, at central level other branches of the government such as ministries of trade, finance, justice and foreign policy may also serve as important gatekeepers to the handling of NCD related efforts. The sub-national and community levels of government are no less important even if often overlooked. Critical to any efforts which hope to take human rights obligations into account will be the engagement of local civil society groups.

The discussion of civil society in this context raised additional points for consideration. Civil society actors working on NCDs are fragmented, and can face restrictions in their freedom of association and expression in countries where these rights are not respected. This greatly limits their ability to present a coherent advocacy response at local and global levels. Human rights organizations have to date expressed limited interest in

NCDs, and efforts to bring together civil society organizations working in these fields has occurred sporadically at best. Opportunities for shadow reporting, convening, and lobbying remain underutilized. Participants noted the lessons to be learned from the links that were forged among civil society organizations in relation to HIV, whose tenacious efforts resulted in important advances not only programmatically, but politically.

3.4.2.2 Financing flows

With regard to cooperative efforts between countries, participants suggested that high-income countries with the ability to provide foreign aid have a significant responsibility to assist with NCD prevention and control beyond their borders. Other participants, however, cautioned that, in the context of declining international aid, forming effective and sustainable linkages between donor and recipient countries might be difficult to ensure. In many cases, foreign aid for health offsets state spending (where the duty to provide healthcare arguably rests), resulting in the redirection of state funds to non-health related expenditures. Funding locally-based NGOs working on NCDs and H&HR was recognized as most economical and effective, but the opportunity for channeling resources to them is unclear. Bringing human rights into foreign aid conversations might be particularly useful in some contexts and particularly troublesome in others, for example when human rights language is misused, whether deliberately or inadvertently, to serve an unrelated political or economic agenda.

Participants agreed that the status quo financing of international, national, and subnational efforts targeting NCDs is largely insufficient and that the same is true of human rights funding more generally. Recognizing the constraints that finite resources and the global economic crisis impose on governance and on investments in health more specifically, the need for adequate and sustainable financing of NCD work was underscored. In a context of an ever-expanding array of health priorities, the human and economic impact of neglected NCDs must be documented and exposed to stimulate investment in this domain. Potential donors interested in financing initiatives linking NCD responses and human rights remain to be identified, motivated and actively solicited.

3.4.4 Current limitations and next steps

Participants recognized the need for research to identify the most effective mechanisms for NCD responses not only in programmatic terms, but also as relates to policy and governance. While policy is key to what is done in this area, participants noted the limited attention to actual implementation of policy in current efforts towards NCD-related accountability. Examples of evaluation tools which take policy and governance structures into account in others areas, notably HIV, may offer useful models for moving forward. Drawing on international commitments, such models have detailed relevant human rights considerations, made explicit what policy implementation can look like, clearly identified government commitments, engaged civil society and ultimately enhanced transparency and accountability. Incorporating a H&HR perspective into similar guidelines for the monitoring and evaluation of NCD prevention and control could be hugely beneficial in promoting accountability.

Understanding the power and influence of diverse stakeholders at every level from the global to the local, including the private sector, social movements, various governmental organizations, and other constituencies, will be critical to the development of efficient accountability mechanisms and effective governance both vertically in relation to governance structures at all levels, as well as across and among countries and through international cooperation.

3.5 Conclusion

Within each of the four topic areas discussed above, a range of potential synergies became apparent suggesting actions which could be capitalized upon in both the short and long term. Certain themes emerged across the discussions, in particular the importance of multi-sectoral action and the need for work at many different levels

from local to global. Importantly, participants recognized that many of the barriers to joint work on NCDs and human rights stemmed from little more than the lack of knowledge of how best the fields might be brought together, rather than antagonisms or irreconcilable differences in approach.

4. Moving Forward

4.1 Introduction

Opportunities exist in both the short- and long-term to move forward work at the intersection of human rights and NCDs. A sense of urgency pervaded discussions about the political spaces that may benefit from attention to these linkages in the short-term, but there was also great interest in the research opportunities that, in the longer term, can inform political and programmatic actions through the production and dissemination of evidence and good practice.

4.2 The Research Agenda

The research agenda in this area is potentially complex, encompassing both conceptual and operational challenges. While detailed attention is required to determine how best human rights might be incorporated into NCD responses for positive impact on health and rights outcomes, cross-cutting this work is the need to determine how the fulfillment of rights might best decrease the NCD burden and how NCDs and the responses (or lack thereof) brought to address them may impact the fulfillment of human rights.

4.2.1 Conceptual research

To date, there has not been an effort to link the conceptual frameworks that drive research around NCDs with those that drive research around human rights. The development of conceptual models and frameworks which work to link these approaches would be an important contribution to advancing the research agenda in this area. Participants began discussions about what such models would look like, and agreed this would be a fruitful area of work to take forward. Key would be to explore every option, including not only models which have already been developed to address NCDs or human rights or simply to bring the other in as an "add-on." To test different models, it would be useful to determine whether an NCD entry point, a human rights entry point, or perhaps even some other entry point which has not yet been conceptualized, is most effective in the NCD realm for defining relevant operational questions, for example in the areas of health promotion or service provision.

Another area thought by participants to be key concerned how human rights considerations would be brought into the conceptual work that is being done around the governance, financing and delivery of NCD-related services within different countries. Noting the legal obligations which attach to rights, it was concluded that this would provide not only a solid base for targeted operational research but could potentially contribute to ensuring some level of accountability of domestic and international actors to develop, implement, and evaluate packages of integrated NCD-related services in a rights-friendly way suitable to different country contexts and priorities.

Participants agreed that with regard to any conceptual work undertaken, operational research would be vital to verify the legitimacy of what is being proposed and to determine how it can best be applied in practice.

4.2.2 Operationalising research

At an operational level, research is needed in relation to disease burden and delivery of services, as well as with respect to the larger legal and policy context and structural barriers more generally. Identification of the populations most vulnerable to and affected by NCDs would seem a logical entry point. Attention could then

be focused on identifying health disparities and, using a rights lens, linking these to barriers to equal access and uptake of NCD related- services, or other structural determinants which lead to inequalities. Disaggregation of disease burdens and risk factors could be an important step towards identifying core areas of need in specific countries or regions. To do this effectively would, in turn, require identification and development of appropriate methodologies and metrics for work at the intersection of NCDs and human rights.

Research with respect to the legal and policy context would be useful for beginning to identify structural barriers to the availability and quality of NCD services within specific localities, as well as ultimately how solutions may vary across different geopolitical contexts or constitutional frameworks. More specifically, attention could be given to identifying how effective judicial systems, and the potential for litigation as a means to claim rights in relation to NCDs, enable states to protect rights, and how effective particular laws or forms of regulation are in improving NCD-related outcomes.

Considering both NCDs and human rights as entry points for operational research highlighted new areas for exploration, and the need for the engagement of a variety of disciplinary perspectives to address NCD prevention and control effectively. Finally, it was recognized that providing such evidence to treaty bodies, governments, civil society and donor institutions could help galvanize state action, promote government accountability and mobilize additional funding (See Annex E for more detail).

