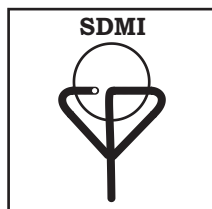


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Journal of the Slovenian Medical Informatics Association
Revija Slovenskega društva za medicinsko informatiko
Informatica Medica Slovenica
VOLUME / LETNIK 14, NO. / ŠT. 1-2
ISSN 1318-2129
ISSN 1318-2145 on line edition
<http://ims.mf.uni-lj.si>

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About the Journal

Informatica Medica Slovenica (IMS) is an interdisciplinary professional journal that publishes contributions from the field of medical informatics, health informatics, nursing informatics and bioinformatics. Journal publishes scientific and technical papers and various reports and news. Especially welcome are the papers introducing new applications or achievements.

IMS is the official journal of the Slovenian Medical Informatics Association (SIMIA). It is published two times a year in print (ISSN 1318-2129) and electronic editions (ISSN 1318-2145, available at <http://ims.mf.uni-lj.si>). Prospective authors should send their contributions in Slovenian, English or other acceptable language electronically to the Editor in Chief Assist.Prof. Gaj Vidmar, PhD. Detailed instructions for authors are available online.

The journal subscription is a part of the membership in the SIMIA. Information about the membership or subscription to the journal is available from the secretary of the SIMIA (Mrs. Mojca Paulin, marija.paulin@zzzs.si).

O reviji

Informatica Medica Slovenica (IMS) je interdisciplinarna strokovna revija, ki objavlja prispevke s področja medicinske informatike, informatike v zdravstvu in zdravstveni negi, ter bioinformatike. Revija objavlja strokovne prispevke, znanstvene razprave, poročila o aplikacijah ter uvajanju informatike na področjih medicine in zdravstva, pregledne članke in poročila. Še posebej so dobrodošli prispevki, ki obravnavajo nove in aktualne teme iz naštetih področij.

IMS je revija Slovenskega društva za medicinsko informatiko (SDMI). Izhaja dvakrat letno v tiskani (ISSN 1318-2129) in elektronski obliki (ISSN 1318-2145, dostopna na naslovu <http://ims.mf.uni-lj.si>). Avtorji člankov naj svoje prispevke pošljejo v elektronski obliki glavnemu uredniku doc.dr. Gaju Vidmarju. Podrobnejša navodila so dosegljiva na spletni strani revije.

Revijo prejemajo vsi člani SDMI. Informacije o članstvu v društvu oziroma o naročanju na revijo so dostopne na tajništvo SDMI (Mojca Paulin, marija.paulin@zzzs.si).

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Editorial ■

As the newly appointed Editor-in-Chief of the journal, I cordially greet all the readers. I hope to merit the trust of the SIMIA leadership and of my predecessor, who proposed my nomination. I also hope that the goals I will try to achieve together with the new Editorial Board will meet wide approval. At the same time, I apologise for the delay with this issue, which should be at least partly justified by the changes described below, as well as by the contents of this double issue.

I do not believe that anything is ever either completely new or remains completely unchanged, so I have never approved the widely known phrases either about the new times or about standing on giants' shoulders. An unquestionable novelty in our journal is the emphasis on international aspects, which is related to the openly expressed desire to make our journal indexed by the MEDLINE bibliographic database. The basis for this is the internationality of the Editorial Board. Thus, without worrying about possible injustice or fearing resentments, I first have to thank the successful and esteemed academic colleagues from abroad who kindly agreed to co-operate – Riccardo Belazzi from Italy, Bjoern Bergh from Germany and Izet Mašić from Bosnia and Herzegovina. My next thanks goes to the top-class (bio)physicist Primož Zihel. Needless to say, I continue to count on proven dedication and competence of all other old and new Editorial Board members.

Not everyone is regularly visiting the website of our journal (<http://ims.mf.uni-lj.si/>), so it is worth emphasising that it has been corrected and updated. The most substantially important are the two changes to the Instructions for Authors, which complete the extensions of the editorial practice:

- In addition to the five existing article types, we may occasionally publish an open discussion on a selected article (opinions from the readers and/or invited experts together with the author's reply);
- In addition to articles in Slovenian or English, we may occasionally publish articles in German,

Italian, Croatian, Bosnian, Serbian or Montenegrin language, whereby like the Slovenian ones, they must include the title and abstract in English.

Perhaps the things listed so far look to some like much ado about formalities instead of dealing with the journal's contents. However, like in many other fields of life and work, I find the things that the majority considers as the currently most important to be the last or a sweet worry. Namely, contributions have and will be coming from various disciplines, from health care information systems to medical image analysis, from biostatistics to pharmacokinetics, and from many other fields, with scientific, technical, educational or other scope – and we have been and will be composing our journal from them to the best of our abilities.

In my personal view – without concealing the link to Taoism and Stoicism – the path is more important than the destination. This is because it demonstrates the motives, and as an unconventional psychologist I dare judging people and their deeds by the underlying motives. The motives, in turn, reveal themselves through means of expression, which, in a scientific or technical publication, entail language, data displays and citations. And it is in those aspects that I/we will strive to impose care and excellence without compromise.

And since the Season holidays are coming, bringing mountains of good wishes and tangible gifts, I will bind my wishes with this excellence. I start with displaying data, which I consider a truly universal and crucial topic in the information society: give, buy or borrow – discover and read the works of Edward Tufte, Stephen Few, Howard Wainer and Naomi Robbins! If possible, also of Leland Wilkinson, William Cleveland and Colin Ware. Then follow up with literature classics! And then remind yourself of the noble ideals and manifold lives of great men of the Antiquity and Renaissance. And a(n even) better medical informatics (Slovenica) will be – the path!

Gaj Vidmar

Uvodnik ■

Kot novi glavni urednik revije od srca pozdravljam vse bralke in bralke. Upam, da bom upravičil zaupanje vodstva SDMI in svojega predhodnika, ki me je za to vlogo predlagal, ter da bodo načrti, ki jih bom skušal izvesti skupaj z novim uredniškim odborom, naleteli na večinsko odobravanje. Hkrati se opravičujem za zamudo pri izidu, ki jo vsaj delno pojasnjujejo spodaj opisane spremembe, upam pa, da tudi vsebina pričujoče dvojne številke.

V resnici ni nič nikoli povsem novo in nič nikoli povsem enako, kot je bilo, zato se mi znane fraze o prelomnih spremembah ali pa o stanju na ramenih velikanov nikoli niso zdele smiselne. Nesporna sprememba pri naši reviji je poudarjena mednarodna usmerjenost, ki je povezana z odkrito željo po uvrstitvi v bibliografsko podatkovno zbirko MEDLINE, temelj za to pa je mednarodno sestavljen uredniški odbor. Zato moram brez fraz o morebitnih krivicah in brez strahu pred morebitnimi zamerami najprej izpostaviti uspešne in ugledne akademske kolege iz tujine, ki so prijazno privolili k sodelovanju – Riccarda Belazzija iz Italije, Bjoerna Bergha iz Nemčija in Izeta Mašiča iz Bosne in Hercegovine. Nato se zahvaljujem vrhunskemu (bio)fiziku Primožu Ziherlu. Seveda tudi pri vseh ostalih dosedanjih in novih sodelavcih računam na dokazano predanost in kompetentnost.

Ker vsakdo ne spremlja redno spletne strani revije (<http://ims.mf.uni-lj.si/>), je vredno poudariti, da je popravljena in posodobljena. Vsebinsko najpomembnejši sta dopolnili navodil avtorjem, ki zaokrožata razširitev uredniške prakse:

- poleg dosedanjih petih vrst prispevkov bomo po potrebi objavljali tudi odprto razpravo (open discussion) o izbranih prispevkih (mnenja bralcev oziroma vabljenih razpravljalcev in odgovor avtorjev);
- poleg prispevkov v slovenščini ali angleščini bomo izjemoma objavljali tudi prispevke v nemškem, italijanskem, hrvaškem, bošnjaškem, srbskem ali črnogorskem jeziku

(seveda pa morajo tudi ti vsebovati naslov in povzetek v angleščini).

