

DISCUSSION PAPER

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Working Group on Infectious Diseases

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I. Introduction

This paper sets out some of the central issues involved in the care, prevention and control of infectious diseases, most notably with regard to Human Immunodeficiency Virus (HIV), tuberculosis (TB) and malaria. It will identify some of the main ethical issues that arise with infectious diseases and the policies that address them at the national and international level, and promote discussion among National Ethics Committees (NECs).

Infectious diseases are a leading cause of illness and death worldwide. In 2008, 8.7 million people died of infectious diseases.¹ Approximately five million people die from HIV, TB, and malaria each year.² Mortality rates from infectious diseases are particularly high among children. Infectious diseases cause 58% of deaths in children under five.³

Infectious diseases disproportionately affect poor communities and low and middle income countries (LMICs).⁴ Lower respiratory infections, diarrhoeal diseases, HIV/AIDS, tuberculosis, and malaria are amongst the top ten causes of death in low income countries (LICs).⁵

Improvements in living conditions, sanitation, and antibiotics have led to a decline in infectious disease related mortality in high income countries (HICs) over the past century.⁶ Lower respiratory infections are the only type of infectious disease amongst the top ten causes of death in HICs.⁵ However, they continue to account for a significant number of deaths: 3.7% of deaths in HICs were due to lower respiratory infections in 2008.⁵ In the UK, for example, infectious diseases are estimated to be the underlying cause of over 10% of deaths and around one in three consultations in primary care.⁷

While many countries have policies and programmes for the prevention and control of infectious diseases, these are far from comprehensive, and differ in scope and scale.

¹ Global Health Observatory Data Repository [online database]. Cause-specific mortality 2008. Geneva, World Health Organization (<http://apps.who.int/ghodata/>, accessed 21 June 2012).

² Vittoria M, Granich R, et al. The global fight against HIV/AIDS, tuberculosis, and malaria current status and future perspectives. *American Journal of Clinical Pathology*, 2009, 131: 844-48.

³ Global Health Observatory Data repository; WHO; <http://apps.who.int/ghodata/?vid=1480>

⁴ *Global report for research on infectious diseases of poverty*. World Health Organization, 2012 (http://whqlibdoc.who.int/publications/2012/9789241564489_eng.pdf, accessed 21 June 2012).

⁵ The top 10 causes of death. WHO, 2011 (<http://www.who.int/mediacentre/factsheets/fs310/en/index.html>, accessed 21 June 2012).

⁶ Anderson GF, Chu E. Expanding priorities — confronting chronic disease in countries with low income. *New England Journal of Medicine*, 2007, 356: 209-11.

⁷ *Health Protection in the 21st Century*. UK Health Protection Agency, October 2005 (www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1194947403055, accessed 21 June 2012).

II. Ethical dilemmas and principles

Dilemmas

In considering policies for the prevention and control of infectious disease, a complex set of factors are necessarily involved. Important public health issues are at stake, and states need to take steps to protect and promote the health of their citizens. Public health measures often involve a number of ethical dilemmas, not least because public health activities can involve coercive measures. Ethical dilemmas can arise:

- where vaccination is made compulsory, either by law, or by denying non-vaccinated children access to school;
- where compulsory notification of individuals with certain diseases means that their privacy may be compromised;
- where some individuals are denied effective treatment because they do not belong to a priority group;
- where people might be isolated or quarantined against their will because of their infectivity and/or their high-risk behaviour; and
- where scarce resources need to be distributed.

At the same time, there are a number of ethical issues relating to support for populations that are most affected or most at risk from infectious diseases. Ethical dilemmas can arise:

- where policymakers must decide which research (funded by HICs) should be prioritized;
- where expensive public information or education programmes might help reduce risk of infection and transmission;
- where investment in social infrastructures, including those discussed in the Millennium Development Goals (MDGs) can help reduce the incidence of certain diseases; and
- where international cooperation, often facilitated by international organizations, can help minimize the rapid spread of disease.

Principles

In each case, a number of ethical considerations and principles need to be considered in order to arrive at appropriate policy responses. The following relevant principles are adapted from the WHO'S *Guidance on ethics of tuberculosis prevention, care and control*⁸:

Social justice/equity – A focus on social justice calls attention to the underlying root causes and existence of inequalities in society and requires that we explicitly address them. In some cases, this may mean a redistribution of resources to compensate for existing inequalities and further actions to prevent their perpetuation. Given the role of socioeconomic factors, especially extreme poverty, in increasing the risk of infectious diseases and the progress of disease, the pursuit of social

⁸ *Guidance on ethics of tuberculosis prevention, care and control*. World Health Organization, 2010 (whqlibdoc.who.int/publications/2010/9789241500531_eng.pdf, accessed 21 June 2012).

justice must now become a key component of infectious disease control. This is also applicable to how we treat different groups – for example, all persons with infectious diseases should be treated the same way.

