The Importance of Timely Information in National Cancer Screening Programmes

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Abstract. The Ministry of Health of Slovenia decided to support the introduction of two new organised screening programmes for cancer, one for breast and the other for colon cancer in 2005. This was an addition to the first, already running, programme for cervical cancer. Two of them are entrusted to the Institute of Oncology while the National CINDI programme takes care of the third one. Besides connection to some external public databases, cancer screening programmes require national Cancer Registry data. High quality and user friendly information support for citizens and medical professionals following doctrinal requirements and possible changes is a must.

Keywords. cervical cancer, breast cancer, colon cancer, healthcare information, early detection, screening information system architecture

1. Introduction

The main objective of the introduction of organised screening programmes in Slovenia is a reduction of mortality due to breast, colon and cervical cancer, so three national screening programmes were introduced; ZORA for early detection of cervical cancer, DORA for early detection of breast cancer and SVIT for early detection of colon cancer.

In Slovenia we record high numbers of opportunistic breast mammographies but since they are (or better were) not performed in an organised fashion and not according to strict screening standards and guidelines [1], the outcomes do not meet the quality otherwise attainable through organised breast screening programmes. In contrast we have colon cancer, which has the highest rise in incidence occurring as such to both females and males, partly as a result to the rise of risk factors and partly due to ageing. All of the cancer screening programmes rely on identification of preclinical disease by relatively simple tests [2].

It was originally planned that all screening programmes will be managed through a central screening office, which would offer consolidated logistics, information system support and central call centre for sending invitations to different screening programmes [3]. The central screening office would also offer support in guidance and quality for the diagnostic part of the screening programmes. The Health ministry of Slovenia has approved additional funds for new equipment, infrastructure, execution and management of aforementioned screening programmes [4]. Unfortunately, due to certain political and private initiatives, the today reality is different.

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2. Overview of the Current Cancer Screening Programmes

The main objective of the screening programmes is early discovery of certain cancers. The target population for breast and colon cancer screening programmes was determined to be in the age group of 50 to 69 years. However, in the case of cervical cancer the target population includes also younger women aged 20 to 64 years.

The national breast cancer screening programme called DORA sends invitations for mammographies to women aged 50 to 69. The mammographies are then carried out in either of the two main diagnostic centres (Ljubljana, Maribor) or in one of the mobile centres. Every two years women in the target age group receive a letter of invitation to undergo a screening mammography. If women, who undergone screening mammography, are found suspicious or marginal, they are scheduled for diagnostic and possibly therapeutic procedures by the respective centre.

In the case of national screening programme for early detection of colon cancer called SVIT, every person in the target age group receives a package which contains two vials for stool samples. Vials containing stool sample are then sent to a special laboratory, which processes all samples. If stool sample of the participant is found positive for colon cancer, then the participant is scheduled for a diagnostic - therapeutic colonoscopy at the nearest regional centre for more accurate and final diagnosis. After the establishment of clinical diagnosis, the process of screening is terminated. All the participants receive invitations and the vials for stool samples every two years regardless of the outcome of their latest colonoscopy result.

In the cervical cancer screening programme called ZORA, each woman aged 20 to 64 is invited to perform a preventive gynaecological examination with Papanicolaou smear taken. Invitations are sent to women once in every four years. Women aged 65 to 74 years are not invited but are offered screening when they attend gynaecologist for other reasons.

3. Technical and Information Background of the Screening Programmes

3.1. Common and Domain-Specific Properties of the Screening Programmes

All of the three Slovenian cancer screening programmes were supposed to be carried out at the same institution which would also provide the organisational and software platform. Due to several reasons this solution was not empowered. As a consequence each of the screening programmes uses different organizational, information and communication system solutions.

The national screening programme for prevention of colon cancer – SVIT – is carried out with the CINDI Slovenia, which resides in the Community Health Centre of Ljubljana and uses their organisational and information technology solutions.

Other two national screening programmes DORA and ZORA are carried out under the auspices of the National Cancer Registry which dwells at the Institute of Oncology in Ljubljana. The Cancer Registry of Slovenia is one of the oldest population-based registries in Europe, being founded as a special service for collecting and processing data on cancer incidence and cancer patients’ survival.