Morda se bo doslej naštetu komu zdelo izpostavljanje formalnosti namesto ukvarjanja z vsebino revije. A kot na množici drugih področij življenja in dela, se mi tudi tu ravno tisto, kar se večini zdi trenutno najpomembnejše, zdi najmanjša oziroma sladka skrb. Prispevki so in bodo prihajali s področij od zdravstvenih informacijskih sistemov do analize medicinskih slik, od biostatistike do farmakokinetike in od marsikod drugod, z znanstvenimi, strokovnimi, pedagoškimi ali drugačnimi ambicijami – in iz njih smo in bomo po najboljših močeh sestavljali našo revijo.

Pač pa je zame – brez skrivanja povezave s taoizmom in stoicizmom – od cilja pomembnejša pot. Kajti ravno v njej se kažejo motivi, z vidika motivov pa si kot nekonvencionalen psiholog drznem presojeti ljudi in njihovo delo. Motivi pa se kažejo skozi sredstva izražanja, torej pri znanstveni oziroma strokovni reviji (predvsem) skozi jezik, prikaze podatkov in navedene vire. In tu bom(o) skušal(i) brezkompromisno uveljavljati skrbnost in odličnost.

In ker se začenja čas praznikov in z njimi gora dobrih želja in konkretnih obdarovanj, bom svoje želje povezal s to odličnostjo. Začenjam s prikazom podatkov, ki se mi zdi v informacijski družbi zares univerzalna in usodna tema: podarite, kupite ali si izposodite – odkrijte in preberite si dela Edwarda Tufteja, Stephena Fewa, Howarda Wainerja in Naomi Robbins! Po možnosti tudi Lelanda Wilkinsona, Williama Clevelanda in Colina Warea. Nato storite enako z literarnimi klasiki! In nato se spomnite visokih idealov in vsestranskega življenja velikih antičnih in renesančnih ljudi. In (še) kakovostnejša medicinska informatika (Slovenica) bo – na poti!

Gaj Vidmar

■ **Infor Med Slov:** 2009; 14(1-2): 1-2

Research Paper ■

Establishing a Personal Electronic Health Record in the Rhine-Neckar Region

Oliver Heinze, Bjoern Bergh

Abstract. We present the underlying vision, the approach, the current status and the gained experiences in the attempt to establish a personal and electronic health record (PEHR) system in the Rhine-Neckar Region. First, an electronic health record (EHR) shall be implemented, which is in a second step expanded by a personal health record (PHR) in order to form a PEHR. Integration between the PEHR and the source systems is achieved with international standards (HL7, DICOM, IHE) and existing technologies. Non-image information (alphanumeric data, e.g. reports, lab results) is replicated; image information is replicated and then referenced after 3 months for capacity reasons. The approach to use off-the-shelf technologies and existing international standards proved successful but current HIS/EPR systems need to improve their support. Major issues could be indentified for the management of access rights and data privacy when using only EHR approaches. PHR is superior for as well ethical as technical reasons. More attention has to be paid to organisational aspects in order to truly empower patients.

Uvajanje osebnega elektronskega zdravstvenega zapisa v regiji Rhine-Neckar

Izveček. Prispevek predstavlja vizijo, pristop, trenutno stanje in pridobljene izkušnje glede uvajanja sistema osebnega elektronskega zdravstvenega zapisa (OEZZ) v regiji Rhine-Neckar v Nemčiji. Prvi korak je uvedba elektronskega zdravstvenega zapisa, ki v drugem koraku z vključitvijo osebnega zdravstvenega zapisa postane OEZZ. Integracija poteka po mednarodnih standardih (HL7, DICOM, IHE). Neslikovni podatki so podvojeni, slikovne pa se podvoji in nato nanje sklicuje. Pristop se je pokazal kot uspešen, a potrebno je izboljšanje podpore. Glavni izzivi so povezani z upravljanjem dostopnih pravic in zasebnosti podatkov. V prihodnje bo potrebno več pozornosti posvetiti opolnomočenju pacientov.

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■ **Infor Med Slov:** 2009; 14(1-2): 3-9

Introduction

In maximum care hospitals like the University Hospital Heidelberg, a substantial and increasing amount of patients is jointly treated with other care providers in the region. This reflects a general trend towards shared care which has taken place in Germany since the year 2000 due to substantial changes in the reimbursement system. An optimised prevention, diagnosis, treatment and rehabilitation strategy for the patient requires a tight and seamless integration of all participating care providers including hospitals, practices, rehabilitation institutes, labs and home care facilities.¹ This cross-institutional communication and the underlying data exchange can not at all or only partially be achieved with the existing hospital based HIS/EPR (Hospital Information System/Electronic Patient Record) or physician practice systems. It requires broadening the current scope to a cross-institutional shared electronic health record (EHR) which provides all required information to all participating care providers.²

This trend is supported by an increasing interest of patients to actively participate in their health care. Hassol et al.³ showed that most patients have a positive attitude towards online access to their patient record. Sprague⁴ indicates that mainly chronically ill patients have a substantial interest in their personal records and even wish to manually add information or remarks. Those desires require a new generation of patient records which is called personal health records (PHR).⁵ PHRs allow in addition to EHRs the manual data entry of information like e.g. wellness, alimentation, pain diaries or the upload of technical measurements from home care devices like weight, blood pressure or even ECGs by the patients themselves. Another main differentiator between PHR and EHR lies in the fact that the patient has full control of his personal record.

The objectives of this paper are to present the ISIS project (InterSectoral Information System), an attempt to establish a personal and electronic

health record system in our region, and to describe the underlying vision, the technical approach and the current status as well as the gained experiences.

Objectives

ISIS aims to improve the overall quality of patient treatment and in addition to demonstrate economic benefits. The co-operation partners shall have access to all relevant information, allowing a quicker, easier and more efficient diagnostic procedure and an optimized therapy. Multiple and duplicate examinations can be avoided and new co-operative treatment schemes supported in an optimal way.

The overall objectives of the ISIS project are the following:

- Empower the patient and maintain his citizen rights;
- Ensure that all participating care providers have access to all treatment relevant information and documents when required in an electronic way;
- Fulfil all data privacy and security regulations;
- Find a technically feasible and pragmatic solution allowing immediate implementation.

Vision

In a first step, an infrastructure for a cross-institutional communication will be installed which will host a physician moderated EHR and integrate a series of co-operating hospitals (Gesundheitszentren Rhein-Neckar GmbH, Universitätsklinikum Heidelberg) and physician practices. Once this is achieved, the focus shall be directed towards citizens and patients and the EHR shall be expanded to a PHR. The latter step empowers citizens and patients by having full

ownership as well as mastery of their personal documents and files allowing them to maintain their citizen rights and act self-determined also in the field of healthcare which in our view is the only appropriate way to deal with eHealth.

ISIS will provide an integrated and unified web-based view to all medical documents without replacing the primary source systems. The ISIS patient record will apart from the required administrative patient data like e.g. patient demographics and ADT information (admission, discharge, transfer) include diagnoses, important reports and discharge letters as well as OR information and images deriving from PACS systems. Technology-wise this will include data formats as ASCII tags, PDF, TIF as well as XML (CDA). Currently existing information systems within hospitals and practices remain untouched and will be interconnected employing standardized interfaces like HL7 and DICOM and web-based protocols. To ensure intra-operability also with future systems all interfacing should be achieved by national and international standards like HL7 and DICOM as well as IHE which will be exploited to a maximum in order to avoid proprietary solutions by all means. Full compliance with the German national telematics infrastructure shall be maintained wherever possible. The access rights and policies will be managed by a particularly granular rights and role based concept.

Methods

The ISIS project consists of three main phases. In phase 1, an EHR will be established between the University Hospital Heidelberg and its four partner hospitals from the Gesundheitszentren Rhein-Neckar gGmbH. In phase 2, the EHR will be expanded to further hospitals in the region and a series of physician practices will be included. Finally, in phase 3, a PHR will be developed and merged with the EHR.

