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# Tuberculosis and human rights in Iceland

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## **Tuberculosis and human rights in Iceland**

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**Tuberculosis** kills 2 million people each year. The global epidemic is growing and becoming more dangerous. The breakdown in health services, the spread of HIV/AIDS and the emergence of multidrug-resistant TB are contributing to the worsening impact of this disease.

*WHO Fact sheet No. 104 on Tuberculosis revised in April 2000.*

## I. Introduction

This thesis is a study of the current public health measures to control tuberculosis (TB) in Iceland in light of Iceland's obligations under international human rights law. The control of TB is an interesting example to evaluate public health measures from a human rights perspective. First, it stigmatizes people, linking them with poverty and shame. Second, it is more prevalent in the most vulnerable groups of society, which is known to pave the way for discrimination.

UNAIDS has published a *Protocol for the identification of discrimination against people living with HIV*, identifying ten fields of social life where arbitrary discrimination should be targeted: health care, employment, justice/legal process, administration, social welfare, housing, education, reproductive and family life, insurance and other financial

services, access to other public accommodations or services (e.g., funeral services). The present study is not as broad as this protocol but focuses mainly on public health measures towards those suspected of being TB-infected. This is due to the fact that in contrast to HIV/AIDS there are very few people with active TB infection living and working in society. After an infection has been detected, the success rate of treatment approaches 100%.

At present there is no accepted framework to evaluate public health measures in light of human rights. There are basically two questions in the present thesis:<sup>1</sup> (1) to what extent the current practice of controlling TB is in fact laid down in law, e.g., in regulations or laws, and, in turn, (2) how these legal rules match Iceland's obligations under international human rights law.

The thesis is divided into five chapters. Chapters two and three provide the background for the present study in the context of Icelandic as well as international law. Chapter two is a bird's-eye view of the history of international response to infectious diseases and a short history of human rights assessment of public health measures. Icelandic law, regulations and public health practice are the focus of chapter three where the history of public health measures to control TB in Iceland is presented. Included here is the history of increasing protection of people's individual rights with infectious diseases in Icelandic law and the Constitution.

Chapter four is the centre of the study, a human rights assessment of the current measures taken to control TB in Iceland. The last chapter summarizes conclusions.

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<sup>1</sup> These questions are based on the strict scrutiny that limitations to protected human rights have to meet under international human rights law.

During the work and research that this thesis is based on, I have had open access to different sources of information and the support of numerous people. Although the history of public health measures to control TB is quite well documented up to 1970, it is yet to be written for the last several decades. Therefore I had to rely on help from a group of practicing medical doctors, especially Dr. Thorsteinn Blöndal, the head of the *Center of TB and Pulmonary Diseases* and Chief Epidemiologist Dr. Haraldur Briem. Director of Public Health Dr. Sigurdur Gudmundsson gave me access to the institution's archives, as did health institutes in two different corners of the country: Ísafjörður and Thórshöfn. This was valuable in my search for documentation of current practice of TB control. Practicing physicians at Iceland's main prison (Litla-Hraun) and Iceland's biggest rehabilitation facility (Vogur) were extremely helpful, as were many others, including the staff of the Ministry of Justice regarding information on the letter and practice of the Act on legal capacity.

I am also very grateful to the Society of Specialists in the Treatment of Infectious Diseases for setting up a seminar for the presentation and collection of information in connection with this thesis.

Last but not least I am indebted to Prof. Gudmundur Alfredsson for his constant encouragement (and supportive impatience) as well as my tutor professor Katarina Tomasevski for insightful critique and comments as this work has proceeded.

## Tuberculosis

Tuberculosis is caused by the pathogen *Mycobacterium Tuberculosis typus humanum* (M. tuberculosis). The human immune system generally controls the infection but cannot eradicate the pathogen. This results in that most people infected by M. tuberculosis do not develop a clinical disease. In that population the only trace of the contact with the TB is a positive tuberculin test reflecting a successful immune response. The period from exposure to the bacillus to manifestation of illness, the latent period, can be as short as a few weeks and as long as a lifetime.

Untreated the natural course of tuberculosis is the following. As mentioned the latent period of the disease varies in length. In fact, most cases of active TB in Iceland are re-activated latent infections in the elderly. Untreated, an individual with active infectious disease can on average transmit the disease for two years. After that time he either recovers or dies. During these two years the average patient spreads the disease to 20 individuals. Of those infected, two develop clinical manifestations of tuberculosis, one of which is the active infectious form. The active form of the disease can normally be treated with simultaneous use of a combined treatment of three out of the five “first line” anti-tuberculosis medicines (Isoniazid, Rifampicin, Pyrazinamid, Ethambutol or Streptomycin).

## II. Tuberculosis and Human Rights

The control of infectious diseases and epidemics has been the task of governments from the birth of modern states. This can even be traced back to ancient times.<sup>2</sup> Traditional public health measures grew out of attempts at the surveillance and treatment of communicable diseases. TB became one of the main objectives of such measures following the industrial revolution when it became the most deadly disease in the world. Iceland's history of compulsory screening, case reporting, contact investigation, quarantine and mandatory treatment of TB is part of a worldwide legacy where public health measures have reflected limited recognition or respect of individual rights.

International law on infectious diseases can be dated back to international co-operation in the 19<sup>th</sup> century. The transnational spread of epidemics led to one of the first efforts at international conferences to render "borders impotent and undermine a government's ability to protect public health."<sup>3</sup> The product of those conferences, renamed as the International Health Regulations (IHR) by WHO in 1969, had as its main objective diminishing the negative effects of infectious disease control on international travel and trade by setting limits for public health measures in the world's harbours and at borders between states. The IHR were, to put it mildly, only to a limited extent aimed at protecting individuals suspected of being infected by diseases, if at all.

The IHR were modified slightly in 1973 and 1981.<sup>4</sup> In 1995 the WHO General Assembly called for revision of the IHR (Res. 48.7).<sup>5</sup> After a series of consultations and

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<sup>2</sup> Rosen, G: *A history of public health*, 136-149.

<sup>3</sup> Fidler, D: *International Law and Infectious Diseases*, 4-6.

<sup>4</sup> WHO: *Global Crisis – Global Solutions, Managing public health emergencies of international concern through the revised International Health Regulations*, WHO/CDS/GAR/2002.4

efforts of specialists, an initial draft was disseminated to Member States earlier this year.<sup>6</sup>

The results of this review formed the basis of an amended draft put to an Intergovernmental Working Group (IGWG) in November 2004.<sup>7</sup> Member States will be asked to endorse a final draft to be presented to the World Health Assembly in 2005 for adoption.

Despite recent discussions following the outbreak of SARS, the latest draft of the revised IHR<sup>8</sup> strengthens protection of individual integrity and the rights of persons by restricting public health measures (art. 17) to non-invasive forms, making invasive measures subject to informed consent (art. 36) and banning measures exceeding WHO's recommendations under the regulations (art. 34). These are signs of how human rights discussions of health-related topics are strongly influencing the revisions of IHR.

Paradoxically interest in the interconnections between TB and human rights has its roots in the human rights debate on the control of the much more recent disease HIV/AIDS. A brief overview of the status of human rights work in the field of HIV/AIDS is useful to put the work on TB and human rights into perspective.

*i) International response to HIV/AIDS.* The HIV/AIDS epidemic evoked an unprecedented but strong civil and political response to strengthen the rights of infected individuals. Within academic circles of international human rights law and public health,

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<sup>5</sup> WHO: Revision of the International Health Regulations, Report by the Secretariat, A56/25, 24 March 2003.

<sup>6</sup> WHO: Revision of the International Health Regulations, Report by the Secretariat, EB 113/3 Rev. 1 15 January 2004.

<sup>7</sup> It is possible to follow the work of the Intergovernmental Working Group on the Revision of the International Health Regulations up to the World Health Assembly on WHO's web-page: <http://www.who.int/gb/ghs/e/index.html>

<sup>8</sup> WHO: International Health Regulations, Working paper for regional consultation, IGWG/IHR/Working paper/12.2003, 12. January 2004.



it was argued that protection of human rights was an essential part of a successful public health strategy in response to this new threat. A broad consensus developed in favour of voluntary testing and a non-coercive strategy based on informed consent and non-discrimination.<sup>9</sup>

In the forum of international organizations the institutions of international health took initiative in dealing with human rights issues of infected patients.<sup>10</sup> Under the banner of WHO's Global Programme on AIDS (GPA), which began in 1986, the interconnections of human rights and health and not least human rights *in health* were explored. Public health strategies to meet the threat of AIDS were analyzed in light of their impact on human rights, including the right to privacy, individual autonomy and information.<sup>11</sup> Human rights bodies followed GPA's path.<sup>12</sup> As a result of this extensive work human rights standards developed. International and regional forums have adopted numerous declarations, statements and recommendations on human rights and HIV/AIDS.<sup>13</sup>

In 1996 these efforts were reorganized under a single banner, the Joint United Nations Programme on HIV/AIDS (UNAIDS). A considerable part of UNAIDS work is on relevant human rights issues, both in theory and practice.

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<sup>9</sup> Dubler, NN and Bayer R, the Dual Epidemics of Tuberculosis and AIDS: Ethical and Policy Issues in Screening and Treatment, *Am J Public Health* 1993 May; 83(5):649-54.

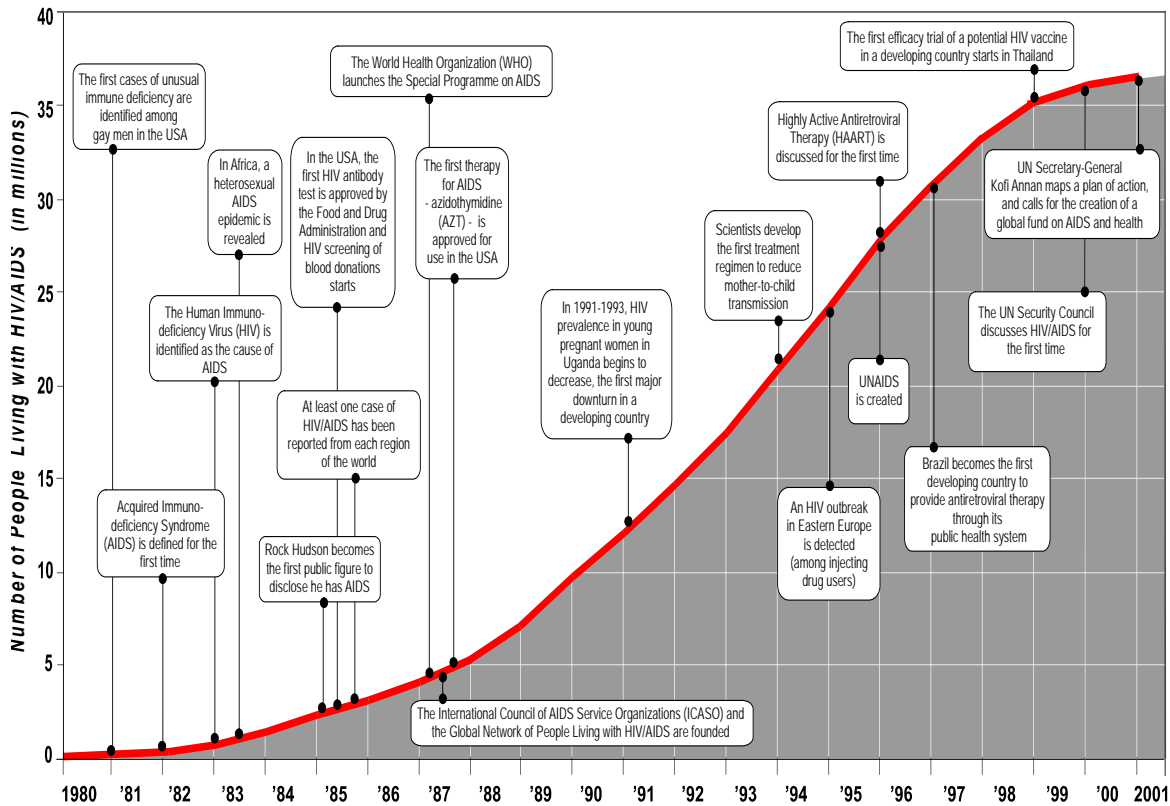
<sup>10</sup> Tomasevski, K, Before AIDS, Beyond AIDS: Human Rights of People with Contagious Diseases, in Mahoney, KE and Mahoney, P, *Human Rights in the Twenty-first Century, A Global Challenge*, 191-207, 193.

<sup>11</sup> WHO, Second Informal Consultation on Health and Human Rights: Towards a WHO Health and Human Rights Strategy, Geneva 3-4 April 2000 (Draft Meeting Report), HSD/GCP/June 2000.

<sup>12</sup> The history of the recognition of the importance of human rights in the context of HIV/AIDS is summarized in Appendix I of International Guidelines on HIV/AIDS and Human Rights. Second International Consultation on HIV/AIDS and Human Rights, UNAIDS (HR/PUB/98/1) 1998.

<sup>13</sup> Alfredsson, G and Tomasevski, K: *A Thematic Guide to Documents on Health and Human Rights*, 47-66. International Guidelines on HIV/AIDS and Human Rights. Second International Consultation on HIV/AIDS and Human Rights, UNAIDS (HR/PUB/98/1) 1998, Appendix I.

## 20 years of HIV/AIDS



June 2001



ii) *Human rights jurisprudence on HIV/AIDS.* The European Court of Human Rights (ECHR) has dealt with HIV/AIDS in its judgements under a number of articles.<sup>14</sup> Under article 3 (on prohibition of inhuman treatment) the UK government would have violated the article by expelling an AIDS patient to a country where his life-expectancy would have been shortened by lack of medical care and support.<sup>15</sup> Under article 5 (on the liberty and security of the person) procedures relating to the release or sentencing of prisoners have been dealt with in cases of AIDS in conjunction with the article 14 ban on

<sup>14</sup> For an overview: Reid, K, *A Practitioners Guide to the European Convention on Human Rights*, 148-152.