Solidarity – Solidarity can have different definitions, but is in essence a social relation of a particular kind. It is primarily about standing together as a group, community or nation. It is often appealed to in discussion about justifications for the welfare state or shared risks through insurance pooling, and in thinking about how states might defend the interests of vulnerable groups within their population. Infectious diseases such as infectious diseases increase the risks of harm for whole populations. Such risks can be reduced where strong community ties result in cooperative action to enforce the conditions for flourishing, disease-free lives.

Common good – An infectious disease not only threatens the health of an infected individual, but of the whole population. The removal or reduction of a threat of infection from a society is therefore something that we can all benefit from. Moreover, there is evidence that individual health is shaped by the social environment. Therefore, we all gain from a society with strong public health facilities to address infectious disease control and treatment. It is important to think about how the disease is spread, how it might be prevented, and how communities can be empowered to respond to it.

Autonomy – Respect for patient autonomy has often dominated discussions of ethical issues in many areas of health care. Autonomy can be defined in many ways, but is generally seen as guaranteeing individuals the right to make decisions about their own lives, including health care. While it is not the only value that is important, nor the one that always ought to take priority, it requires consideration in debates about ethical infectious disease policy. For example, respecting autonomy means that patients generally should have the right to choose among treatment options.

Reciprocity – Within societies it is common for some members to put themselves at greater risk of harm for the sake of others. A good example of this would be when individuals, either health-care workers (HCW) or members of the community, seek to treat those with infectious diseases, knowing that they themselves might be at greater risk of harm. Reciprocity seeks to express the idea that these individuals deserve benefits in exchange for running such risks. It might include an obligation to minimize the risks to individual care-givers (by providing protective equipment) as well as positive interventions to treat and compensate individuals when harm occurs as a result of providing care.

Effectiveness – The idea of effectiveness includes the duty to avoid doing things that are clearly not working, as well as the positive obligation to implement proven measures that are likely to succeed. Effectiveness is linked to the concept of efficiency, which requires that limited resources be used in the most productive manner possible. Evidence of effectiveness (or lack of it) in TB programmes requires ongoing monitoring, surveillance and research.

Subsidiarity – This value promotes the idea that decisions should be made as close to the individual and communities at local level as possible. The goal is that this results in decisions reflecting local interests, concerns and beliefs, and ensures the highest possible involvement by the public.

Participation – This principle requires that the public be encouraged to participate in the decision-making process, and that reasons be provided for decisions.

Transparency and accountability – This principle requires that decisions be made in an open manner, and that the decision-making process be fair, responsive and evidence-based.

III. Policy questions

The following section identifies a number of policy questions that arise in the context of infectious diseases. These are not intended to be exhaustive – there may be other issues, and the specific questions may differ in the context of different types of diseases, and different types of responses. For example, vaccinations are available for TB, but not for HIV; malaria does not spread rapidly in the way that airborne diseases might; and influenza is not as closely linked to poverty and social conditions as TB.

Prevention

Public information and education

Depending on the type of infectious disease, and the way in which it spreads, a number of control strategies could be used in addition to public education programmes to enable people to alter their behaviour for risk reduction. For example, advice about safer sex, regulations on food hygiene and best practice in healthcare can minimize the spread of certain diseases. Other ‘low-tech’ strategies, such as the use of mosquito nets for preventing malaria, can also be effective in lowering disease burden.

Vaccination provides two types of benefit – one to the individual as protection from disease; the second by way of developing ‘herd immunity’ if a sufficient proportion of the population is vaccinated. There can be risks associated with vaccinations, but these are usually small. Vaccination averts an estimated 2-3 million deaths per year according to the WHO and UNICEF.⁹ The incidence of diseases such as tetanus, measles and polio has been greatly reduced in many countries, and smallpox has been eradicated. However, the rate of vaccination in some countries remains low, often for economic reasons, and for some infectious diseases, such as HIV and malaria, vaccination is not available despite ongoing research programmes.

Millennium Development Goals

Given the close association between poverty and disease (both infectious and non-infectious disease), one of the principle measures for reducing the burden of infectious diseases would be to address the demands of the MDGs.^{10,11,12} The MDGs set specific targets for tackling HIV/AIDS, TB and malaria.¹³ They also lay out more general goals such as ending extreme poverty and providing universal education, which would also help reduce the burden of infectious diseases.¹⁴

⁹ Global Immunization data. WHO and UNICEF, May 2012; (http://www.who.int/immunization_monitoring/diseases/en/, accessed 21 June 2012).

¹⁰ *Global report for research on infectious diseases of poverty*. World Health Organization, 2012 (whqlibdoc.who.int/publications/2012/9789241564489_eng.pdf, accessed 21 June 2012).

¹¹ Phipps S. The Impact of Poverty on Health. Canadian Institute for Health Information, 2003 (https://secure.cihi.ca/free_products/CPHIImpactonPoverty_e.pdf, accessed 21 June 2012).