4.3 The Political Agenda

As highlighted above, the political environment in which work at the intersection of NCDs and human rights is taking place is evolving rapidly. Opportunities for influencing this agenda in both the short- and long-term were identified in an effort to strategically maximize potential impact.

To move the political agenda forward in the first instance will require awareness raising about these linkages among key constituencies. This will entail the production of key materials, advocacy briefs, training opportunities, publication in scholarly journals and the use of appropriate e-lists and other forms of communication.

Operationalising the Global Action Plan offers a crucial opportunity to bring human rights into the Plan's implementation at the national and sub-national levels as well as to incorporate attention to human rights into global level progress indicators. Benchmarks that encompass human rights considerations will also be important to ensure that monitoring organizations and civil society actors have the means to hold states accountable when certain goals are not met.

Other suggested platforms where efforts must be made to ensure the linkages of these topics at the global level include the proposed UN interagency task force on NCDs, the proposed Global Coordination Mechanism, the UN human rights mechanisms, the Millennium Development Goals review process and the post-2015 agenda. A UN inter-agency task force on NCDs would be key to ensuring due attention to human rights in global efforts, as well as in the work of individual agency activities relevant to NCDs or their risk factors – whether guidelines, plans or technical assistance. It was also noted that figuring out ways to facilitate systematic attention to NCDs in human rights treaty body and Universal Periodic Review processes would be important and achievable in the short-term. Advocacy for and monitoring of the inclusion of HR principles and attention to NCDs in the post 2015 agenda will be critical as we move forward.

Participants agreed that joining NCD initiatives and a human rights framework will require a multi-sectoral approach involving many actors, including UN agencies, governments, civil society, the private sector and academia. Despite the predominant focus in conference discussions on the global level, participants noted that action must occur at many levels, from the grassroots, sub-national, and national, to the regional and international. Recognizing that training will be needed to ensure that the links are clear for all relevant actors,

participants nonetheless noted that points of engagement already exist at each of these levels to place NCDs and rights on the global agenda while also adapting initiatives to local or regional geopolitical contexts.

5.0 Conclusion

Over the course of the conference, participants came to appreciate the under-explored potential for synergies between human rights and tackling NCDs. The opportunity for learning across fields was recognized as a key step to move this work forward. Nonetheless, with increased understanding of the conceptual linkages between these two areas, opportunities for operationalizing these ideas in the short-term were identified, along with a range of areas for further research and political action. Some of this can be done through existing efforts in the fields of both public health and human rights while in other instances, new approaches designed to explicitly bring together human rights and NCD responses are likely to be required.

The important role of civil society was mentioned time and again throughout the conference, with the hope that NCD- and human rights-related advocates join forces for greater impact on areas of mutual interest. These may include: raising awareness of the linkages between NCDs and human rights; holding governments accountable for an appropriate response; supporting civil society actors to develop a more explicit "watchdog" function; lobbying policymakers to include attention to human rights in the context of the GAP; lobbying donors to increase financial support for a combined H&HR approach to NCD prevention and control; and informing citizens of their rights and potential avenues for fulfillment and redress.

Arising from the conference, various work products and next steps were proposed. These included: advocacy materials for use by civil society; advocacy for government action to incorporate attention to human rights into NCD responses; the development of academic training and research initiatives to promote attention to NCDs and human rights; conceptual and operational research on a wide range of topics and across disciplines; engagement with ongoing global, regional and national processes that constitute opportunities for drawing attention to the synergies between NCD responses and human rights; and specific follow-up at global and regional meetings to further explore and catalyze the synergies between NCD responses and human rights (See Annex F for further detail).

The scope for moving forward work at the intersection of NCDs and human rights is vast. Challenges persist not just with regard to developing a fuller understanding of these linkages at the conceptual level but to galvanize action at the different levels of implementation and among the wide range of relevant actors. Despite these challenges, participants recognized valuable opportunities for action. At the close of the conference, energy for moving forward this work was high – an opportunity on which we must now capitalize.

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Annex B: Conference Agenda

Thursday, May 30, 2013
Day 1: Linkages and Commonalities: NCDs, Health and Human Rights
The first day will explore the commonalities and linkages between NCDs, health and human rights.

13:30-14:00	**Opening** Welcome Participant Introductions Meeting Objectives Review of Agenda	*Chair: Sofia Gruskin*
14:00-15:15	**Mini Presentations and Plenary Discussion** NCDs and Health	*Chair: Sofia Gruskin* Mauricio Hernandez Hans Hogerzeil Jon Samet
15:15-15:45	Refreshment Break	
15:45-17:00	**Mini Presentations and Plenary Discussion** NCDs, Health and Human Rights	*Chair: Sofia Gruskin* Joseph Amon Lawrence Gostin Alison Dundes Renteln
17:00-17:30	**Reflections and Conclusions**	*Chair: Sofia Gruskin* Katherine Deland Rajat Khosla Daniel Tarantola
17:30-19:00	**Opening Reception** (Nazarian Pavilion)	

Friday, May 31, 2013
Day 2: Synergies and Outcomes: Health and Human Rights Approaches to NCDs
The second day will open with discussion of substantive issues arising from Day 1 as well as a roadmap for the day ahead. Participants will then break into groups to discuss the current state of knowledge in carefully selected areas of relevance, and then reconvene in plenary in the afternoon to discuss how to move work forward in each of these areas.

9:00-9:45	**Plenary Discussion** Overview Of the Day Issues Arising From Day 1 Definitional Challenges Around Key Concepts	*Chair: Alex Capron* Sofia Gruskin Daniel Tarantola

9:45-10:15	Refreshment Break	
10:15-12:15	**Working Groups** Current State of Knowledge 1. Conceptual and Operational Linkages Between NCDs and Human Rights ***(Meeting Room – Alumni A)*** 2. Equality in Access to Quality Medicines, Commodities and Services ***(Meeting Room – Alumni B)*** 3. NCDs, Human Rights and the Law ***(Meeting Room – Club A)*** 4. Governance and Accountability for NCD Prevention and Control ***(Meeting Room – Club B)***	 *Chair: Robert Beaglehole* *Chair: Susana Fried* *Chair: David Patterson* *Chair: Soon-Young Yoon*
12:15-13:45	Lunch	
	Mini Presentations and Plenary Discussion Moving Forward the Current State of Knowledge	
13:45-14:30	1. Conceptual and Operational Linkages Between NCDs and Human Rights	*Chair: Robert Beaglehole* Laura Ferguson Laurent Huber Rajat Khosla
14:30-15:15	2. Equality in Access to Quality Medicines, Commodities and Services	*Chair: Susana Fried* Stewart Landers Gerald Yonga
15:15-15:30	Refreshment Break	
15:30-16:15	3. NCDs, Human Rights and the Law	*Chair: David Patterson* Ana Sofia Charvel Oscar Cabrera Sueli Dallari
16:15-17:00	4. Governance and Accountability for NCD Prevention and Control	*Chair: Soon-Young Yoon* Heather Wipfli Syeda Rahman Douglas Webb
17:00-17:30	**Reflections and Conclusions**	*Chair: Alex Capron* Joseph Amon Richard Daynard

19:00	**Optional Group Dinner** (El Cholo)	

Saturday, June 1, 2013

Day 3: Moving Forward the Agenda: NCDs, Health and Human Rights

Building on the previous two days, the third day will foster discussion on concrete steps for moving this work forward conceptually and operationally. The first plenary will focus on the Global Action Plan, the follow-up to the UN Declaration, and the post-2015 goals. The second plenary will focus on developing a research agenda with attention to research priorities, evidence gathering and knowledge sharing across disciplines.