<sup>15</sup> *D v. United Kingdom*, May 2, 1997, R.J.D., 1997-III, No. 37.

discrimination.<sup>16</sup> Violations have not been found. Article 6 (on fair trial within a reasonable time) has been relevant in a number of cases where proceedings regarding compensations for being infected by contaminated blood have taken too long, given the individuals' condition.<sup>17</sup> Article 8 on respect for privacy was deemed to be violated in a case where someone's identity and medical condition were published in a court order.<sup>18</sup>

*iii) International response to TB.* Recent developments have raised awareness of TB in the western hemisphere. Two things are most important: increased resistance of TB to drugs and co-infection of TB and HIV. Strains of *M. tuberculosis* have proved to be resistant to the classic first line anti-tuberculosis medication.<sup>19</sup> This has put considerable pressure on health care in a number of countries. Treatment of infections with resistant strains is very expensive as well as associated with higher rates of treatment failure and death.<sup>20</sup> The single most important factor causing resistance worldwide is insufficient treatment of TB, either much too short treatment with proper medication or treatment with only one drug (where three are necessary). Cases of multi-resistant strains have frequently been reported among intravenous drug users and immune-compromised patients. AIDS patients are represented in both groups.

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<sup>16</sup> Grice v. United Kingdom, 22564/93, April 14, 1994, 77-A D.R.

<sup>17</sup> X. v. France, March 31, 1992, Series A, No. 234-C, 14 E.H.R.R. 483.

<sup>18</sup> Z. v. Finland, February 25, 1997, R.J.D., 1997-1, No. 31.

<sup>19</sup> Espinal, MA et al: Global trends in resistance to antituberculosis drugs. *N Engl J Med*, 2001; 344: 1294-1303. Blöndal, Th et al: Tuberculosis. Resistant mycobacteria. *Læknaneminn*, 1993; 46: 36-43.

<sup>20</sup> Espinal, MA et al: Standard short-course chemotherapy for drug-resistant tuberculosis: treatment outcomes in 6 countries. *JAMA* 2000; 283:65-8. Cited in: Espinal, MA et al: Global trends in resistance to antituberculosis drugs. *N Engl J Med*, 2001; 344: 1294-1303. Blöndal, Th et al: Tuberculosis. Resistant mycobacteria. *Læknaneminn*, 1993; 46: 36-43.

**Tuberculosis in the world**

In 1993, the World Health Organization (WHO) took an unprecedented step and declared tuberculosis a global emergency. It is estimated that between 2000 and 2020, nearly one billion people will be newly infected, 200 million people will get sick, and 35 million will die from TB - if control is not further strengthened.

*WHO Fact sheet No. 104 on Tuberculosis revised in April 2000.*

No declarations or conventions on TB and human rights have been adopted by international organizations. WHO has led considerable work on TB control in its more than 50-year history. In late 1998 WHO launched the Stop TB initiative raising the profile of the “force for action” against TB. Its mandate is to expand awareness, accelerate action, improve TB control strategies, develop investment mechanisms and create new partnerships.<sup>21</sup> The “accelerated action” as laid out in declarations and plans of Stop TB is almost solely based on a medical model of disease control. The priorities of the programme are defined in the Declarations adopted at the two Stop TB Conferences that have been held in Amsterdam and Washington. These conferences have been attended by the partners<sup>22</sup> of the project as well as representatives of governments from all over the world.<sup>23</sup>

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<sup>21</sup> WHO: Towards a TB-free future, Prepublication Conference Issue, 2001.

<sup>22</sup> The most important among the partners is The World Bank.

<sup>23</sup> Representative of governments from high-burden countries (80%) but not full participation of all of the financial superpowers (G7 countries) or several of the smaller “rich” countries of the world.

**The International Guidelines of 1996 on HIV/AIDS and Human Rights provide a non-exhaustive list of rights relevant to HIV/AIDS. Most of them are highly relevant to TB as well.**

**Human rights relevant to HIV/AIDS**

(a non-exhaustive list)

The right to non-discrimination, equal protection and equality before the law.

The right to life.

The right to the highest attainable standard of physical and mental health.

The right to liberty and security of person.

The right to freedom of movement.

The right to seek and enjoy asylum.

The right to privacy.

The right to freedom of opinion and expression and the right to freely receive and impart information.

The right to freedom of association.

The right to work.

The right to marry and to found a family.

The right to equal access to education.

The right to an adequate standard of living.

The right to social security, assistance and welfare.

The right to share in scientific advancement and its benefits.

The right to participate in public and cultural life.

The right to be free from torture and cruel, inhuman or degrading treatment or punishment.

*HIV/AIDS and Human Rights*

*International Guidelines 1996*

In Stop TB's approach TB control is praised as "a global public good". Although the Amsterdam Declaration to Stop TB of 2000 adopted at a ministerial conference recognizes that tuberculosis is "much more than a health concern", and that "it is a

complex socioeconomic problem that impedes human development, and cannot be defeated by the health sector acting alone”, its main tools to achieve its goals rest on detection (diagnosis) of disease, access to medication and the use of Directly Observed Therapy Strategy (DOTS). This reflects domination of a traditional medical approach to TB control. The Declaration does not mention human rights and neither does the follow-up, “Washington Commitment to Stop TB”, adopted by the first Stop TB Partners Forum.<sup>24</sup> The same is true for the Global Plan to Stop TB endorsed in Washington at the same event.<sup>25</sup> Nevertheless, recent publications reflect increasing awareness of human rights issues.<sup>26</sup>

*iv) Academic literature on TB and human rights.* Academic work on TB and human rights is only a small fraction of the work done on HIV/AIDS. Some of the earliest articles, which are post-1990, focus on the “dual epidemics of TB and HIV/AIDS”.<sup>27</sup> Furthermore, most of the literature is American, dealing with alleged violations of civil liberties protected by national remedies rather than human rights protected under international law. The historical reason for this is the revision of health codes of many major US cities in the early 1990s. The new code strengthened the powers of health officials to use “involuntary detention for persistently non-adherent patients”<sup>28</sup> as a

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<sup>24</sup> Stop TB: Washington Commitment to Stop TB, October 2001.

<sup>25</sup> WHO: Global Partnership to Stop TB. Highlights: First Stop TB Partners’ Forum. Geneva 2001. In the aftermath it has been celebrated by making TB “the only disease in history for which a global control and investment plan, complete with detailed resource needs [exists].”

<sup>26</sup> WHO: Guidelines for the Control of Tuberculosis in Prisons (in collaboration with the International Red Cross, WHO/TB/98.250. Geneva 1998.

<sup>27</sup> However, TB has been dealt with in the context of human rights surveys of special groups, such as prisoners, women, immigrants in earlier texts, etc.

<sup>28</sup> Lerner, BH. Catching Patients: Tuberculosis and Detention in the 1990s. CHEST 1999; 115: 236-41.

response to increasing numbers of TB cases and cases of multi-drugresistant strains in particular.<sup>29</sup>

The lessons learned by the HIV/AIDS debate were ever present.<sup>30</sup> A series of articles questioned powers to take coercive action and highlighted the discriminatory character of some of the proposed measures.<sup>31</sup> Arguments were formulated in favour of regulations sensitive to civil liberties and human rights and the principle of using the “least restrictive alternative” necessary to serve the desired aim. At present, articles are being published where the use of “short-term incarceration”<sup>32</sup> and “legal action”<sup>33</sup> to ensure treatment of TB are evaluated. It is interesting in our context that a paper drawing lessons from a number of different evaluative articles concludes that similar rules can lead to quite different outcomes in terms of the number of detained individuals but, even more interestingly, very different lengths of confinement.<sup>34</sup>

Writings on TB and human rights in light of obligations under international law can only be traced back a few years.<sup>35</sup> Until 2001 the only document found in the UN databases on TB and human rights was a fairly new UNAIDS publication on

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<sup>29</sup> Gostin, LO: Controlling the Resurgent Tuberculosis Epidemic: A 50-State Survey of TB Statutes and Proposals for Reform. *JAMA* 1993; 269: 255-61.

<sup>30</sup> Lerner, BH. Catching Patients: Tuberculosis and Detention in the 1990s. *CHEST* 1999; 115: 236-41.

<sup>31</sup> Annas, GJ. Control of Tuberculosis – The Law and the Public Health. *NEJM* 1993; 328: 585-8. Bayer, R. The Dual Epidemics of Tuberculosis and AIDS: Ethical and Policy Issues in Screening and Treatment. *Am J Public Health* 1993; 83: 649-54. Bayer, R. Public Health Policy and Tuberculosis. *J Health Politics, Policy and Law*. 1994; 19: 149-55. Gostin, LO: Controlling the Resurgent Tuberculosis Epidemic: A 50-State Survey of TB Statutes and Proposals for Reform. *JAMA* 1993; 269: 255-61. Reilly RG. Combating the tuberculosis epidemic: the legality of coercive treatment measures. *Columbia J Law Soc Probl* 1993; 27: 101-149.

<sup>32</sup> Burman, WJ et al. Short-term Incarceration for the Management of Non-compliance with Tuberculosis Treatment. *CHEST* 1997; 112: 57-62.

<sup>33</sup> Gasner, MR et al. The Use of Legal Action in New York City to Ensure Treatment of Tuberculosis. *NEJM* 1999; 340: 359-66.

<sup>34</sup> Lerner, BH. Catching Patients: Tuberculosis and Detention in the 1990s. *CHEST* 1999; 115: 236-41.

<sup>35</sup> Heymann, SJ et al. Mandatory Public Health Programs: To What Standards Should They be Held. *J Health and Human Rights* 1999; 4: 193-203.

Tuberculosis and AIDS.<sup>36</sup> This non-binding best practice manual is an analysis of the human rights issues with co-infection of AIDS and TB. In 2001 the first special analysis of a human rights approach to tuberculosis was published by WHO under the Stop TB program's "Guidelines for Social Mobilization".<sup>37</sup> It looks at the "human rights dimensions of issues affecting people's vulnerability to contracting TB and their access to TB cure." The issues addressed are TB and poverty, children, women, migrants and refugees and TB in prisons. Since 2001, WHO has started a publication series on health and human rights. The second issue of August 2001, Health and Freedom from Discrimination and the fourth issue of December 2003, International Migration, Health and Human Rights, are highly relevant to TB.

v) *Human rights jurisprudence and TB*. The word tuberculosis is mentioned in eight ECHR judgments.<sup>38</sup> Three cases deal with claims made by infected individuals. The first case, from 1971, was a claim that a TB patient had not got treatment according to his condition.<sup>39</sup> The claim was declared inadmissible as manifestly ill-founded.

In the case of *Khafaoui v. France*, the Court did not support the claim that he could not have left Tunisia to appear before a French court because of tuberculosis. The argument had been dismissed by French courts as well as the claim that the diagnosis of tuberculosis excluded imprisonment.<sup>40</sup> The European Court of Human Rights nonetheless found a violation of Article 6-1 on other merits of the case.

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<sup>36</sup> Tuberculosis and AIDS: UNAIDS Point of View. UNAIDS, October 1997.

<sup>37</sup> Stop TB. A human rights approach to TB. Stop TB Guidelines for Social Mobilization. WHO/CDS/STB/2001.9.

<sup>38</sup> The ECHR database.

<sup>39</sup> The "Ooms" case; *De Wilde, Ooms and Versyp ("vagrancy") v. Belgium*, 2832/66, 2835/66, 2899/66, June 18 1971, A12, No. 191.

<sup>40</sup> *Khalfaoui v. France*, 34791/97, December 14, 1999, R.J.D. 1999-IX, No. 1225.

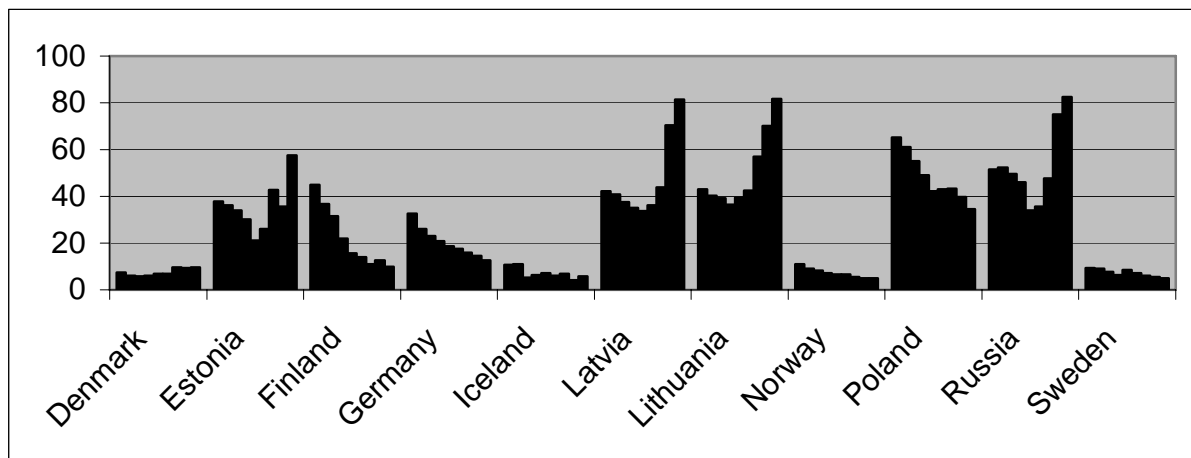


In the case of Schuler-Zgraggen v. Switzerland, a tuberculosis patient was discriminated against on the basis of sex (Article 14 taken together with Article 6 p. 1) by the assumption that women give up work when they give birth to children and accordingly lose their right to pensions granted to them previously on basis of bad health.