¹² *Dying for Change*. World Health Organization and World Bank (www.who.int/hdp/publications/dying_change.pdf, accessed 21 June 2012).

¹³ *Health and Millenium Development Goals*. World Health Organization, 2005 (www.who.int/hdp/publications/mdg_en.pdf, accessed 21 June 2012).

¹⁴ Health and the Millenium Development Goals

Monitoring

Surveillance

Surveillance programmes can be very important in the context of infectious diseases for a number of reasons. First, they allow trends in the incidence, prevalence and spread of infectious diseases to be monitored, which in turn allows public health intervention strategies to be developed. Data about the incidence of HIV, TB and malaria is included in this kind of surveillance. The collection of data on the incidence of disease involves collecting data relating to individuals, but as the significance of the data lies in the general epidemiology of the disease, individual data can usually be anonymized.¹⁵

Anonymization may not be possible in certain cases where there is a legal requirement for notifying health authorities. Cases requiring notification will vary between countries, but might include diseases such as rabies, typhoid, cholera or smallpox. Identifying information about the individual might be disclosed in these cases, irrespective of the person's wishes or any consideration of privacy. One important question is whether diseases that carry a strong stigma, such as HIV, should be exempt from this type of notification.

International cooperation

Increasingly there is a need for international surveillance, as trends and rates of infection of prevalent diseases need to be monitored. Surveillance is also important because new diseases can spread rapidly, and interventions might need to be developed quickly to avoid worldwide outbreaks of highly infectious disease. Recent examples have included SARS in 2002/3 and H5N1 ('bird flu') in 2006/7. International travel and trade can significantly increase the risk of worldwide transmission. Effective communication and cooperation is needed for developing prevention strategies and, if possible, vaccines and treatments.

Control and treatment

Prioritization

Where infectious diseases are prevalent, important decisions need to be made about the extent to which vaccinations or treatments can or should be provided to the population. This issue is particularly acute in LMICs where resources are unlikely to support comprehensive coverage. Policies are needed for allocating limited resources (vaccinations and other treatments), and determining the order in which these are to be given in the event of an outbreak. For example, decisions might need to be made about whether to prioritize children and elderly individuals on the grounds that they are particularly vulnerable, the working population on the grounds that their economic activity will be important, or healthcare workers on the grounds that they need to provide healthcare for others. The system of allocation may vary depending on the type of disease and the specific scenario, but it is important to prepare and publicize policies in advance, so that there is a shared understanding of how outbreaks will be managed.

¹⁵ *Public health: ethical issues.* Nuffield Council on Bioethics, 2007(<http://www.nuffieldbioethics.org/sites/default/files/Public%20health%20-%20ethical%20issues.pdf>, accessed 21 June 2012).

Isolation and quarantine

Isolation refers to restrictions on the actions of a person who is known to be infected by a particular disease (usually one that is highly infectious and dangerous); whereas quarantine generally refers to restrictions on the movements or actions of an individual or a group of people who are known or believed to have been exposed to an infectious agent. Isolation and quarantine should only be used in a case where there is a significant risk of transmission of a serious disease. Authorities will sometimes restrict people's movement without their consent, thereby intruding on privacy and liberty. While quarantine and isolation can be an effective way to control the spread of infectious diseases, strong justification is needed because these measures limit people's essential freedoms.

Communication

The mass media and other communications outlets influence public response to outbreaks. The *WHO Outbreak Communication Guidelines* lay out five guidelines for effective communication: building trust between communicators, policymakers, and the public; announcing outbreaks early in order to lessen public anxiety and to promote risk reducing behaviours; approaching communication with transparency; considering the public perception of risk; and planning risk communications in advance.¹⁶

Preventing discrimination by healthcare workers

Health care workers should not refuse to treat seropositive patients. Infected individuals should not be subjected to discrimination.

Disclosing personal medical information

Public health initiatives often involve a delicate balance between protection of individual privacy and protection of public health. Countries should consider drafting policies that address how and when physicians should inform unsuspecting sexual partners and public health authorities of a patient's infection. Guidelines should be drafted for public health authorities who need to trace uninfected individuals and the sexual partners of infected persons. Not all countries have established policies that address these issues.

¹⁶ *WHO outbreak communication guidelines*. World Health Organization, 2005 (www.who.int/infectious-disease-news/IDdocs/.../whocds200528en.pdf, accessed 21 June 2012).

Case Study: A current dilemma- treatment versus prevention of HIV

The use of antiretrovirals (ARVs) for treatment and for prevention of HIV is a dynamic and rapidly evolving field. Important new evidence has emerged demonstrating the benefit of ARVs for treatment as prevention (TasP) in addition to oral pre-exposure prophylaxis (PrEP). The use of ARVs not only for treatment, but also for prevention, poses ethical dilemmas in terms of priority-setting and fair allocation of resources.

