iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

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Czech comprehensive ICT model integrating multiple data sources

Description and implementation guide

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Abbreviations

CANCON	Cancer Control Joint Action
CC	cancer centre
CCCN	comprehensive cancer care network
CNCR	Czech National Cancer Registry
CZ-DRG	Diagnosis Related Groups, Czech system
ICD10	International Statistical Classification of Diseases and Related Health Problems, 10th revision
ICD-O	International Classification of Diseases for Oncology
ICT	Information and communications technology
iPAAC	Innovative Partnership for Action Against Cancer
NCC	National Cancer Centre
NHIS	National Health Information System
NRRHS	National Registry of Reimbursed Health Services
TNM	TNM (tumour, nodes, metastasis) cancer staging system
UZIS	Institute of Health Information and Statistics of the Czech Republic (*Ústav zdravotnických informací a statistiky ČR*)

Executive summary

The essential **legal** (amendment of the Act on Health Services and the National Health Information System regulation) and **technical** (new methodology of Czech National Cancer Registry considering integration of epidemiological, administrative, laboratory and clinical data collections) **background have been put in place**. The final planned part of the comprehensive ICT model (**proposal for the Act on eHealth**) has been prepared and approved in 2021, including the accompanying proposal on departmental reference statistics, which will form the legal basis for collection and publishing of cancer care performance indicators.

Essential **technical infrastructure** (Information and Data Departmental Interface), which will further support the integration of electronic health care records and laboratory results, is being built.

The restructured Czech National Cancer Registry utilising an integrated system (notifications, pathology data, cancer care data) was previously designed, and between 2019 and 2020, pilot data collection from cancer care providers took place to fully transition to the innovated data collection system.

The appropriate classification of cancer care in administrative **reimbursement data** is further supported by new diagnostic related group (DRG) classification system for acute health care, abbreviated as CZ-DRG. Since January 1st, 2021, full implementation of the CZ-DRG has taken place in the Czech Republic, empowering equity, efficiency, and transparency in reimbursement and monitoring of the Czech acute inpatient care for cancer patients. Appropriate **microcosting of cancer care** on the national level is supported through the network of CZ-DRG reference hospitals.

The methodological document **Organization and quality evaluation of cancer care** was previously issued following the outcomes of CANCON joint action. Conditions for certification of Cancer Centres were issued in November 2019. The newly developed comprehensive ICT model was piloted by cancer centres to produce performance indicators for certification. Further continuous monitoring of performance indicators utilising the comprehensive ICT model is prescribed to successfully certified Cancer Centres.

These indicator sets are one of components of the cancer information system that has been set up on the basis of a comprehensive ICT model. The **national cancer control reporting** will be further elaborated, harnessing all the data sources, some of them still under ongoing development. Reporting will be available at both national and regional levels, as well as at the level of Cancer Centres and networks. Open datasets will be developed for further use by different users from national and regional administration, academia, etc. The Czech Childhood Cancer Information System is described as one particular tool based on complex data provided by the comprehensive ICT model, aimed at one of high-priority cancer control topics. Meanwhile, the National Health Information Portal has been established as a source of health information for the general public.

Legal, technical and organizational background and the experience with piloting of the comprehensive ICT model are described in this document.

2 Background

The task 7.5 of the iPAAC joint action focuses on piloting of comprehensive information and communication technology (ICT) model which would integrate multiple data sources (dedicated registries with general administrative data and selected parts of healthcare records) in functional national cancer care information system. The population-based integration will involve three principal levels (standard cancer registries – epidemiology, health care records generated by participating providers of cancer care, administrative data on cancer management, distribution of care and related costs). Implementation at the level of the whole country will enable to potentially test all key outcomes recommended on the basis of other WP7 tasks in future. The model will also address fundamental issues associated with integration of longitudinal data at large scale, mainly legal background, personal data protection and access to relevant cost data. The model will be developed and implemented in the Czech Republic in two principal modes of functioning: as ICT background supporting cancer care providers, and as a national system integrating datasets to get control over all consecutive phases of cancer care, including the long-term surveillance.

3 Legislation to establish the comprehensive model

Completely new amendments of essential acts have been prepared and are currently being implemented. The legal base for linkages of multiple data sources under the auspices of the National Health Information System was therefore prepared and legally approved**.**

3.1 Legal background of the National Health Information System

The aim of the novel legislation was to clearly define the **competence of the Institute of Health Information and Statistics of the Czech Republic (*Ústav zdravotnických informací a statistiky ČR*, UZIS)** as the **administrator of the National Health Information System (NHIS)** with well-defined competencies and obligations. The novel amendment of the Act on Health Services (Act No. 372/2011) included further specification and partially redefining the content and purpose of the NHIS in accordance with the new mission of UZIS (especially in the field of evaluation of indicators of quality and safety of health services and ensuring the quality and sustainability of the system reimbursement of health services from the public health insurance), the new definition of content and functionality of the **National Registry of Healthcare Professionals** and establishing the **National Registry of Reimbursed Health Services**. In NHIS, **health registries form an interconnected system, and it is possible to link the collected data for the specified purposes**. An important newly introduced elements are the results of selected laboratory tests, which will be also part of the National Health Information System. These data are a valuable addition to the comprehensive analytical approach. Data obtained from information systems of public administration and health insurance companies can be used for operating these health registries.

Source including the full text of the legislation (in Czech), § 70 - § 78:

https://www.zakonyprolidi.cz/cs/2011-372/zneni-20220101

3.2 NHIS and data protection

Due to the fact that the legal regulation of personal data protection is implemented both in the legal code of the Czech Republic and in the General Regulation on Personal Data Protection at the EU level (GDPR), an **explicit regulation was chosen by law**. By setting the rules by law, the protection of privacy and personal data is fully ensured. The effective legislation precisely defines the scope of processed data, respect the principle of proportionality of the scope in relation to the explicit purpose of personal data processing, which are in particular the fulfilment of the following societal needs imposed on the health sector. Security and control over the personal data of data subjects will be strengthened.

In principle, personal data are stored within UZIS. Within UZIS, only a few authorized persons always have access to these data, who are bound by the duty of confidentiality, and any access to and all operations with these data are secured and recorded. UZIS makes the data available to other persons only if it is obliged to do so on the basis of a legal regulation. In order to comply with all of our above-mentioned legal obligations, personal data is also processed by external IT service providers, who are bound by confidentiality obligations and must provide maximum guarantees on the technical and organizational security of personal data protection.

3.3 Act on eHealth

Digitisation of healthcare has been largely uncoordinated in the Czech Republic. The priority for health service providers is always to provide health services to patients in the interest of quality care for their health. Healthcare providers face technological limitations and non-existent standards and recommendations from central authorities when transferring copies of medical records, or their separate parts or extracts, thus addressing their ad hoc needs, which of course generates additional costs and burdensome system by solving recurring problems.

In particular, the target state of electronic healthcare will bring the following benefits:

- Automation of processes related to the **acquisition of master data** and, with the **transfer of medical documentation**, also its separate parts or extracts from it electronically.
- Increasing legal certainty for healthcare professionals and providers when working with master data.
- **Expression of patients' rights** in the field of electronic healthcare or, more precisely, regulation of the rights and obligations of patients when using e-health services to which they will have access, and at the same time regulation of the protection of their personal data against misuse in the use of e-health systems.
- **Growth in the quality of health services** (or provided healthcare) and **higher efficiency** of healthcare in the Czech Republic. In the longer term, the proposed legislation will also have a positive impact on increasing the health of citizens in the Czech Republic and the quality of the provision of health services in the Czech Republic.

Source including the full text of the legislative proposal (in Czech):

https://www.psp.cz/sqw/text/tiskt.sqw?O=8&CT=1163&CT1=0

Source including the full text of the legislation (in Czech), Act on the Digitisation of Healthcare (Act No. 325/2021):

https://www.zakonyprolidi.cz/cs/2021-325

3.4 Departmental reference statistics

New areas of evaluation and processing of data are introduced due to the implementation of new components to NHIS, as well as the new competencies of UZIS: **production of departmental reference statistics**, which are closely linked to the electronic healthcare, as they will be processed (based on data kept in registries) and published in the electronic form.