Neither of these two rulings rested on the fact that TB is an infectious disease, nor did they deal with any public health measures taken on basis of TB infection.

### III. Laws on tuberculosis, public health and human rights in Iceland

The incidence of TB in Iceland has been stable in recent years with around 10 cases each year (1997-2003).<sup>41</sup> This equals on average about 4 new cases per 100,000 inhabitants each year in a population of 280,000. These numbers are low by any international standard.<sup>42</sup> The figure below shows trends in the Scandinavian and neighbouring countries.



Tuberculosis - Case notification rates (per 100 000 population), 1982-1998, 2-year intervals.<sup>43</sup>

Most cases of TB in modern Iceland are re-activation of a latent TB infection in elderly patients. Another important source of active and reactivated TB is immigration from countries where TB is endemic. Two Icelandic AIDS patients have had documented HIV-

<sup>41</sup> [www.landlaeknir.is](http://www.landlaeknir.is) (health statistics)

<sup>42</sup> Dye, C et al. Global Burden of Tuberculosis. Estimated Incidence, Prevalence, and Mortality by Country. Consensus statement. JAMA, August 18, 1999-Vol 282, No. 7 (677-686).

<sup>43</sup> Task Force on Communicable Disease Control in the Baltic Sea Region: Recommendations, Healthy Neighbors, 19 December 2000.

Country	1999		2000		2001		2002	
	Total no.	Per 100 000	Total no.	Per 100 000	Total no.	Per 100 000	Total no.	Per 100 000
Denmark	571	10.7	548	10.3	517	9.7	429	8.0
Norway	273	6.2	238	5.3	297	6.6	256	5.7
Sweden	493	5.6	458	5.2	440	5.0	418	4.7
Finland	565	10.9	537	10.3	494	9.5	475	9.1
Iceland	12	4.0	9	3.0	15	5.0	8	3
Estonia	609	42.1	596	43.4	555	40.6	522	38.2
Latvia	n.a.	-	1 712	70.2	1 729	73.1	1535	65.4
Lithuania	2 846	76.9	2 668	72.2	2 606	74.7	2097	60.5

Tuberculosis (all forms) reported by the national/regional state institutes for infectious disease control (in Russia not including prison system) by year of notification.<sup>44</sup>

TB co-infections.<sup>45</sup> Co-infection of TB and HIV can be seen as a special clinical category. TB infection has been shown to speed up the development of AIDS in HIV-positive individuals, and a TB infection can become active in only a few weeks in a HIV-positive patient.<sup>46</sup> Practically all AIDS patients infected by TB develop the active form of the disease.

*i) Icelandic law on the control of communicable diseases.* Until the end of 1997 the control of communicable diseases in Iceland was prescribed in a number of laws that originated from the pre-antibiotic era, the first half of the 20<sup>th</sup> century and even the last part of the 19<sup>th</sup> century. Among them was the Act on the control of tuberculosis from

<sup>44</sup> Task Force on Communicable Disease Control in the Baltic Sea Region: Report of the Program Group on Tuberculosis. 22. March 2004. Source of data: [http://www.epinorth.org/english/epi-data/byDisease/tub\\_t.shtml](http://www.epinorth.org/english/epi-data/byDisease/tub_t.shtml)

<sup>45</sup> Thorvaldsson, S et al. Tuberculosis infection and tuberculosis in the foreign born in Iceland. *Læknablaðið* 1997; 83: 810-6.

<sup>46</sup> Kato-Maeda, M et al. How molecular epidemiology has changed what we know about tuberculosis. *West J Med* 2000; 172: 256-259.

1939. A single act “on control of communicable diseases”<sup>47</sup> entered into force 1 January 1998, prescribing powers to control all infectious diseases, TB being one of them. The present act included all the measures prescribed in the older laws. It is therefore necessary to give an overview of their development.

*The first Icelandic law on communicable diseases.* Icelandic laws on communicable diseases can be divided into three parts according to their contents: laws to stop the spread of diseases from abroad, laws to stop the spread of diseases within the country and special laws concerning particular diseases (or categories of diseases). The first law on communicable diseases was passed by the Icelandic parliament, Althingi, in 1875. It focused on the first mentioned category and was a response to the fears that foreign diseases would enter the country. These measures were directed against pox and “the Asiatic cholera” and dealt mostly with ships as “carriers” of disease.<sup>48</sup> “Infected” ships had to raise a green or white flag. Physicians were to examine the ones suspected of carrying diseases. The dead were to be buried and the sick cared for, at the expense of the ship, but special facilities for quarantine and care of patients were to be built by the government.

The laws on communicable diseases relevant to this study predating the present law were:

- i) *Act on control of tuberculosis*, No. 66, 30 December 1939. Based to a large extent on the Act on tuberculosis, No. 43, 27 June 1921, that had incorporated existing laws, No. 31, 23 October 1903.

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<sup>47</sup> No. 19, 17<sup>th</sup> of April 1997.

<sup>48</sup> The fear of “Asiatic diseases” was common all over Europe in the 19<sup>th</sup> century. It was one of the main reasons for the first international initiatives on the control of communicable diseases. Fidler, D. *International Law and Infectious Diseases*, 28-35.

ii) *Act on control of communicable diseases*, No. 34, 12 April 1954. Despite the name, it merely aimed at disease control on borders, harbours/airports. It was passed in response to the adoption of International Health Regulations, WHO 1951. It was, to a large extent, based on the Act on control of communicable diseases from abroad, No. 24, 6 November 1902, as amended, No. 65, 19 June 1933.

iii) *Act on epidemics*, No. 10, 19 March 1958. This was based on the Act on control of the spread of communicable diseases, No. 2, 31 January 1896, as amended, No. 24, 16 November 1907, No. 66, 19 June 1933.

iv) Act on control of sexually transmitted diseases, No. 16, 28 April 1978, as amended, No. 7, 7 April 1986. This was based on Act No. 16, 20 June 1923.

***ii) A brief history of laws and public health measures for control of tuberculosis.***

Tuberculosis has probably existed among Icelanders from the times of the island's first settlers in the 10<sup>th</sup> century.<sup>49</sup> According to historical documents, the disease did not become a significant source of illness or death until the end of the 19<sup>th</sup> century. TB was first cultured in Iceland 1890.<sup>50</sup>

Public health measures to control TB date back to the same period. Systematic reporting of the disease began two years earlier, 1888, by initiative of the Director of Public Health (Surgeon General) but was poor in quality and quantity the first decades. The incidence and prevalence of TB is thus unknown until around 1920. Nevertheless, it

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<sup>49</sup> Based on lesions in old skeletons.

<sup>50</sup> Sigurdur Sigurdsson. Tuberculosis in Iceland. *Læknablaðið* 1976; 62: 3-50 (p. 4).

can be said that the first public health measures predated the first law on the control of tuberculosis that entered into force in 1903.

*The first laws.* Apart from establishing reporting of TB as an obligation of every physician, the act of 1903 only prescribed measures to regulate the use of spit-cans and the sanitation of floors in public places. Higher ambitions of public health officials fell short for lack of funds. The first sanatorium for TB was financed by private funds in 1910.

*The second act and lack of funds.* In 1921 a revised law on TB was proposed. The bill was meant to shift the focus of public health measures towards diagnosis and prevention instead of mere isolation of the patients. Testing in schools was started, and infectious individuals were excluded from teaching, nursing and several other professions. A guarantee of free hospitalization for the poor was a significant step introduced by the law. Several other facilities and measures had been proposed. During the parliamentary debate proposals to establish research facilities, houses and sanatoriums for the sick were rejected, as well as proposals to increase public education and spread of information on the causes of tuberculosis.<sup>51</sup> The reasons given were financial.

*Quarantine and increased budget.* Quarantine remained the chief measure to control TB until the introduction of anti-tuberculosis medication. Hospitals and sanatoriums grew in number in the first decades of the 20<sup>th</sup> century, and the public spending related to TB increased to claim 7.5% of the state budget in 1932.

*The epidemic at its peak.* The epidemic reached its peak with the highest number of new cases found in 1933 when close to 10% of the total population covered by reporting proved to have a new infection or a relapse of an older one. The total number of

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<sup>51</sup> Sigurdur Sigurdsson. Tuberculosis in Iceland. Læknablaðið 1976; 62: 3-50 (p. 7).

registered TB patients peaked in 1935, but tuberculosis mortality rates declined steadily. Mortality was highest 1925-1930 with a mortality rate around 200-217 per 100,000 inhabitants, dropping by half in the next decade. During these years one of every five deaths in Iceland was caused by tuberculosis.<sup>52</sup>

*Nationwide screening.* The office of Medical Director of TB Control was established in the country in 1935. The surveillance of the disease changed dramatically in the following years. Earlier some TB testing had been done in schools. After 1935 nationwide screening began. Individuals were tested with tuberculin, and all positive reactors were X-rayed in search of active disease. Individuals that were not tested or had incomplete tests were X-rayed as well. These measures were compulsory.

*Shift of focus confirmed by law.* In the revised *Act on the control of TB of 1939* the focus shifted from protection of children to TB-screening and testing of the general population, followed up by tracking of those infected with both active and passive TB.<sup>53</sup> In this respect the law followed the practice already in place. Physicians were obligated to test every individual suspected of having TB and give instructions to prevent the disease from spreading. Reports of new TB-cases should now be sent within a week to the physician of the province.

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<sup>52</sup> Sigurdur Sigurdsson. Tuberculosis in Iceland. *Læknablaðið* 1976; 62: 3-50 (p. 7).

<sup>53</sup> *The Act of 1921* focused on the protection of children from TB. This was based on the generally accepted theory at the time that TB was primarily a disease infectious to children. No one with infectious TB could work as a teacher. No children were accepted in school without a certificate that they did not have infectious TB. If an individual living in a home with children caught infectious TB, he had to move immediately. If he resisted orders to this effect, the responsible physician was empowered to seek assistance from law enforcement officers.

The law of 1939 distinguished between inactive TB (infected patients with non-active (latent) disease), active TB (active disease) and infectious TB (active TB that could spread).<sup>54</sup> The prescribed public health measures depended on the same categorisation.

Broad population TB-testing in Icelandic towns					
	Year	Population	% tested	Cases	New cases
Reykjavik	1945	45800	98,15	71	71
Akureyri	1949	6900	99,4	40	8
Vestm.eyjar	1950	3500	99,5	15	1
Husavik	1951	1180	99,1	7	0
Siglufjordur	1952	2550	98,5	-	1
Isafjordur	1953	2250	98,8	-	1
Saudarkrokur	1954	880	-	-	1

*Mandatory medical examination.* Physicians were authorised to force people to be tested for the disease. They could seek assistance of the police if necessary. In case of resistance the chief of police decided if the individual should be tested. Only one instance is documented where this was necessary.<sup>55</sup> In the following years, 1940-1945, 58,837 (47% of the nation) were tested. In the towns the percentage of the population attending the screening was incredible. 1945 was a record year with 40.8% of the nation tested.<sup>56</sup> In the capital Reykjavik, 99.32% of the 45,800 inhabitants attended the screening. The remaining 0.68% were “either away from home or had moved.” The figures from other towns were similar.

*Quarantine.* The act of 1939 increased the powers of physicians enormously. Individuals and households could not only be forced to take TB tests, but those with documented infectious TB could be forced to stay in hospitals or “TB sanatoriums”. All decisions and requests thereon were to be made by the Medical Director of TB Control or one of the six specialized TB clinics in the country. Quarantine was a dramatic event.

<sup>54</sup> Act on the control of tuberculosis, No. 66 1939, article 1.

<sup>55</sup> Sigurdur Sigurdsson. Tuberculosis in Iceland. Læknablaðið 1976; 62: 3-50 (p.12).

<sup>56</sup> Sigurdur Sigurdsson. Tuberculosis in Iceland. Læknablaðið 1976; 62: 3-50 (p.13).



Individuals could face being away from their loved ones for years, and the possibility of dying without seeing them again was never far off.

*Use of force.* On resistance the chief of police could issue an order for the transport and quarantine of the patient, after consulting the Medical Director of TB Control. The transport was to be paid by the patients if it became a police operation. Forced hospitalization and quarantine under these provisions was used “a few times”, “especially in the case of alcoholic TB patients.”<sup>57</sup> Those with infectious tuberculosis were to be separated from others in hospitals, sanatoriums, mental institutions, nursery homes, prisons and similar institutions.

*Reporting.* A register of people infected with tuberculosis was kept in each part of the country pursuant to the Act of 1939.<sup>58</sup> A copy was to be sent to the Director of Public Health each year. New patients should be registered within a week of diagnosis.<sup>59</sup> If a TB patient moved, the treating physician was responsible for notifying his colleagues closest to the new home. The registry included the full identity of those infected.

In practice, the Chief Physician of Tuberculosis collected the TB reports from around the country and kept the registry. The same individual held the position from 1935-1970. When he retired, a successor was not hired. Half of the salary was used to raise the wages of the Director of Public Health, and the assumption was that he would take on the obligations to keep the register. This was not done. No TB statistics are available from 1970-1975. In 1975 the Chief of Tuberculosis and Pulmonary Diseases in Reykjavík volunteered to collect the reports and keep the register. This initiative was welcomed

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<sup>57</sup> Sigurdur Sigurdsson. Tuberculosis in Iceland. *Læknablaðið* 1976; 62: 3-50 (p.13).

<sup>58</sup> Article 5, Act No. 66, 1939.

<sup>59</sup> Article 4, Act No. 66, 1939.

although it was not according to law, but neither was the arrangement for the register with the Chief Physician of Tuberculosis.