TasP describes HIV prevention methods that use early ARVs in HIV-positive persons to lower the viral load and decrease the probability of HIV transmission. The HPTN 052 trial demonstrated the benefit of earlier initiation of ART for the HIV-positive individual to prevent onward transmission to HIV-negative partner.¹ Concerns with TasP include determining when ARV treatment should be initiated, as resource constraints mean therapy cannot begin as soon as an individual tests positive for HIV.² TasP can also present a moral hazard to HIV-positive individuals, who may rely solely on ART to decrease disease transmission.

PrEP describes HIV prevention methods that use daily ARVs in HIV-negative persons to prevent transmission. The effectiveness of PrEP has been established in men who have sex with men as well as serodiscordant, heterosexual couples.^{3,4} The implementation of PrEP in the field poses operational research questions such as the feasibility of administering ARVs to HIV-negative individuals on an ongoing manner.⁵

*Ethical Questions for Discussion:*⁶

Clinical studies have demonstrated the effectiveness of both TasP and PrEP in certain populations. Because of current resource constraints, access must be prioritized for those in urgent need. What degree of effectiveness is required to justify decisions about whether or not to use these interventions? In which at-risk populations should these interventions be used?

- Many countries have not yet provided ARVs to all infected individuals who could clinically benefit. What considerations should guide decisions about providing ARVs for both TasP and PrEP?
- In those settings where all, or a vast majority, of individuals with HIV have had their clinical needs met by the provision of ARVs, what considerations are involved in providing ARVs for TasP or PrEP as compared to competing health care needs?
- TasP and PrEP are relatively new uses for ARVs. What considerations should govern the creation of surveillance mechanisms to oversee the impacts of these interventions on HIV prevention, clinical events and the possible emergence of resistant strains of HIV?
- In the case of scarce medical resources, procedural standards should govern decision making regarding the allocations of ARVs. How can ARV access be prioritized in a fair and ethically defensible manner?

¹ Cohen MS, Chen YQ, McCauley M, et al. Prevention of HIV-1 infection with early antiretroviral therapy. *N Engl J Med* 2011; 365:493-505.

² Consultation on Antiretroviral Treatment for Prevention of HIV Transmission: Meeting Report. WHO. 2-4 November 2009.

³ Grant RM, Lama JR, Anderson PL et al. Preexposure chemoprophylaxis for HIV prevention in men who have sex with men. *N Engl J Med* 2010; 363:2587-2599.

⁴ Baeten J et al. Initial results of the Partners PrEP trial of oral pre-exposure prophylaxis in serodiscordant couples. Late breaker, 6th IAS Conference on HIV Pathogenesis, Treatment and Prevention. Rome, Italy, 17-20, 2011 [MOAX0106].

⁵ WHO SUFA Exec Summary

⁶ Based on: *Seven Questions on Principles and Processes in Fair Decision Making*. Presentation at SUFA meeting by Ron Bayer, Mailman School of Public Health, Geneva 2012

IV. Responsibilities of key stakeholders

Responsibilities of states and intergovernmental organizations

Insofar as states have a general responsibility to enable their citizens to lead healthy lives, and to secure the provision of healthcare for those who need it in order to maintain or return to good health, it should be a priority for states to seek to both prevent and treat infectious diseases. The capacity that states have to achieve this is clearly very varied. LMICs often do not have adequate financial and organisational resources for prevention and control. These countries carry the double burden of being most severely affected by infectious diseases, and least able to respond to them.¹⁷

Many HICs, on the other hand, have developed major public health programmes, including public information, vaccination and control strategies to minimise the risk and burden of infectious disease. It can be argued that HICs should also provide some support to resource-poor countries. Many HICs have pledged to commit 0.7% of their GNPs as aid to developing countries as part of the 1970 General Assembly Resolution, the Monterrey Consensus, and other agreements.¹⁸ This aid would include assistance with infectious diseases.¹⁹ Few HICs actually meet the target.²⁰

The increasing mobility of individuals allows infectious diseases to spread rapidly across the globe. International and intergovernmental organisations bear some responsibility for addressing infectious disease management and control, either directly through their own programmes, or indirectly by providing states with the means, policies or advice that would enable them to build their capacity.

Responsibilities of NECs

The precise role of NECs varies between countries. However, core responsibilities include providing a forum for the discussion of bioethical issues at a national level, and influencing national policies by publishing recommendations on these issues. NECs' responsibilities with respect to the infectious diseases may include the following:

- In countries where policies are non-existent or underdeveloped, NECs should take an active role in bringing public attention to infectious diseases, discussing its ethical context, advising on potential requirements, and conducting awareness and education campaigns;
- In countries where guidelines exist, NECs should monitor the comprehensiveness of their policies, and the extent to which they match up with appropriate ethical standards;

¹⁷ *Global report for research on infectious diseases of poverty*. World Health Organization, 2012 (whqlibdoc.who.int/publications/2012/9789241564489_eng.pdf, accessed 21 June 2012).