9:00-10:00	**Mini Presentations and Plenary Discussion** Moving Forward the Political Agenda	*Chair: Douglas Webb* Katherine Deland Claudio Schuftan Susanne Volqvartz
10:00-10:30	Refreshment Break	
10:30-11:30	**Mini Presentations and Plenary Discussion** Moving Forward the Research Agenda	*Chair: Onyebuchi Arah* Gunilla Backman Laura Ferguson Mauricio Hernandez
11:30-12:00	**Wrap-up and Closing**	*Chairs: Sofia Gruskin* *Daniel Tarantola*

Annex C: Background Paper: Attention to Non Communicable Diseases By the United Nations Human Rights Treaty Bodies

Overview

Key Messages:

- None of the human rights treaties mention NCDs explicitly, but "other diseases" as noted in the ICESCR can be understood to include NCDs.
- General Comments on the right to health and other rights draw attention to obligations to address NCDs and their risk factors.
- Treaty bodies are increasingly asking countries to report on NCD prevention and control activities, providing an avenue for accountability which remains to be further explored.
- Other human rights mechanisms lag behind the treaty bodies in according attention to NCDs.

In order to determine what useful linkages could be made between non communicable diseases (NCDs) and human rights, a brief assessment was made of relevant work within the formal human rights system. This system comprises a range of UN human rights mechanisms including the human rights treaty bodies, reports by the Special Rapporteur on the Right to Health and the Universal Periodic Review.

Cognizant that this work is still in its early stages and that its impact at country level is yet to be fully understood, the analysis was restricted to the treaty bodies as this is where the most relevant information was found to exist. The scope of the review was then further limited to the two treaties where, at this time, there appears to have been the most activity around NCDs: the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the Convention on the Rights of the Child (CRC). These treaties were reviewed, along with any relevant General Comments, reporting guidelines, and Concluding Observations issued by the treaty body, for content explicitly addressing NCDs or relevant risk factors. Restricted to the four NCDs that constitute the focus of this conference, this analysis addressed how NCDs have been mentioned generically and individually as well as how their main risk factors have been discussed.

NCDs are not explicitly mentioned in any human rights treaty. The right to health as it appears in the ICESCR refers to "[t]he prevention, treatment and control of epidemic, endemic, occupational and other diseases", which has been understood to encompass NCDs. The first explicit mention of NCDs by any human rights mechanism came in 2000 in General Comment 14 on the right to the highest attainable standard of health issued by the Committee on Economic, Social and Cultural Rights. More recently other bodies have further extrapolated on States' obligations in relation to NCDs, with particular focus on prevention by addressing the main NCD risk factors. General Comment 15 on the child's right to health in the CRC (2013) includes the most extensive reference to NCDs and their risk factors, encompassing attention to obesity, physical activity, education on healthy lifestyles and regulation of the advertising and sale of tobacco, alcohol and "fast" foods.

Both the Committee on Economic, Social and Cultural Rights and the Committee on the Rights of the Child require States parties to report on some aspects of NCD prevention and control in their periodic reports, which is an important step towards accountability. If States parties fail to report on these issues, or report issues which raise concerns, the treaty body can highlight these shortcomings and make recommendations for State action for which the State can be held accountable in the subsequent reporting round.

In recent years, the Committees have paid increasing, if unsystematic, attention to harmful use of alcohol, tobacco use, nutrition, physical exercise and access to medications for NCDs.

Glossary of Terminology[1]:
Treaty body: A committee of independent experts appointed to monitor the implementation by States parties of the core international human rights treaties.

General Comment: A treaty body's interpretation of the content of human rights provisions, including thematic issues.

Reporting Guidelines: Each treaty body produces written guidelines for States parties giving advice on the form and content of the reports which States are obliged to submit under the relevant treaty.

Concluding Observations: The observations and recommendations issued by a treaty body after consideration of a State party's report refer both to positive aspects of a State's implementation of the treaty and areas where further action is recommended. The treaty bodies are committed to ensuring effective follow-up to their concluding observations.

In the pages that follow, further details are provided with regard to how NCDs have been addressed by the Committee on Economic, Social and Cultural Rights and the Committee on the Rights of the Child. The section on each of these treaties includes: brief commentaries, relevant language from the treaty itself, relevant extracts from General Comments, relevant guidelines for reporting under the treaty, and relevant concluding observations on country reports from the treaty body.

[1] http://www2.ohchr.org/english/bodies/treaty/glossary.htm

ICESCR: The Right to the Highest Attainable Standard of Health (Article 12)

Overview
The ICESCR contains the most explicit and comprehensive article on the right to health. 160 countries have ratified the ICESCR. It adopts a broad conception of the right to health that includes freedoms (such as the right to control one's health and body) and entitlements (e.g. to equality of access to health care), and consists of two basic components: healthy living conditions and health care.
Relevant text
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.
2. The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include the necessary for:
a. The provision for the reduction of the stillbirth-rate and of infant mortality and for the healthy development of the child;
b. The improvement of all aspects of environmental and industrial hygiene;
c. The prevention, treatment and control of epidemic, endemic, occupational and other diseases;
d. The creation of conditions which would assure to all medical service and medical attention in the event of sickness."

General Comment No. 14, 22nd Session Committee on Economic, Social and Cultural Rights, August 2000

Overview
In 2000, General Comment 14 on the right to the highest attainable standard of health explicitly noted that responsibility for this right encompasses attention to NCDs highlighting, in particular, the increasing burden of cancer.

Relevant text
Paragraph 10: [Since its adoption in 1966, the world health situation has significantly changed]
"…formerly unknown diseases such as HIV/AIDS and cancer, as well as the rapid growth of the world population, have created new obstacles for the realization of the right to health which need to be taken into account when interpreting article 12."

Paragraph 11: "The Committee interprets the right to health, as defined in article 12.1, an inclusive right extending not only to timely and appropriate health care but also 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, healthy occupational and environmental conditions, and access to health-related education and information, including on sexual and reproductive health."

Paragraph 15: "The improvement of all aspects of environmental and industrial hygiene" (art. 12.2 (b)) comprises, *inter alia*, … the prevention and reduction of the population's exposure to harmful substances such as radiation and harmful chemicals or other detrimental environmental conditions that directly or indirectly impact upon human health… Article 12.2 (b) also embraces adequate housing and safe and hygienic working conditions, an adequate supply of food and proper nutrition, and discourages the abuse of alcohol, and the use of tobacco, drugs and other harmful substances."