For the implementation of as well the EHR as the PHR products developed by ICW AG (Walldorf, Germany) were chosen. The EHR will be based on the »professional exchange server« (PXS) product which includes a master patient index (MPI) as a basis for cross-institutional patient identification and a so-called virtual patient record (VPR). As PHR the product "LifeSensor" will be used.

For the first phase, it was decided to host the whole server backend for ISIS/PXS in the University Hospital's data centres. They are located in a separate subnet which is physically separated from the hospital's LAN. All access procedures are brokered by a web server positioned in the demilitarised zone (DMZ) of the University Hospital's firewall. All connections to this web server are SSL encrypted and employ https communication. On top of that, all external communications have to be secured via a VPN tunnel (virtual private network).

The overall architecture of ISIS is described in the following (Figure 1). All primary systems in the connected hospitals and physician practices send ADT information using an HL7-ADT message to the ISIS/MPI. For this purpose routine messages deriving from the regular data communication servers are duplicated and routed to ISIS.

After completion of the HL7-ADT message the MPI checks via complex mathematical matching algorithms whether the patient is already available in the MPI. Should this not be the case, a new index reference patient is generated. Alternatively, are matching patient demographics found within the MPI, the above mentioned matching algorithms will calculate »likelihood factors«. Above a certain threshold value, both patients are automatically merged. Beneath this threshold, the patient is put into a worklist which has to be processed manually by a clearing board installed in the University Hospital.

All clinical documents are transferred from the primary systems to ISIS via an HL7-MDM message and stored redundantly in the VPR; hence all clinical documents will exist in two

copies. One in the primary source system and one in the ISIS record. The term VPR is misleading since the documents are not only referenced as “virtual” would indicate but copied. The name was just maintained from the original manufactures’ branding.

Access to the VPR application will be granted via a standard web browser. This can be achieved in two ways. The first one is a manual logon directly to the ISIS platform and the second is a connection with the primary system. In the latter case, the patient and user context from a primary system are used in order to call the web-frontend of the ISIS platform and to jump immediately to the matching patient, removing the need for an additional manual logon for the users. Both approaches do not require any additional client installation on the users' PC.

Copying data does only partially apply to imaging objects deriving from PACS systems within the project partners' sites. A full duplication of all PACS systems would mean a tremendous data amount resulting in a substantial financial investment which did not appear as a preferable approach. Hence instead of replicating all images they will only be stored temporarily and then referenced after erasure. This image integration will be conducted via a CHILI web server (CHILI GmbH, Heidelberg, Germany). Imaging data to be interconnected with the ISIS record will be forwarded via DICOM from the PACS source system to the CHILI web server which is located in the ISIS subnet and stored here temporarily. Upon image arrival, the CHILI web server will generate an HL7-MDM message filled with demographics and study related information derived from the DICOM header of the incoming images and forward this to PXS. PXS will then generate an entry in the patient document list in the VPR. When this entry is selected by the user the images are requested and displayed in the web-frontend of the CHILI web server. This web server cache shall be configured in order to hold approximately three months of imaging data from the co-operation partners and works with the »first-in first-out« principle. When the requested

images derive from the above mentioned 3-month time interval they will immediately be displayed. When the images are older and hence erased from the cache, they will be requested automatically by the CHILI web server via DICOM from the primary PACS system and then delivered for display.

All requirements resulting from data privacy and protection regulations will be considered and fulfilled according to the currently existing legal frameworks. This includes patient approval for data storage within ISIS in general in a very granular way. Each user, as well as the primary systems, are authenticated to the platform in order to get access. A role-based access concept allows a highly sophisticated and differentiated access to the patient data only when a treatment context is present and can be proven based on the ADT messages. In the case of referrals which are not associated to ADT messages, access rights can also be provided manually for a limited time period which may be applicable in cases of second opinion or advice. In addition to the above mentioned methods, the system provides an emergency button, which allows a quick and effective access to the patient core information. In all cases including the emergency scenario, all user actions and accesses to documents are logged in detail.

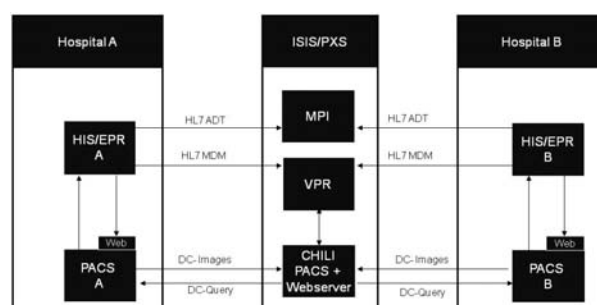


Figure 1 System architecture of ISIS (InterSectoral Information System). PXS = Professional Exchange Server; MPI = Master Patient Index; HIS/EPR = Hospital Information System/Electronic Patient Record; DC = DICOM.

Results

The conceptual stage of ISIS has been concluded and phase 1 is in implementation. On the technical side all hard and software installations of PXS including the MPI and VPR as well as the network configurations of the ISIS servers and subnets have successfully been accomplished and tested. On the university hospital side all required changes to the message-based communication have been implemented. This includes the HL7-ADT messages which were extended by the information whether the patient has approved data storage in ISIS. An additional HL7 messaging path was created in cases where the patient would initially approve but at a later point in time withdraw his approval. For the patient information a workflow procedure has been established together with the patient administration department and the treatment contracts have been modified to inform the patients about the features of ISIS and their rights in this context. For the MDM messages special mimics have been developed in-house for the hospital's EPR in order to enable document exports. This task required a thorough analysis of documents to be exported and the point in time for the export. It was decided to export only finally approved documents. However, even then amendments or revisions may occur which had to be considered in an updating mechanism throughout the data flow chain. According implementations and tests are currently being conducted for the partner hospitals.

The experiences within the project as so far have clearly indicated that there exist two main areas of problems for the implementation of an EHR. Whilst the technical issues were difficult but solvable by sticking to pragmatic approaches and established standards, we faced substantial problems with the data privacy aspects. The essential experience from our project is that despite the information which is currently communicated within the community that eHealth was safe, we could not find a solution satisfying all requirements of all involved

stakeholders: the patients, the care providers in particular physicians and the IT. An in-depth analysis revealed that the requirements of each group were comprehensible but, and this is the crucial point, contradictory. Fulfilling all needs and requirements of one party would automatically lead to a breach of desires of another group of stakeholders and vice versa.

Discussion

Our experiences indicated that HIS and EPR software manufacturers are facing new requirements. Until so far the capabilities of the systems were concentrated on receiving data from various hospital internal subsystems. However, cross-institutional data exchange requires in addition the export of all documents and in addition of structured information like diagnoses or procedures and other elements like e.g. medication data in a standardized way. We could not solve those requirements with the functionality natively provided by the HIS/EPR systems involved in our project and hence had to develop it in-house, which is obviously an unsatisfactory situation since by far not all hospitals and regions will have the capabilities and knowledge to do that. Since the request for cross-institutional data exchange is tremendously increasing we believe that the pressure on the software manufactures will rise and hopefully in the near future lead to an extended support of the applicable IHE-XDS profiles (Integrating the Healthcare Enterprise - Cross-enterprise document sharing). This trend would certainly be supported by more and more hospitals requesting this functionality as a substantial criterion for a HIS/EPR selection. But also another message can be derived from this situation. With the evolving HIS/EPR market we see companies becoming more international and offering Pan-European products. They will not be able to implement and maintain integration with a variety of national or even regional EHR solutions or "standards". A fragmented market would only lead to a lack in quality and seriously jeopardize the sustainability.

Hence we strongly recommend abstaining from trying to foster national standards in favour of using international standards wherever possible.

It was evident that conventional data privacy and access policies do not at all suit the needs and requirements for cross-institutional communication via EHRs. Since it is impossible to simultaneously fulfil all needs of all participating stakeholders (patients, care providers, IT) the particular interests obviously have to be weighted against each other. We believe that priority should be given to the citizens and patients. It is in all our interest that traditionally established in-house concepts are substituted or completely replaced in order to achieve proper privacy and not violate the citizen's rights. We conclude that in particular the nationwide implementation of EHRs requires much more thoroughly conceptualized and implemented data privacy approaches unless citizen maturity and self determination is abandoned to a high extent as can be observed in an astonishingly high amount of EHR projects across Europe. This carries a substantial risk for abuse and the inherent jeopardy can hardly be underestimated considering the upcoming of personalised medicine and the increasing amount of genetic information prospectively to be found in EHRs.