¹⁸ The 0.7% target: an in-depth look. Millennium Project, 2006; <http://www.unmillenniumproject.org/press/07.htm>).

¹⁹ *Health and Millenium Development Goals*. World Health Organization, 2005 (www.who.int/hdp/publications/mdg_en.pdf, accessed 21 June 2012).

²⁰ Net official development assistance from DAC and other OECD members in 2011. OECD, April 2012; (www.oecd.org/dataoecd/44/13/50060310.pdf).

- In countries where well-developed policies and processes exist, NECs should monitor the extent to which the policies and processes match up with international standards, promote informed debate, and provide support where appropriate, to other NECs;
- NECs should work with and advise international and intergovernmental organizations; and
- NECs should ensure care and treatment of vulnerable populations, in particular ensuring that research participants and their communities gain access to treatments.

V. Relevant activities by NECs

NECs have not published an enormous amount of literature on the ethical issues involved with infectious disease, but literatures reviews did reveal a number of relevant activities.

Annex 1 lists policies on HIV/AIDS, Malaria, TB and influenza that have been released by NECs. The policies and position papers that were found through literature reviews are summarized in this section.

HIV/AIDS

Many NECs have released policy statements and opinions related to HIV/AIDS. Algeria, Belgium, France, Luxembourg, Netherlands, Portugal, South Africa, Sudan and Tunisia have policy statements that address HIV testing. France has released several more specific papers on issues such as childbearing by a couple in which one spouse is seropositive and recommendations on increasing availability to antiretroviral treatment for HIV.

Malaria

Malaria does not appear to be specifically mentioned in any documents released by NECs.

Tuberculosis

The French NEC published a document that discusses ethical issues involved in TB management. The New Zealand NEC published *Ethical Values for Pandemics*, which has a section specifically focusing on TB.

Influenza

Several NECs (Belgium, Cyprus, Finland, France, Greece, Ireland, New Zealand, Switzerland and United Kingdom) have published documents related to influenza. These documents discuss ethical issues that arise during pandemics.

VI. Questions for discussion

The purpose of this paper has been to identify and briefly discuss some of the ethical issues that arise in the context of infectious diseases. Infectious diseases are a significant threat, particularly in LMICs. All states, as well as international and intergovernmental organizations, need to have policies in place that address the present burden of infectious disease and try to anticipate the risks that will arise when new diseases or global pandemics emerge.

The policies currently in place may vary in terms of their scope and their effectiveness, and different countries may have different needs. Nevertheless, discussion among NECs may be helpful in identifying and illuminating a number of issues that need to be addressed. Discussion might be directed at the following:

Generally,

- Understanding the scope and scale of the issues and helping to identify local needs / policies
- Considering what issues are at stake and identifying relevant ethical perspectives
- Considering what work has been done locally and internationally and whether local opinion on the ethical aspects of policy is needed
- Assisting with mapping international policies;
- Sharing experience, understanding and best practice;
- Assisting with education and awareness campaigns

Specifically,

- How should the government allocate limited resources (such as vaccines and medications) during a pandemic? What system should they use for prioritizing access to medications (e.g. prioritizing based on individual vulnerability, necessity in pandemic response effort, age, quality adjusted life years)?
- Under what circumstances is quarantine/isolation justified?
- How can the privacy of seropositive individuals be protected when public authorities need to be notified about an individual's disease status?
- How can governments and NECs work with the media to improve coverage of pandemics and promote the most effective public health response?
- How should countries cooperate to ensure that those regions that are most severely affected by a disease receive treatment?
- Should guidelines be developed to address health care workers duties during pandemics? What should governments and communities do to protect health care workers?
- Should workplaces or authorities be allowed to test individuals for infectious diseases?
- How should governments protect seropositive individuals from discrimination in the workplace, clinical settings, insurance companies, etc.?
- What should be the policy for notifying the partners of infected individual's about their disease status?

- Under what circumstances should individuals be able to obtain exemptions from “mandatory” vaccinations?
- What types of programs should be instituted to mitigate the risk of infection among high risk groups (e.g. safe needle programs)?

Annex 1.