Paragraph 25: "… reaffirms the importance of an integrated approach, combining elements of preventive, curative, and rehabilitative health treatment. Such measures should be based on… attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity."

Paragraph 36: "[States parties'] obligations include … information campaigns, in particular with respect to HIV/AIDS, sexual and reproductive health, traditional practices, domestic violence, the abuse of alcohol and the use of cigarettes, drugs and other harmful substances."

Paragraph 37: "[States'] obligations include… the dissemination of appropriate information relating to healthy lifestyles and nutrition, harmful traditional practices, and the availability of services".

Paragraph 51: "Violations of the obligation to protect follow from the failure of a State to take all necessary measures to safeguard persons within their jurisdiction from infringements of the right to health by third parties. This category includes such omissions as… the failure to discourage production, marketing and consumption of tobacco, narcotics and other harmful substances…"

Guidelines for Country Reporting

Overview
The Committee on Economic, Social and Cultural Rights issues reporting guidelines for States to ensure that topics of relevance are addressed in countries' periodic reports on their steps towards implementation of the Covenant.

Relevant text
Paragraphs 44 & 45: Under the right to adequate food, States are requested to: "Provide information on the measures taken to ensure the availability of affordable food in quantity and quality sufficient to satisfy the dietary needs of everyone, free from adverse substances, and culturally acceptable… [and to] indicate the measures taken to disseminate knowledge of the principles of nutrition, including of healthy diets.

Paragraph 56: Under the right to health, States are requested to "Provide information on the measures taken to ensure… that drugs and medical equipment are scientifically approved and have not expired or become ineffective".

Paragraph 57: Also under the right to health, States are requested to "Provide information on the measures taken… to prevent the abuse of alcohol and tobacco, and the use of illicit drugs and other harmful substances, in particular among children and adolescents, ensure adequate treatment and rehabilitation of drug users, and support their families… [and] to ensure affordable access to essential drugs, as defined by the WHO, including anti-retroviral medicines and medicines for chronic diseases".

Committee on Economic, Social and Cultural Rights Concluding Observations

Overview
Every year, the Committee reviews reports from ten countries and, in response, raises issues of concern on which it asks countries to act and to report back on during the subsequent reporting round. The extent to which the Committee's responses in relation to NCDs will result in concrete change at the country level is an area to be monitored, and will be made clear in the next reporting round. Relevant extracts from the Committee's responses from 2010-2011 are provided

below.

Relevant text
2011 Report[1]:
ARGENTINA: "The Committee is concerned about the high level of tobacco consumption in the State party, especially among women and youth… The Committee recommends that the State party ratify and implement the WHO Framework Convention on Tobacco Control and develop effective public awareness and tax and pricing policies to reduce tobacco consumption, in particular targeting women and youth."

CAMEROON: "The Committee notes with concern the high rate of smoking in the State party, despite measures taken to cut the consumption of tobacco… The Committee recommends that the State party design effective policies to combat tobacco consumption, strengthen its prohibition on tobacco product advertising, enact legislation imposing a strict ban on smoking in all closed public areas, and intensify public awareness-raising campaigns. It also recommends that the State party allocate part of its revenue from taxes on cigarettes to discourage smoking."

ESTONIA: "The Committee is concerned about alcohol consumption which remains high despite measures taken, such as the increase in the excise tax on alcohol and the prohibition of sales during specific hours… The Committee recommends that the State party intensify its efforts aimed at combating alcohol abuse, including through awareness-raising campaigns."

2010 Report[2]:
MAURITIUS: "The Committee is concerned about the lack of information on the effectiveness of the strategies developed to combat chronic diseases, especially diabetes, tobacco use, and obesity and overweight… The Committee recommends that the State party evaluate the effectiveness of its strategies to combat the above-mentioned health problems, and if necessary, undertake further measures to that end."

Convention on the Rights of the Child (CRC)

Overview
Article 24 of the CRC concerns the States parties' obligations for the child's "right to health". 193 countries have ratified the CRC. Although the right to health in the ICESCR is also applicable to children, this right in the CRC focuses specifically on children (up to the age of 18) and States' obligations with regard to child health.

Relevant text
"State parties shall… take appropriate measures:… To combat disease and malnutrition… through the provision of adequate nutritious food and clean drinking-water… [and] to ensure that all segments of society, in particular parents and children, are informed, have access to education and are supported in the use of basic knowledge of child health and nutrition."

[1] http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G12/415/96/PDF/G1241596.pdf?OpenElement
[2] http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G11/422/91/PDF/G1142291.pdf?OpenElement

General Comment No. 15, Committee on the Rights of the Child, March 2013

Overview
General Comment 15 on the right to health in the CRC addresses health comprehensively, including explicit attention to NCDs, but was only recently published so its impact is not yet known. Noting that NCDs usually manifest in adulthood but are shaped by behaviors that can take root in childhood, interventions to promote physical activity and education on healthy lifestyles and to regulate the advertising and sale of tobacco, alcohol and "fast" foods are recommended.

Relevant text
Paragraph 5: "Children's health is affected by a variety of factors, many of which have changed during the twenty years…This includes attention to new health problems and changing health priorities, such as: HIV/AIDS, pandemic influence, non-communicable diseases…"

Paragraph 26: "Comprehensive primary healthcare programs should be delivered alongside proven community-based efforts including preventive care, treatment of specific diseases and nutritional interventions."

Paragraph 38: "The Committee is concerned by the increase in mental ill-health among adolescents, including the development and behavioral disorders; depression; eating disorders; anxiety; psychological trauma resulting from abuse, neglect, violence or exploitation; alcohol, tobacco and drug use."

Paragraph 44: "States are required to introduce into national law, implement and enforce internationally agreed standards concerning children's right to health, including the International Code on Marketing of Breast-milk Substitutes, as well as the WHO Framework Convention on Tobacco Control…"

Paragraph 45: "Adequate nutrition and growth monitoring in early childhood are particularly important. Where necessary, integrated management of severe acute malnutrition should be expanded through facility and community-based interventions, as well as treatment of moderate acute malnutrition, including therapeutic feeding interventions."

Paragraph 47: "States should also address obesity in children as it is associated with hypertension, early markers of cardiovascular disease, insulin resistance, psychological effects, a higher likelihood of adult obesity, and premature death. Children's exposure to "fast" foods that are high in fat, sugar or salt, energy-dense and micronutrient-poor, and drinks containing high levels of caffeine or other potentially harmful substances should be limited. The marketing of these substances especially focused on children should be regulated and their availability in schools and other services controlled."

Paragraph 59: "Children require information and education on all aspects of health to enable them to make informed choices in relation to lifestyle and access to health services. Information and life skills education should address a broad range of health issues including, inter alia,

healthy eating and promotion of physical activity, sports, and recreation… and the dangers of alcohol, tobacco and psychoactive substance use."

Paragraph 62: "Preventive health should address communicable and non-communicable diseases, and incorporate a combination of biomedical, behavioral and structural interventions. Preventing non-communicable diseases should start early in life through the promotion and support of healthy and non-violent lifestyles for pregnant women, their spouses/partners, and young children."