We believe that PHRs offer the only possible solution to address and solve the described privacy issues. In PHR scenarios, the focus is on the patient and citizen who are the exclusive owners and only actors in granting and taking access rights to cross-institutional information. In our eyes PHRs are the only way to ensure citizen-centred eHealth and maintain full citizen self-determination in the long run, unless a breach of the civil rights is accepted. But apart from the ethical justification we also consider PHRs technology-wise an easier approach to establish cross-institutional data exchange. Both aspects together laid the conceptual foundation for our project. In addition a PHR-based eHealth concept will also be capable of easily integrating home care and ambient assistant living systems in order to establish a fully integrated clinical documentation.

Since we believe that elements classically considered being either only EHR or PHR have to be merged we call it Personal Electronic Health Record (PEHR).

In general astonishingly little attention is paid to the organisational aspects surrounding eHealth and the importance appears under-estimated. Although the concept of "empowering" the citizen is universally present in eHealth discussions, and often mentioned as one of the big advantages, the degree of concreteness is very low and the visions are quite blurry when compared to the elaborate level of technological proposals and solutions. There is a lot of work to do including a general definition of ethical principles for eHealth, putting the citizen in the centre, and a revision of the existing legal frameworks, in particular in order to strengthen the patients' rights and to establish substantial fines for violations of data privacy. Evidently, the citizen can also not be left alone with the task to appropriately manage access rights to clinical documentation in a PHR context. Similar to seeking a lawyer's advice in legal matters we imagine a neutral supporting structure in the medical domain.

Conclusion

Our experiences in the ISIS project show that the concept of using technologies and international standards existing today in combination with a pragmatic system architecture approach is valid and demonstrates quick results. However, HIS and EPR vendors have to extend their capabilities in order to better support cross-institutional data exchange. But the most important experience is that a major revision and re-thinking of data access and privacy concepts has to take place in the eHealth domain. Especially considering the trend towards personalised medicine and the upcoming inclusion of genetic information into cross-institutional patient records, emerging from the evolving integration of bio- and medical informatics, demands an appropriate solution.

We believe that PHRs are a strong asset in order to avoid abuse and allow full data privacy and patient empowerment. Other than today the patient has to be put in the middle of the ongoing eHealth discussion in order to maintain his rights and decide which institution and which physician has access to which information, if any. In order to achieve this degree of patient empowerment ethical guidelines have to be provided, the legal framework has to be adjusted and especially designed support structures have to be established which have to be neutral and provide full trust to the citizen.

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Research Paper ■

Automated Preparation of the Book of Abstracts for Scientific Conferences using R and LaTeX

Avtomatska priprava knjige povzetkov za znanstvene konference z uporabo R in LaTeX

Lara Lusa, Andrej Blejec

Abstract. The organization of a scientific conference can be a very demanding and time-consuming duty. Two challenging tasks are the preparation of the detailed program and of the book of abstracts. To make these tasks easier to handle, we developed the *generbook* package, which includes some functions written in R language and a LaTeX template for the book of abstracts. This paper describes the package and how to use it; it also shows how it was used for the organization of an international statistical conference.

Izvilleček. Organizacija znanstvene konference je zahteven podvig. Dve posebej zahtevni nalogi sta priprava programa konference in knjige povzetkov. Da bi olajšali njuno izvedbo, smo izdelali paket *generbook* v okolju R, ki vključuje več funkcij v jeziku R in predlogo za knjigo povzetkov za stavni sistem LaTeX. Prispevek podaja podrobne napotke za uporabo paketa in vključuje primer njegove uspešne uporabe pri organizaciji mednarodne statistične konference.

■ **Infor Med Slov:** 2009; 14(1-2): 10-18

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Introduction

The organization of a scientific conference can be a very demanding and time-consuming task. The organizing committee of a small academic conference is typically a small group of people from the scientific staff of the organizing institution, with limited administrative support and funding availability. Therefore, the organizing committee has to handle many different aspects: advertising the conference, preparing the abstract submission form and the set-up of a method to efficiently manage the submissions, managing communication with the conference participants, selecting the contributions that will be presented at the conference, preparing the documents requested by the participants, preparing the detailed scientific program and the book of abstracts, and managing last-minute cancellations and special requests from the participants.

The preparation of the detailed program of the conference and of the book of abstracts can be perceived as tasks that are performed only once during the conference preparation. In practice, the program, and consequently the book of abstracts, changes many times, as participants communicate last-minute cancellations or submit additional contributions, ask to change the schedule of their talks, or to make corrections to the submitted abstracts. These last minute modifications are particularly tedious if the program and the book of abstracts are handled and prepared with a word processor that requires the modifications to be made manually. This would therefore be the case when using Microsoft Office Word, at least without complex automation using macros. Each small modification to the program or the book of abstracts would require some manual editing, which is not only time consuming but can also easily introduce errors into the final document.

The book of abstracts usually includes a program overview of the conference, a detailed program, all the abstracts accepted for presentation, and an alphabetical index of the authors. Hereafter, we will refer to all these parts simply as “the book of

abstracts”. There are three key features needed to automatically produce the book of abstracts:

1. A database that contains the information about each submitted abstract (the names of the authors, affiliation of each author, the title of the contribution, the abstract text etc. – *contributions database*);
2. A file that indicates which contributions will be included in the final program and their schedule (*program file*);
3. A computer program that will automatically produce the final book of abstracts by reading the program from the program file, and the detailed information about the contributions from the contributions database.

If these three features are available, it is easy to produce the book of abstracts, and it is straightforward to update it if needed.

This paper focuses on the automated preparation of the book of abstracts. We describe some functions written for this purpose in R language¹ and a LaTeX² template for the book of abstracts. These R functions and the LaTeX template were used for the preparation of the annual Applied Statistics International Conference held in September 2009 in Ribno, Slovenia (*AS2009 Conference*). Hereafter, we will refer to the R functions and the LaTeX template as the *generbook* package.

The rest of the paper is organized as follows: in the Methods section, we describe the abstract submission management, the R functions for the generation of the book of abstracts and the LaTeX template for the book of abstracts; in Results and Discussion, we show how the developed functions and the template were used for the AS2009 Conference and discuss the issues in the application of such methods for conference management; in the Conclusion, we discuss the advantages of using our approach or similar automated approaches for preparing a book of abstracts.

Methods

Here, we describe how to prepare the files needed to automatically produce the book of abstracts with *generbook*: the set of functions that we wrote in R language for this purpose and the LaTeX template for the book of abstracts. The files are freely available at <http://sites.google.com/site/lara3107/Home/software/generbook>.

To use the package *generbook*, the users must download and install R and have on their computer a program to compile the LaTeX documents; such programs are available on most Linux distributions, while Windows and Mac OS X users can download freely available programs for this purpose – MikTeX for Windows (<http://www.miktex.org/>) or MacTeX for Mac OS X (<http://www.tug.org/mactex/>).

Contributions database

The most straightforward way to obtain the contributions database is by handling the submission of the contributions using a form posted on the World Wide Web. Many websites offer freely available tools for developing and posting web forms; some examples are the forms that can be created with Google Docs (<http://docs.google.com>, using the forms available in the Docs spreadsheet), LimeSurvey (<http://www.limesurvey.org>) or 1ka (<http://www.1ka.com>). Of course, it is possible to create the database also when more traditional methods are used for submissions, such as submissions through electronic or regular mail. This approach is not very practical if the contributions database is needed, since the information about each submission has to be retrieved and then added manually to the database.

The package *generbook* can be used together with a contributions database in which each contribution represents a record in the database. The records contain information about the contribution (title

and abstract) and about the authors (their names, academic affiliations, contact information, and indication of which author is going to present the paper at the conference).