*BCG vaccination.* Extensive plans for nationwide vaccinations against tuberculosis (BCG) were formulated in 1947-1948.<sup>60</sup> No change was made in the act. The plans were never realized for a number of reasons. Vaccinations were nonetheless used for uninfected relatives of TB patients, health workers working with TB, students planning trips to countries where TB was endemic and others actively seeking vaccination.<sup>61</sup>

*Anti-tuberculosis medication.* The tuberculosis epidemic in Iceland had declined dramatically when anti-tuberculosis medication was introduced in 1947<sup>62</sup>-1952<sup>63</sup>. It was effective in diminishing mortality, but its effect on the spread of the infection is questionable. This is also true for all other public health measures taken against TB in Iceland, as well as internationally<sup>64</sup>, although the Icelandic case has not been a subject of specific research.

*Screening in schools.* Mandatory tuberculin<sup>65</sup> tests in schools were one of the first public health measures taken in Iceland, and it outlived most other measures. As late as in 1993 the Director of Public Health recommended that all eight-year-old schoolchildren be tuberculin-tested, and repeated screening was recommended at fifteen.<sup>66</sup> It was finally stopped in 1996 when the prevalence of positive tests had been low and almost

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<sup>60</sup> Sigurdur Sigurdsson. Tuberculosis in Iceland. *Læknablaðið* 1976; 62: 3-50 (p. 35).

<sup>61</sup> Sigurdur Sigurdsson. Tuberculosis in Iceland. *Læknablaðið* 1976; 62: 3-50, (p. 36-37).

<sup>62</sup> Streptomycin. Sigurdur Sigurdsson. Tuberculosis in Iceland. *Læknablaðið* 1976; 62: 3-50 (p. 15).

<sup>63</sup> Isoniazid. Sigurdur Sigurdsson. Tuberculosis in Iceland. *Læknablaðið* 1976; 62: 3-50 (p. 15).

<sup>64</sup> The question of whether “public health had a significant impact on the decline of TB mortality rates in several countries” is dealt with in: Fairchild, AL et al.: Public Health Nihilism vs. Pragmatism: History, Politics, and the Control of Tuberculosis, *Am J Public Health*, Vol. 88 (7) 1998, 1105-1117.

<sup>65</sup> Percutan Moro-tests were used for children under 12. Intracutan Mantoux-tests were used for older children.

<sup>66</sup> Director of Public Health. *Landlæknir* (og “berklayfirlæknir”), Dreifibréf Nr. 12/1993 (ÓÓ/hþ). 11. október 1993.

unchanged for two decades (0.5 positive per 1000 tested).<sup>67</sup> The decision was taken after publication of research that demonstrated these facts.

*Screening of immigrants.* In the 1990s leading Icelandic specialists argued that the emphasis should be shifted from schoolchildren to immigrants with origins in areas where TB was endemic.<sup>68</sup> The arguments were based on research showing that 32 of 468 cases of TB 1975-1996 were among foreign-born individuals. The incidence during the period was 18.0 against 8.4 among those born in Iceland.<sup>69</sup> The numbers were significantly higher in certain subgroups, e.g., with Asian-born people, the incidence was 173.7.

In 1993 a letter by the Director of Public Health stressed the importance of taking tuberculin tests and pulmonary X-rays during medical examinations of immigrants applying for residence permits, “when appropriate”.<sup>70</sup> The reason for the letter was the recent rise in TB reported in the USA. The existing “rules” had been published in a letter of the Director of Public Health to all doctors in 1978.<sup>71</sup> They required: a) general medical examination, b) tuberculin test and c) pulmonary X-ray if the tuberculin test was positive. If the immigrant was to work in the food industry, a stool sample was collected for salmonella culture.

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<sup>67</sup> Gunnbjörnsdóttir, MI et al. Incidence and prevalence of positive tuberculin skin test reactions among schoolchildren, *Læknablaðið* 1996; 690-8.

<sup>68</sup> Blöndal, Th. Control of tuberculosis – Where are we heading?, *Læknablaðið* 1996; 82 528-9. Gunnbjörnsdóttir, MI et al. Incidence and prevalence of positive tuberculin skin test reactions among schoolchildren, *Læknablaðið* 1996; 690-8. Thorvaldsson, S et al. Tuberculosis infection and tuberculosis in the foreign born in Iceland: *Læknablaðið* 1997; 83: 810-6.

<sup>69</sup> Thorvaldsson, S et al. Tuberculosis infection and tuberculosis in the foreign-born in Iceland. *Læknablaðið* 1997; 83: 810-6.

<sup>70</sup> Director of Public Health. Landlæknir (og “berklayfirlæknir”), Dreifibréf Nr. 12/1993 (ÓÓ/hþ). 11. október 1993.

<sup>71</sup> Referred to in: Landlæknir. Læknisskoðanir útlendinga vegna dvalarleyfis. Dreifibréf Nr. 8/1992 (MH/hþ) 22. September 1992.

The Director of Public Health issued revised rules after receiving suggestions from the National Committee on Communicable Diseases in April 1994.<sup>72</sup> A distinction was made between immigrants entering the country to work in the food industry and others. The former group was subjected to control for tuberculosis and had to submit stool samples in search of parasites and communicable diseases. Other immigrants applying for residency were to be advised to have a medical examination for TB if indicated. Later the same year, all health facilities across the country received a letter from the Chief Physician of the Department of Tuberculosis and Pulmonary Disease in Reykjavík.<sup>73</sup> In the letter physicians were encouraged to test more frequently for tuberculosis when issuing health certificates to immigrants, not just in the case of individuals working in the food industry.

The mixed recommendations with questionable authority under law led to uncertainty about existing rules and, as a matter of fact, left the decision on proper procedures, to a large extent, in the hands of the examining doctors issuing the health certificates. This in turn can lead to discriminatory practice.

In a letter to the National Committee on Communicable Diseases, the Directorate of Immigration raised the question of what “rules” applied or should apply to the mandatory medical examination of immigrants. When the committee was dissolved by a decision of the Minister of Health in April 1995, it had not given an answer and did not do so until its

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<sup>72</sup> Director of Public Health. Landlæknir, Tilmæli um sóttvarnareftirlit með útlendingum (ÓÓ/kg) 7. April 1994.

<sup>73</sup> Department of Tuberculosis and Pulmonary Diseases, (Th.B/DJ) 22. October 1994.

heir presented non-binding recommendations in a letter issued by the Director of Public Health in 2000.<sup>74</sup>

*iii) Current laws and provisions prescribing public health measures for control of tuberculosis.* The present *Act on communicable diseases* entered into force 1 January 1998.<sup>75</sup>

*Organisation.* The Director of Public Health is responsible for control of TB as well as all others communicable diseases under the auspices of the Minister of Health.<sup>76</sup> A State Epidemiologist shall be hired for the office of the Director of Public Health<sup>77</sup> to plan and co-ordinate disease control, keep a registry, follow international epidemics and distribute information to physicians, be available to consult with them in daily practice as well as the general public in matters related to communicable diseases and their prevention. The organization of tuberculosis control differs from older laws where a special physician was responsible for TB registration as well as TB control strategy.

*Definitions and categories of diseases.* Communicable diseases are to be divided into two categories under the current act by issuing a regulation thereon. A distinction shall be made between diseases that are a “threat to the general public” and those that are not.<sup>78</sup> The latter are reported anonymously to the State Epidemiologist according to the law. Diseases that are a “threat to the general public” shall be reported with full identity (case reporting).<sup>79</sup> TB is one such disease.<sup>80</sup> The categories are not fixed, and the

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<sup>74</sup> Director of Public Health. Landlæknir, Tilmæli sóttvarnarlæknis og leiðbeiningar um berklaskoðun á þeim sem sækja um dvalarleyfi á Íslandi. Dreifibréf 6/2000 (Sóttvarnarlæknir).

<sup>75</sup> No. 19, 17 April 1997.

<sup>76</sup> Act on communicable diseases, No. 19/1997, Article 4 .

<sup>77</sup> Section of Infectious Disease Control.

<sup>78</sup> No. 19, 17 April 1997.

<sup>79</sup> Act on communicable diseases, No. 19/1997, Article 3 .

<sup>80</sup> “Atypical tuberculosis infections” are categorized with the more benign diseases.

Minister of Health has actually issued three minor changes to the list since 1999. In the present regulation TB is included in the category of threatening diseases to be reported with full identity.<sup>81</sup>

*Duties of individuals.* The Act defines a general obligation to refrain from infection and avoid becoming infected and infecting others.<sup>82</sup> Individuals infected with diseases that are a threat to others have a duty to seek medical care without delay, follow instructions on treatment and prevention, in case of confirmed infection, and provide all relevant information needed to trace the infection.

*Duties of physicians.* A physician is under a legal duty to report communicable diseases according to the act.<sup>83</sup> If he has knowledge or reasons to believe that an infected patient does not follow instructions on medication or behaviour this shall be reported immediately to the State Epidemiologist.

*Powers in individual cases.* The State Epidemiologist has the power to intervene in individual cases of infections that are “a threat to the general public” if he deems that the measures taken by the responsible physician are insufficient. These measures are “medical examination”, “quarantine in a hospital facility” and “other necessary measures”.<sup>84</sup> The assistance of the police can be sought if necessary. Nonetheless, the act specifically provides that coercive measures should only be taken if less restrictive measures have proved insufficient.

*Powers to take special measures.* The Minister of Health can issue special measures to control epidemics according to suggestions by the National Committee on

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<sup>81</sup> Regulation on reporting of communicable diseases, Minister of Health (IP) 12 February 1999.

<sup>82</sup> Act on communicable diseases No. 19/1997, 7<sup>th</sup> article.

<sup>83</sup> Act on communicable diseases No. 19/1997, 8<sup>th</sup> article.

<sup>84</sup> Act on communicable diseases No. 19/1997, 14<sup>th</sup> article.

Communicable Diseases<sup>85</sup>, if reporting to the State Epidemiologist suggests there is danger of an outbreak.<sup>86</sup> These are measures, “such as vaccination, quarantine of the infected, disinfection, quarantine of parts of the country or the country as a whole, closing of schools and banning public gatherings.”<sup>87</sup> A recent amendment to the law provided that the State Epidemiologist had powers to “access all necessary information and places that he deems necessary to do epidemiological research and trace the origin of infections.”<sup>88</sup> The act does not require that the least restrictive alternative be used when regulations of special measures are issued by the Minister of Health.

*Measures against spread to/from Iceland.* In the original act the Minister of Health was given powers to issue a special regulation on measures to control epidemics from abroad in article 13.<sup>89</sup> The same article provides that the regulation is supposed to be in accordance with the International Health Regulations, which Iceland has ratified. A recent amendment to the law prescribes that if the State Epidemiologist thinks there is a danger that communicable diseases of threat to the general public enter the country, he can propose that the Minister of Health issue a regulation on compulsory medical examination of individuals suspected of carrying these diseases.”<sup>90</sup>

*iv) Strengthening of human rights in Icelandic law.* Having reviewed current laws prescribing powers to take public health measures to control communicable diseases, we

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<sup>85</sup> A consultative body in matters of policy and specific action. Act on communicable diseases, No. 19/1997, Article 6 .

<sup>86</sup> Act on communicable diseases, No. 19/1997, Article 12

<sup>87</sup> The State Epidemiologist can take immediate action in these lines if deemed necessary under extraordinary circumstances.

<sup>88</sup> Act on amendments to the Act of communicable diseases, No. 19/1997. Addition to Article 12.

<sup>89</sup> Act on communicable diseases, No. 19/1997, Article 13.

<sup>90</sup> Act on changes to the Act of communicable diseases, No. 19/1997. Addition to Article 12.

turn to acts and provisions protecting the rights of individuals infected or suspected of being infected with communicable diseases.

Public health measures predated human rights considerations in the control of communicable diseases in Iceland by more than a century. Until the 1990s few, if any, provisions of existing Icelandic law protected the rights of infected individuals. The only, vague exceptions were the rights of individuals suspected of having polio and other diseases subject to the Act on epidemics of 1907,<sup>91</sup> to have tests to clear themselves of this suspicion and get proper treatment if available. The laws on TB did not have similar provisions. This did not change until the 1997 Act on communicable diseases. Some steps strengthening human rights in Icelandic law were taken before that, during the 1990s.

Protection of privacy regarding information in medical records was strengthened in 1990 when the *Act on Registration and Processing of Personal Data*<sup>92</sup> entered into force. In 1994 the European Convention on Human Rights (ECHR) was incorporated into Icelandic legislation with *Act No. 62 of 1994*.<sup>93</sup> Accordingly it can be evoked directly in Icelandic courts unlike other human rights treaties.<sup>94</sup> In 1997 a revised Act on legal competence provided guarantees of due process and courts review of all decisions of all forced hospitalization (involuntary commitment) and forced medication.<sup>95</sup> A revised Act on Protection of Individuals with regard to the Processing of Personal Data (No. 77/2000)

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<sup>91</sup> This “right” was added by amendment to the law in 1927, in light of the then known fact that individuals could be infected without having symptoms, adding the category “suspect” (of carrying a disease) to the individuals subject to the law.

<sup>92</sup> No. 121, 28 December 1989.

<sup>93</sup> See, Appendix I.

<sup>94</sup> Appendix I, The effects of international human rights treaties in Iceland.

<sup>95</sup> Rules and procedures leading to involuntary commitment are much more detailed and protect patient rights more extensively than older laws.

[http://domsmalaraduneyti.is/interpro/dkm/dkm.nsf/pages/eng\\_competence](http://domsmalaraduneyti.is/interpro/dkm/dkm.nsf/pages/eng_competence)



incorporated an EU directive dealing with the same issue (No. 95/46/EC) that came into force in 1998.