Specific issuance of a list of these departmental reference statistics and evaluation methodologies by UZIS is currently a necessity that will significantly increase the information value of NHIS for both the general and professional public. The provision in the new legislation lists the following areas in which departmental reference statistics are issued:

a) macroeconomic characteristics of healthcare,
b) availability of health services, their staffing and technical and material equipment,
c) quality indicators of health services,
d) performance indicators of providers,
e) population health indicators; and
f) indicators of the quality and performance of prevention programmes.

These areas are also highly relevant for the monitoring of cancer control.

Specific departmental reference statistics and deadlines for their publication will be published in frequency laid down by implementing legislation as well as their list. **Reference departmental statistics will be mainly complex statistics, the calculation of which is non-trivial, requires a consistent validation of data, and the interpretation of which is of great importance and can influence the behaviour of the public towards health services** (e.g., quality of care indicators), **towards their own health** (e.g., recommending screening programmes) **and can significantly boost patient confidence in the healthcare system.**

It will also be statistics by which the Czech Republic presents itself in mandatory statistics OECD, WHO and EUROSTAT benchmarks, and which are relatively prone to misinterpretation of some indicators; therefore, standardization strengthening is desirable. Following the progress of new technologies and the possibility of using data in the form of open data, however, due to the special categories of personal data, it is necessary to define this departmental reference statistics specifically for the health sector with an emphasis on ensuring a strict protection of personal data.

Source including the full text of the legislation (in Czech), § 73a:

https://www.zakonyprolidi.cz/cs/2011-372/zneni-20220101

4 Organizational background for cancer control in the Czech Republic

The methodological document **Organization and quality evaluation of cancer care was issued following the outcomes of CANCON joint action**. Conditions for certification of Cancer Centres were issued in November 2019. The newly developed comprehensive ICT model was piloted by cancer centres to produce performance indicators for certification. Further continuous monitoring of performance indicators utilising the comprehensive ICT model is prescribed to successfully certified cancer centres.

4.1 Organization and evaluation of the quality of cancer care in the Czech Republic[1]

The main goal of this document is to strengthen the quality of cancer care in the Czech Republic, which faces a significantly growing number of patients requiring long-term care. In particular, the growing prevalence of cancer requires strengthening of the organization of cancer care in terms of diagnosis, treatment and follow-up, both nationwide and in individual regions. The below-described measures do not disrupt the structure, integrity, and functionality of the existing network of comprehensive **cancer centres (CC), which forms the backbone infrastructure of cancer care in the Czech Republic**. The document is based on the National Cancer Programme of the Czech Republic, and will be further developed regarding the expected updates of international and national recommendations concerning the organization of cancer care.

Based on the concept, it is **necessary to establish binding methodologies for reporting data into the Czech National Cancer Registry (CNCR)**, methodologies for data evaluation for expected reports of availability and quality of care indicators, and methodologies for the activities of multidisciplinary teams of CCs. Newly prepared methodologies must go through a review procedure and must be approved by health insurance companies. In this sense, the concept must be supplemented and updated regularly.

Articles 2 and 3 of the document define the concept of the organization of cancer care in regions of the Czech Republic and strengthen the leading coordination and professional position of the CCs. Article 4 defines the position of the so-called **National Cancer Centres (NCCs)**, which operate within the CC network. NCCs are conceived as coordinating entities of scientific research, and their establishment expands the possibilities of international cooperation in the CC network. The NCCs act in a coordinated manner, in particular as national contact points for international cooperation, and do not replace the scope and competencies of professional societies or networks of complex cancer centres. By establishing the NCCs, the Czech Republic responds to important stimuli from abroad, especially to EU activities leading to European networks of specialized reference centres. Given the potential transfer of these activities into the organization of cross-border healthcare, the organization of international clinical studies and research, it is important that national contact points, i.e. NCCs, are established in the cancer care segment according to the given criteria.

[1]Source in Czech:
https://www.mzcr.cz/wp-content/uploads/wepub/14605/36101/V%C4%9Bstn%C3%ADk%20MZ%20%C4%8CR%2013-2017.pdf

Article 5 of the document defines the **new organization and content of the centralized evaluation of the availability and quality of cancer care at all set levels**, always using representative reference data of the CNCR and other information sources of the NHIS. The newly described system of evaluated indicators distinguishes three levels of evaluation: the **local level** (individual centres, providers), the **level of regional cancer groups** (contracted cooperation of hospitals and possibly other providers on a regional basis with set internal structure and rules of care organization) and the **regional level** (epidemiological evaluation, based on the total population burden of cancer). The set concept of reporting and evaluation envisages a close cooperation with UZIS as the administrator of the NHIS.

4.2 Centres of highly specialized cancer care in the Czech Republic[2]

It is necessary to adequately **concentrate costly cancer care to highly specialized centres** so that the funds are spent efficiently and effectively. Centralization of care for cancer patients allows the creation and maintenance of sufficient erudition of all members of the multidisciplinary teams providing cancer care. The erudition of healthcare professionals is possible to obtain and maintain only with a sufficient number of performed procedures (especially in demanding surgical procedures). It is developing rapidly and the diagnostic area, requiring an expensive instrumentation (CT, MR, high end ultrasound device, PET/CT, scintigraphy, etc.), specialized examinations (molecular biological specification of tumours), but also a high erudition of physicians. Centralization of care creates the conditions for gaining and maintaining erudition and, at the same time, allows to increase the effectiveness of care, i.e., to reduce the resources spent on diagnosis, treatment and other monitoring the patient while maintaining or even increasing the quality of provided care. Last but not least, the concentration of patients and specialized diagnostic and treatment procedures is of key importance for postgraduate education and is taken into account in the system of education.

The criteria for the inclusion of health service providers in the network of highly specialized cancer care centres (CCs) were prepared by a working group composed of representatives of the Czech Society for Oncology, the Society of Radiation Oncology, Biology and Physics, representatives of health insurance companies and representatives of the Czech Ministry of Health.

In the case of providers who obtain the status of CC, the performance of the centre, quality and results of the provided healthcare will be monitored, based on data available in the National Health Information System (especially the CNCR) and on the basis of care reported to health insurers. See chapter 6.2.2 for details on monitoring.

[2]Sources in Czech:
https://www.mzcr.cz/wp-content/uploads/wepub/18134/39365/Vestnik%20MZ_11-2019.pdf
https://www.mzcr.cz/wp-content/uploads/2020/07/Seznam-center-vysoce-specializovan%C3%A9-onkologick%C3%A9-p%C3%A9%C4%8De-2020-indik%C3%A1tory-kvality.pdf

5 Contents of the comprehensive ICT model

5.1 National Health Information System architecture

Four essential components supporting a nationwide collection of data on cancer care have been established (Figure 1):

- the National Registry of Healthcare Providers,
- the National Registry of Healthcare Professionals,
- the National Registry of Reimbursed Health Services, and
- the National Registry of Hospitalizations.

The main advantage of the NHIS is **reference data background** covering representative data on healthcare providers, professionals and consumed/reimbursed services. **The NHIS thus forms an infrastructure supporting cancer registration at all levels.**

