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SESSION I: Problems associated with the lack of coordination in national and international health statistics

**CONDITIONS FOR THE ADEQUATE FUNCTIONING OF HEALTH STATISTICS AS A PART OF
NATIONAL STATISTICS**

Supporting paper submitted by the Institute of Public Health of the
Republic of Slovenia¹

Introduction

1. Health statistics has a long-standing tradition in Slovenia. It dates as far back as 1890 and is of even bigger importance nowadays. In 1976, the health statistics was legally grounded and its essence has not been altered until the present day. Great changes during the beginning of 1990's demanded that the statistical system be entirely reformed. At the beginning of 1992, new Health Care legislation and Health Care Insurance legislation was adopted.

2. Slovenian health statistics is almost fully centralised. Institute of Public Health of the Republic of Slovenia is responsible for collecting, analysing and processing of medical data. Institute provides data (HFA; HSI etc.) for government and other institutions like WHO, UNICEF, World Bank etc.

Major effects on the health statistics arising with the new legislation (with new conditions)

a) Positive effects

New legal background

3. Within the new Health Care law, article 54 requires a preparation of new regulating records in Health Care System. On the other hand, the Data Protection law (DPL), which was adopted in 1992, requires that a national law should define personal data to be collected, analysed and transacted. The second generation DPL is now at the end of the parliamentary procedure. It is completely standardised with the newest European Directive and introduces new

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rules during the data exchange (asymmetric cryptography, health care number etc.)

4. Recognising that Slovenia is a member of the Council of Europe and associated member of the European Union, it was necessary to implement the fundamental values of European recommendations to the new Health Care Record Law that is now in parliamentary procedure. The purpose of the project was to define the most vital elements of the medical records. Therefore the new law defines purpose, content, administrators, dates, storage time, senders of data, users of data (interfaces with other institutions on the national level) and define whether data are identifiable or anonymous. It also validates the electronic signature.

5. Nevertheless, DPL still defined under which condition personal data should be collected, analysed, processed, or transacted. This subordination to the DPL sometimes causes dismay among epidemiologists because of the anonymity of personal data which often make a scientific research project impossible.

Use of personal data

6. The first important results were that data protection has been increasingly dealt with in various medical professional meetings. Subjects within health care system have become more sensitive and inclined to a more sensible use of personal data. General accessibility to personal data and familiarity of that phenomenon suddenly disappeared and was transferred with the raise of awareness considering the use of personal medical data. New HC Register law offered an opportunity to data administrators to: a) set up a realistic extent of data and b) to provide a legal background for their medical record. New HC Record law is register pointed law.

Modernisation of medical data registers

7. There are lots of reasons that have instigated the modernisation of almost all health care data registers. New ICD 10, new health care legislation, new conditions and general needs are just some of the main reasons why we have successfully modernised primary health care data register, outpatient and hospital health care data register. With modernisation we have introduced unique definitions, standards and methodologies.

Unification of data structure

8. In Slovenia we still use predominantly diskette media to transfer data from regions to the Institute of Public Health, and vice versa. We have developed and implemented electronic data interchange network in communication between these institutions. With unification of data structure we have achieved the condition under which we can transfer data through this network (during September and October of 1998) . Nevertheless our data structure is not yet completely unified with the EDIFACT standard.

b) Problems

Polymorphism of existent networks

9. Increasing electronic communication with medical data raises some questions. Current information technologies offer some closed networks like Health Care network, Health Insurance network, Government Centre for Informatics network etc. All of them are still in process of independent and mutually uncoordinated development. Nevertheless the needs for data transactions exceed capability of the networks mentioned above.

Security demands

10. The newest European Directive defines cryptographic mechanism as an obligatory model. An electronic document can be (and must be!) protected by encryption and by reverse process called the decryption. In a so-called asymmetric system, the decryption key and the encryption key are different. It is vital that at a national level, a public service and common key (key management), is established for all users of the Slovenian Health Service.

Different numbers of identification

11. There are several numbers of identification currently in use. The most important is PIN (Personal Identification Number) managed by Statistical Office of the Republic of Slovenia. It is a 13-digit number which is assigned to every new-born and to any person to whom it either hasn't been assigned by mistake or when it needs to be corrected. It is entered in the majority of personal documents, such as personal identification card, passport, driving licence but also in the medical documents like charting list, mortality data base etc. Some of registers like cancer register, vaccination register, perinatal information system are updated by means of the PIN. Many of research projects use PIN to access the data held in the Central Register of Population.

12. In health care there are two numbers: Health insurance office use insured person number, in hospital care there is a patient number used within the hospital area. New data protection law requires that the health care system must have a special, so-called health care number. It is not quite clear who will manage and share this number within the health care system.

Lack of interest

13. Lack of interest and unawareness of statistical data being useful for giving guidelines of health care system even by those who are responsible for health policy. The legislation explicitly quotes both - the subject and the administrator of the public health system, while the dedicated funds cover only one man-year of professional work on the subject. By general assumption, the move is not due to the rationalisation but presumably an attempt to neutralise the medical control over the national public health service network. On the other hand, the national health insurance institution is observed to meet the new national financial strategy, disregarding some items from the new Health Service Law.

Self-efficiency of the therapeutic sphere

14. The Slovenian medical science and health service has reached a considerably high level in many therapeutic areas. Being recognised as such, the therapeutic sphere often does not recognize the need of medical statistics in public health politics. The phenomenon reflects the lack of

tradition in civil service.

Rapid changes in number of local self communities units

15. In 1994, a rather rapid process of administrative changes in the area of local community structure and organisation started. Later in that year referendums were organised and the total number of local communities increased from 65 to 147. Over the years 1995 and 1996, the structures were being established. Primary health care had been even previously under the authority of the local communities and it had remained so after these changes had taken effect. Therefore, the state decided to reorganise its internal administration leaving little room for the specificities of the individual areas of social services. In 1998, more local communities are to be established which will lead to an even more complex and difficult running of the health related data at primary level, since the observed populations at the level community will quite often be under 10,000, very often under 5,000 people.

Conclusions

16. In Slovenia the registration of vital events and other features within health care statistics system is satisfactory. The present system has been developed for several decades and will be developed further more. Main task is close and logical integration with an already well organised statistical office and other administrators within health care system.

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