Along with the incorporation of the ECHR and the Act on patients' rights, the most significant step in strengthening the protection of human rights in the Icelandic legal system was a considerable amendment in 1995 of the human rights section of the *Icelandic Constitution of 1944*. The objective was to bring the provisions into line with Iceland's obligations under international human rights law. Numerous provisions relevant to the present study were strengthened in the process:

*Article 65:* Everyone shall be equal before the law and enjoy human rights irrespective of sex, religion, opinion, ethnic origin, race, colour, property, or birth or other status.

*Article 67:* No one may be deprived of his liberty except as permitted by law. [...] Any person deprived of his liberty for reasons other [than being suspected of criminal conduct] shall be entitled to have the legality of the measure reviewed by a court as soon as possible. If his deprivation of liberty proves to have been unlawful, he shall be released forthwith.

*Article 71:* Everyone shall enjoy freedom from interference with privacy, home, and family life. Bodily or personal search or search of a person's premises or possessions may only be conducted in accordance with a judicial decision or a statutory provision. [...] Notwithstanding the provisions of the first paragraph above, freedom from interference with privacy, home or family life may be otherwise

limited by statutory provisions if this is urgently<sup>96</sup> necessary for the protection of the rights of others.

*Article 76:* Everyone shall be entitled to necessary assistance in case of sickness, invalidity, infirmity by reason of old age, unemployment and similar circumstances, as further laid down by law.

*v) Current laws protecting the human rights of individuals infected by communicable diseases.* Specific protection of the rights of individuals infected by communicable diseases, as well as other patients, was provided in the *Act on Patients Rights*, passed by Althingi in 1997.<sup>97</sup> The objective was to entitle patients to specific rights in accordance with general human rights and human dignity by strengthening their legal status regarding the health service. A ban on discrimination “on grounds of gender, religion, beliefs, nationality, race, skin colour, financial status, family relationship or status in other respects” is laid down in article 1. It is also clear from the act that its provisions do not apply exclusively to Icelandic patients but also to “any person using the health service.”<sup>98</sup>

*The Act on patients' rights* served to support the confidential relationship between patients and health workers by clearly defined rules of confidentiality and privacy. Other relevant rights and principles laid down by the act are:

- i) the principle of informed consent for treatment and participation in research,
- ii) the right to refuse treatment “without prejudice to other law”,

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<sup>96</sup> The requirement of “urgency” was added during the parliamentary debate.

<sup>97</sup> No. 74, 28<sup>th</sup> of May 1997. It entered into force on the 1<sup>st</sup> of July 1997.

<sup>98</sup> Act on patients' rights, No. 74, 1997, article 2.

- iii) the right to information about health status and rights as a patient (in a language the patient understands),
- iv) rules of confidentiality of medical information and professional secrecy of health workers.

The *Act on communicable diseases* of 1997 that entered into force on 1 January 1998 defined rights of individuals who are infected or suspected of being infected by a communicable disease.

*Confidentiality.* “Strict confidentiality” shall be kept regarding sensitive information in the register of infectious diseases.<sup>99</sup> The law defines this as an obligation of the State Epidemiologist rather than framing it as the infected individuals' right to privacy, which is the case in the Act of physicians.<sup>100</sup>

*Least restrictive measures.* The principle is that measures in individuals' cases to prevent the spread of infectious disease must not take a coercive path unless all less restrictive alternatives have been tried (article 14).

*Involuntary confinement.* If the State Epidemiologist deems it necessary to quarantine individuals, he can do so against their will. Under these circumstances the State Epidemiologist has to file a case before a judge as soon as possible. The judge is obligated to rule without unreasonable delay. The confined person has a right to legal representation. Involuntary confinement may not exceed 15 days unless a new case is filed. All decisions can be appealed to the Supreme Court.

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<sup>99</sup> Act on communicable diseases, No. 19/1997, Article 3.

<sup>100</sup> Act on physicians, No. 53/1988.

*Cost of diagnosis and treatment.* The act permits the diagnosis and treatment of diseases that are a “danger to the general public” to be paid in full from public funds.<sup>101</sup> This authorisation is used and full coverage provided.<sup>102</sup> The same is true for the diagnosis of patients that are subjected to medical examination to trace infections or as a mandatory measure under the act.

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<sup>101</sup> Act on communicable diseases, No. 19/1997, Article 17, as amended, from 9 May 2000.

<sup>102</sup> Regulation No. 131/1999.

#### **IV. Human rights assessment of public health measures to control tuberculosis in Iceland**

In this chapter the current practice in public health, existing law and regulations relevant to the control of TB in Iceland will be assessed and the relevant human rights issues defined. Before dealing with human rights implications of measures to control TB, it is appropriate to evaluate how Iceland meets its obligations to protect public health in the context of TB.

**i) Obligations to protect public health.** The traditional role of governments in the control of infectious diseases is recognized in international human rights law in two ways: a) as obligations to take positive measures to control epidemics and b) by acknowledging the protection of public health as a legitimate restriction of other protected rights.

Iceland has ratified three human rights treaties containing obligations to control epidemics.<sup>103</sup> The first international provision signed and ratified by Iceland on the control of infectious diseases is laid down in article 11 of the European Social Charter on the right to protection of health:

With a view to ensuring the effective exercise of the right to protection of health, the Contracting Parties undertake, either directly or in co-operation with public or private organizations, to take appropriate measures designed, inter alia, [...]

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<sup>103</sup> An overview of Iceland's ratifications of the most relevant human rights treaties is provided in Appendix I.

3. to prevent as far as possible epidemic, endemic and other diseases.

Iceland has ratified the International Convention of Economic, Social and Cultural Rights. Article 12 states an obligation to “recognize the right of everyone to the enjoyment of the highest attainable standard of physical and mental health.” Although the interpretation of this article and the specific obligations imposed by it are still being debated, it is undisputed that it imposes an obligation to control infectious diseases. The steps taken to achieve the full realization of the right to health shall include those necessary for “the prevention, treatment and control of epidemic, endemic, occupational and other diseases.”<sup>104</sup>

The Committee on Economic, Social and Cultural Rights' General Comment 14 on the convention regarding the right to the highest attainable standard of health interprets this “right to treatment” as requiring “the creation of a system of urgent medical care in cases of accidents, *epidemics* and similar health hazards.”<sup>105</sup> The control of disease is interpreted as referring to the use and improvement of “epidemiological surveillance and data collection on a disaggregated basis, the implementation or enhancement of immunization programs and other strategies of infectious disease control.”<sup>106</sup>

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<sup>104</sup> Article 12 of the ICESCR. These obligations are strengthened by the interpretation of obligations under other international treaties. Article 6 of the International Convention on Civil and Political Rights on the right to life has been interpreted to include measures to eliminate epidemics. In its general comment on the article, the Human Rights Committee stated: “The right to life has been too often narrowly interpreted.” (General Comment No. 6 on the Right to Life (Art. 6 of the Covenant) adopted by the Human Rights Committee. (16<sup>th</sup> session, 1982), para. 5.) In light of this it concludes that “the protection of this right requires that States adopt positive measures”, and that “it would be desirable for State parties to take all possible measures to reduce infant mortality and to increase life expectancy, especially in adopting measures to eliminate malnutrition and epidemics.” (General Comment No. 6 on the Right to Life (Art. 6 of the Covenant) adopted by the Human Rights Committee. (16<sup>th</sup> session, 1982), para. 5.)

<sup>105</sup> Committee on Economic, Social and Cultural Rights General Comment 14, The right to the highest attainable standard of health (article 12) E/C.12/2000/4, CESCR, para. 16. (Emphasis added)

<sup>106</sup> Committee on Economic, Social and Cultural Rights General Comment 14, The right to the highest attainable standard of health (article 12) E/C.12/2000/4, CESCR, para. 16.

***Health service in Iceland and the right to health<sup>107</sup>***

**Availability** Sufficient quantity of health service for the whole population.

**Accessibility**

financial Affordable health service.

geographic Within reach of everyone.

cultural Respect the culture of the users.

**Quality** Available service must be of adequate quality.

**Equality** Available service must be equally accessible to everyone.

Although still disputed regarding some details, the more general obligations derived from the right to health have to be addressed in the context of TB in Iceland. The right to health does not imply a right to be healthy or even establishment of the best available health services although it is phrased as “the right to the enjoyment of the highest attainable standard of physical and mental health”. It nevertheless implies obligations to provide certain basic health services and facilities fundamental to health. More importantly, it implies that the health services shall be available in a non-discriminatory manner.

It has been proposed that there is a set of “guiding principles” for the right to health in the context of health services.<sup>108</sup> These are *availability*, financial, geographic and cultural *accessibility*, *quality* and *equality*. The previously mentioned scheme, originally developed to analyze state obligations under the right to education,<sup>109</sup> does not account for the first government obligation under the right to health, effective protection against health hazards against which people cannot protect themselves. The establishment of systems for the control of communicable diseases is indeed a reflection of this fundamental obligation.

Iceland respects its obligations regarding the right to health by providing universal access to medical attention and treatment with low service fees. In the case of TB control, all service and treatment is free of charge.<sup>110</sup> Judged by health statistics, Iceland is a world leader in the sphere of health from its record low numbers of infant mortality, exceptionally high life expectancy and good general health status, which exceeds the standards of international human rights treaties by far. The same seems to be true for the Icelandic system of TB surveillance, reporting, tracing and treatment as well as for the health service in general. Without known exception mini-epidemics have been detected and eliminated before spreading farther.<sup>111</sup> TB control in Iceland seems to be among the most effective in any international comparison with reference to incidence, prevalence and reaction to individual infections. Under the current Stop TB plan for Europe, Iceland is one of 24 countries with a low TB burden and incidence.<sup>112</sup>



<b>Infectious diseases (TB) and the right to health in Iceland</b>	
<b>Obligations</b>	<b>Iceland</b>
Acute medical care in epidemics	v
Surveillance	v
Data collection	v
Screening (not general)	v
Immunization programme	v
Treatment (free)	v

**ii) Human rights implications of TB control measures.** There are still no specific provisions protecting human rights of individuals with communicable diseases in international human rights law.<sup>113</sup> Nevertheless, it has become increasingly acknowledged that almost every aspect of the control of communicable diseases has human rights implications.<sup>114</sup> For a study on a specific infectious disease, this means that a “seemingly narrow topic, infectious diseases, explodes into an exploration of the nature of international human rights law itself.”<sup>115</sup> This can be demonstrated by the list of human rights relevant to HIV/AIDS provided in the International Guidelines of 1996 for HIV/AIDS and Human Rights published by UNAIDS provided in Table 1 of the present study.

Iceland is under an obligation to respect all of the listed rights. Iceland is a party to numerous United Nations human rights instruments as well as most of the Council of Europe conventions relating to human rights. The following are some of the most relevant instruments in the context of infectious diseases:

<b>Measures to control TB</b>	<b>Protected human rights</b>	
	<b>Article and treaty</b>	
Surveillance	Right to privacy	17 ICCPR, 8 ECHR <b>1 ECAPPC, 10 EBC</b>
Reporting	Right to privacy	17 ICCPR, 8 ECHR <b>1 ECAPPC, 10 EBC</b>
Vaccination	Consent, Right to integrity	5 EBC
Tracing of infections	Right to privacy	17 ICCPR, 8 ECHR <b>1 ECAPPC, 10 EBC</b>
Mandatory testing	Consent, Right to integrity	5 EBC

- i) International Convention on the Elimination of All Forms of Racial Discrimination of 7 March 1966;
- ii) International Covenant on Economic, Social and Cultural Rights of 19 December 1966;
- iii) International Covenant on Civil and Political Rights of 19 December 1966, including the two Optional Protocols;
- iv) Convention on the Elimination of All Forms of Discrimination against Women of 18 December 1979;
- v) Various International Labour Organization Conventions, including the Freedom of Association and Protection of the Rights to Organize Convention 1948 (No. 87);
- vi) European Social Charter of 18 October 1961; a revised form, which was opened for signature on 3 May 1996, entered into force 1 July 1999;
- vii) (European) Convention for the Protection of Human Rights and Fundamental Freedoms of 4 November 1950, including Protocols Nos. 1-8

and Protocol 11 – including the recognition of the jurisdiction of the European Court of Human Rights;

- viii) (European) Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data of 28 January 1981;
- ix) European Convention for the Prevention of Torture and Inhuman or Degrading Treatment or Punishment of 26 November 1987;
- x) Convention on the Rights of the Child of 20 November 1989.
- xi) (European) Convention on Human Rights and Biomedicine of 19 November 1996 (signed by Iceland 4 April 1997, not yet ratified).

**iii) Limitation of individual rights for the protection of public health.** Having listed the protected rights potentially violated by measures to control TB, we turn to the question of when such measures are legitimate under international human rights law even though they infringe on protected human rights. Most human rights are subjected to both express limitation clauses and implied limitations in their interpretation.

Public health traditionally outweighed human rights in state practice. This is reflected in international human rights law where public health measures are respected as a legitimate restriction of individual rights. All the major human rights conventions recognize public health as a legitimate reason for government interference with certain rights. Express limitations for the protection of public health are found in articles 12(3), 13, 18(3), 19(3b), 21 and 22(2) of the ICCPR<sup>116</sup> (the right to liberty, thought, conscience and religion, expression and assembly) and 8-11 of the ECHR (the right to privacy and family life, religion, expression, assembly and association).<sup>117</sup>

The explicit limitation clauses serve two aims:

- (i) To state legitimate limitations to the entitled rights, and
- (ii) To protect against arbitrary restrictions by providing a list of legitimate aims.

In other words, limitations are, and should be, subjected to strict scrutiny. This is well established in the practice of the European Court of Human Rights<sup>118</sup> and the Human Rights Committee, reflected in the Siracusa principles,<sup>119</sup> an authoritative statement on the interpretation of ICCPR published by a group of distinguished scholars. To sum up, limitations to human rights are exceptional, and the public authority has the burden of proof that they are “necessary, legitimate and proportional.”<sup>120</sup> The necessary conditions for limitations are to be “prescribed by law”, “practiced according to law” and “necessary in a democratic society” that cannot be assessed without reference to a particular situation.