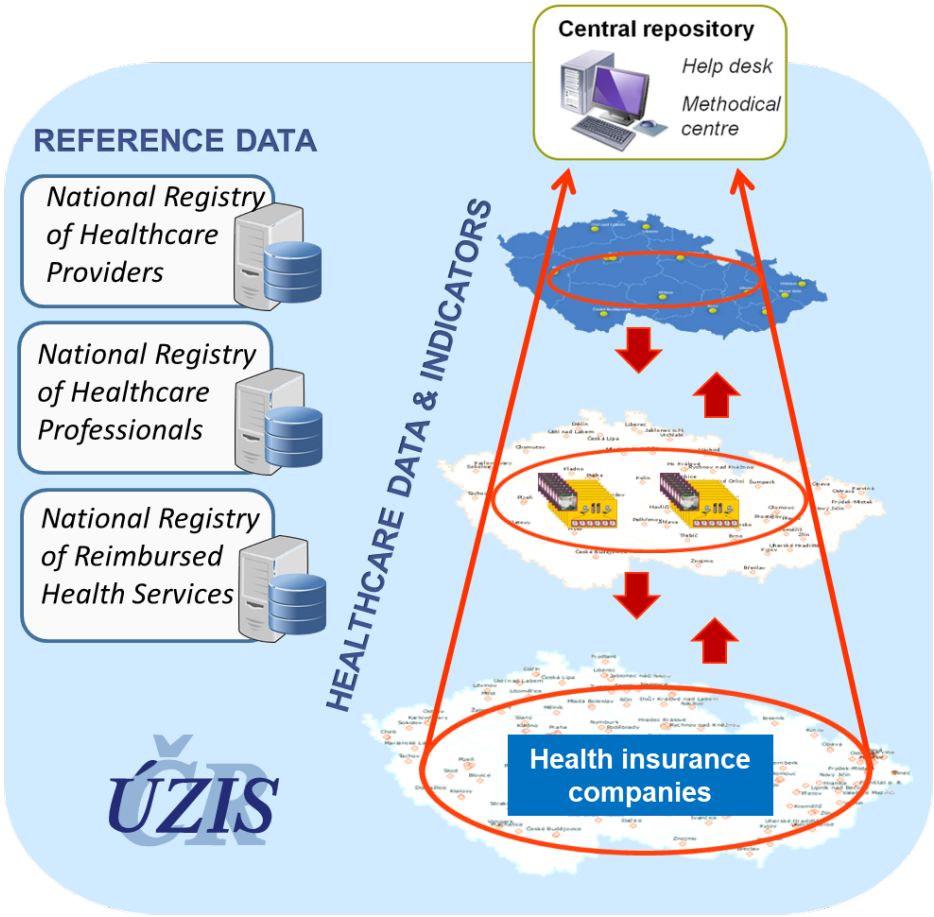

Figure 1. Structure of the National Health Information System.

5.2 Reference data background

5.2.1 National Registry of Healthcare Providers

The newly established information system **covers all relevant providers and interconnecting laboratories, diagnostic units, cancer screening units, healthcare providers, palliative centres,** etc.

The purpose of the National Registry of Healthcare Providers is to perform the **agenda of registration of health service providers**, social service providers who provide health services and persons providing health services.

The standardization of all data will allow:

- to determine the **structure and scope of health services and care provided**, to define key problems, to predict the further development of the need for health services and providing input parameters for the compilation of partial strategies at the level of individual regions and at the national level,
- **to provide information to the general public** via the public part of the registry, i.e., a complete overview of all healthcare providers in the Czech Republic, regardless of their establishers, as well as data on the profile and scope of care provided by individual medical facilities, contact details for the given medical facilities and other details (https://nrpzs.uzis.cz/, website in Czech).

5.2.2 National Registry of Healthcare Professionals

The National Registry of Healthcare Professionals is a non-public registry that contains **comprehensive data on all healthcare professionals who provide health services**. The National Registry of Healthcare Professionals is enshrined in the Czech legislation, namely in Act No. 372/2011 Coll., on Health Services and Conditions for their Provision (Health Services Act), § 76 and § 77, as amended.

The registry includes the following groups of data (the list is narrowed for better clarity), where each group can be entered and edited in the registry by another entity, such as educational institutions (universities, high schools, the Institute for Postgraduate Medical Education and others), healthcare providers and social services, medical chambers and many others in accordance with the law:

- personal data (name, surname, gender, title, date of birth, birth number, document number, permanent residence and more),
- other contact details (email, phone, data box and more),
- acquired competencies (basic professional competence, completed strain, specialized competence, special professional competence),
- employment (identification of the provider in which the worker performs the job, time range from when, or until when, the worker is employed, job position, department / workplace / field, form of care and type of care),
- information on professional ban, or expulsion from the chamber.

5.2.3 Administrative data on healthcare

The **National Registry of Reimbursed Health Services (NRRHS)** is one of the most important components of the whole system. Thanks to implemented reimbursement rules, the Czech healthcare system is **capable to control all consumed healthcare services** (the vast majority of healthcare related to cancer care is reimbursed from the public health insurance).

NRRHS **collects data reported by all approximately 30,000 providers of health services** to health insurance companies, so it is the widest and most comprehensive data source within the NHIS. However, data collection in the registry is set so that it does not burden the provider: **it uses already implemented data collection** by health insurance companies, which then transmit these data to the NRRHS. This significantly decreases the burden on providers, with only seven health insurance companies contributing to the NRRHS instead of 30,000 health service providers. The registry contains data on **individual reimbursements** of healthcare providers, **data on healthcare providers**, data on **personnel**, **technical and material equipment** of workplaces and the necessary lists and code lists (Figure 2). Simply put, the registry contains all reported and recognized services, products and materials that have been provided to a given patient at a given healthcare provider as part of his or her care.

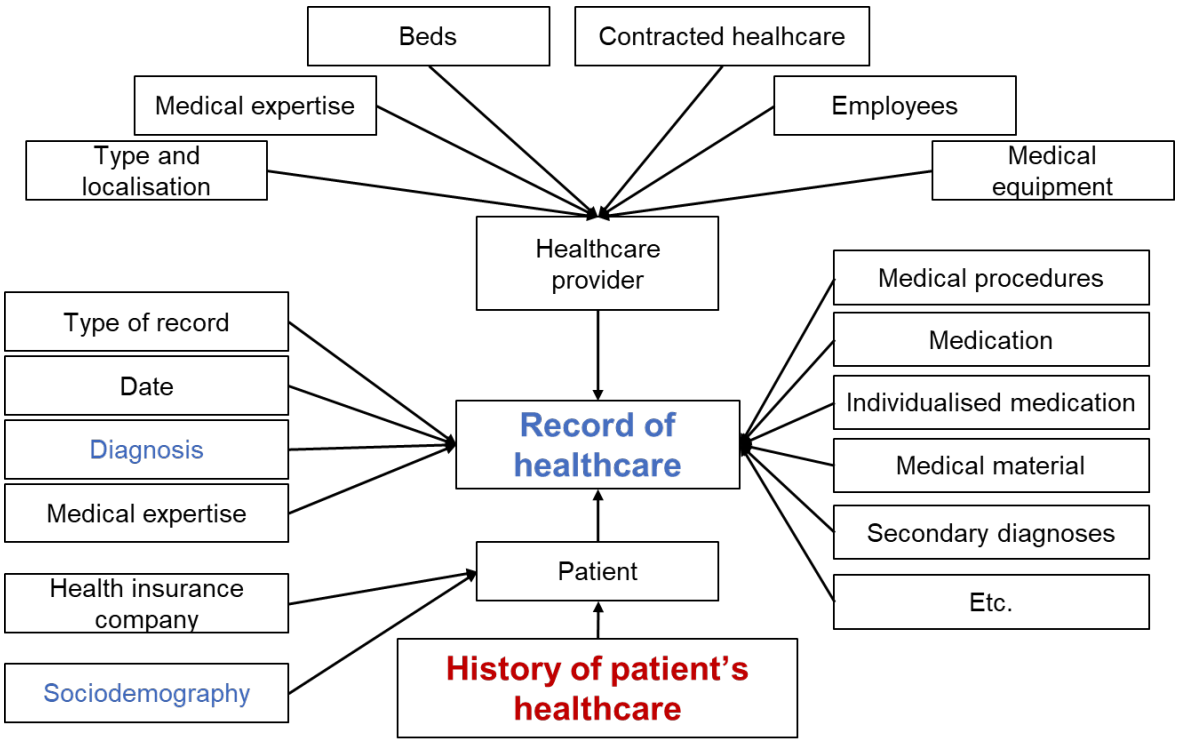

Figure 2. Data model of the National Registry of Reimbursed Health Services (NRRHS).

Data from all seven health insurance companies are transmitted via the NRRHS Data Interface[3], in a delimited text file format. These data are transferred in batches for the past quarter, with a two-month delay from the end of the respective quarter. Health insurance companies can use the web interface (NRRHS Portal) or web services and a secure FTP transmission for data transfer. For the planned transfer of laboratory results data, the transfer of individual records via the REST API will be used, analogous to the already ongoing collection of COVID-19 test results or vaccinations. The collection will take place continuously from a larger number of providers (in the order of hundreds) and will be made available in the CUD database of the eReg system. Full processing into the analytical data warehouse will again take place in batches, with a monthly or quarterly frequency.