In order to maintain high flexibility in the layout of the abstracts as they appear in the book of abstracts, some information must be split in separate fields. For example, the name of each author is split into three different fields: first, middle and last name; similarly, the affiliation of each author is split into institution, city and country. Table 1 reports the fields that must appear in the contributions database for using *generbook*.

Two fields can be added to the database after the submission is complete.

1. A unique identification number (*AbstractID*) assigned to each contribution and used in the program file to uniquely identify them.
2. A variable indicating if the contribution was accepted for presentation at the conference (*AbstractOK*, with value TRUE if the contribution was accepted, FALSE otherwise)

In order to use the *generbook* package, the database has to be in text format with the fields delimited by tabulation (*tab-delimited file*). Most databases can be easily exported into such format. The user can choose any name for the fields in the original database, as they do not need to have pre-specified names.

Table 1 Fields included in the contributions database.

	Field	Example
Contribution	Title	The Voyages of the Starship USS Enterprise
	Abstract	In this paper we present the voyages of the starship USS Enterprise and its five-year mission: to explore strange new worlds; to seek out new life and new civilizations; to boldly go where no man has gone before.
	Topic 1	Exploration of the Outer Space
	Topic 2	Starships
Author 1	First Name	James
	Middle Name	T.
	Last Name	Kirk
	Institution	Starfleet
	City	San Francisco
	Country	U.S.A. - Earth
	e-mail address	JTKirk@starfleet.org
	Presenting (Yes/No)	Yes
Author 2	First Name	Spock
	Middle Name	
	Last Name	
...	Institution	Vulcan Academy of Science
	City	
	Country	Vulcan
	e-mail address	spock@vulcan.org
AbstractID	101	
AbstractOK	TRUE	

Note: If more than one author is selected as presenting author, the first one selected is used as presenting. After the submission, a unique identification number is assigned to each contribution (AbstractID=101 in this case). If all the authors have the same affiliation, it will be reported only once in the final abstract.

The program file

To use *generbook* to generate the detailed program of the conference and the book of abstracts, the program of the conference has to be specified in a tab-delimited file where each record (row) of the file refers to a session. The main pieces of

information required are: the name of the session, when and where it will be held, who is going to chair it, and which abstracts are scheduled in the session. Some fields can be left empty if they do not apply. For example, if a record refers to a break, the fields for the chair of the session and for the abstracts will remain empty. Table 2 reports the variables that the user can specify for each of the sessions.

Table 2 Variables included in the program file.

Variable	Example
Name	Exploration of the Outer Space
Day	1
DayLong	SUNDAY, September 20, 2009
DayShort	Sunday, September 20
DayTable	Sunday
Room	Hall 1
TimeBegin	10.30
TimeEnd	12.30
Abstract1	101
Abstract2	23
Abstract3	21
Abstract4	81
Abstract5	

Note: The variables refer to a single session of the conference. The day of the session is reported in four different ways: as a number (Day, indicating the order of the conference days - 1 for the first day, etc.), with a long (DayLong), short (DayShort), or very short (DayTable) denomination. The reason is that in different parts of the book of abstracts we need different level of details. For example, when preparing the table with the outline of the program we use just the day of the week, while for the detailed program the longer denomination is used.

Additional variables can be added by the user of *generbook* to the program file or to the contributions database.

Functions written in R

We wrote some functions in R to automate the preparation of some parts of the book of abstracts. These functions are useful because they perform some tasks that would be time-consuming if performed manually. Hence, they allow the user to automatically obtain a new book of abstracts each

time the program is modified (i.e., changes are made to the program file) or any correction is made to the contributions database.

R function: `generate.abstracts()`

This R function retrieves pieces of information from the contributions database and generates a separate text file (*abstract file*) for each contribution. The abstract file contains the information that will be included in the book of abstracts regarding the contribution: the title, the names of the authors, their affiliations and e-mail addresses, and the text of the abstract.

To use the `generate.abstracts()` function, the user needs to specify: where the contributions database is located, in which directory to save the abstract files, and which are the columns of the contributions database that contain the information relevant for the generation of the abstract files (i.e., which columns contain the identification number of the abstract, the title of the contribution, the text of the abstract, the names of the authors, their affiliations and e-mails, etc.). These pieces of information are the arguments of the `generate.abstracts()` function.

As an example, we show the content of the abstract file that would be generated for the contribution described in Table 1 (file 101.tex), and in Figure 1 (upper panel) the resulting abstract as it would appear in the book of abstracts.

```
\A
{The Voyages of the Starship USS Enterprise}
{\Presenting{James T. Kirk}$^1$\index{Kirk,
JT} and Spock$^2$\index{Spock}}
{\Affiliation{$^1$Starfleet, San Francisco,
Earth};
\Email{JTKirk@starfleet.org}
\Affiliation{$^2$Vulcan Academy of Science,
Vulcan};\Email{spock@vulcan.org}}
{Topic1: Exploration of the Outer Space, Topic2:
Starships. Abstract ID: 101}
{In this paper we present the voyages of the
starship USS Enterprise and its five-year mission:
```

to explore strange new worlds; to seek out new life and new civilizations; to boldly go where no man has gone before.}

It can be noted that in this abstract file, we defined some new LaTeX commands (in bold). The purpose was to maintain a highly flexible style of the abstracts. The new commands are defined in the preamble of the LaTeX template for the book of abstracts (see below the description of `Book.tex`) and can be easily modified by the users of *generbook*.

The main new command is `\A`, which specifies the formatting style of the abstracts, taking as arguments: the title (#1), the names of the authors (#2), the affiliation and e-mails of the authors (#3), the keywords (#4) and the text of the abstract (#5). `\A` is defined as follows:

```
\newcommand{\A}[5]{
\begin{minipage}{\textwidth}
\Title{#1}
\Author{#2}
\AffiliationAndEmail{#3}
\Keyword{#4}
\Abstract{#5}
\end{minipage} }
```

The formatting of each of the arguments is further specified by five newly defined LaTeX commands (`\Title`, `\Author`, `\AffiliationAndEmail`, `\Keyword`, and `\Abstract`). The definitions of these commands can be found in the LaTeX template for the book of abstracts included in the *generbook* package (`Book.tex`).

A simple example of the flexibility of this approach can be seen comparing the upper and lower panels of Figure 1. To obtain the abstract reported in the lower panel, we modified the `\Title` command, using italic fonts instead of bold fonts; the `\Author` command, removing the centering and the italic fonts; and the `\Presenting` command, indicating the presenting author with an asterisk instead of underlying their name.

Sunday, September 20

Exploration of the Outer Space

Exploration of the Outer Space

The Voyages of the Starship USS Enterprise

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In this paper we present the voyages of the starship USS Enterprise and its five-year mission: to explore strange new worlds; to seek out new life and new civilizations; to boldly go where no man has gone before.

The Voyages of the Starship USS Enterprise

James T. Kirk*¹ and Spock²

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In this paper we present the voyages of the starship USS Enterprise and its five-year mission: to explore strange new worlds; to seek out new life and new civilizations; to boldly go where no man has gone before.

Figure 1 The contribution described in Table 1 as it would appear in the book of abstracts, using the default settings of *generbook* (upper panel) and redefining some of the LaTeX commands (lower panel, obtained by modifying the \Author, \Title and \Presenting commands in the LaTeX template file).

These modifications required the change of few lines of code in the preamble of the LaTeX template of the book of abstracts (Book.tex). If we had not used this approach, a user interested in changing the style of the abstracts should have changed the code of the R function, which would have been more complicated. Even more work would have been required to introduce these changes in a manually edited book of abstracts.

R function: generate.programOverview()

This R function uses the program file and produces the LaTeX input file (programOverview.tex) that contains the program overview of the conference. The program overview is a table that reports the names and times of the sessions, but not the list of the abstracts that are presented in each session. An example of a program overview table produced with *generbook* is shown in Figure 2.