For the purpose of the present thesis, the practice of TB control will be scrutinized by answering five questions reflecting the criteria that limitations on protected rights have to meet. Besides the general question of whether TB control is a legitimate aim in limiting rights, the specific aspects of that control have to be:

- i) legitimate
- ii) prescribed by law
- iii) practiced according to law
- iv) relevant and sufficient/efficient to serve the aim (TB control)

- v) the least restrictive alternative (proportional to the served aim)

**iv) TB control as a compelling public interest.** Before moving on, it is necessary to address the question of whether the control of TB relates to a compelling public interest. This is a central question common to the human rights analysis of all measures to control TB.

As previously stated it is well established that the protection of public health is a compelling public interest. On the other hand, there is no established or fixed definition of what constitutes a threat to public health. In Iceland TB is categorized with diseases that are a “threat to the general public”, as mentioned previously, in a regulation based on the Act on communicable diseases.<sup>121</sup> No specific mention of TB or any other disease is found in the Act itself.<sup>122</sup> Is this categorization reasonable?

First, as for TB, its legacy as the world’s deadliest disease through the ages is a natural background to a proper answer in a global perspective. Second, although TB’s incidence and prevalence is low in Iceland, it is still present and at least a potential source of morbidity and mortality. Third, TB is an airborne disease that spreads with casual contact. Each individual with active disease can start a micro-epidemic in his nearby surroundings. This is known to have happened in Iceland.<sup>123</sup> If no action is taken, only a few infectious individuals can spread the disease to a considerable number of people in a short time. But this is only true for the pulmonary and infectious form of the disease.

TB is one of 35 diseases that “can be a threat to the general public” according to the regulation on the reporting of diseases under the Act on communicable diseases. Unlike the pre-existing law the regulation does not distinguish between the different

forms of the disease.<sup>124</sup> In other words, the formal powers of public health officials to take measures to control TB under the current act are not sensitive to the different forms of the disease. The different forms of TB are nonetheless relevant in assessing the legitimacy of public health measures that have implications for protected human rights according to the principle of proportionality. Consequently, health officials are given excessive powers in cases of non-infectious TB under the current law and regulations on the control of infectious diseases. Whether these excessive powers are abused cannot be answered in the abstract but has to rest on an analysis of the current practice of measures to control TB.

**v) Analysis of specific measures to control TB.** The measures for TB control at the heart of a human rights analysis in an Icelandic context are those specifically mentioned in articles 12-15 in the Act on communicable diseases: surveillance and (case) reporting, tracing of infections, mandatory testing/medical examination, vaccination, quarantine and “other necessary measures”. Further measures mentioned in article 12 of the present Act, such as closing of schools, banning public gatherings, quarantine of whole provinces or the country, are not specifically dealt with in this thesis. The reason is that they deal with highly hypothetical measures to control tuberculosis that are irrelevant to the current practice of tuberculosis control in Iceland.

The human rights assessment of each of the defined measures will be divided into description of the current practice and analysis of relevant human rights provisions (law).

### *Reporting*

**Current practice:** TB is one of 35 diseases that “can be a threat to the general public” according to a regulation on the reporting of diseases under the Act on communicable diseases. As TB is included in this category, physicians are under an obligation to report all diagnoses or suspected cases of TB to the State Epidemiologist without delay according to article 9 of the act. The regulation states that a case report shall include at least the following:

1. Name and number of the disease diagnosed.
2. When, how and which diagnosis was verified.
3. Identity and sex of the infected.
4. Medical district of the infected and place of residence.
5. Name of reporter, medical identity number, place of work, signature and date of report.

A single form is used to report all diseases that “can be a threat to the general public”. The form affects the practice. The reporting is case reporting where full identity of the infected is included: name, address, profession, workplace and country of origin. Further information includes when and where the infection occurred, when and where the illness began, where the individual became infected, and where he has dwelt from the first appearance of the illness. The physician is also required to identify the route of transmission, whether the infected has a history of vaccination, whether medical treatment has been provided and whether the treating physician has traced the infection.

In practice, the Centre for Tuberculosis and Pulmonary Disease in Reykjavik keeps a registry of all TB cases diagnosed in Iceland, based on reporting to the State Epidemiologist. The Centre is the national centre for medical examination of immigrants according to the regulation.<sup>125</sup> Furthermore, it traces infections case by case if indicated, is available for consultations with practicing physicians around the country and is the national centre of treatment for tuberculosis. This practice has been unchanged from the mid-1970s and has its historical reasons.<sup>126</sup>

**Analysis:** Case reporting, including identity, is potentially a violation of the right to privacy that is protected in numerous human rights instruments that Iceland has signed and ratified. Among them is the protection of privacy under article 8 of the ECHR. As previously stated a human rights analysis of case reporting in light of the right to privacy is to a large extent a question of legitimate limitations of that right. Both aspects of reporting have to be analyzed: its contents (i) and its organization (ii), in light of the strict criteria that limitations have to fulfil (as prescribed by law, according to law, relevant and sufficient for a legitimate aim, and whether it is the least restrictive alternative).



**Dagur B. Eggertsson**

*i) Contents. Prescribed by law?* In practice, all cases of TB are reported without delay with a number of details about the infected individual and the circumstances under which the infected caught the infection and became ill. This practice is established by a form-sheet sent out by the State Epidemiologist with reference to the Act on communicable

diseases and the existing regulation on the reporting of diseases. Under the present headline, “Prescribed by law?” the main issue is whether the present regulation has any basis in the act. The answer is yes. Article 3 of the Act on communicable diseases gives powers to the Minister of Health to issue a regulation on the control of diseases. In the same article the act provides that case reports on diseases that can be a threat to the general public shall be submitted, including identifiable personal information.<sup>127</sup>

*According to law?* It is almost a tautology to determine whether the present regulation is according to law as the act prescribes that diseases shall be categorized by issuing a regulation. Neither the act nor the regulation includes a criterion for determining what diseases are potentially “dangerous to the general public” although infectious diseases are split into those that are and those that are not. A preliminary list of diseases was provided with the parliamentary bill for the act. It is split into the two categories. The list was a mixture of clinical syndromes (i.e., “blood-borne infections”, “endocarditis”),

## **The protection of the right to privacy**

### **European Convention on Human Rights**

#### **Article 8**

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

Other general clauses: Article 12 of UDHR, Article 17 of ICCPR.

aetiological causes of diseases (i.e., HIV, meningococcal disease), and what can be called functional definitions (“infectious hepatitis B”), divided according to routes of infection.

The present regulation did not follow the above-mentioned list in detail but is based on aetiology to a large extent. In the case of TB the regulation is totally un-sensitive to the fact that *M. tuberculosis* can cause disease in different forms, some of which can reasonably be categorized as a potential threat to the general public and others which cannot. The regulation on reporting makes no distinction between pulmonary and non-pulmonary TB or between inactive TB (infected but not active (latent) disease), active TB (active disease) and infectious TB (active TB that can spread). Neither does the case reporting form that defines the practice. This is not a violation of the Act on communicable diseases.

It is however questionable if the current case reporting form is according to the present regulation and Act on communicable diseases. In the present form all the information needed to trace an infection is included even if it is obvious that the need for tracing is an exception. Some of the information, i.e., country of origin, seems even irrelevant to the State Epidemiologist except as a part of academic epidemiological research. In other words, the case reporting form seems to include information that exceeds the prescribed contents defined in the regulation on reporting.

**Special protection of privacy  
in research and medicine  
Article 10 – Private life and right to  
information**

1. Everyone has the right to respect for private life in relation to information about his or her health.
2. Everyone is entitled to know any information collected about his or her health. However, the wishes of individuals not to be so informed shall be observed.
3. In exceptional cases, restrictions may be placed by law on the exercise of the rights contained in paragraph 2 in the interests of the patient.

**European Convention on  
Human rights and Biomedicine**

*Relevant and sufficient?* Case reporting and tracing of infections are classical public health measures to deal with large-scale epidemics as well as micro-epidemics. In modern Icelandic settings a diagnosis or suspicion of active TB leads to testing and treatment of individuals who are in close contact with the infectious patient. In 1992 a patient with active TB infected 32 individuals before being diagnosed.<sup>128</sup> This shows that reporting can be instrumental in controlling the spread of infectious tuberculosis. But the same arguments are not necessarily valid in the case of latent/inactive or non-infectious TB. Individuals with the inactive form of the disease can be identified by a positive tuberculin test. Such findings can be used to trace the origin of an infection to a patient with active tuberculosis (the carrier). This was the rationale behind the TB-screening in schools. Those are the main reasons supporting the collection of travel or residential history of tuberculin-positive individuals.

Another reason for registration of personal information in the case of inactive infection is that inactive disease can develop into the active and infectious form of TB. It is impossible to predict which cases will develop into the active form and which will not. To prevent activation of the disease an isoniazid treatment of 9 months is suggested for all that have a positive Mantoux-test, and where there is a suspicion of recent infection (in the last 1-2 years). This treatment is voluntary and provided free of charge. Such treatment prevents 90% of inactive TB infections from becoming active.

On the other hand, what is central to the success of follow-up of tuberculin-positive cases that are to be treated with isoniazid is the establishment of trust between the health system and the patient and regular contact of the infected with the health system in case of illness to prevent a delay in diagnosis. The importance of trust

underlines that respect for privacy must be a cornerstone in a successful public health policy in the area of infectious diseases. Confidentiality in the processing of information must be guaranteed. Only the pivotal information needed to trace infections should be collected.

*Least restrictive alternative?* Case reporting is a legitimate measure, but the components, the concrete contents of the reporting, can be excessive, relative to the legitimate aim. Whether the measure is *proportional to the legitimate aim pursued* is a different way to phrase the same question. Reporting with full identity is necessary where tracing is necessary but not in the case of the inactive form of the disease in the absence of an epidemic. Then it is excessive, unproportional.

*ii) Organisation of reporting. Prescribed by law?* According to the Act on communicable diseases the State Epidemiologist shall collect reports (and case reports) on infectious diseases. No special provisions deal with TB or a TB registry. Medical records are to be treated as sensitive personal information according to the Act on protection of privacy.<sup>129</sup> The State Epidemiologist is under a special obligation to respect privacy regarding all identifiable information in reports and registries of infectious diseases according to article 3, paragraph 3, of the Act on communicable diseases. The same paragraph prescribes that the same rules shall apply to the registries as to other medical records.

The strengthened protection of the right to privacy in Icelandic law reflects an international trend. From general protection of privacy in the ECHR in 1951 and the ICCPR from 1976, such rights have been strengthened further in the European

Convention for the Protection of Individuals with Regard to Automatic Processing of Personal Data from 1981(Data Convention), which was ratified in Iceland in 1991, and still further in the European Convention on Human Rights and Biomedicine of 1996, which has only been signed but not ratified by Iceland. Within the EU privacy rights have been strengthened considerably, and the 2001 revision of the Privacy Act was based on Directive 95/46/EC of the European Parliament and of the Council of October 24, 1995, on the protection of individuals with regard to the processing of personal data and on the free movement of such data.

The Icelandic practice and existence of the Icelandic TB registry, however, seems to be based more on history and tradition than on law. Since 1975 a nationwide TB registry has been run by the Centre for Tuberculosis and Pulmonary Disease. This practice is not prescribed in the Act on communicable diseases, and this accordingly calls for the question of whether the current collection of personal data violates the Privacy Act. The Privacy Act defines the legitimate processing of sensitive information in article 9.<sup>130</sup> The processing of data is prohibited unless one or more of the requirements listed in article 9 are met. Two paragraphs are especially relevant. Paragraph 1 states that the registered person can permit the processing of information. Paragraph 8 provides that the processing of sensitive personal information is legitimate if the processing is “necessary because of treatment or normal administrative functions in the health sector.” This covers the information collected from patients treated by the Centre but not sensitive information from other TB-patients handed over by the State Epidemiologist to the Centre. Under the Privacy Act the State Epidemiologist has the option of entering into contracts delegating

responsibility of the storage and processing of sensitive information, given that certain conditions are fulfilled. Such contracts have to be formal and written.

In light of the special needs for confidentiality in the processing of personal information included in the registry of infectious diseases acquired under the Act on communicable diseases, it is questionable whether the State Epidemiologist could sign such agreements in the case of a TB-registry. Given the facts, the question of whether a formal agreement would be legitimate does not arise, as it is non-existent at present. The delivery of information from the State Epidemiologist to the Centre for Tuberculosis and Pulmonary Disease seems to be a clear violation of existing law. In short, the organization of tuberculosis control did not change according to the new Act on communicable diseases of 1997. Neither has the fact that the Centre keeps a TB-registry. The current practice is based on tradition but is neither according to the previous nor the current law.

**Conclusions:** TB is rightfully seen as a potential threat to public health. Measures to control TB can accordingly be legitimate limitations of protected human rights. Case reporting and the collection of identifiable personal information can be regarded as legitimate measures. However, in Iceland, neither the contents nor the organization of case reporting fulfils the requirements that such legitimate limitations have to meet.

*Contents.* The information collected is excessive, relative to the legitimate aims pursued. This practice exceeds the permitted information prescribed in the regulation of reporting under Icelandic law. Furthermore, the register falls short of human rights

obligations as it includes more private information than is needed for the active tracing of infected individuals.

*Organisation.* The register of tuberculosis patients treated by the Centre for Tuberculosis and Pulmonary Diseases does not violate the provisions of existing law. However, in the absence of a written agreement between the Centre and the State Epidemiologist according to the Privacy Act it is a violation of the current law to send reports of other TB-infected patients (not treated by the Centre) from the State Epidemiologist to the Centre without the explicit permission of the relevant patients. The current practice would thus constitute a violation of the right to privacy protected under numerous human rights instruments ratified by Iceland.