Health insurance companies that transfer data to the register do not transmit data with the direct identification of the individual using his/her so-called "insured person's number", with a few exceptions. The services of basic registers are used for this purpose, which ensure unambiguous translation of person identifiers between different systems, so-called AIFOs (agenda-related identifier of a physical person). These identifiers are different for each communicating agenda. This minimizes the possibility of unauthorized linkage of data from different systems. Every data transfer is also recorded and citizens have the opportunity to learn about it.

NRRHS data processing (Figure 3) takes place in batches by individual insurance companies for the past quarter. The **transferred data are downloaded to the Data Integration Server** server from the NRRHS Portal manually or using an automatically started task. The process outputs are continuously stored in the process database NRRHS DWH[4]. During data processing, data are then sent to translate the patient identifiers into the NRRHS PIM[5] system (and from there on to the NRRHS AIS, system to communicate with basic registers) and load them back. After complete processing of insurance companies' data for a given quarter and their control, the data are transferred to the analytical database NRHZS BI[6] using a manually started process, where their final processing, validation and access to analytical teams takes place.

[3] Documentation in Czech: https://www.uzis.cz/index.php?pg=registry-sber-dat--narodni-registr-hrazenych-zdravotnich-sluzeb#datove-rozhrani

[4] It is used for temporary storage of processed data and as a transfer node between the portal and the analytical data warehouse NRRHS BI

[5] NRRHS PIM is a system that serves to manage patient identifiers from health insurance companies and their transformation into identifiers, which are further used internally for analytical tasks.

[6] Data warehouse for analytical tasks

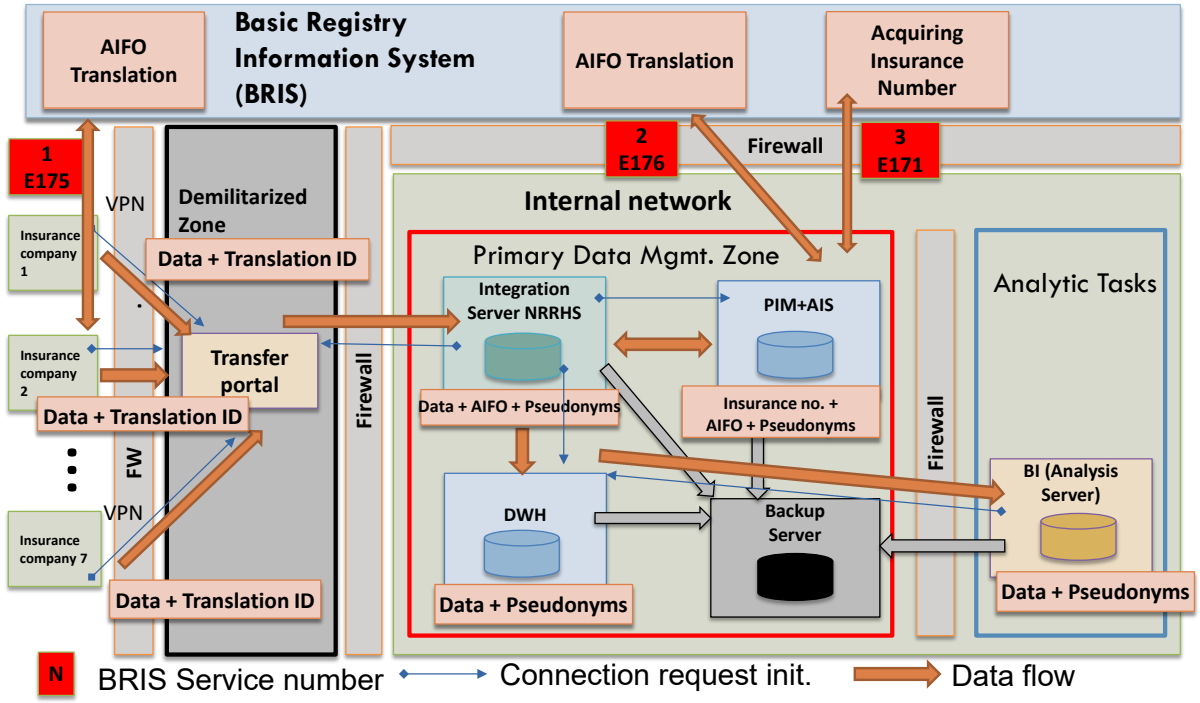

Figure 3. Simplified scheme of data processing in the NRRHS.

Since 1 January 2022, the NRRHS can be extended with the results of laboratory examinations from healthcare providers. Selected results of laboratory examinations will be collected according to the Methodology and data interface for the collection of laboratory results to NRRHS (document in preparation). The REST API web services will be used for the transfer of individual laboratory values. The transferred data will be stored in the CUD system database, from where they will be loaded into the NRRHS and further processed into the analytical data warehouse.

5.2.4 National Registry of Hospitalizations

The purpose of the registry is to have a source of information on the health status of the population. At the same time, the National Registry of Hospitalizations provides data for **evaluation of the activities of individual inpatient facilities and their wards**. Data from the registry are an important tool for healthcare management and determining the concept and implementation of state health policy, needed to define the optimal network of inpatient healthcare facilities. The resulting information from the registry is transferred to the database of the World Health Organization (WHO) and other international organizations.

The statistical unit is the completed stay of a hospitalized patient in the ward. Every completed hospitalization of a patient (either a Czech citizen or a foreign national) in one inpatient department of the inpatient care provider becomes a mandatory report, regardless of the method of admission and termination (discharge, transfer, death).

List of data items:

1. Data on inpatient medical facility (reporting unit)

- facility ID
- region, district of the seat of the facility
- type of facility
- department, serial number of the department
- workplace

2. Patient information

- birth number (from which sex and age are derived)
- date of birth
- gender
- marital status
- employment
- the municipality of the place of permanent residence
- EU residence

3. Data concerning the admission and stay of the patient in the inpatient care facility

- admission recommended by
- date of admission (day, month, year)
- admission time (hour, minute)
- reason for admission
- start of symptoms - date (day, month, year)
- basic diagnosis - diagnosis of the underlying disease that is the cause of hospitalization according to ICD10
- hospitalized for the first time in his life for the basic diagnosis

- external cause (applies not only to injuries), diagnosis (ICD10)
- other diagnoses (ICD10) (new to unlimited extent)
- date of operation (day, month, year)
- operation time (hour, minute)
- main surgical diagnosis, diagnosis of a disease that is the main cause of surgery according to ICD10
- nosocomial infection (monitored in all patients)
- type of operation
- reoperation (repeated operation of the patient in connection with the main surgical diagnosis)
- postoperative complications
- number of days in the Intensive Care Unit (ICU)
- DRG group (classification of the patient according to the DRG (diagnosis related group))
- number of days of hospitalization interruption
- date of discharge (death)
- hour, min. discharge (death)
- patient category (number of days in a certain condition)
- basic cause of death (Id) - fill in the diagnosis (ICD10) of the primary cause of death taken from the death certificate
- immediate cause of death (Ia) - fill in the diagnosis (ICD10) of the immediate cause of death taken from the death certificate
- termination of hospitalization
- need for further care after discharge

4. List of performed procedures within the patient's hospitalization (performance sentence)

- procedure code (according to the list of medical procedures)
- number of performed procedures
- date of procedure

5.3 Czech National Cancer Registry

Cancer registration is provided by the Czech National Cancer Registry (CNCR). In view of rising accessibility of national reference data, the reporting by providers on cancer cases is being optimized (in data model, focus and extent) and the **burden by direct notification is being reduced.**

Basic CNCR record includes:

- CNCR notification
- pathology report
- cancer care reimbursed by health insurance company
- death certificate

The CRCR allows for extension of datasets through additional specific clinical data collections (Figure 4).