Paragraph 65: "States should protect children from solvents, alcohol, tobacco and illicit substances, increase the collection of relevant evidence, and take appropriate measures to reduce the use of such substances among children. Regulation of advertising and sale of substances harmful to children's health and of promotion of such items in places where children congregate, as well as in media channels and publications that are accessed by children are recommended."

Paragraph 66: "The Committee encourages States parties that have not yet done so to ratify the UN International Drug Control Conventions, and the WHO Framework Convention on Tobacco Control."

Paragraph 81: "Among other responsibilities and in all contexts, private companies should… comply with the International Code of Marketing of Breast-milk Substitutes; limit advertisement of energy-dense, micronutrient-poor foods, and drinks containing high levels of caffeine or other substances potentially harmful to children; and refrain from the advertisement, marketing and sale to children of tobacco, alcohol and other toxic substances or the use of child images."

General Comment No. 16: On state obligations regarding the impact of the business sector on children's rights, February 2013

Overview

The CRC's General Comment 16 on state obligations regarding the impact of the business sector on children's rights highlights the possible long-term negative impact on health of marketing to children of potentially harmful products. As with General Comment 15, it was only published this year so its impact is yet to be determined.

Relevant text

Paragraph 19: "The marketing to children of products such as cigarettes and alcohol as well as foods and drinks high in saturated fats, trans-fatty acids, sugar, salt or additives can have a long-term impact on their health."

Paragraph 57: "States are also required to implement and enforce internationally agreed standards concerning children's rights, health and business including the World Health Organization Framework Convention on Tobacco Control, International Code of Marketing of Breast-milk Substitutes and relevant subsequent World Health Assembly resolutions."

Guidelines for Country Reporting

Overview
The Committee on the Rights of the Child issues reporting guidelines for States to ensure that topics of relevance are addressed in countries' periodic reports on their implementation of the Convention. The current guidelines were adopted in 2010; it is likely that these will be revised in coming years to reflect the content of recent General Comments, including with respect to NCDs.

Relevant text
"Under disability, basic health and welfare, States should provide relevant and updated information in respect of… Efforts to address the most prevalent health challenges and promote the physical and mental health and well-being of children, and to prevent and deal with communicable and non-communicable diseases… and measures to protect children from substance abuse…"

Committee on the Rights of the Child Concluding Observations

Overview
Every year, the Committee reviews country reports and, in response, raises issues of concern on which it asks countries to act in the following years and to report back during the subsequent reporting round. Five recent reports were analysed for mention of NCDs or relevant risk factors and provide illustrative examples of the inconsistencies in the level of current attention to NCDs. The extent to which the Committee's responses will result in concrete change at the country level is an area to be monitored, and will be made clear in the next reporting round.

Relevant text[3]:
ARGENTINA (2010): "The Committee notes with concern disparities in chronic malnutrition between the national average (8 per cent) and the average of north-western Argentina (15.5 per cent). While noting the adoption of the Programme for the Integral Care of Adolescents, the objectives of which, among others, are to reduce… the abuse of alcohol and other drugs, the Committee remains concerned at the high incidence of substance use and abuse by adolescents."

BELGIUM (2010): "The Committee is concerned about drug and substance use among adolescents in the State party. It is also concerned at the rise in obesity among children, in particular adolescents, in the State party. The Committee recommends that the State party continue and strengthen efforts to combat drug and substance among adolescents and manage overweight and obesity among children… The Committee recommends that the State party take all necessary measures to prevent drug and alcohol abuse."

GRENADA (2010): There is no mention of any NCDs or their risk factors.

JAPAN (2010): There is no mention of any NCDs or their risk factors.

[3] http://daccess-dds-ny.un.org/doc/UNDOC/GEN/G12/434/76/PDF/G1243476.pdf?OpenElement

NIGERIA (2010): "The Committee… notes with concern information that the population in the Niger Delta suffers from respiratory problems, such as asthma and bronchitis, as a result of toxins released from gas flaring. The Committee is furthermore concerned about the negative effects on children of global climate change, including in the context of the desertification in the northern states… and its related effects on the health of children, such as malnutrition."

"The Committee urges the State party… to consider nutrition as a national priority and to provide appropriate resources for the implementation of nutrition programmes and to ensure their full integration into government health structures."

Conclusion

The increase in attention to NCDs by the human rights treaty bodies is encouraging. Even as the impact this will have on the ground is yet to be determined, as has been demonstrated in other key areas relevant to health and well-being, there is great potential to use the range of mechanisms offered through the formal human rights system to move the NCD agenda forward. These mechanisms can usefully set directions and boundaries applicable to NCDs from a human rights perspective, ensuring attention to key populations within a framework of legal accountability.

Annex D: Background Paper: Attention to Human Rights in Global Policies and Strategies Relevant to Non Communicable Diseases

Overview

Key Messages:

- The global policy environment relevant to NCDs comprises a range of different types of documents, with different legal and political weight, and with inconsistent attention to human rights.
- In these documents, rhetorical statements regarding human rights appear more often than actionable statements, thus limiting their operational potential.
- Sometimes the language of human rights is invoked but lacks legal grounding.

In order to determine what useful linkages could be made between non communicable diseases (NCDs) and human rights, an assessment was made of the attention to human rights which exists to date in global NCD policies, strategies and other relevant documents. The global policy environment for NCDs, comprises a range of documents, some addressing NCDs in general, others outlining strategies for tackling specific NCDs and others addressing some of the common risk factors for NCDs.

Documents for inclusion in this review were selected entirely from the WHO website, specifically the pages related to NCDs generally, particular diseases, and specific risk factors. Documents listed under "key publications" were prioritized alongside those that were most readily available, recent, and seemed to include policy recommendations. Documents were searched for "right" to identify any potential mention of human rights.

There is differing attention to human rights across diseases and risk factors, with more significant attention placed on the articulation of rights in recent years. Policy reports and strategies tend to draw on international human rights commitments broadly affirming the right of everyone to the highest attainable standard of physical and mental health. The right to health is usually then contextualized by support of a multi-sectoral approach to NCDs that responds to health needs without discrimination. Other consistent themes evident in policy recommendations include support for accountability mechanisms, attention to marginalized communities, and emphasis on the right of access to medical care. However, mention of human rights is often fleeting and rhetorical with little detail provided on what this might mean in the context of the policy or strategy, nor importantly its implementation.With this year's Global Action Plan for the Prevention and Control of Non-Communicable Diseases, there is increased mention of human rights as a guiding principle in the effort to combat NCDs, with particular reference to the right to health. This includes some degree of operational language advocating for a stronger, coordinated and multi-sectoral approach that ensures non-discrimination, empowerment, and participation of critical stakeholders, including interest groups and affected individuals as well as states and local communities.

Disease-specific documents generally fail to include any discussion of human rights, beyond occasional reference to the right to health or the WHO Constitution. There are a few references to other rights but this is often cursory and without analysis or explanation. Nonetheless, a WHO guide to cervical cancer care and treatment specifically discusses the importance of reproductive rights and attention to gender equality, while a WHO strategy on chronic respiratory disease advocates for the right to live and work in an environment with clean air. Nonetheless, documents discussing diabetes, cardiovascular disease, or cancer more generally give very little, if any, attention to human rights.