#### *Vaccination*

**Current practice:** Mandatory BCG vaccination for TB was planned on a large scale in Iceland, but the plans were never realized. At present BCG is only used to a limited extent in Iceland. Compulsory BCG vaccination is not practiced. Everyone who seeks vaccination with BCG is vaccinated free of charge. In specific circumstances vaccination is recommended. Those

#### **Proposed criteria for permitting routine immunisation, balancing human rights with public health**

1. The danger to public health must be substantial.
2. The condition must have serious consequences if transmitted.
3. The effectiveness of the intervention in safeguarding the majority of the public against the particular malady must be well established.
4. The intervention must be the most appropriate, the least invasive, and the most conservative means of achieving the desired public health objective.
5. The individual must be provided with appreciable benefit not dependent on speculation about hypothetical future behaviour of the patient.
6. The burden to the individual human rights and health must be balanced against and found to be substantially outweighed by the benefit to society in helping prevent a highly contagious disease or other potentially calamitous condition from affecting the public health.

**Hodges, FM et al.: Prophylactic interventions on children: balancing human rights with public health, J Med Ethics 2002; 28: 10-16.**

recommended for vaccination, however, do not sign any kind of consent sheet. Neither do those spontaneously seeking vaccination.

**Analysis:** Vaccination of any kind is an intrusive public health measure, and its necessity must be weighed against human rights implications. By mandatory vaccination a whole set of preliminary questions from a human rights perspective follows. The key issue is the balance between individual autonomy and the protection of a population against a particular infectious disease. Mandatory vaccination has been dealt with as an example of justifiable limitation of human rights before the European Court of Human Rights.<sup>131</sup> In general it could be said that for the balance to be in favour of mandatory vaccination, the infection vaccinated against must be a present threat, have grave consequences if it spreads, and the vaccine has to be effective (protective). Individual risks imposed by side-effects of the vaccination have to be outweighed by society's overall gain .

BCG is not compulsory in Iceland. Its human rights implication is thus similar to most other voluntary medical procedures. Our analysis will thus be focused on the protection of human rights in receiving medical service, access to vaccination and informed consent.

The protection of individuals in medical settings is not explicitly provided for in the UDHR, ICCPR or ECHR. It can be argued that protection is implied in the right to physical integrity. In the development of provisions, from the first human rights treaties to the latest treaty on biomedicine, the focus has shifted from mere protection of subjects of human experimentation, represented originally by the authoritative but non-binding Nuremberg Code of 1947<sup>132</sup>, to a broad acknowledgement of the principle of “voluntary,



informed, competent and understanding” consent as a basic requirement in all medical settings in the recent European Convention on Human Rights and Biomedicine (ECB) from April 1997.

The European Convention on Human Rights and Biomedicine entered into force in 1999. Iceland has signed it but has not yet ratified it. The ECHR was the first legally binding international text designed to preserve human dignity, rights and freedoms through a series of principles and prohibitions against the misuse of biological and medical advances. It stated that the interest of human beings must come before the interests of science or society. Unlike the influential Helsinki Declaration of the World Medical Association, the Convention does not distinguish between research and treatment in its requirements of informed consent. In article 5 the Convention states that: “An intervention in the health field may only be carried out after the person concerned has given free and informed consent to it.” Free and informed consent, on the other hand, legitimizes every medical intervention if the four requirements are fulfilled. This is in accordance with the Icelandic Act on patients' rights, article 7, which urges that such consent be written.<sup>133</sup>

**Conclusion:** Voluntary vaccination with free and informed consent is not a violation of human rights. It nevertheless calls for a process to confirm consent according to law. The current practice of voluntary BCG vaccination in Iceland should include a formal consent form where the necessary information on side-effects and expected protection from the vaccine should be stated as well as other relevant information necessary to make an informed choice to be vaccinated or not. By signing such a consent-form the vaccinated

individual would verify that the four requirements of free and informed consent had been met: voluntary, informed, competent and understanding.

### *Quarantine*

**Current practice:** There are no reports or other evidence of cases of quarantine on the grounds of TB infection in Iceland since the middle of the 20<sup>th</sup> century. Patients with diagnosed or suspected active TB are nevertheless kept in isolation when they need treatment in hospital settings.<sup>134</sup> This, to my knowledge, has never been challenged.

**Analysis:** Several human rights treaties protect the freedom of movement and the right to liberty and security of the person. Limitation clauses previously dealt with apply in every case. Under the Act on infectious diseases, patients are, e.g., under an obligation to follow instructions on treatment and prevention in cases of infection confirmed by their respective physicians. The older Act on control of tuberculosis gave each and every physician powers to have his way regarding medical examination, quarantine and “other necessary measures”, even against the will of infected individuals or people suspected of being infected. The new act prescribes that all such actions must happen at the initiative of the State Epidemiologist.

The right to liberty and security of the person also implies due process in the case of limitations to that right. Current law guarantees due process before a judge for cases of quarantine, cf. article 15 of the Act on communicable diseases in accordance with similar

articles in the Act of legal competence. Each case has to be argued before a court “as soon as possible” and ruled on “without delay”.<sup>135</sup>

**Conclusion:** Quarantine has not been used in TB cases in Iceland for decades. Isolation used during hospitalization of patients with active TB has never been challenged. Icelandic law and practice seems in accordance with international human rights standards in guaranteeing due process in all cases of medically proposed and/or involuntary quarantine and isolation.

#### *Mandatory TB testing*

Under this heading we deal with three closely connected and probably the most frequently used measures of TB control: screening, tracing of infections and mandatory medical examination.

**Current practice:** *Mandatory medical examination.* Mandatory medical examinations are among the measures that the State Epidemiologist can take to stop the spread of diseases that are “a threat to the general public”.<sup>136</sup> He can seek the assistance of the police on resistance or “lack of co-operation”. There are no records of cases of TB-patients where the assistance of police has been needed since the early 20<sup>th</sup> century. In practice, mandatory medical examination is most commonly practiced as a part of either screening for or tracing of TB.

*Tracing of infections* is often a case of mandatory testing of a particular group that has been or is suspected of having been in contact with an individual with active TB.

*Screening of groups.* General screenings for TB on the whole population in Iceland only exist in public health history. TB testing in schools was the last general screening of the country's residents. It was discontinued in the last decade.

Following international reports of a rise in TB in prison settings, all prisoners were screened by means of Mantoux testing in the late 1990s. The screening was on a voluntary basis. Three prisoners refused testing and were offered pulmonary X-rays to detect active TB. They all accepted X-raying as a substitute. As no infections were detected among the prison population, TB tests are only offered in prisons on a voluntary basis and if clinically indicated. Drug users in rehabilitation programs are only tested for TB if clinically indicated.

In recent years screening has been directed at groups of immigrants. The reason given is that in surveys they have proved to have an excessive incidence of TB. All immigrants from outside the area defined by the European Economic Area Trade agreement have to undergo medical examination. Those under the age of 35 are screened for TB by Mantoux testing.<sup>137</sup> If positive the test is complemented by a pulmonary X-ray. Active TB is treated with a three-drug treatment. Non-active TB is treated with a single drug if the infection is likely to have occurred in the last two years.

Adopted children are both Mantoux-tested and X-rayed. Individuals infected by HIV are offered a number of tests and medical procedures to map the current status of their disease. Mantoux-tests and pulmonary X-rays are included. The TB-status of all

## Compulsory and voluntary TB testing in Iceland

	TB test	Comp/vol.	Ident./anon.	Reporting of cases	Cost
General population	If clinically indicated	Voluntary	Identifiable	Full identity	Free
Refugees	All/Mantoux/X-ray	Compulsory	Identifiable	Full identity	Free
Immigrants	All/Mantoux/X-ray	Compulsory	Identifiable	Full identity	Free
Children of foreign origin	All/Mantoux/X-ray	Compulsory	Identifiable	Full identity	Free
Individuals with HIV	Mantoux/X-ray	Voluntary	Identifiable	Full identity	Free
Prisoners	Mantoux/X-ray <sup>138</sup>	Voluntary	Identifiable	Full identity	Free
Drug addicts in re-hab	If clinically indicated	Voluntary	Identifiable	Full identity	Free

Table X. Information gathered by interviews with doctors responsible for the respective fields in Iceland during the summer of 2001.

HIV patients are known, implying that they all have consented to such tests.

**Analysis:** *Tracing of TB.* Several rights protected by international human rights treaties are relevant for mandatory medical examination and TB testing. The standards to which mandatory public health programs should be held have been proposed in the *Journal of Health and Human Rights*, dealing with the case of Directly Observed Therapy on TB. Building on the Universal Declaration of Human Rights and the ICCPR, four standards were proposed:<sup>139</sup>

First, it should be clear that failure to implement the mandatory program would impact on the rights of others [...].

Second, even if a mandatory program is shown to be effective at preventing individuals from causing harm to others, it needs to be the least restrictive feasible alternative [...].

[Third,] a mandatory program must be not only effective but more effective than a voluntary program [...].

[Fourth,] the program must be fairly and equitably administered.

These standards reflect the general limitation clauses of several human rights treaties as analyzed earlier.

**Conclusions:** Building on the mentioned standards, it seems obvious that tracing of infections is a standard example meeting the first three mentioned standards. The reasons are the following:

1. If TB infection is not traced, it will spread to more individuals than if action is taken.
2. Tracing is directed at a group on factual basis that makes mandatory testing a much more effective strategy than “blind” screening.
3. Effective tracing can prevent a micro-epidemic from developing into a macro-epidemic. A voluntary program runs the risk of losing control of this development.

Fourth, “the program must be fairly and equitably administered”, has to be assessed on a case-by-case basis.

**Analysis:** *Screening of groups.* The same arguments and analysis presented in the chapter dealing with vaccination apply to voluntary screening. This simplifies the discussion as most screenings of individuals and groups are voluntary. The only mandatory screening is in the case of immigrants and adopted children.

*“Other necessary measures”*

“Other necessary measures” under the Act on infectious diseases have to be subjected to the same rule as other provisions, that mandatory measures should only be taken if less restrictive ones have proved insufficient. Of possible “other measures” under the act, mandatory medication and forced medication will be discussed briefly.

**i) *Mandatory medication (DOTS).*** The most widely used form of mandatory medication in the world is Direct Observed Therapy (System) (DOTS), where a health worker watches (observes) the patient while he takes his medicine. This is not practiced in Iceland although all other requirements on infrastructure and other issues of DOTS are met.

**ii) *Forced medication.*** Forced medication is not specifically mentioned in the Act on communicable diseases. Does this mean that forced treatment is precluded, for example, if a patient with active tuberculosis refuses to take the necessary medication? My answer is yes. Even if article 14 provides that medical examination, quarantine and “other necessary measures” are legitimate “to prevent or stop the spread of infections that threaten the general public”, I would argue that forced medication would not fall within “other necessary measures”. The reason for this is that quarantine of an individual is sufficient to “prevent or stop the spread of infections”, and adding forced medication would not serve this legitimate public health purpose. Forced medication is thus not a

measure prescribed by law. Second, forced medication is not part of least restrictive, alternative public health measures prescribed in article 14 of the Act of communicable diseases.



## V. TB screening of immigrants in Iceland

There is no official policy of TB control in Iceland. Based on practice, it could nevertheless be said that the screening of immigrants for TB is the heart of the *de facto* policy. A special chapter dealing with it therefore seems called for. Within international law the field of movement or restrictions of freedom of movement over national borders can be divided into three categories: entry, travel and residence.<sup>140</sup> Both entry and residence are subjected to conditions in Iceland.

Foreign nationals have no *a priori* right to enter a state.<sup>141</sup> Such entry falls within the sovereignty of that state. Furthermore, “each country is sovereign in determining the conditions of access to its territory.”<sup>142</sup> However, almost every state has restricted their jurisdiction in this respect by entering into mutual agreements with other states. Second, even though human rights are predominantly obligations of states towards their own citizens, or in some case all inhabitants, a commitment to the general principle of non-discrimination provides restriction to the measures taken. A ban on discrimination implies objective criteria and a basis in law, even in the case of non-nationals. Third, domestic law often provides protection that exceeds obligations under international agreements and law.

The legal status of foreigners entering Iceland can be divided into three categories, based on regional agreements and/or the lack of such an agreement.

*1. Citizens of the Nordic countries.* The Nordic countries have entered into agreements giving each others residents full rights to travel and live in other Nordic countries without any restrictions whatsoever. Citizens of the Nordic countries do not have to apply for residence permits in other Nordic countries. They subsequently need no further address in the context of TB-control.

*2. Citizens of the EEA-countries.* The most influential agreement on free movement of people to Iceland is the Agreement on the European Economic Area (EEA) entered in 1994. It provides the right to free movement for workers between the countries within EU and EFTA that are parties to EEA. These rights have been extended to job seekers, students, graduates, retired people and the unemployed.<sup>1</sup>

*3. Citizen of non-EEA-countries.* This group is largest and only protected by IHR, general obligation in international human rights law and domestic Icelandic law.

#### *Citizens of the EEA countries*

Non-Nordic individuals from the EEA countries have the right to stay in Iceland for three months without a special permit or six months if they are actively seeking a job. After that they have to apply for a residence permit. After the EEA agreement entered into force, the question arose whether workers from the EEA could be subjected to medical examination, making a health certificate a prerequisite of a residence permit.