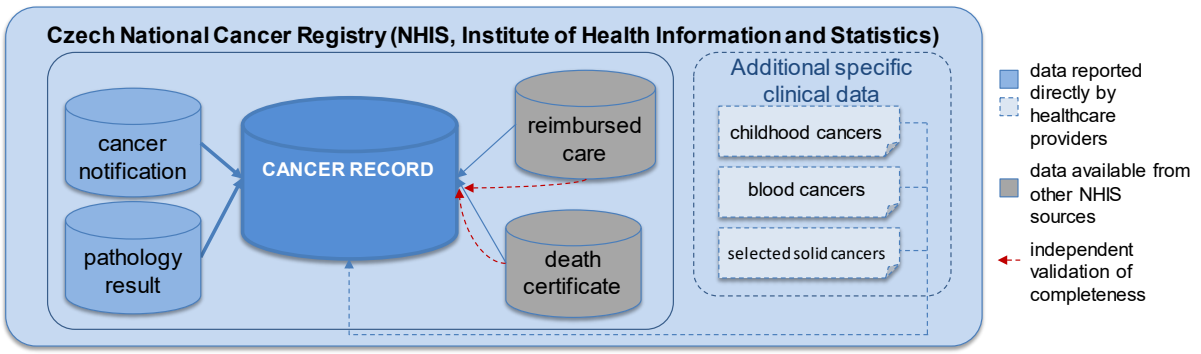

Figure 4. Data flow in the innovated Czech National Cancer Registry (CNCR).

5.3.1 Data items: CNCR notification

1. Data related to the patient's state of health in relation to his illness
    - personal identification number
    - name and surname
    - permanent residence country of origin
    - foreigner x homeless
2. Data on neoplasm
    - date of diagnosis
    - diagnosis (narrative)
    - code of the ICD10
    - diagnosis determined on the basis of (clinically clear; clinical examination; laboratory examination, markers; cytology; histology of metastasis; histology of the primary tumour; autopsy; DCO = information on the tumour is not in the medical documentation, but is listed only on the death certificate)
    - morphology - narrative description, determined by the method of histology / cytology
    - laterality (right, left, bilateral, omitted, unknown)
    - TNM classification to describe the anatomical extent of the disease: extent of the primary tumour (T), absence or presence and extent of metastases in the regional lymph nodes (N) and absence or presence of distant metastases (M)
    - pTNM classification - postoperative histopathological classification based on findings obtained during surgery and pathological examination (pT, pN, number of examined and number of positive nodes, pM); the "y" symptom is given in case of examination during or after neoadjuvant treatment; for selected diagnoses, other specific markers listed in the TNM classification are listed
    - localization of metastases clinical stage extent of the disease (localized, advanced, unknown)
3. Identification of the reporting medical workplace
    - provider/department ID
    - reporting workplace - established the diagnosis of a neoplasm / treats a patient with a neoplasm

5.3.2 Data items: pathology result

I. Report from the pathologist / cytologist examination
(standard test result / report for doctors)

- Patient
  - Name, surname [text]
  - Birth number [code]
- Department of Pathology / Cytology
  - Identification of the medical workplace [provider/department ID]
  - Doctor's name [text]
- Clinician's workplace
  - Identification of the medical workplace [text]
- Examination
  - Date of collection [date]
  - Examination date [date]
  - Main diagnosis [code ICD10]
  - Finding [free text with formatting]

II. Result for CNCR
(parametric data for CNCR, coded by the workplace of pathology / cytology)

- Diagnosis of neoplasm [code ICD10]
- Morphology type: histology / biopsy / autopsy / cytology / other [derived from part I.]
- Morphology [XXXX / XX code ICD-O-3 + grade]
- Topography [CXXX code ICD-O-3]
- pT [TNM code]
- pN [code according to TNM]
- number of examined nodes [number]
- number of positive nodes [number]
- pM [TNM code]
- Residual tumor [RX / R0 / R1 / R2 according to TNM]
- precancer - degree of dysplasia [low grade lesions / high grade lesions]

5.4 Information and Data Departmental Interface

A dedicated infrastructure is being established by UZIS to provide key functions for the eHealth system. This will notably allow standardization of data exchange and provision of new data items for the ICT model (Figure 5).

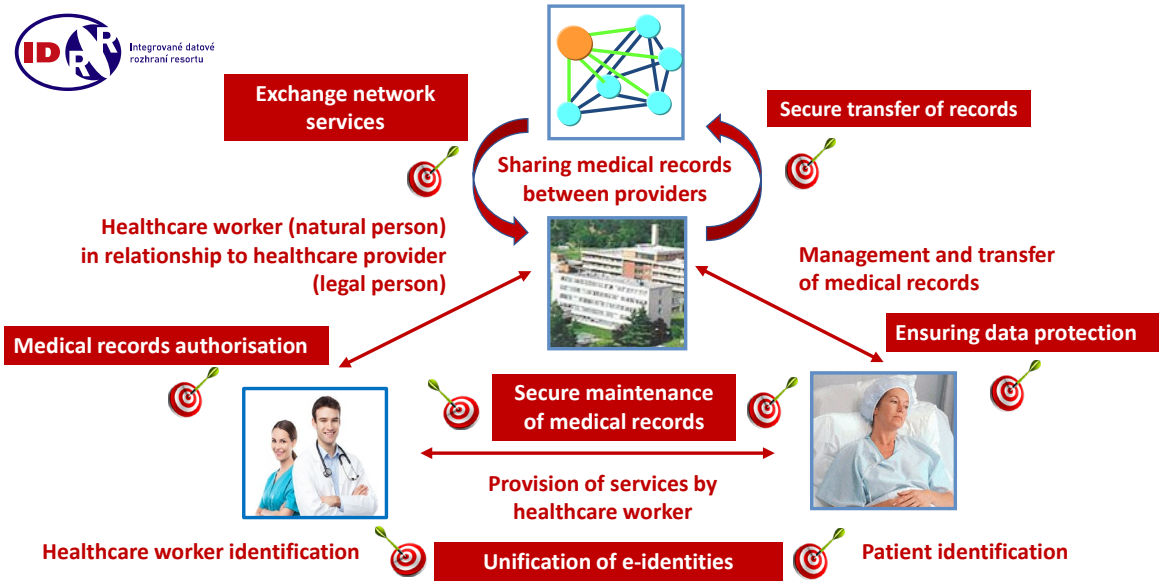

Figure 5. Overview of foreseen eHealth system functions.

eHealth standards are standards defining the structure, content and format of data files and data messages, interfaces for keeping and transmitting medical records in electronic form and their security, classification, nomenclature and terminology for their use.

For the purposes of monitoring the quality of reimbursed health services and for fulfilling the purpose of the NHIS, **results of laboratory tests will be entered into the National Registry of Reimbursed Health Services**. The transmission of data under this provision will be carried out mainly automatically and is a great benefit from the point of view of the practical introduction of automated electronic services health care usable by all authorized persons in the National Registry of Reimbursed Health Services.

5.5 Cancer care micro costing: reference hospitals and CZ-DRG

A new diagnostic-related group (DRG) classification system for acute health care, abbreviated as CZ-DRG, has been under preparation at UZIS since 2015. The system provides a **more detailed classification of acute health care, including patients hospitalized with cancer**. CZ-DRG is used for setting the **prices** of inpatient health services, healthcare **monitoring and reimbursement**, as well as **productivity and economic benchmarking**. Each hospital can use the system for future hospital activity and budget impact modeling and planning.

In 2019, a pilot study implementing one part of the newly developed CZ-DRG into Czech reimbursement mechanisms was set up, starting from the 1 January 2020. The implementation **included selected areas of acute care related to highly specialized cancer care in gynaecologic and thoracic surgical oncology**. The aim of the pilot operation in 2020 was to test the functionality of the classification and to prepare hospitals for a real start of the new classification system in 2021.

Since 1 January 2021, the CZ-DRG system has been fully implemented, with all inpatient care being classified in the new system and more than 44 % of care being reimbursed according to the new system, including most of the surgical cancer care. The full implementation of the CZ-DRG has therefore helped to strengthen equity, efficiency, and transparency in reimbursement and monitoring of the Czech acute inpatient care for cancer patients.

The economic part of CZ-DRG is primarily based on the cost accounting methodology, which allows us to assign cost data to classified inpatient cases based on economic and administrative data, which are supplied by a set of cooperating providers of acute inpatient care, the so-called **reference hospital network** (Figure 6). This set of representative providers of acute inpatient care supplies data to the **central data repository of reference hospitals**, which is the primary data source for the development of CZ-DRG and its components. Therefore, detailed production (service) and economic (expense) data are available in each of the reference hospitals.

