

# The Czech National Healthcare Information System will considerably enhance information support to diabetology – Editorial

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Dear Readers,

The collection of studies presented in this supplement brings valuable information on the care of patients suffering from diabetes in the Czech Republic. Understandably, the studies mainly focus on monitoring of serious complications relating to the development of the disease, treatment availability and its current and overall results. It is no coincidence that it is in these areas where data analyses bring the most valuable feedback for doctors and for the management of medical treatment alone. On the other hand, the published studies may also be interpreted as a kind of ‘tasting’ of what can yet be achieved through a truly systemic and consistent collection of data. It is a challenge the resolution of which the present development of the National Health Care Information System (NZIS) still owes to diabetic patients and their doctors and that we are now endeavouring to live up to. The high values of incidence and prevalence of this disease alone justify the need of systematic monitoring of epidemiology and treatment availability and its quality and results. Considering that the National Cancer Control Programme receives such backing through the National Cancer Register along with tens of relating partial registers, it is difficult to explain why the same attention has not been paid to diabetology and its data. The articles in this supplement demonstrate a commitment to collaboration not only among the professional medical public, but also on the part of health insurance companies. This is a very good basis for expanding the NZIS services which we are currently trying to achieve.

However even a most up-to-date information service for any segment of medical care will involve some load of work for the professional staff and doctors. It is not possible to avoid the need for some part of the data to be collected manually and then validated and reported. The main task within the modernisation of NZIS is to minimise this burden and therefore maximally utilise the already existing data sources. I have in particular in mind the data from healthcare information systems and the data accumulated in the databases of health insurance companies. Still the willingness to collaborate

alone is not enough for the completion of the data analysis. The administrators of such data must have an appropriate legal authorization and the data processing itself must be carried out in a manner considering the very important protection of personal data. For this purpose we have prepared an amendment to the Healthcare Services Act No 372/2011 Coll., in which we define new data components and functions, whose implementation will certainly be also supported by the National Diabetes Programme.

The following paragraphs briefly summarise the main benefits of the proposed amendment that are in agreement with the themes and conclusions of the articles published in this supplement. The main items of the amendment include the following:

1. The law newly defines a NZIS administrator which is the ÚZIS ČR. The previous legislation allowed for delegation of this power to several subjects including newly established legal entities, which is not acceptable with regard to the necessary protection of personal data and the necessity to clearly define competences in this area. It is impermissible that the maintenance of such valuable departmental data be handed over between different subjects or divided among multiple entities.
2. The law newly defines that one of the main purposes of use of NZIS data is the evaluation of healthcare quality. Healthcare quality evaluation, or more precisely generation of objective indicators of healthcare quality, is certainly one of the basic purposes of NZIS existence and departmental data collection. The use of NZIS data for the evaluation of healthcare quality is in compliance with applicable international standards and commitments the Czech Republic agreed to adhere to.
3. The law newly defines the National Medical Staff Register in the form that corresponds to the judgement of the Constitutional Court (No. 437/2012 Coll.). This register is newly defined as a fully non-public reference system without which it would be difficult to imagine any meaningful start of digitalization of the Czech healthcare agendas. Without this system

it is also not possible to credibly quantify the numbers of medical professionals, evaluate the availability of staff capacity nor carry out staff resources planning. The reference system will provide for electronic identification of staff capacity according to different fields of expertise, specialisation and special professional competence. The draft law defines the register so that it is not competitive toward the already existing databases, e.g. of professional societies, instead it will serve also these subjects as a source of reference information.

4. The law newly defines the obligation of health insurance companies to provide fully representative data on the paid care for analyses within NZIS, that means, a national register of paid healthcare services will be newly established. This system can also be seen as a database that will enable control of healthcare paid from public health insurance, which is certainly a legitimate right of the state as the dominant healthcare payer. The secondary effect of the new register operation will be significant diminishing of the redundant data collection which in the form of resort reports obtains data already included in the data registers of health insurance companies. The register will be build up in collaboration with health insurance companies and these will also benefit from the data validation and produced analyses.

Another important point of the proposed amendment is the establishment of the National Diabetes Register as a legitimate part of NZIS, founded on the appropriate legal authorisation. The proposal for the register is based on the following:

- It is an important and so far missing medical register focused on one of the most serious segments of care from the epidemiological and curative point of view in the Czech Republic. The growing incidence and prevalence of people with diabetes calls for optimisation of the provided care, evaluation of its quality and effectiveness and also predictive assessment of the curative and epidemiologic load. The monitoring of these statistics is increasingly required by leading international organisations, namely in the studies analysing the state and performance of healthcare systems (OECD, WHO, EUROSTAT). The new register will minimise the accumulation of the administrative burden on outpatient and inpatient care providers

regarding patients with diabetes. The establishment of the register requires an intensive collaboration with health insurance companies and maximum utilization of the data already available.

- As in other NZIS medical registers, the register will process personal data needed for patient identification; socio-demographic data (age, gender, occupation) influencing a patient's health condition (basic risk and prognostic factors), data regarding the disease and its treatment, personal and family history related to the disease, including a classification of the type and stage of the disease, selected laboratory values, provision of dispensary care and information regarding (possible) death of a patient; data required for identification of the providers who determined the diagnosis, provided the treatment and dispensary care.
- Specific purpose: a register focused on monitoring of availability, quality and long-term results of the care for patients with diabetes and also a register evaluating prevalence of diabetes as a serious comorbidity of other diseases, e.g. malignant tumours.
- Accessibility of processing: the processing is entirely non-public – the register is not intended for any public processing or publication of personal data; the access to primary records in the register is only enabled to appointed employees of the administrator (ÚZIS ČR).
- The time limit for keeping personal data: 25 years after a patient's death their personal data is anonymised.
- Update periodicity: annual

I believe that the above stated enhancement of the National Healthcare Information System will provide new and comprehensive data for the Czech diabetology, whose subsequent utilization will produce benefits particularly for patients with this disease.

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*Delivered to the editors on 25. 10. 2015*