NGO Efforts To Bring Human Rights Into Global Policy

While attention to human rights in global policy and strategy documents has been scarce, NGOs have been working to highlight the linkages between NCDs and human rights.

For example, in 2011, the NCD Alliance published two documents that sought to bring human rights into the NCD response (NCDs and the Rights-Based Movement; Non-Communicable Diseases: The Human Rights Factor). Both documents emphasize the importance of the right to health, highlighting that core obligations include: access to health facilities, provision of essential drugs, and the pursuit of a national public health strategy. The rights to equality and non-discrimination, information, education, and participation are also identified as critical for responding to NCDs. The role of international and national law is highlighted with regard to accountability and regulating the private sector. Attention is also given to the social determinants of NCDs as well as populations that might be considered particularly vulnerable for whom additional efforts might be required in the NCD response.

Similarly, documents relating to specific risk factors generally do not mention human rights as being integral to the NCD response but non-discrimination and the right to health are emphasized in several documents. The areas of under-nutrition and malnutrition constitute an important exception as human rights are most frequently mentioned in documents on this topic. Worth considering here is that even as the worlds of human rights and NCDs are just beginning to connect, under-nutrition and malnutrition relate to concerns familiar to those working in maternal and child health, an area where human rights have been much more systematically considered. This is partially because attention to these linkages has been on the global agenda for two decades, but it is also the case that there are distinct human rights with direct applicability to these issues entrenched in the international human rights framework such as the right to adequate standard of living, which explicitly includes the right to adequate food and nutrition (e.g. International Covenant on Economic, Social and Cultural Rights Article 11, Convention on the Rights of the Child Article 27).

Across the broad topic of NCDs, there is inconsistent attention to human rights in global policies, strategies and other documents. In recent years there has been more frequent mention of human rights but this often remains superficial with little explanation of what is meant by the language being invoked. Sometimes the language of rights is used with no international legal grounding. At other times, human rights concepts (e.g. participation and accountability) are included but without taking advantage of the legal grounding that presentation within a human rights framework would offer. There are some areas of NCD prevention and control where the

relevance of human rights remains particularly underexplored (e.g. diabetes, cardiovascular disease, alcohol consumption and physical exercise.)

In the pages that follow, we provide further details with regard to how human rights are discussed in key documents on NCDs generally, some that are disease-specific and some that are risk factor-specific. A full list of documents consulted for this review is also included.

Documents on NCDs Generally

The 2008-2013 Action Plan for the Global Strategy for the Prevention and Control of Non-Communicable Diseases does not make reference to human rights. In contrast, the WHO Global Action Plan for the Prevention and Control of Non-Communicable Diseases: 2013-2020 (GAP) includes several mentions of human rights and rights concepts.

One of the overarching approaches to the GAP plan is a "human rights approach" recognizing that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being, without distinction of race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status, as enshrined in the Universal Declaration of Human Rights."

With regard to actionable measures, the concepts of participation, empowerment and non-discrimination are addressed throughout the plan, and the role of legislative and regulatory measures is acknowledged. Human rights are mentioned twice in the context of community participation and empowerment with the need for engagement with human rights organisations highlighted. Repeated references are made to the need for countries to contribute to efforts to improve access to affordable, safe, effective and quality medicines and technologies, including through the full use of trade-related aspects of intellectual property rights (TRIPS) flexibilities.

Despite this, other relevant WHO documents including Prevention and Control of Non-Communicable Diseases: Guidelines for Primary Health Care In Low-Resource Settings (2012) and A Prioritized Research Agenda for Prevention and Control of Non-Communicable Diseases (2011) fail to address human rights in any way.

The 2011 Global Status Report on Non-Communicable Diseases asserts the "fundamental right" of persons living with and dying from cancer "to do so with dignity and comfort, irrespective of their disease or where they live". More concretely, it urges a multi-sectoral response to NCDs that encompasses attention to the legal environment, implementation of international agreements such as the Framework Convention on Tobacco Control (FCTC) and human rights accountability including the use of appropriate human rights treaties and reporting mechanisms.

The 2011 Political Declaration on the Prevention and Control of Non-Communicable Diseases reaffirmed "the right of everyone to the enjoyment of the highest attainable standard of physical and mental health" and, on a more practical level, recognized "the urgent need for greater measures at global, regional and national levels to prevent and control non-communicable diseases in order to contribute to the full realization of the right of everyone to the highest attainable standard of physical and mental health".

Disease-Specific Documents

Cancer

Neither the World Health Assembly resolution on cancer prevention and control (WHA58.22; 2005) nor the WHO The Fight Against Cancer: Strategies that Prevent, Cure and Care (2007) mentions human rights. In contrast a WHO programmatic document, Comprehensive Cervical Cancer Control: A Guide to Essential Practice, published in 2006, includes attention to various human rights in conceptualizing relevant issues. These include the "right to accessible, affordable and effective services for the prevention of cervical cancer", "the right of everyone to equitable, affordable and accessible health care", reproductive health rights as formulated in the Programme of Action adopted at the 1994 International Conference on Population and Development in Cairo, women's "right to make their own decisions about their health (involving their partner or family if they so wish)" and the right to freedom from pain.

Chronic Respiratory Disease

WHO's Global Surveillance, Prevention and Control of Chronic Respiratory Diseases: A Comprehensive Approach (2007) indicates that everyone has the right to health as well as the right to live and work in an environment where the air is clean or "the right to breathe healthy air".

Cardiovascular Disease

The Global Atlas on Cardiovascular Disease, Prevention And Control (WHO 2011) specifies the right to "the enjoyment of the highest attainable standards of physical and mental health" and also notes that the "prevention and control of NCDs is a key action in ensuring sustainable human rights and human development".

In 2013, WHO published A Global Brief On Hypertension: Silent Killer, Global Public Health Crisis which notes WHO's mandated role to include addressing the right to health but does not mention human rights beyond this.

Diabetes

The Collaborative Framework For The Care and Control Of Tuberculosis and Diabetes (WHO 2011) does not mention human rights.

Risk Factor-Specific Documents

Tobacco

The WHO Framework Convention on Tobacco Control (FCTC; 2003) reaffirms the right of all people to the highest standard of health. States parties are committed "to give priority to their right to protect public health". It is noted that the right to health is "without distinction of race, religion, political belief, economic or social condition" and attention is given to the child's right to health. Importance is accorded to legislative measures across multiple spheres to regulate the supply of tobacco and to reduce the demand for it.

Alcohol
The 2010 Global Strategy to Reduce Harmful Use of Alcohol, published by WHO, proposes a range of legislative measures to regulate, for example, the marketing and pricing of alcoholic beverages. In addition, it notes that people who choose not to drink alcohol "have the right to be supported in their non-drinking behaviour and protected from pressures to drink," even as there is no legal grounding for this right.

Physical Activity
The Global Strategy on Diet, Physical Activity and Health makes no mention of human rights.