The authors of this article were involved only in development of the ZORA and DORA platforms, therefore, more technical-based discussion will be focused on cervical and breast cancer screening programmes.
3.2. High Level of Interoperability

One of the main requirements to achieve high quality of national screening programmes DORA and ZORA is also a reliable and modern information system with a population repository which has to be regularly updated through a connection to Central Population Registry (CPR) and Spatial Data Registry (SDR). With this up-to-date population repository it is assured, that invitations are sent to right persons at the right address. It should be also assured that all the gathered histology and cytology laboratory results are linked to the right person.

Figure 1. Interoperability of breast and cervical cancer screening systems

In order to increase the value of gathered data at the base information system, the communication and data exchange between screening and Cancer Registry information system should be timed and established. The interoperability and different communication pathways between information systems are shown in Figure 1. To avoid data duplication, inconsistencies, easier maintenance and backup procedures, central personal repository was developed. It stores personal (demographics) and domain specific data such as names, addresses, dates of birth and possibly dates of death, unique national personal identifiers, previous known cancers, lab results etc.

3.2.1. DORA – Software Solution for National Breast Cancer Screening Programme

DORA information system supports professionals involved in the DORA screening programme. It consists of several independent modules, each tailored to the needs of certain departments as shown in Figure 2.

- **DORA register**: It supports DORA call centre for preparing and sending invitations. It is also used to prepare notifications with final results of the screening programme. Personal data are acquired from daily updated data from National Central Population Registry and National Spatial Data Registry.
- **DORA mammography**: It supports radiographer’s work and communicates with local or DORA PACS system in order to obtain PACS identifiers. This unique PACS identifier is later used in the screening application to enable radiologist’s seamless integration between DORA and PACS viewer.
3.2.2. ZORA – Software Solution for Early Cervical Cancer Detection

ZORA information system supports call centre and gathers laboratory results from collected gynaecology smears. Call centre sends out invitations to women, advising them to see their personal gynaecologist on regular basis. For easier data manipulation and statistical overview of collected data (based on returned cytology and histology results) the transactional part of the information system was extended by means of Oracle data warehouse and Business intelligence solutions (BI). Through BI end users were offered predefined and standardized reports. In addition a tool for creation of users’ own ad-hoc queries is also provided.

3.2.3. ZORA Web Portal for Online Gathering of Cytology and Histology Lab Results

The ZORA web portal [5] is a web application and serves as an extension to ZORA software solution. It is used as a national portal for gathering pathology and cytology laboratory results of collected gynaecologist smears. The web portal offers the histology and cytology laboratories a centralised and standardised way of inputting and transmitting laboratory results into central ZORA registry.
4. Results of the Cancer Screening Programmes

At the time of writing this article there were results available for two of the three screening programmes, the ZORA (cervical cancer) [5] and the DORA (breast cancer) [6]. The SVIT (colon cancer) [7] screening programme is still in its early stage, so no definitive results for a certain period of time are available.

ZORA programme exists from 2003. In the years 2005 and 2006 there were almost 90,000 invitations sent out. Out of those, not considering a small percentage of women who had recently been examined or had undergone hysterectomy, about 15,500 results were received – a score of 18% of all invited. The first invitations for the DORA programme were sent out in the spring of 2008. Out of 407 invited 334 were later scheduled for mammography. 219 women underwent mammography, out of those 18 were subjected to additional treatment with 3 cancers discovered.

5. Conclusion

Further steps in development of screening programmes in Slovenia should be taken in the direction of combining all current and future programmes under one roof. This would bring great advantages in several fields which will help to decrease cost of maintenance and execution of all screening programmes. Adding new screening programmes in the future would also be much easier since they could rely on the knowledge and resources already established considering the fact that basic principles of screening programmes are more or less the same. The screening process always starts with the selection of suitable candidates according to certain doctrinal rules, followed by sending invitations to those participants and submitting them to some medical examination procedure. The screening process wraps up with the received result of the performed medical examination while sending out a notice to participant.

A single national institution for support of all cancer screening programmes would provide a centralised and easier overview of gathered data, enabling higher information and work quality together with standardisation of work processes and lower infrastructure and working costs. From the point of view of support and development of information and communication technology only one set of applications and central infrastructure would be required. The timely (aka early!) information will thus be obtained leading to the achievement of the main objective – the reduced mortality.

References