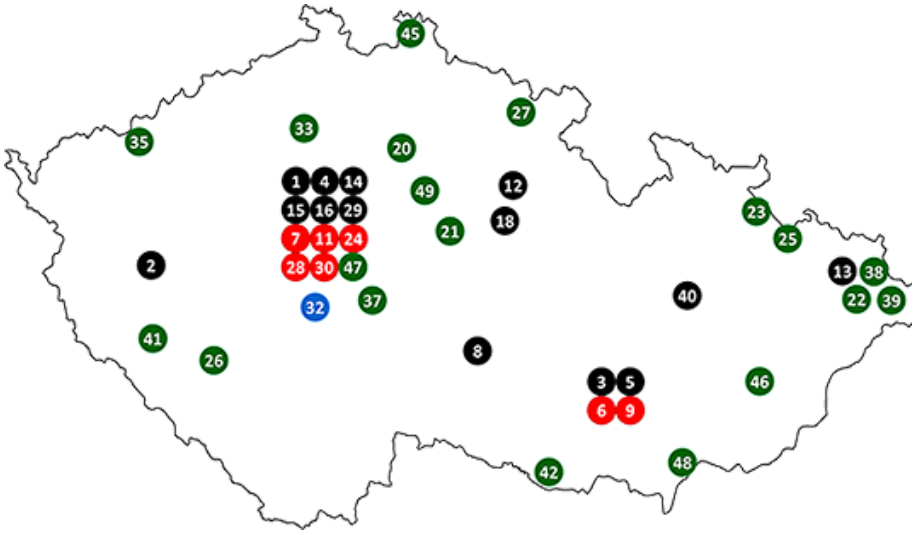

Figure 6. Czech providers of acute inpatient care that are part of the reference hospital network.

The **reference hospital network,** which is an integral part of the development and cultivation of the CZ-DRG system, is also legislatively specified within the framework of Section 41a of Act No. 48/1997 Coll., On Public Health Insurance. The inclusion of each hospital within the reference network is voluntary, the provider undertakes to collect and transmit data and implement the developed methodologies and code lists within its operation. On the contrary, the duty of UZIS is to properly secure the collected data and to maintain confidentiality about the facts that are the subject of cooperation within the reference network.

During the development of CZ-DRG, a completely **new cost-accounting model** has been set up and implemented within the reference hospitals network to calculate relevant costs associated with each acute patient treated in these hospitals. The methodical standards can help individual hospitals to improve their internal processes, costs allocation, and achieve better management of patients and related costs. Moreover, the system provides a fundamental basis for modeling public expenditure on the provision of acute inpatient care.

The economic model of the total costs of an inpatient case divides these costs into direct and indirect (Figure 7), i.e., according to whether we can clearly assign costs specifically to the patient (direct costs) or not (indirect costs). The essence of the cost accounting is the quantification of the number of consumed units attributable to individual activities as well as direct costs; in other words, costs are allocated according to the consumed activities that were carried out in the inpatient case. The cost accounting methodology is based on the principles of the so-called **Activity-Based Costing** (ABC), which allows us to consider costs according to the actual place of origin of the health care provided, and thus correctly link the costs and services.

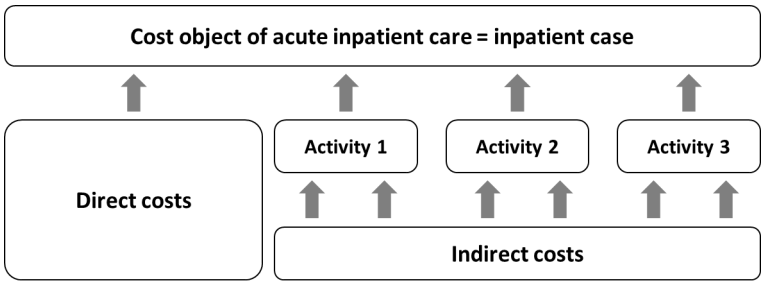

Figure 7. Simplified model of cost accounting of an inpatient case based on the principles of Activity-Based Costing.

The aim of cost accounting according to the ABC method is to find out what activities are carried out and to quantify how much each activity costs (through activity unit costs). The costs are thus first assigned to the defined activity and only then to the cost object, i.e., the inpatient case. Within the acute inpatient care providers, this general description can be demonstrated by the example of quantifying the total costs of hotel services of patients in a standard ward, where the given activity unit is one day in a standard ward, or operating services, where the given activity unit is a minute spent by a patient in the operating room. The costs are then given based on the costs per activity unit and the volume of activity provided. Therefore, if the costs per one treatment day on a standard ward are quantified, it is easy to quantify the total costs consumed by this patient during the entire stay with the given provider over the total number of treatment days.

The economic model of an inpatient case within the CZ-DRG system thus distinguishes the following structure of indirect costs per hospitalization case according to the monitored activity:

- cost of staying in a standard ward,
- cost of staying in an intensive care unit,
- costs of operational services,
- costs of requested care (complementary care).

Both direct and indirect costs and its structure with the CZ-DRG system are shown schematically in Figure 8.

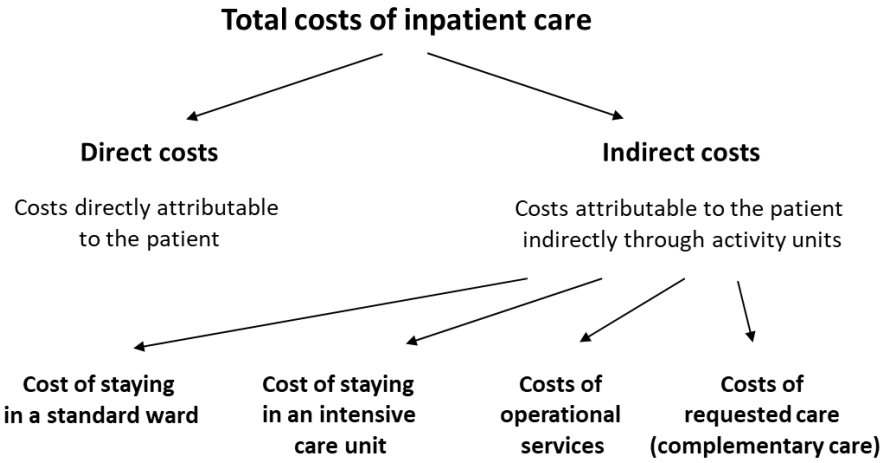

Figure 8. Structure of costs of an inpatient case according to the principles of Activity-Based Costing in the CZ-DRG system.

Within the CZ-DRG system, the reference hospitals are also provided with a **self-benchmarking tool for hospital activity and economic indicators** that employs both the new classification system as well as the cost calculation method. Moreover, validation procedures have been developed within the CZ-DRG project for the reference hospitals to get feedback on their hospital activity and economic data quality.

6 Functionalities of the model: opportunities for producing relevant cancer information

6.1 Cancer registry linkage supporting production of cancer data

The established integrated ICT background allows for linkages to produce relevant cancer intelligence datasets (Figure 9).

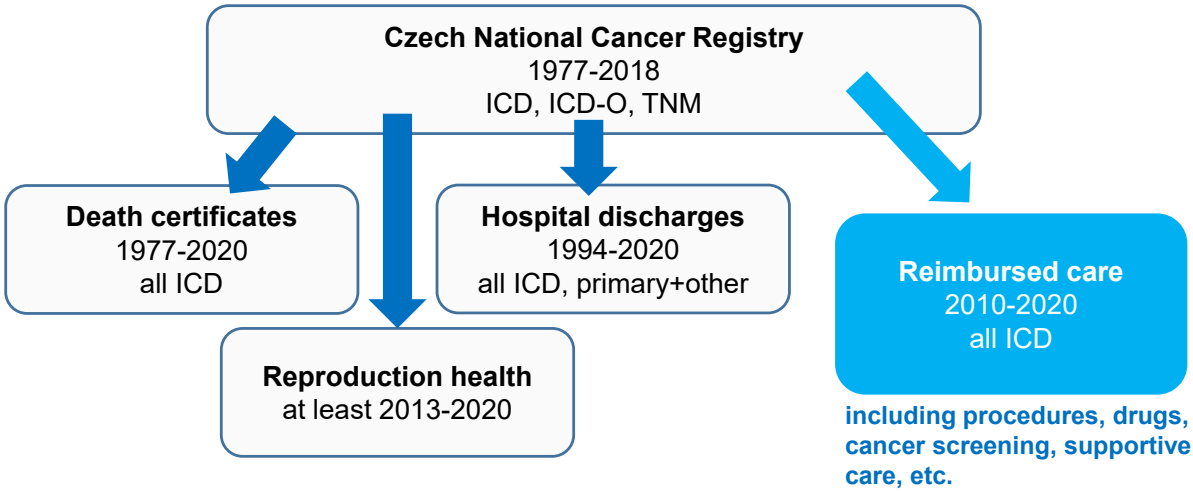

Figure 9. Linkage of health registries to extend reporting capabilities.