Nutrition
There is no recent global strategy to address overweight or obesity. However, more than in any other area, relevant strategies, policies and plans in the area of under-nutrition in early life often include actionable attention to human rights. Various documents recognize a right to sufficient or adequate food (Essential Nutrition Actions Improving Maternal-Newborn-Infant and Young Child Health and Nutrition (2011); Indicators to Monitor the Implementation of The Comprehensive Implementation Plan (2011); Diet, Nutrition and the Prevention of Chronic Diseases (WHO Technical Report Series 916, 2003); A Review of Nutrition Policies (2010)). The duty to "protect the breastfeeding rights of working women" is underscored in Essential Nutrition Actions Improving Maternal-Newborn-Infant and Young Child Health and Nutrition.

A Review of Nutrition Policies explains that: "The realization of the rights to food and health requires that nutrition entitlements are translated into legal provisions and policy commitments to ensure that duty-bearers at all levels respect, protect and fulfill their obligations, through facilitation, promotion or provision as necessary. It also requires effective accountability and claim mechanisms which rights holders and social organizations can access and which should provide timely recourse mechanisms". It also notes that sociopolitical structural determinants affect human rights and malnutrition and describes an "intercultural rights-based gender approach" for improving malnutrition. However, neither Developing Country Scale-up Plans (2011) nor the Set of Recommendations on the Marketing Of Foods and Non-Alcoholic Beverages to Children (WHO 2010) make any reference to human rights.

Conclusion

Signs of increasing attention to human rights in NCD-related policy documents are encouraging. However, even as explicit mention of human rights in documents to date remains insufficient, this offers an entry point for new understanding, analysis and action.

List of Documents Consulted

WHO Documents
General

- Global Action Plan for the Prevention and Control of Non-Communicable Diseases: 2013-2020. Available at: http://apps.who.int/gb/ebwha/pdf_files/WHA66/A66_9-en.pdf

- Prevention and Control of Non-communicable Diseases: Guidelines for Primary Health Care in Low-Resource Settings. 2012. Available at: http://www.who.int/nmh/publications/phc2012/en/
- A Prioritized Research Agenda for Prevention and Control of Non-Communicable Diseases. 2011. Available at: http://www.who.int/cardiovascular_diseases/publications/ncd_agenda2011/en/
- Global Status Report on Non-Communicable Diseases. 2011. Available at: http://www.who.int/nmh/publications/ncd_report_full_en.pdf
- Action Plan for the Global Strategy for the Prevention and Control of Non-Communicable Diseases: 2008-2013. Available at: http://www.who.int/nmh/publications/9789241597418/en/

Disease-Specific

- The Fight Against Cancer: Strategies That Prevent, Cure And Care. 2007. Available at: http://www.who.int/cancer/publicat/WHOCancerBrochure2007.FINALweb.pdf
- Comprehensive Cervical Cancer Control: A Guide To Essential Practice. 2006. Available at: http://whqlibdoc.who.int/publications/2006/9241547006_eng.pdf
- World Health Assembly Resolution On Cancer Prevention And Control (WHA58.22). 2005. Available at: http://www.who.int/ipcs/publications/wha/cancer_resolution.pdf
- Global Surveillance, Prevention And Control Of Chronic Respiratory Diseases: A Comprehensive Approach. 2007. Available at: http://www.who.int/gard/publications/GARD%20Book%202007.pdf
- A Global Brief On Hypertension: Silent Killer, Global Public Health Crisis. 2013. Available at: http://www.who.int/cardiovascular_diseases/publications/global_brief_hypertension/en/
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- Collaborative Framework For The Care And Control Of Tuberculosis And Diabetes. 2011. Available at: http://www.who.int/diabetes/publications/tb_diabetes2011/en/

Risk factor-Specific

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- Global Strategy on Diet, Physical Activity and Health. 2004. Available at: http://www.who.int/dietphysicalactivity/strategy/eb11344/strategy_english_web.pdf
- Essential Nutrition Actions Improving Maternal-Newborn-Infant and Young Child Health and Nutrition. 2011. Available at: http://www.who.int/nutrition/EB128_18_backgroundpaper2_A_reviewofhealthinterventionswithaneffectonnutrition.pdf
- Indicators to Monitor the Implementation of the Comprehensive Implementation Plan. 2011. Available at: http://apps.who.int/gb/ebwha/pdf_files/EB130/B130_10-en.pdf
- Developing Country Scale-up Plans. 2011. Available at: http://www.who.int/nutrition/EB128_18_backgroundpaper3_developingcountryscaleuppl

ans.pdf
- A Review of Nutrition Policies. 2010. Available at: http://www.who.int/nutrition/EB128_18_Backgroundpaper1_A_review_of_nutritionpolicies.pdf
- Set Of Recommendations On The Marketing Of Foods And Non-Alcoholic Beverages To Children. 2010. Available at: http://whqlibdoc.who.int/publications/2010/9789241500210_eng.pdf
- Diet, Nutrition and the Prevention of Chronic Diseases (Technical Report Series 916). 2003. Available at: http://whqlibdoc.who.int/trs/who_trs_916.pdf

United Nations Political Declaration

- UN Political Declaration on the Prevention and Control of NCDs. 2011. Available at: http://www.un.org/en/ga/ncdmeeting2011/pdf/NCD_draft_political_declaration.pdf

NCD Alliance Documents

- NCDs and the Rights-Based Movement. 2011. Available at: http://www.ncdalliance.org/sites/default/files/rfiles/NCD%20Alliance%20briefing%20paper%20-%20NCDs%20and%20the%20Rights-Based%20Movement%20(web)_0.pdf
- Non-Communicable Diseases: The Human Rights Factor. 2011. Available at: http://www.ncdalliance.org/sites/default/files/rfiles/NCDs%20and%20Human%20Rights%20-%20longer%20doc%20(1%20July%202011).pdf

Annex E: Avenues for Research

There was wide-ranging discussion about the need for further research on how human rights might best contribute to NCD prevention and control, and a number of potential areas for research were highlighted. Following a brief section on definitional and methodological challenges, these research topics have been categorized into conceptual and operational research and are presented below. Each category has been further divided using sub-headings that include key points from the discussion and illustrative research topics.

Definitional and methodological challenges

- Participants emphasized the need for terminology and definitions in the context of NCD prevention and control and health and human rights to be further clarified. Specific issues to be considered include:

    - What is meant by NCDs? Does this include, for example, mental health, injury, and disability? How should these diseases be categorized and with what implications for how research is conceptualized?

    - What work is needed to clearly identify violations of international human rights law in the context of NCD prevention and control?
        - For example, can inadequate labeling of industrialized food be labeled a violation of a human right? And, if so, how?

    - How should progressive realization of the right to health be defined in the context of NCD prevention and control?

    - What is the overlap between human rights and ethics in the context of NCD prevention and control?

- With regard to methodologies employed, what types of evidence will be convincing to different actors to link NCD prevention and control with human rights? Causal pathways are complicated and "traditional" public health study designs might not be appropriate. Formative research is needed on how best to do research that explicitly seeks to assess the impact of human rights protection and violation on NCD prevention and control.

