



MINISTRY OF
SOCIAL AFFAIRS AND HEALTH
National Advisory Board on Health Care Ethics
(ETENE)
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ADVISORY OPINION

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Parliamentary Legal Committee

Government Bill 26/2001 to Parliament on the processing of personal data when carrying out punishments

The parliamentary Legal Committee asked The National Advisory Board on Health Care and Ethics (ETENE) for an advisory opinion on the subject of the Government Bill on the processing of personal data when carrying out punishments. The Bill includes provisions on the Criminal Sanctions Agency's registers, the data they contain, their usage and the principles of data processing. In addition, there are provisions on the registration of health-related information and one on exceptions from the obligation on secrecy for health care professionals. Considering ETENE's field of expertise, the Board's opinion was presumably invited specifically on the provisions related to health care.

The aim of the Finnish Prison Service is to create a uniform prisoner data system comprising all the information on the enforcement of penalties, prison health care and prisoners' activities and supervision. Personal health care issues constitute information that does not necessarily relate to the other information entered in the register. Under Finnish law, health care registers and patient documents everywhere else are unit-specific and data cannot usually be transferred from one unit to another without the patient's consent. Elsewhere in the law, emphasis is laid on the protection of privacy and the fact that individual units are only allowed to transfer medical records to the extent necessary for processing the issue at hand, and always only with the patient's permission.

The preambles of the Bill refer to recommendation R (98) 7 of the Council of Europe Committee of Ministers which repeatedly stresses that prisoners must be guaranteed confidentiality which is to be respected like that of the population at large (C13). On the subject of HIV and other infectious diseases, the document states that prisoners must be allowed consensual, anonymous HIV tests according to the existing laws. An infected prisoner may only be isolated on the same medical grounds as are applied in a non-prison environment. HIV infection should not lead to discrimination.

The basic principle of the central register project is that the entire Finnish Prison Service is considered as a single entity where documents can be transferred from one unit to another without special measures, or accessed by all units if a prisoner is moved from prison to out-patient care, for instance. The Bill emphasises that only health care professionals are allowed access to the health care register. The same applies in other health care units as well; patient documents are only accessible to health care professionals, with the additional restriction that access is only allowed to those who are personally involved in the patient's treatment (and work in that par-

ticular unit). Otherwise, patient information may only be processed or transferred with the patient's consent. It is important to consider whether the aim of this new legislation is to secure a functional new data system or to improve prison health care and conditions. If we want or need a centralized health care register in the first place, it should preferably not be connected to other databases.

The Bill also suggests that, for reasons of safety, a physician or a health care professional specified by a physician should be entitled to give information to the governor of a penal institution uninhibited by the professional secrecy obligation if a prisoner has contracted HIV or hepatitis or some other disease liable to cause public hazard, and there is a specific risk that it may spread. It remains unclear whether the health care professional is entitled to refuse to pass on such information even if the prison governor insists. The Bill also states the prison governor is obliged to keep such information secret. It is questionable, however, whether the information can be kept a secret if the prison governor takes action by isolating the prisoner or suggesting special protection for prison officers etc.

Key issues in health care ethics include patient rights, fairness and respect for the patient's rights of self-determination and human dignity. These issues are dealt with in various international declarations and conventions, such as the Council of Europe's Convention on Human Rights and Biomedicine, with particular emphasis on people with reduced capacity or possibility for self-determination in matters such as consenting to testing and treatment. The Finnish Act on Medical Research, for instance, contains separate provisions on examining prisoners. The right not to consent to the transfer of personal data is an issue related to the right of self-determination which concerns all sectors besides health care. There has been a lot of discussion in Finland on whether health care professionals should be given the right to deviate from their secrecy obligation in matters related to genomes, if the data in question could benefit the patient's family members or close relatives, for example. Without the patient's consent, health care professionals are still not allowed to disclose a patient's HIV or hepatitis infection even if the patient's close relatives stand the risk of becoming infected, too. Very often in such situations the patients inform their kith and kin themselves.

From the ethical point of view it is worrying that prisoners should have a different status from other people in health care matters. Under the Bill, health care professionals are not even required to ask for a prisoner's consent to disclose information that may be very difficult and sensitive from the point of view of the patient. Presumably, the aim is to protect prison staff from health risks. If this provision comes into effect, both current and future prisoners will have to be informed of the matter. Passing the provision might well cause prisoners to conceal their diseases even from health care professionals, so that they will not receive proper care, and, in consequence, the risk of the infection spreading among the prison staff will increase considerably.

Should the Bill be enacted, it begs the question whether similar laws are needed to regulate the non-prison population, too. Such provisions are aimed at controlling the rights of self-determination and privacy of some by limiting those of others – with good intentions but potentially harmful consequences. Any provisions restricting human rights should be considered very profoundly, to determine how far we can go

in restricting the rights of persons whose right of self-determination is already limited, and who depend on other people to pass on and receive information.

Many European countries consider the duty to report to be unfounded. We fail to see why Finland should be a pioneer in restricting the protection of privacy.

The National Advisory Board on Health Care and Ethics (ETENE)

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