Documents Published by NECs on HIV/AIDS, Malaria, TB, and Influenza

HIV/AIDS

Algeria: Conseil National de l'Éthique des Sciences de la Santé

- Mobilités Internationales et VIH : Rapport final Décembre 2003

Belgium: Le Comité consultatif de Bioéthique de Belgique

- Avis n°20 du 18 novembre 2002 relatif aux tests génétiques prédictifs et tests HIV dans le cadre des relations de travail
- Avis n°17 du 10 juin 2002 relatif aux aspects éthiques des autotests de dépistage du virus de l'immunodéficience humaine (VIH) (+Annexe à l'avis n°17)

France: Comité Consultatif National d'Ethique pour les sciences de la vie et de la santé (CCNE); National Consultative Ethics Committee for Health and Life Science

- Problems connected to marketing self-test kits for HIV screening and diagnosis of genetic disease. 2004/11/04
- Ethical questions raised when a couple, in which the man is HIV-positive and the woman is HIV-negative, wish to bear a child 1998/02/10
- Recommendation on making available an antiviral treatment for AIDS 1996/03/07
- Opinion on screening for infection by the AIDS virus 1992/03/08
- Opinion on ethical problems raised by action to combat the spread of infection by the human immunodeficiency virus (HIV). Report 1988/12/16
- Opinion on ethical problems raised by an assessment of AIDS risks by testing blood donors for specific antibodies. Report 1985/05/13

Luxembourg: Commission Consultative Nationale d'Ethique pour les Sciences de la Vie et de la Santé (C.N.E.); National Consultative Ethics Committee for Life Sciences and Health

- Avis 1992.1: Avis au sujet de tests de dépistage obligatoires de l'infection par le virus HIV

Netherlands: Gezondheidsraad (Health Council of the Netherlands)

- Reconsidering the policy on HIV testing, November 20, 1999

Portugal: Conselho Nacional de Ética para as Ciências da Vida (National Council of Ethics for the Life Sciences)

- Report-Opinion on the obligatoriness of AIDS tests (January 1996)
- HIV-testing following occupational exposure (July 2006)

South Africa: The South African Medical Research Council Ethics Committee

- Ethical Guidelines for HIV Prevention Trials²¹

Sudan: Sudanese National Ethics Review Committee

- National HIV/AIDS policy notes that ²² A comprehensive HIV/AIDS treatment program involves treatment for AIDS related diseases such as tuberculosis
- That Sudan is a party to the Abuja Declaration and Framework for Action on HIV/AIDS, tuberculosis and Other Related Infectious

Tunisia : Comité National d'Ethique Médicale de Tunisie

- Le VIH-SIDA, problèmes éthiques et juridiques (décembre 2009)

Malaria

Objective: To identify National Ethics Committee published opinions on the control and care of malaria.

Search methods: The following methods aim to replicate those used for the “National Ethics Committee Documents on Tuberculosis”

- Data sources: NEC websites in malaria-affected regions (AFRO, SEARO, WPRO Latin America and Caribbean), as profiled on WHO website and UNESCO Global Ethics Observatory Medical ethics institutions: <http://www.unesco.org/new/en/social-and-human-sciences/themes/global-ethics-observatory/access-geobs/>
- Target data: Publicly accessible opinion papers on malaria
- Search terms: The following list of terms aims to reflect possible ethical issues related to the control and care of malaria.
- Malaria
- Control
 - residual spraying
 - bednets OR nets
 - insecticide
 - vector management
 - DDT
- Care
 - rapid diagnosis
 - presumptive treatment
 - chemoprophylaxis
 - drug resistance

²¹South African Medical Research Council Ethics Committee, 2006b, Book 5: HIV Preventive Vaccine Research, Online, Available from <http://www.sahealthinfo.org/ethics/ethicsbook5.pdf> (10th August 2010)

²² Sudanese National Ethics Review Committee National Health Policy, 2004, National Policy on HIV/AIDS, Online available from <http://www.fmoh.gov.sd/English/Health-policy/doc/National%20Policy%20HIV.pdf> (12th August 2010)

- Inclusion and exclusion criteria: All available statements will be accessed and reviewed. Statements in languages other than English and French will be translated using Google Translator.

Findings:

In Africa, 35 NECs were identified and twelve of these had functioning websites. In Asia 49 committees were identified and provided 7 relevant websites. In Latin America and the Caribbean, 42 committees were identified and provided 11 websites. Not all websites had relevant pages of policies, committee statements, or positions.

No references to malaria or any of the other key terms were found among policies or positions. As the TB review highlighted, related ethical issues (such as clinical trial guidelines) exist, but do not specifically mention malaria.

Tuberculosis

In general, most NECs have not published documents containing reference to TB. The NECs statements varied quite widely in both scope and nature. Some dealt broadly with ethical issues related to infectious diseases, some focused on mandatory treatment and isolation, and still others only briefly referenced TB in regard to treatment of HIV. As a very broad summary, the NECs from high income countries tended to concentrate more on mandatory detention and isolation, and there was a consensus that in certain circumstances such measures may be justified. Alternatively, NECs from lower income countries tended to emphasize issues of distributive justice or the relationship between HIV and TB.

Specific Content of Statements:

France: National Consultative Committee of Ethics has published an opinion paper on TB and BCG in response to consideration of removal of compulsory BCG vaccination.²³

- Even if it does not take sides in the debate on the relationship between benefits and risks of such a vaccine, even if it considers that, light of recently published results of epidemiological studies conducted in countries which have conducted a cost-effective program of screening, prevention and assessment, the ultimate abolition of the compulsory character currently can be considered, he recommends extreme caution in the approach removal of the mass vaccination with BCG, since the termination of former abrupt. This routine immunization, without the prior establishment of a screening well organized nationally, would face a growing inevitability of risk of tuberculosis, including severe forms.