Program Overview

		Hall 1	Hall 2
Sunday	10.30 – 11.00	Registration	
	11.00 – 11.10	Opening of the Conference	
	11.10 – 12.00	Invited Lecture	
	12.00 – 12.20	Break	
	12.20 – 13.40	Exploration of the Outer Space	Borg Assimilation Strategies
	13.40 – 15.00	Lunch	
	15.00 – 16.20	Romulan Diplomacy	New Class M Planets
	16.20 – 16.40	Break	
	16.40 – 18.00	Positronic Brain Development	Klingon Language
	19.00	Holodeck Reception	
Monday	9.10 – 10.00	Invited Lecture	
	10.00 – 10.20	Break	
	10.20 – 11.40	Non-Betazoid Telepaths	Stress Management Under Warp
	11.40 – 12.00	Break	
	12.20 – 13.40	History of the United Federation of Planets	Nosocomial Infections on Starships
	13.00 – 14.30	Lunch	
	14.30	Excursion to Mars	
	19.00	Closing of the conference	

Figure 2 Example of a program overview table generated with *generbook*.

R function: generate.program()

This R function uses the contributions database and the program file, and produces two files that are necessary to generate the book of abstracts:

- program.tex – the file that contains the LaTeX input file with the detailed program of the conference, i.e., the detailed program lists for each session with the titles of the contributions and the names of the authors;
- abstracts.tex – the file that contains the LaTeX input file for the part of the book of abstracts that incorporates the abstracts; in our current implementation of *generbook*, the abstracts appear in same order as in the detailed program and each session is separated from the others; the names of the sessions and the dates appear in the header of the document (see the header in Figure 1 for an example); this is obtained by redefining the header commands in the document for each new session.

LaTeX template for the book of abstracts

The LaTeX template file for generating the book of abstracts is called `Book.tex` and it can be downloaded from the web site of the *generbook* project. The template file can be used as the basis for any book of abstracts and it requires few manual modifications to adapt its style to the user's preferences.

As announced in the description of the R functions, we defined some new LaTeX commands in the preamble of the `Book.tex` file. These commands define the style that is used for the abstracts (see the description of `\A` in the "Functions written in R" section), and the page style and layout of the book of abstracts.

After the preamble, the `Book.tex` document is very simple as it uses the LaTeX `\input` command to read and process files that were either already generated by the *generbook* package (`programOverview.tex`, `program.tex` and `abstracts.tex`) or previously prepared by the user. The user needs to prepare the LaTeX documents containing the front matter of the book of abstracts (`cover.tex` file), i.e., the title page, the edition notice, the page with the names of the members of the scientific and organizing committee, etc. An example of the `cover.tex` file is included in the *generbook* package and can be adapted.

We prepared some additional LaTeX files that can be useful for completing the book of abstracts: the `notes.tex` file that specifies a page of the book of abstracts devoted to notes, the `empty.tex` file containing an empty page, and the `sponsor.tex` file that contains the information about the sponsors of the conference.

A simplified version of the `Book.tex` document contains the following commands (comments to the code are preceded by the `%` symbol):

```
% includes the front matter of the book
\input{cover.tex}
% includes the program overview
```

```
\input{programOverview.tex}
% includes the detailed program
\input{program.tex}
% includes all the abstracts to be presented
% at the conference
\input{abstracts.tex}
% makes the index of authors
\printindex
% includes the pages for taking notes
\input{notes.tex}
% includes the information about the sponsoring
% of the conference
\input{sponsors.tex}
```

Figure 3 summarizes the use of the *generbook* package. It shows the files that the user needs for using *generbook* (the files represented in solid boxes), the files that can be prepared using the R functions of *generbook* (in dashed boxes), and which files are inputted into other LaTeX files (indicated with dashed arrows). The final document in PDF form is obtained by compiling the LaTeX source file `Book.tex` (e.g., using the `pdflatex` program, which is included in the Windows distribution of MikTeX).

Results and Discussion

We used the *generbook* package to generate the book of abstracts of the AS2009 Conference. The book of abstracts was printed and published online.³

We handled the submission of the contributions using the forms available in Google Documents. The preparation and publication of the form is straightforward, and it does not require any programming knowledge. In our form, we considered the possibility of having at most six authors. The submission form that was used can be seen at <http://spreadsheets.google.com/viewform?hl=en&formkey=cmhvV0FPYk5CNk9oNGlwzbzF6TIIzdIE6MA> (note that submissions are closed).

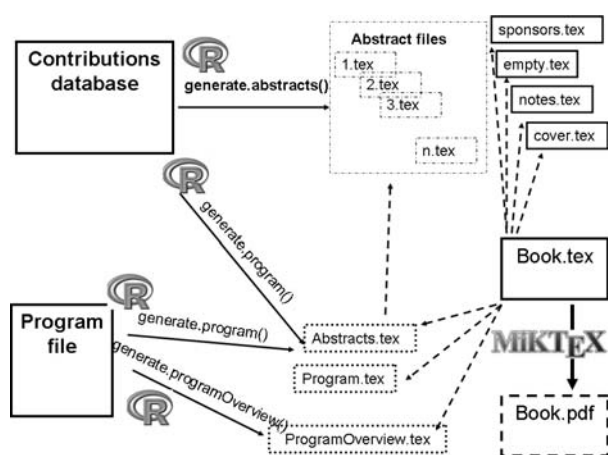


Figure 3 Use of *generbook* package. The files represented in boxes with solid lines are the those that must be prepared by the user, while those in boxes with dashed lines are produced by using the *generbook* package (as indicated by solid arrows, listing the function or program used to generate the file). Dashed arrows represent the connections between a LaTeX file and the input files that are included in it.

The spreadsheet with the contributions was exported into a tab-delimited text file and a unique identification number was assigned to each contributed abstract (*AbstractID*); this number was communicated to the authors and used for all further communications with them. The abstract files were generated using the `generate.abstracts()` function. Few manual corrections were needed. The most common problem was the use of symbols that were misinterpreted when included in a LaTeX document (for example, the symbol “%” marks the beginning of a comment in LaTeX, so it had to be substituted with “\%”).

We prepared a temporary version of the book of abstracts that included all the contributions, and we used this book for selecting the contributions for the conference. This temporary book was very helpful in the selection process, as it provided a clear and organized display of the abstracts. The decision about the contributions was included in the contributions database by defining a new variable (*AbstractOK*).

The program was specified by preparing a program file as described above, and the abstracts that were

selected for each session were identified by their *AbstractID* number.

We used the R functions of *generbook* to create the LaTeX documents containing the program overview, the final detailed program and the complete abstracts, in the same order as they appeared in the program. The style of the book was defined in the preamble of the LaTeX template and it was easy to modify.

Most importantly, last minute changes to the program were handled easily: the only required manual changes were those on the program file. Everything else was produced automatically: the new LaTeX input files were generated using the R functions, and the LaTeX file of the book of abstracts was recompiled. In this way, the book of abstracts was updated in all its parts. The final book of abstracts can be viewed on-line.³

Manually updating any changes of the program in the book of abstracts can be very cumbersome and it can easily introduce some errors into the final document. For example, a simple change like switching two sessions would require the modification of the following parts of the book of abstracts if handled manually: the content of the program overview table, the detailed program, the order in which the complete abstracts appear in the book, and the page references in the index of authors.

Conclusions

In this paper, we presented the *generbook* package, a freely available set of R functions and of LaTeX templates that can be used to generate the book of abstract of scientific conferences. The package also provides some simple tools for managing the conference program.

In our experience, *generbook* proved to be a valuable tool in the organization of the AS2009 Conference, reducing the tediousness of manually updating the files and the probability of making

errors. The system has proven to be sufficiently robust yet versatile.

The package is relatively easy to use for anyone with basic knowledge of R and LaTeX. Although some commercial alternatives to our system exist, the presented package has the advantage of being freely available (open source), and features flexibility rarely found in other systems. Our package can be seen in the framework of reproducible computing, as it provides a reproducible solution for the preparation of the book of abstracts.