The Ministry of Foreign Affairs ruled that this was possible in the case of tuberculosis, based on EU Directive 64/221. The Annex to the Directive lists diseases which might endanger public health and, as such, can justify refusal of entry or refusal of a residence permit. It includes “tuberculosis of the respiratory system in an active stage or showing a tendency to develop.” The National Committee on Communicable Diseases accordingly issued guidelines making TB control a prerequisite of residence permits for people working in food-related industries.<sup>143</sup>

However, despite the powers under Directive 64/221, the Ministry of Justice issued a regulation on EEA foreigners, where a medical examination was not made a prerequisite for residence permits.<sup>144</sup> This meant in practice that only non-EEA foreigners had to provide health certificates with their applications for residence. Furthermore, although the revised Act on Foreigners, No. 96/2002, provides that “Application for a permit to stay as provided for [...] may be denied if a situation applies which may provide an occasion to deny the foreigner entry into Iceland, a stay in Iceland, or employment in Iceland, under other provisions of law,” a danger to public health was excluded from the list of justifiable reasons to refuse entry or expel EEA citizens. The only way to exercise such refusal or expulsion was with reference to “state security or urgent national interest” or “public order and security”.<sup>145</sup>

The argument was that it is “no longer reasonable and not obligatory under the EEA agreement” to limit the free movement of EEA citizens on the basis of a presumed danger to public health.<sup>146</sup> Since 1 January 2003 it is not required by law to make medical examination and TB-testing part of the application process for residence permits for EEA citizens. Accordingly, it would constitute a violation of human rights to practice either. I have found no examples of such practice. Neither has there been a rise in TB cases following the discontinuation of such tests for Europeans from EEA countries.

### *Non-EEA citizens*

Non-EEA citizens applying for residence and work permits are the only group subjected to mandatory medical examination and TB-testing in Iceland, in other words, general

screening (described earlier). With regard to the law, at least three questions have to be answered; first, is it in accordance with international law to make screening for TB a condition for residence, and, second, is it in accordance with Icelandic law, and on what premises? Third, such screening has to be evaluated according to how the current practice conforms to these conclusions.

The first question has a short answer.<sup>147</sup> As mentioned, “each country is sovereign in determining the conditions of access to its territory.”<sup>148</sup> This includes the condition of providing medical certification of health status when individuals from outside the EEA apply for a residence permit in Iceland.<sup>149</sup> It can, however, be argued that any conditions required should be defined and applied in a non-discriminatory manner. This shifts the focus to the second question, Icelandic law. Article 66 of the Constitution states that limitations to entry and residence in Iceland have to be laid down by law: “The rights of aliens to enter and reside in Iceland, and the reasons for which they may be expelled, shall be laid down by law.”

In the context of tuberculosis these constitutional requirements are fulfilled in the Act on Foreigners. The Minister of Justice has issued rules, including the condition of medical certification for residence permits under article 3 of the act.<sup>150</sup> The condition is further reinforced by article 6 of the Act on Foreigners Right to Work, No. 97/2002, which states that one of the conditions for a work permit is that “sufficient medical certification” is provided.<sup>151</sup> This affects the situation of each applicant as a working permit is a prerequisite for a residence permit in Iceland.

Further rules on what tests or examinations are to be included in medical certification are, however, lacking. It could probably be argued that this is a well-known

fact at the Directorate of Health. An amendment to the law in 2000 shows recognition of the lack of a legal basis for the screening of applicants for residence permits. The new legal provisions provide that “if the State Epidemiologist considers that there is a danger of importation of infectious diseases to the country threatening public health, he can ask the minister to draw up a regulation for medical examination of groups of people coming to the country that might be bearers of such diseases.”<sup>152</sup>

To date no regulations have been issued based on this provision. This implies that the current practice is not based on law. This has led to differences in the practice of medical practitioners when it comes to issuing medical certificates. The most serious consequence is the absence of safeguards for applicants’ rights that are at the heart of the requirements in both the Constitution and the Act on communicable diseases.

Apart from the Act on communicable diseases, the Act on patients' rights protects all users of the health services equally,<sup>153</sup> making informed consent a condition for intrusive medical tests or treatments.<sup>154</sup> The Act on patients' rights thus protects foreigners applying for residential status from mandatory TB-testing in the absence of rules set under the Act on communicable disease.

The procedural guarantees in the Act on patients' rights and the Act on communicable diseases with further reference to protection of privacy under the Constitution and subsequent law lead to the conclusion that the current practice of general mandatory screening is a violation of human rights in the absence of a legal basis.<sup>155</sup> The existence of guidelines (without bases in law) that do not involve counselling and informed consent leads to a practice that violates protected rights under the Act on patients' rights as well as a number of human rights. Furthermore, the absence of rules to

handle the vulnerable situation of individuals applying for residence permit seems to leave the door open for discrimination.

**Conclusions:** In the absence of clear rules or regulations issued on a legal basis, mandatory screening of non-EEA foreigners contradicts Iceland's commitment to human rights as expressed in the country's Constitution and protection of individual rights under law. Mandatory medical examination as part of the process of issuing a residence permit can be supported with reference to the right to health in the sense that states have obligations regarding "the prevention, treatment and control of epidemic, endemic, occupational and other diseases." This means that intrusive tests and procedures can rightfully be part of that examination in the absence of signs or symptoms of active disease. Such practices, however, cannot be established without violating protected human rights unless procedural safeguards are provided. The ruling of the Ministry of Justice not to screen EEA citizens, irrespective of TB incidence in their home countries, raises the question of whether the unconditional screening of non-EEA citizens is, in fact, discriminatory.

According to Iceland's status as a low-prevalence country in the context of TB, it would probably be wise to explore a less restrictive alternative in screening immigrants, with emphasis on voluntary testing and active case finding as recommended for low-prevalence countries by WHO. Furthermore, as long as medical examination is a condition for residence permits, it is pivotal that guidelines on such procedures be issued. They should respect both the law and human rights as well as being based on sound arguments on the most effective public health strategies to tackle TB. A proposed

guideline for TB-testing would be to test all immigrants requesting it, and when such tests are clinically indicated.

## VI. General conclusions

In the present thesis we have explored how “all public health measures are intrusive.”<sup>156</sup> The protection of public health is nevertheless an obligation of every state. This tension between the protection of public health and the rights of the individual is exactly what makes public health highly interesting from a human rights perspective. It both sets in focus the legitimate restrictions on protected human rights and raises the question of what legal protection and fair procedures are necessary when such restrictions are legitimate. As we have concluded, Iceland cherishes its obligations towards the protection of public health but fails to provide for necessary protection of individual rights in the collection of sensitive information on TB and screening of immigrants.

These conclusions illustrate that TB control is a good test case for public health policy in terms of its sensitivity to human rights. Does the policy take notice of the two different forms of TB, infectious and non-infectious? Sensitivity to that fact shows whether public health measures are visibly and proportionally connected with aims, e.g., whether policy is directed towards a *threatening disease* (the infectious form) or simply *the fear* of TB (all forms). As we have seen, the current Icelandic regulations fail to take notice of this crucial difference.

Accordingly, the main conclusions of the thesis are that despite good results in terms of TB-incidence and prevalence, service that is free of charge and an effective system of surveillance and tracing, the current practice (or regulations) of TB control is not sufficiently sensitive to human rights. This could and should be addressed by a



human-rights-sensitive approach in a coherent TB-policy for Iceland. Such policy is non-existent at present.

**An outline of a human-rights-sensitive national TB-policy.** In the absence of an official TB-policy in Iceland, two recent proposals or guidelines for such policies will be reviewed briefly. First, in a recent article in the prestigious *Journal of Health and Human Rights*, a human-rights-sensitive approach to TB is proposed by adapting and applying existing guidelines for HIV/AIDS.<sup>157</sup> This would not take note of the different routes of distribution of the two diseases, the difference between casual and intimate contact and the radical difference that TB can be cured, but patients with HIV/AIDS have a totally different prognosis. The proposal therefore seems a bit banal, not only from a medical perspective but also in light of human rights. In the case of the infectious, airborne TB bacillus, the strictly voluntary and confidential approach that has been established with regards to HIV/AIDS seems to be off the mark in fulfilling the obligations of states to protect public health and control potential epidemics.

The second proposal from recent literature seems a more viable path towards a human-rights-sensitive TB-policy for Iceland. This is to follow the schematic analysis of a tool developed at the Harvard School of Public Health, coined: “A Human Rights Assessment for the Formulation and Evaluation of Public Health Policies” (HRAFEPHP).<sup>158</sup> Its seven-step approach is designed to balance the public health benefits of a policy against its human rights burdens. Although the tool could use a shorter name (HRAFEPHP!), it seems to highlight some of the main questions under each of the seven steps to illuminate the tasks and alternatives that policymakers face in

framing a human-rights-sensitive TB-policy. For increased clarity I have added step II ½, adverse effects.

**Step I, Purpose?** A policy of tuberculosis control only exists in the form of established practice but not in the form of an official document or regulation. Issuing of health certificates is at the heart of the policy of tuberculosis control as the only active screening for tuberculosis practiced in the country. In contrast to the issuing of health certificates for meat, pets, housing or industries, there is currently no regulation or clearly formulated policy on the issuing of health certificates for immigrants in Iceland.

Searching for a defined purpose in the current official regulations or documents leaves us with few clues. The recommendation of the Director of Health regarding the issue of health certificates for

immigrants defines neither the goals of TB control nor the purpose of issuing health certificates for immigrants although it gives a broad statement of the need for medical examination and diagnosis to start treatment and vaccination as soon as possible.<sup>159</sup> This would be the first of three possible goals of TB control, the protection of the health of immigrants. Other goals implied in the practice could be preventing the importation of

### **Human rights impact assessment**

Step I: Clarify the Public Health Purpose  
 Step II: Evaluate Likely Policy Effectiveness  
 Step II 1/2: Evaluate (unexpected) adverse effects  
 Step III: Determine Whether the Public Health Policy Is Well-Targeted  
 Step IV: Examine Each Policy for Possible Human Rights Burden  
 Step V: Determine Whether the Policy Is the Least Restrictive Alternative That Can Achieve the Public Health Objective  
 Step VI: If a Coercive Public Health Measure Is Truly the Most Effective, Least Restrictive Alternative, Base It on the "Significant Risk" Standard  
 Step VII: If a Coercive Measure Is Truly Necessary to Avert a Significant Risk, Guarantee Fair Procedures to Persons Affected

tuberculosis and/or eradication of the disease.<sup>160</sup>

The danger of importation does not seem to be a part of the Icelandic government's rationale for TB-screening as no regulations have been issued under the Act on communicable diseases under the premises of a “danger of importation of infectious diseases.” This almost leaves out the third (but unmentioned) purpose of Iceland’s TB-policy: the eradication of tuberculosis. That is, as a matter of fact, the official TB-policy of neighbouring country Norway leads to a similar practice in terms of the TB-screening of immigrants.

To reflect how the defined purposes lead to different approaches with different human rights implications in TB control, a short elaboration seems appropriate:

1. **Voluntary approach.** A free health service, including diagnosis and treatment of TB and other diseases, can be a sound and legitimate public health policy for immigrants who are without insurance coverage for the first six months in the country. This can contribute to successful integration, build trust towards public institutions as well as provide necessary counselling and treatment for medical problems. It is, however, questionable whether such service is best provided by mandatory means by centres specialized in tuberculosis rather than primary health care that will continue to service the respective immigrants.

2. **Mandatory approach “at the borders”.** Mandatory medical examination to stop the spread of the potentially dangerous disease, tuberculosis, is not mentioned in recommendations but is referred to in the Act on communicable diseases. This might seem a sound and legitimate public health policy and is indeed practiced by several countries. There is, however, no convincing evidence that tuberculosis among the

immigrant population measurably affects the epidemiology among the indigenous population.<sup>161</sup> Accordingly, this does not seem to be a sound purpose for a successful TB-policy as its mandatory measures can undermine trust between immigrants and the institutions of society, e.g., health care, which can be at least equally important to deal with future epidemics or activations of latent TB-infections within a given population.

**3. Mandatory/eradication approach.** The eradication of TB is not mentioned as a goal of Iceland's policy but is surely seen as a long-term commitment.

**Step II, Effective?** A sound policy has to be evaluated and re-evaluated by its impact. Its goals have to be clearly defined and preferably be measurable. It is impossible to fully evaluate the current practice of TB control in the absence of a defined purpose or measurable goals.

**Step II ½, Adverse effects?** A sound policy has to take into account the possible adverse effects of each approach. A voluntary approach could have the unwanted effect that infectious TB might go undetected, and undetected latent infections could remain undetected until becoming activated. A mandatory approach, on the other hand, could lead to a false feeling of security and perhaps a lack of trust between (infected) immigrants and public service and therefore delay contact with the health system in the case of symptoms.

**Step III. Well targeted?** A sound policy should target a well-defined problem, i.e., infectious TB, and the relevant population. From an economic perspective it is furthermore necessary to focus the search or screenings on producing a better outcome than the alternative of doing nothing. From a human rights perspective it has to be

critically examined whether vulnerable groups are targeted merely because they are an “easy catch” rather than a sound target group.

**Step IV. Human rights burdens?** Every public health policy towards TB control has human rights aspects. To weigh the protection of public health against human rights burdens, it is necessary to analyze the burdens of each policy option.

**Step V. Least restrictive alternative?** In light of a valid purpose and goals of TB control, the policy that imposes the least human rights burdens should be put into practice. This places an obligation on policymakers to evaluate alternative (and less restrictive) approaches to serve the aims of each policy option.

**Step VI. Significant risk?** In the case of policies where coercive action seems to be the only effective and least restrictive alternative, it nevertheless has to be evaluated in each individual case whether there is a significant risk to the public. This is meant to “replace decisions on irrational fear, speculation, stereotypes.”<sup>162</sup> This seems to be highly relevant in the context of TB-screening of immigrants.

**Step VII. Fair procedures?** Where all the above conditions are met, there nevertheless has to be a guarantee of fair procedures for the persons targeted and/or affected by the relevant public health measures.

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