²³ National Consultative Committee of Ethics, 2006, Notice on TB and BCG in response to consideration of removal of compulsory BCG vaccination, Online Available From http://translate.googleusercontent.com/translate_c?hl=en&sl=fr&tl=en&u=http://www.ccne-ethique.fr/docs/fr/avis092.pdf&rurl=translate.google.com.au&usg=ALkJrhIF8amEVfyPKqFYsRnnMHwRGjDQg (11th August 2010)

- We therefore recommended to precede any change in policy BCG vaccination by strengthening screening practices widespread, especially in schools (medicine school must first Plan concerns), particularly in geographic areas affected (Ile de France, and large urban areas in particular), and in people considered at risk, because from countries with endemic TB or you are living with the illness.
- The existence of people particularly at risk being doubt, it recommends that specific attention vis-à-vis these persons as well as in screening for vaccination, do not become policy vis-à-vis a particular population, the focus on only criteria of social, economic and geographic could be perceived as a form of discrimination or as an excuse for covert discrimination.
- It recommends that vaccination, if it should be reserved for certain persons, are performed in infants and children than for reasons strictly medical appreciated by one doctor (school, PMI, pediatrician and GP), which must, of course, take into account a social situation specifically, to the exclusion of any negative discriminant approach.
- CCNE recommends that any person occupationally exposed to risk of contamination, can be screened, without necessarily target people working in contact with children in precarious situations social or from countries particularly vulnerable. Moreover, it will be one doctor, assisted by social workers and nurses, to estimate specific conditions of a risky situation.
- CCNE would like to see take this thinking to public health strengthen the capacity of medical schools, medical work and Training GPs to help vulnerable people rather than making them the designated officials always a risk present.
- It is hoped that the interest asserted, for testing, skin tests tuberculin intradermal, generalized to all children of school age, and not restricted to children of qualified targets. CCNE recommends to encourage and revive the practice of intradermal injection and train Care Personnel. This technique is in fact necessary, according Current international recommendations, vaccination with BCG and Control of skin reactions to tuberculin.
- It recommends that the approach of TB goes to people by facilitating access to health care facilities "anonymous free "run by social institutions (medicine street), to avoid fear that some people might feel that their health status negative consequences for their inclusion.
- CCNE recommends that an evaluation of cost and effectiveness of a widespread screening is conducted and periodically renewed for a given time, knowing that the establishment of such screening would represent a prerequisite for the abandonment of universal vaccination.

New Zealand: The National Ethics Advisory Committee

- *Getting through together: Ethical Values for a Pandemic* includes reference to restriction of liberty which is in place for TB.²⁴
 - For instance, New Zealanders with tuberculosis may be required to comply with restrictive measures that aim to prevent the disease from

²⁴New Zealand National Ethics Advisory Committee, 2007, *Getting through together: Ethical Values for a Pandemic*, Online Available from: [http://www.neac.health.govt.nz/moh.nsf/pagescm/1090/\\$File/getting-through-together-jul07.pdf](http://www.neac.health.govt.nz/moh.nsf/pagescm/1090/$File/getting-through-together-jul07.pdf) (12th August 2010)

spreading to others. They summaries the following as being guidance on restriction of the liberty of those with infectious diseases

- When possible and appropriate, restrictions should be voluntary rather than compulsory. Measures that promote voluntary compliance will reduce the need for compulsory restrictions.
- Restrictive measures should restrict only those rights that it is necessary to restrict.
- Special attention may be needed for people who are subject to restrictions (for example, to their freedom of movement) to ensure their other rights are protected. Reciprocal support may be appropriate for those people who, in order to protect others, are subject to restrictive measures.
- Restrictive measures can be justified only when all the narrowly defined circumstances set out in human rights law, known as the Siracusa Principles, are met: 1) the restriction is provided for and carried out in accordance with the law 2) the restriction is in the interest of a legitimate objective of general interest 3) the restriction is strictly necessary in a democratic society to achieve the objective 4) there are no less intrusive and restrictive means available to reach the same objective 5) the restriction is not drafted or imposed arbitrarily, that is, in an unreasonable or otherwise discriminatory manner.

Influenza

Belgium: Belgian Advisory Committee on Bioethics

Opinion n° 48 relating to the Belgian influenza pandemic operational plan²⁵

Cyprus

- National Bioethics Commission Statement

Finland: National Ethics Committee

- Statement on Pandemic Preparedness

France: French National Ethics Committee for Health and Life Science

- Opinion N° 106: Ethical issues raised by a possible influenza pandemic

Greece: Hellenic National Bioethics Commission

- Transmissible infectious disease: public interest and autonomy (2011).