Conceptual Research

Conceptual models

- Key principles and models should be developed and tested in order to:
    - Identify an appropriate health and human rights approach to NCD service provision and health infrastructure, using human rights principles such as availability, accessibility, acceptability, quality, participation, equality and non-discrimination and accountability.

    - Identify how human rights mechanisms can best be utilized to increase attention to NCDs at the national level with regard to fulfilling relevant obligations.

- Outline the steps for implementation of the international health regulations and other agreements on trade, human rights, and gender and any potential implications for national NCD responses.

- Identify a health and human rights approach to industry regulation, with specific attention to the distinct roles and responsibilities of, for example, the pharmaceutical industry in contrast to the food and beverage industries.

Mapping exercises

- Mapping exercises of relevant actors should be carried out in order to:
  - Identify all relevant rights-holders and duty-bearers in NCD prevention and control at international, regional, domestic, and local levels.
    - For example, the vertical structures of health systems' governance and financing could be mapped so as to identify where human rights and NCD strategies intersect and diverge.

  - Identify optimal methods for improving donor financing while specifying how civil society, states, and other relevant actors can best generate funds for human rights-based NCD prevention and control efforts.

  - Identify how civil society can be mobilized to participate and advocate for health and human rights actions in NCD prevention and control.

- These mapping exercises could then be evaluated jointly. This would provide not only a solid base for research but also the ability to develop, cost, implement, and evaluate packages of integrated services that promote rights, tracing from financing through to favorable health outcomes for individuals living with, or at risk of, NCDs.

<u>Operational research</u>

- Operational research will be vital in order to verify the legitimacy of any conceptual models developed and identify how they are best applied to NCD prevention and control in practice. Once certain human rights principles and approaches have been developed to improve service provision and/or health system capacity, these should be tested empirically. Outcome and impact assessment will also be useful for evaluating the implementation of various methods, tools, or interventions for NCD prevention and control across the lifecycle.

Outcome and impact assessment:

- Participants proposed the following research topics:
  - How does the fulfillment of human rights affect the NCD burden (whether operating through prevention or treatment)?

  - How does the NCD burden affect the fulfillment of human rights?

  - What are other potential structural barriers to equal access to or usage of NCD prevention and control? How do these differ among different population groups (e.g. by gender)?

- Can the human rights principles of equality and non-discrimination help identify socio-demographic groups disproportionately affected by NCDs and their risk factors and help shape a response to address these inequalities?

- Do certain international trade agreements have a disproportionate impact on NCDs and their risk factors?

Legal and policy research

- Legal and policy research can demonstrate how solutions may vary across different geopolitical contexts or legislative frameworks, especially given the diversity of government actors and their receptivity to human rights. Potential questions to guide research include:

  - How can international human rights law be interpreted and utilized in domestic legal systems to help shape NCD prevention and control efforts?

  - What are effective, ineffective and counterproductive laws and regulations relevant to NCD prevention and control?

  - How can a health and human rights approach to NCD prevention and control be incorporated in countries where constitutions or other legislative frameworks do not include the right to health?

  - How do judicial systems affect the potential for litigation as a means to claim rights or alter the legal environment relevant to NCDs?

- Cost-benefit analysis of various rights-based interventions as well as legal interventions to impact NCD prevention and control should be conducted while also identifying the cost of inaction.

- Comparative analysis of state fulfillment of the right to health with regard to NCDs could provide important evidence for the purposes of motivating state action in this area.

Service delivery

- Appropriate service delivery requires standards, norms, and guidance in order to ensure access and essential dimensions of quality care. Relevant research topics include:
  - How can principles of safety, effectiveness, integration, continuity, and people-centeredness be incorporated into NCD prevention and control, and how can their human rights dimensions most usefully be highlighted?

  - How can such rights principles as availability, accessibility, acceptability, quality, participation and non-discrimination be ensured in the context of NCD service provision?

  - What mechanisms can be utilized to hold providers accountable for access and quality of NCD service provision?

Accountability

- Accountability and monitoring requires health information systems that ensure production, analysis, dissemination, and use of reliable and timely information on health determinants, health system performance, and health status. In the context of human rights and NCDs, research needs include developing global and national monitoring and accountability frameworks and indicators for human rights relevant to NCDs.

- Researchers will need to develop metrics and data collection at national and sub-national levels which can best support NCD and human rights monitoring bodies and help direct NCD responses.

Annex F: Moving Forward

This document summarizes suggested actions for moving forward work around the potential contribution of human rights to NCD prevention and control. This list is organized by different types of actors with illustrative action points highlighted for each. This is followed by attention to some key processes where action could usefully be taken up in the near future.

Civil society

- Short briefing documents are needed to assist civil society in briefing governments, international institutions and international human rights mechanisms on the links between human rights and NCDs. These documents could be organized according to priority topics and areas of focus (e.g implications for access to essential medicines; priorities for the post 2015 agenda).

- A series of short briefing materials are needed to assist civil society in building an advocacy base as well as in promoting outreach and education to the public and potential donors for work linking human rights and NCDs.

Government actors

- In consultation with academia and civil society, gather evidence, and consider potential methods for stricter regulation of NCD-associated industries as well as the development of specific initiatives targeting NCDs and their risk factors with attention to their human rights dimensions.

- Encourage intra-governmental discussions regarding NCDs and health and human rights bringing together various branches of government including those involved in womens' affairs, agriculture, transportation, urban planning, and environmental matters.

- Ensure sufficient attention to NCDs and in particular to underserved populations in working to promote universal health coverage. This may require market segmentation, differential pricing or other means to benefit individuals with NCDs in LMICs otherwise unable to afford pharmaceuticals.

Academic institutions

- In developing cross-disciplinary studies in public health and law, whether through the establishment of new courses or through joint graduate degrees such as the J.D.-M.P.H., give specific and targeted attention to development of courses and course materials focusing specifically on the linkages between NCDs and human rights.

- Devise a curriculum-sharing program, in order to ensure that all interested academics have easy access to syllabi and other educational materials regarding NCDs and human rights.

Develop follow-up meetings
Participants discussed the possibility of hosting follow-up meetings with a regional or topical focus to delve deeper into the intersections of NCDs and health and human rights. Two potential follow-up meetings were suggested:

- East Africa, as coordinated by the Danish NCD Alliance
- Latin America, as coordinated by the National Institute of Public Health and/or Instituto Tecnológico Autónomo de México

Engage with global, regional and national processes
Participants identified global, regional and national process where the synergies between human rights and NCD responses could be promoted by raising awareness of the links through participation, side events and policy briefings. These included:

- Meetings related to the post-2015 framework
- Meetings related to the WHO Global Action Plan for NCDs and its indicators and benchmarks
- The World Health Assembly (WHA) and large global health meetings
- Meetings related to the UN Interagency Task Force on NCDs
- Meetings related to state reporting processes connected with the formal human rights system
- Meetings hosted by regional organizations or trade blocs such as the AU, OAS, NAFTA, ASEAN etc. regarding development, trade, or health cooperation.