The system will also allow future implementation of analytic capabilities proposed within iPAAC tasks 7.2-7.4:

- **linking individual patient's data with administrative and health data**, in order to **describe the complete pathway** of cancer patients from diagnosis to rehabilitation or terminal care, including the use of health care resources at the end of life, and to **assess the adherence of the administered treatments to standard clinical guidelines**.
- integrating data from population-based cancer registry and other administrative data sources, in order to **estimate costs directly related to diagnosis, care and follow-up of cancer patients** (cost profiles).
- estimating the **burden of late effects** in adolescents and young adults (15-39 years at cancer diagnosis) cancer survivors.

6.2 National cancer control reporting

6.2.1 Introduction: types of reporting

The comprehensive ICT model will allow for different types of statistical analysis for the purpose of monitoring and evaluation of cancer control programmes. Notably, the following types of analyses are being performed or are possible:

- Health system reporting
  - Sufficiency of the network of providers
  - Personal capacity
    - Doctors, nurses, other staff, …
    - Number, density in regions, age structure, …
  - Mapping of facilities and physical equipment
  - Development of cancer care reimbursement
- Cancer burden
  - Incidence, mortality, prevalence of cancer according to diagnosis, stage, etc.
  - Effectiveness of early detection
  - Retrospective and predictive analyses for epidemiology, implementation and outcomes research
- Performance and outcomes of care
  - Volume of care provided at different levels
  - Real-world patient pathways and related quality and performance indicators
  - Survival of cancer patients
  - End-of-life care
- Cancer screening and early detection programmes
  - Coverage by population-based cancer screening
  - Performance indicators of screening centres
  - Introduction of population-based pilots (e.g., lung cancer)
- Population health and prevention
  - Lifestyle risk factors
  - Vaccination
  - Preventive check-ups for chronic diseases at primary care

Monitoring and evaluation of cancer screening programmes and early detection is coordinated by the National Screening Centre, UZIS.

Specific examples of already available tools or plans for future development of analytical possibilities are presented in this Chapter.

6.2.2 Support for cancer care management: certification of cancer centres[7]

As of 31 December of a given year, the health service provider, which has been granted the status of a highly specialized cancer care centre (hereinafter referred to as the CC), regularly monitors the following indicators of the quality of healthcare provided and the centre's performance.

A) Regionally specific indicators – mapping of the catchment area

At the regional level, indicators for individual calendar years will be evaluated (comprehensive epidemiological evaluation, the basis is the total population epidemiological burden of the region). **These are parameters intended to describe the population burden of CCs in the catchment area** and to **describe the distribution of cancer care in the catchment area of CCs**. Based on these indicators, a cohort of patients cared for by the CC since the diagnosis of cancer will be established – only in this cohort can the results of treatment, including survival, be evaluated (evaluation including patients migrating to centres at later stages of treatment would be skewed). Regional statistics are evaluated for all diagnoses of cancer and broken down by clinical stages, or according to other risk factors for selected diagnoses (grade, morphological type, etc.) according to the methodology published and updated annually by UZIS:

1. Incidence of treated patients from the region
2. Incidence of treated patients from other regions
3. Prevalence of treated patients from the region
4. Prevalence of treated patients from other regions
5. Completeness of the report to the Czech National Cancer Registry

[7] Source in Czech:
https://www.mzcr.cz/wp-content/uploads/2020/07/Seznam-center-vysoce-specializovan%C3%A9-onkologick%C3%A9-p%C3%A9%C4%8De-2020-indik%C3%A1tory-kvality.pdf

B) Local indicators of the CC's activity

Local indicators of the CC's activities will be evaluated as a whole according to diagnoses and also for selected indicators broken down according to clinical stages, or according to other risk factors for selected diagnoses (grade, morphological type, etc.) according to the methodology published annually and specified by UZIS. The volume of consultations of the multidisciplinary team (MDT) and the volume of innovative pharmacotherapy (indicator 2) will be evaluated as simple numbers of reported procedures in total, without restriction to the selected cohort of patients. Other indicators (indicators 4-6) are evaluated exclusively in the cohort of patients who have started treatment in the CC since the diagnosis of cancer ("own patients", not migrating for care in subsequent phases of treatment) and only for sufficiently numerous diagnoses (typically with more than 100 unique patients per year at the centre).

1. Volume of MDT consultations.
2. Volume of innovative pharmacotherapy according to indications.
3. Time from first contact to start of treatment.
4. Total time and form of completion of hospitalizations.
5. Mortality of hospitalized patients.
6. Survival.

The above-mentioned indicators form the basis of future indicator sets that will be implemented through the newly introduced legislative tool (departmental reference statistics, Chapter XX). **A strategic overview of plans for the development of national cancer control indicators is presented in Appendix 1.**

6.2.3 National cancer control report

The product planned for 2022, fully utilising the described comprehensive ICT model, will include the following topics in particular:

- An overview of the cancer epidemiology in the Czech Republic
- Epidemiology of haematological malignancies in the Czech Republic
- Cancer care in the classification system of acute inpatient care CZ-DRG
- Utilization of innovative pharmacotherapy
- Cancer screening and early detection
- Primary prevention and health literacy

While the full report is being developed, first draft summary report has been prepared as an overview of cancer control in the Czech Republic. **The draft summary report is enclosed as Appendix 2.**

6.3 Open data strategy

One of general approaches to sharing cancer information is providing the underlying data, after certain refinements, de-identification, documentation, in the form of open data.

A global strategy of open data is based on the following crucial factors and motivations:

- the purposes of transparency (enabling verification of spending and financial management of institutions funded by the national budget, of the performance of the institutions, contracts, etc.),
- providing complex population data (population characteristics, epidemiological statistics, medications, performance characteristics, etc.),
- offering fully aggregated data for the scientific and analytical purposes (secondarily created datasets describing groups of objects or subjects or even individual anonymised records of individuals, e.g., anonymised records of births, hospitalisations, surgeries, etc.).

All regimes of the data provision from NHIS strictly require a **certain degree of legislative regulation and must fully meet the criteria set for NHIS by legislation**. Publication of open data must not be misinterpreted as the publication of primary records without any regulation and standardisation. The term “open data”, therefore, does not necessarily describe primary database records (the data may be aggregated, statistically processed, etc.). The dataset design, preparation, and publication should respect the algorithm of dataset preparation shown below, which always respects several principal rules:

(i) individual natural persons must not be identifiable,
(ii) individual legal persons must not be identifiable, unless expressly stated by law,
(iii) secondary processing must lead to the pseudonymisation of the dataset,
(iv) the purpose of the dataset publication must correspond to the NHIS purpose,
(v) the standardised process of approval and publishing must be adhered to.

Step 1 Concept design	Step 2 Concept evaluation	Step 3 Feasibility analysis	Step 4 Dataset production	Step 5 Review	Step 6 Publication
Proposed by state administration, external subjects (health insurance companies, expert societies, research institutions)	Purpose, data availability, feasibility, legal perspective	Data extraction, processing, analysis, validation	Structure, methods of production, metadata description	Personal data protection, factual content, IT solution	National Catalog of Open Data www.uzis.cz

Figure 10. Key steps in the production and publication of an open data set.

Publication of a dataset consists of six consequent steps that describe key phases on the preparation and implementation (Figure 10):

- **Step 1:** Proposal of a dataset concept in the form of short description, which can be brought by any entity; usually a state institution, a health insurance company, a professional (medical) society, a research institution, or an academic institution.
- **Step 2:** The delivered concept is reviewed from the perspective of data availability, export feasibility, design, and personal data regulations.
- **Step 3:** After approval, a methodology for the dataset processing is proposed (data export from central registries, data pre-processing and cleaning, analytical adjustments and validation mechanisms).
- **Step 4:** The dataset is generated in an open data standardised format according to the predefined scheme, including an obligatory description with metadata.
- **Step 5:** Review and validation of the dataset and its content is a mandatory procedure before publication.
- **Step 6:** Final publication of the dataset in the National Catalogue of Open Data (https://opendata.mzcr.cz/).