Ireland: The Irish Council for Bioethics

- Ethical Dilemmas in a Pandemic: Proceeding of the Irish Council for Bioethics Conference 17th October 2006, Dublin

²⁵ Belgian Advisory Committee on Bioethics, 2009, Avis n° 48 du 30 mars 2009 relatif au plan opérationnel belge « pandémie influenza ». Online Available from http://apps.who.int/ethics/nationalcommittees/Opinionsweb/EURO/Belgium_Plan_pandemie_influenza_FR_2009.pdf (21st August 2012)

New Zealand: New Zealand National Ethics Advisory Committee (Kāhui Matatika o te Motu (NEAC))

- Getting through together: Ethical values for a pandemic: One of NEAC's main statutory functions is to advise the Minister of Health on ethical issues of national significance regarding health and disability. The Committee believes that minimising harm from any pandemic, minimising inequalities in the impact of any pandemic, and getting through any pandemic together are issues of this sort. *Getting Through Together* considers ethical issues in a pandemic.

Switzerland: Swiss National Advisory Commission on Biomedical Ethics

- Chapter on Swiss Influenza Pandemic Plan 2006.²⁶
- Chapter on Ethics in Pandemic Influenza National Plan.²⁷ The Swiss National Pandemic Plan states generally on the following isolation procedures
 - “Measures to restrict freedom (e.g. quarantine) are legitimate if they are beneficial, appropriate and necessary. Their introduction must be accompanied by a statement explaining why the measures are appropriate and necessary, what the expected benefit is and what the consequences of failing to comply will be. The living conditions (food, medical care, etc.) of individuals affected by these measures must be guaranteed.”

United Kingdom: The Nuffield Council on Bioethics

- Public health: ethical issues; Chapter 4: Case study-infectious disease²⁸

²⁶ Swiss National Ethics Commission, 2006, Part III: Swiss Influenza Pandemic Plan 2006. Online Available from http://apps.who.int/ethics/nationalcommittees/Opinionsweb/EURO/Switzerland_Distributive_justice_Flu_EN_2006.pdf (21st August 2012) p. 182-186

²⁷ Swiss National Advisory Commission on Biomedical Ethics, 2009, Swiss Influenza Pandemic Plan, Online Available from <http://www.bag.admin.ch/influenza/01120/01134/03058/index.html?lang=en> (11th August 2010) p. 251

²⁸ Nuffield Council on Bioethics, 2007, Public Health: Ethical Issues, Online Available from http://www.nuffieldbioethics.org/fileLibrary/pdf/Public_health_-_ethical_issues.pdf (11th August 2010)

Annex 2.

Relevant Documents Published by WHO

HIV/AIDS

Antiretroviral therapy for HIV infection in adults and adolescents

- http://whqlibdoc.who.int/publications/2010/9789241599764_eng.pdf

Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access

- www.who.int/hiv/pub/progress_report2011/hiv_full_report_2011.pdf

Equity and Fair Process in Scaling Up Antiretroviral Treatment: Potentials and Challenges in the United Republic of Tanzania

- http://whqlibdoc.who.int/publications/2006/9241593644_eng.pdf

Basic Principles for Treatment and Psychosocial Support of Drug Dependent People Living with HIV-AIDS

- http://www.who.int/entity/substance_abuse/publications/basic_principles_drug_hiv.pdf

Guidance on ethics and equitable access to HIV/AIDS treatment and care

- http://www.who.int/entity/hiv/pub/advocacy/en/guidanceethics_en.pdf

Consultation on ethics and equitable access to treatment and care for HIV/AIDS

- <http://whqlibdoc.who.int/publications/2004/9241592338.pdf>

Malaria

Guidelines for the treatment of malaria, second edition

- http://whqlibdoc.who.int/publications/2010/9789241547925_eng.pdf

Tuberculosis

WHO policy on collaborative TB/HIV activities: guidelines for national programmes and other stakeholders

- http://whqlibdoc.who.int/publications/2012/9789241503006_eng.pdf

Guidance on ethics of Tuberculosis prevention, care and control

- http://whqlibdoc.who.int/publications/2010/9789241500531_eng.pdf

Influenza

Pandemic influenza preparedness and response

- http://whqlibdoc.who.int/publications/2009/9789241547680_eng.pdf

Addressing ethical issues in pandemic influenza planning

- http://www.who.int/entity/csr/resources/publications/cds_flu_ethics_5web.pdf

Ethical considerations in developing a public health response to pandemic influenza

- http://www.who.int/entity/csr/resources/publications/WHO_CDS_EPR_GIP_2007_2c.pdf

Global consultation on addressing ethical issues in pandemic influenza

- http://www.who.int/entity/trade/Ethics_PI_consultation_report_WHO_2006.pdf

Epidemics

Research Ethics in International Epidemic Response: WHO Technical Consultation

- http://www.who.int/ethics/gip_research_ethics_.pdf