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Izvirni znanstveni članek ■

Spremljanje funkcijske neodvisnosti v rehabilitacijski bolnišnici: primer učinkovite uporabe preprostega modela zmesi porazdelitev

Monitoring Functional Independence in a Rehabilitation Hospital: an Example of Efficient Use of a Simple Mixture Distribution Model

Gaj Vidmar

Izveček. Predstavljena je uporaba modela zmesi dveh omejenih normalnih porazdelitev na ocenah z Lestvico funkcijske neodvisnosti (FIM) ob sprejemu in odpustu pri pacientih na kompleksni bolnišnični rehabilitaciji. Čeprav je model preprost, ima pomembno pojasnjevalno in praktično vrednost.

Abstract. An application of a mixture-distribution model of two bounded Gaussians on data gathered by assessing patients undergoing complex inpatient rehabilitation using Functional Independence Measure (FIM) at admission and discharge is presented. Even though the model is simple, it has notable explanatory and practical value.

■ **Infor Med Slov:** 2009; 14(1-2): 19-23

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Uvod

Ocenjevalne lestvice so nepogrešljive mere izida na področju rehabilitacije tako pri vodenju obravnave pacientov kot pri raziskovalnem delu. Med najsplošnejše in najpogosteje uporabljane sodi Lestvica funkcijske neodvisnosti (Functional Independence Measure, FIM).¹⁻³ Zelo pomembna je tudi z vidika strukture primerov (*casemix*) v rehabilitacijskih bolnišnicah in na njej temelječega financiranja.⁴ Sestavljata jo motorična podlestvica s 13 postavkami in kognitivna podlestvica s 5 postavkami, pri čemer se vse postavke ocenjujejo z ocenami od 1 do 7, tako da je skupni dosežek na celotni lestvici med 18 in 126, na motorični oziroma kognitivni podlestvici pa med 13 in 91 oziroma med 5 in 35.

O uporabi FIM pri različnih pacientih za različne namene poročajo tisoči člankov, vključenih v bibliografsko podatkovno zbirko MEDLINE. FIM se največkrat uporablja za ocenjevanje zmanjšane zmožnosti po kapi⁵, nezgodni možganski poškodbi⁶, multipli sklerozi⁷, poškodbah^{8,9}, pri Parkinsonovi bolezni¹⁰ in drugih patologijah za namen ugotavljanja rehabilitacijskih potreb¹¹, dokazovanja učinkovitosti rehabilitacije^{7,12}, primerjanja rehabilitacijskih programov¹³ ter napovedovanja funkcijske neodvisnosti ob odpustu iz bolnišnice¹⁴ in na daljši rok⁹. Sprejemljiva zanesljivost FIM je potrjena za širok nabor okolij, ocenjevalcev in pacientov¹⁵. Pri ocenjevanju zmanjšane zmožnosti nevroloških pacientov se je v primerjavi z Indeksom Barthelove pokazal kot bolj veljaven in enako zanesljiv⁴. Zanesljivost, notranjo skladnost in diskriminativno veljavnost postavk so za FIM potrdili pri dvajsetih skupinah okvar.¹⁶

Uvedbo in uporabo FIM na Univerzitetnem rehabilitacijskem inštitutu Republike Slovenije – Soča (URIS; prej Inštitutu RS za rehabilitacijo, IRSR) ter širši pomen FIM v slovenskem prostoru je predstavil predhoni prispevek.¹⁷ Namen pričujočega prispevka je podrobneje predstaviti izbrani ožji problem v okviru analize podatkov, zbranih s FIM na URIS, ki dokazuje, da lahko že razmeroma preprosti verjetnostni oziroma

statistični modeli prinesejo pomembno novo vrednost v strokovnem in poslovnem upravljanju v zdravstvu.

Metode

Prispevek obravnava dosežke na FIM pri 1394 bolnišničnih primerih iz leta 2006, pri čemer je leto v skladu s prakso poročanja v zdravstvu definirano kot leto odpusta.

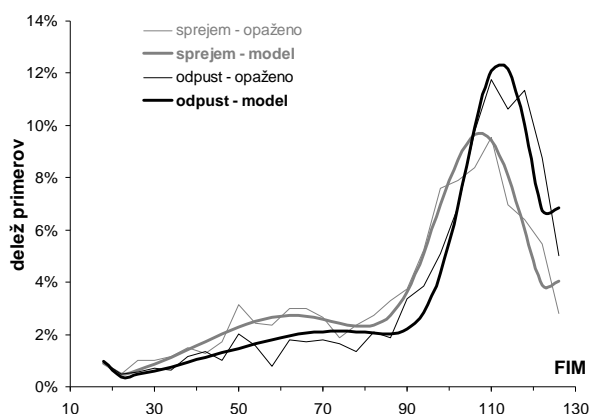
Uporabljeno je modeliranje zmesi porazdelitev, ki se je v zadnjih dveh desetletjih uveljavilo na številnih področjih, ki segajo od biomedicinskega inženiringa¹⁸ preko psihofizike in psihometrije¹⁹ do ekonomije.²⁰

Na podlagi opaženih porazdelitev (slika 1 in predhodne analize¹⁷), teoretičnih razlogov in strokovnih izkušenj smo se odločili za zmes dveh omejenih normalnih (*bounded Gaussian*) porazdelitev. Najprej smo z algoritmom EM (*expectation-maximisation*) določili parametre zmesi dveh normalnih porazdelitev ob sprejemu. Nato smo ocenjeni delež obeh komponent zmesi (za prvo komponento P , za drugo torej $1-P$) pustili konstanten ob sprejemu in odpustu, ocenjeni povprečji in standardna odklona uporabili kot dobre začetne približke ter ob sprejemu in ob odpustu ocenili parametre zmesi omejenih normalnih porazdelitev (v skladu z razponom FIM na razpon 18-126) po metodi največjega verjetja (*maximum likelihood*).

Za oba koraka je bilo uporabljeno prosto dostopno programje: za prvi korak program GMM,²¹ za drugi korak pa program FitDist.²² Oba programa delujeta v okolju Windows v ukaznem načinu tako, da izdelata izhodno besedilno datoteko na podlagi vhodne besedilne datoteke s podatki in besedilne datoteke z ukazi, ki vključujejo parametre modelov. Zaradi jasne dokumentacije in vzorčnih datotek sta oba programa preprosta za uporabo tudi za matematično in računalniško manj večje uporabnike.

Rezultati in razprava

Oblika porazdelitve dosežka na FIM ob sprejemu in odpustu (tudi za leta 2004-2005 in 2007-2009 je zelo podobna kot na sliki 1) kaže, da je zmes dveh unimodalnih porazdelitev primeren model opaženih vrednosti FIM. Z vidika neposredno neopazljivega konstrukta si lahko predstavljamo, da sta ti porazdelitvi normalni (kot pri preprosti obliki analize latentnih razredov – *latent class analysis*), pri čemer je zaradi omejenega razpona lestvice FIM (od 18 do 126) boljši model vsakega od razredov omejena normalna slučajna spremenljivka, torej taka, pri kateri se vse latentne vrednosti pod oziroma nad določeno mejo izrazijo kot minimalna oziroma maksimalna opažena vrednost. Na ta način model upošteva učinek stropa (*ceiling effect*) in tal (*floor effect*), ki pogosto nastopita pri uporabi tovrstnih lestvic. V skladu s tem pri obeh porazdelitvah, ki izhajata iz modela (debeli črti na sliki 1), opazimo zasuk navzgor pri najmanjši in največji možni vrednosti FIM.



Slika 1 Ujemanje opažene porazdelitve FIM ob sprejemu in odpustu z modelom zmesi dveh omejenih normalnih porazdelitev.

Ujemanje modela s podatki je tako ob sprejemu kot ob odpustu zelo dobro, dobljena rešitev pa je:

- $P_1=P=0,37; P_2=1-P=0,63$
- ob sprejemu: $\mu_1=60,64; \sigma_1=21,65; \mu_2=105,7; \sigma_2=10,63$
- ob odpustu: $\mu_1=71,7; \sigma_1=27,74; \mu_2=110,4; \sigma_2=8,574$

Na podlagi tega preprosto ocenimo pričakovano spremembo FIM za vsako od skupin kot razliko povprečij ter izračunamo varianco porazdelitve razlik kot vsot varianc ob sprejemu in odpustu. Tako dobimo preprost poljudni povzetek modela (tabela 1), ki ima pojasnjevalno in praktično vrednost.