An example of processing and publishing process considering the necessary technical steps is shown in Figure 11.

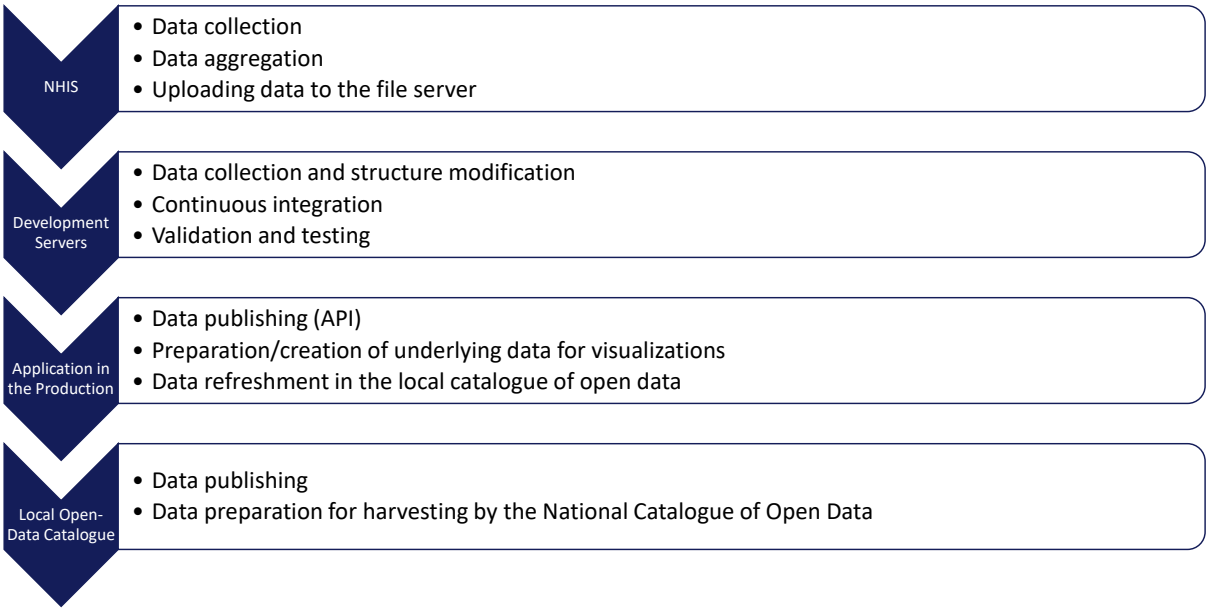

Figure 11. Technical overview of data processing and publishing process.

6.4 Czech Childhood Cancer Information System

The Czech Childhood Cancer Information System is one of information products based on complex data provided by the comprehensive ICT model, aimed at one of high-priority cancer control topics.

An important starting point for cancer programmes is knowledge of the burden of cancer in the population, identification of trends over time and the possibility of international comparison. A significant drawback of the information background in the Czech Republic so far has been the absence of such a reliable interactive tool for children and adolescents with cancer, which would address the above-mentioned issue. The new web portal, entitled the Czech Childhood Cancer Information System, not only provides basic expert information (analyses and publications) on individual diagnostic groups of childhood cancers, but also includes **interactive analytical reporting**, which **offers the user information on incidence, mortality and overall survival in graphical or tabular form**.

The main objective of the portal is to provide the professional and general public with clear and understandable overviews of epidemiological data on the incidence of cancer in children in the Czech Republic and data describing cancer-related mortality. Another ambition is to provide relevant information on the epidemiology of childhood cancer in the Czech Republic and abroad.

The presented analytical outputs and reports are based on all available **data sources** in the Czech Republic. In particular, these involve data from the Czech National Cancer Registry, which have been validated against the clinical database of childhood cancers in the Czech Republic and have been combined with data from the National Register of Hospitalised Patients and data from death certificates. These validated data have been used to determine the incidence and survival rates of childhood cancer patients in the Czech Republic. Data from death certificates have been used to monitor the long-term mortality trends.

The CCCIS web portal is publicly available at **https://ccc-is.uzis.cz**. **The services of the web portal include interactive analytical outputs** that allow the user to directly view epidemiological trends of their selected cancer diagnoses, as well as annotated **analyses** of selected important topics and **publications** dealing with the epidemiology of cancer in children.

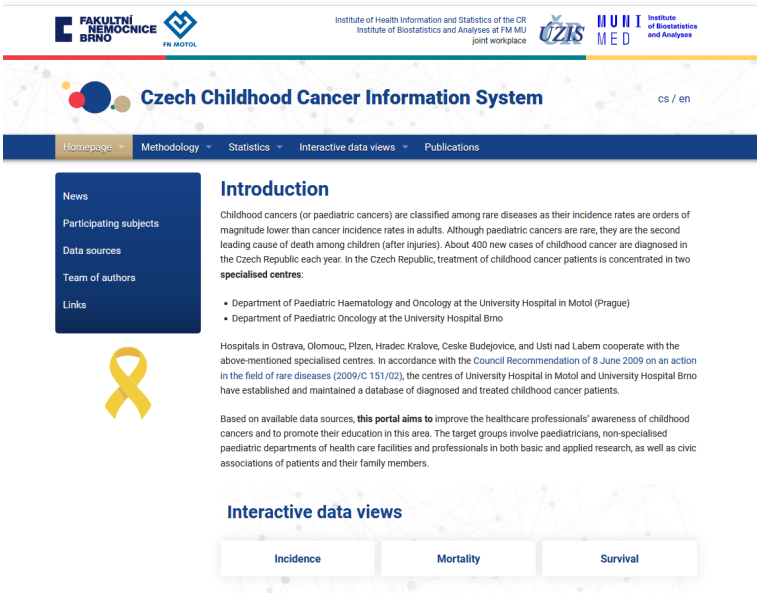

Figure 12. Preview of the main window of the Czech Childhood Cancer Information System web portal.

6.5 National Health Information Portal

As opposed to sophisticated analytical tools to assess population health and cancer care, an easy-to-use portal for the general public is necessary to raise health awareness within the population, and therefore represents another key part of the national cancer information system.

Health-related information on the internet in the Czech Republic is fragmented and often comes from low credibility sources. This fact, combined with relatively low rates of health literacy in the Czech population, presents challenges for promoting healthy behaviour and for achieving improvements in health outcomes. **A national web portal has been developed that allows to aggregate trustworthy information sources and improved public access to them**, and to reduce the spread of fake news in the domain of health-related information on the internet in the Czech Republic.

Development of the National Health Information Portal (www.nzip.cz) was initiated in 2018 under the umbrella of the Ministry of Health of the Czech Republic (main guarantor), the National Institute of Public Health (structure, content), Czech Medical Association of Jan Evangelista Purkyně (structure, content), and the Institute of Health Information and Statistics of the Czech Republic (UZIS, information technologies, development, content).

The portal represents a new platform for **publishing only validated articles and external sources under the supervision of the ministry of health and expert organizations**. Similar nationals web portals focused on health issues have already been analysed and documented as a sustainable and reliable solution in several countries (such as Austria or Australia).

Principles of the common web application and software development life cycle were respected: collection of features and functions, formal specification of requirements, modelling the system, design of visual style, static and functional prototype, implementation, testing, deployment, official launch, pilot operation, maintenance, development of further functionalities (based on user requirements), testing and implementation.

The portal contains six major modules: (1) map of healthcare facilities and services, (2) life situations, (3) prevention and healthy lifestyle, (4) diseases, (5) recommended websites, (6) index of medical terms. Contributions themselves are classified into two categories: (1) full articles and (2) recommended resources (links to other websites).

Primary prevention is emphasized as a key point of cancer control, followed by secondary prevention (check-ups and cancer screening); further services for cancer patients include a map of healthcare services, information for their better orientation in the healthcare system and provided care (diagnosis, treatment, social support, palliative care), their rights and obligations.

The National Health Information Portal should become a stable and sustainable communication channel between the Ministry of Health, medical experts, and the general public (including future patients) that increases health literacy among people and promotes responsibility for their own health.