Velika standardna odklona jasno nakazujeta, da je pri določenem delu pacient pričakovati tudi znižanje FIM (pri čemer so parametri seveda ocenjeni tako, da se delež tovrstnih pacientov ujema z dejansko opaženim).

Tabela 1 Poljudni povzetek modela.

Paciente lahko uvrstimo v dve skupini;
1. skupina, v katero sodi približno 2/3 pacientov, ima povprečni dosežek na FIM ob sprejemu okoli 105,
2. skupina, v katero sodi približno 1/3 pacientov, pa okoli 60 (ločnica skupin je pri okoli 85);
v vsaki skupini je porazdelitev dosežkov na FIM in spremembe FIM približno normalna;
v 1. skupini pričakujemo izboljšanje za 5 točk (s standardnim odklonom 14 točk),
v 2. skupini pa pričakujemo izboljšanje za 11 točk (s standardnim odklonom 35 točk).

Zaključek

Obraavnani model dokazuje, da se da smer in velikost sprememb skupne ocene na FIM oceniti in predvideti na podlagi preprostega modela zmesi dveh omejenih normalnih porazdelitev. Na ta način se da oceniti tudi predvideno uspešnost rehabilitacije ob morebitni spremembi strukture sprejetih pacientov. To je poleg podrobnega poznavanja značilnosti doslej sprejemanih pacientov pomembno za problematiko financiranja

dejavnosti URIS, pa tudi za celotno zdravstveno politiko v državi.

Poudarjana preprostost modela pomeni, da obstajajo številne zahtevnejše statistične metode, s katerimi bi se dalo zbrane podatke analizirati še bolj poglobljeno. Prvi korak bi lahko bil formalni statistični test bimodalnosti na podlagi razmerja verjetij.²⁰ Razpon možnosti za nadaljnje delo sega od zahtevnejšega modeliranja zmesi (npr. bayesovskega²³ ali večrazsežnega,²⁴ s katerim bi hkrati modelirali motorično in kognitivno podlestvico FIM) preko presečnih napovednih modelov (npr. s hierarhičnimi regresijskimi modeli z upoštevanjem zmesi porazdelitev²⁵) do najzahtevnejšega longitudinalnega modeliranja (npr. z modeli latentne rasti²⁶ ali semiparametričnimi mešanimi regresijskimi modeli²⁷).

Pred tovrstnimi poskusi pa moramo ocene na FIM preučiti z vidika teorije odgovora na postavko (Item Response Theory, IRT), zlasti politomnega Raschevega modela. S tem bi ugotovili, ali ocenjevalci uporabljajo celoten razpon ocen pri vseh postavkah, ter ali se težavnost oziroma občutljivost postavk razlikuje med diagnostičnimi skupini. Šele ob povezavi tovrstnih spoznanj z dosedanjimi bi nato lahko pristopili k izdelavi splošnejših napovednih modelov napredovanja funkcijskih sposobnosti pacientov po rehabilitaciji.

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Review Paper ■

Medical Information on Renal Arterial Stenting

Rakesh Sharma

Abstract. Renal artery stenosis (RAS) is a common pathological condition associated with uncontrolled or refractory hypertension, flash pulmonary edema, and worsening renal function. The high prevalence of RAS in patients with coronary and lower extremity vascular disease has been well established. In a recent study on the practice of “drive-by renal shooting”, prevalence of significant RAS was found to be high in patients with suspected coronary atherosclerosis referred for coronary angiography. Another study revealed dramatic increase in volume of renal arterial stenting in the Medicare population. Hence, concerns of over-diagnosis and over-treatment of RAS were raised. However, numerous recent studies demonstrated high success rate of renal artery stent revascularization and its clinical benefits. Aggressive screening and early treatment of RAS are therefore warranted in patients with drug-refractory hypertension and/or worsening renal insufficiency. However, some open issues remain. The paper proposes selection criteria for “drive-by renal shooting” and suggests valid criteria for treating RAS.

Medicinske informacije o ledvičnih arterijskih opornicah

Izvleček. Ledvična artirjska stenoza (LAS) je dobro znano bolezensko stanje, pogosto pri bolnikih s srčno-žilnimi boleznimi. Novejši študiji sta pokazali na visoko prevalenco LAS pri angiografiji pacientov s sumom koronarne ateroskleroze in dramatičen porast vsatavitev ledvičnih artirjskih opornic pri zavarovancih Medicare v ZDA. To je vzbudilo skrb o prepogostem diagnosticiranju in zdravljenju LAS. A druge novejšje študije so dokazale uspešnost in koristnost vstavljanja ledvičnih arterijskih opornic. Prispevek povzema odprta vprašanja glede tega ter predlaga merila za presejalne postopke in zdravljenje LAS.

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■ **Infor Med Slov:** 2009; 14(1-2): 24-35

Is Renal Artery Stenosis (RAS) overdiagnosed?

There are two main causes of RAS, which are fibromuscular dysplasia and atherosclerosis. Fibromuscular dysplasia causes less than 10% of all RAS and is most often seen in young female patients.¹ However, atherosclerotic RAS is by far the most common etiology of RAS (nearly 90%), especially in old aged male patients.² The prevalence of atherosclerotic RAS in an elderly cohort has been reported to be 6.8% in a population-based study using duplex ultrasonography and it also frequently coexists with atherosclerotic disease in other vascular territories; approximately 15 to 23% of CAD, 28-38% of aorto-iliac disease, and 45-59% of lower extremity vascular disease.^{3,4} Most of the patients with RAS are asymptomatic due to a large renal reserve of function. The two main clinical manifestations are renovascular hypertension and ischemic nephropathy. Renovascular hypertension is often difficult to control and can aggravate the heart failure and precipitate the unstable angina. In addition, renal ischemia may lead to an end-stage renal failure and high mortality.⁵ Although RAS can be diagnosed using non-invasive tests with high sensitivity and specificity such as duplex ultrasonography, computed tomography, and magnetic resonance angiography, renal angiography remains the gold standard for the diagnosis of RAS.⁶

Recently, the rapid technology advancement in percutaneous vascular intervention has achieved a high success and very low complication rate in renal arterial stenting. In addition, because of the silent nature of the disease and the frequent association with atherosclerotic disease in other vascular territories, there has a dramatic increase in the practice of simultaneous selective or non-selective renal angiography in patients undergoing cardiac catheterization in order to screen and diagnose the once ignored and underappreciated problem. This practice has been termed as “drive-by renal shooting”. An important clinical study examining the practice of “drive-by renal

shooting” was performed. Based on a set of pre-selection criteria (Table 1), 1149 patients meeting at least one selection criterion were selected for the study but only 851 did have renal angiograms. The results showed 36.9% of all patients had angiographically evident renal artery atherosclerosis, 14.3% of patients had stenosis $\geq 50\%$ in at least one proximal renal artery, 7.3% had severe stenosis $\geq 70\%$, 1% had total occlusion and 1.4% had severe bilateral stenosis $\geq 70\%$ (Table 2).⁷ However, the results of this study triggered the concerns from other experts who viewed the practice of drive-by renal shooting as an indiscriminate testing for RAS or fortuitous documentation of lesions, which might lead to proliferation of procedures laden with morbidity, high cost, and mortality.⁸

Is RAS over-treated?

In a recent study based on the Medicare data, the annual volume of percutaneous renal artery interventions (renal artery angioplasty and stent placement) increased rapidly with 2.4 fold from 1996 to 2000, whereas the annual volume of renal artery surgery declined by 45% during the same period (Figure 1). Most growth in percutaneous renal artery revascularization is attributed to increased performance by cardiologists with an increase of 287%. Although interventional radiology and surgery increased the volume by 63% and 153% respectively, the total volume contributed by these 2 specialties was relatively small (Figure 2). This explosive growth in annual procedure volume by cardiologists varied in different regions of U.S., but the highest rate was seen in the Southeast region by 1443% (Figure 3).⁹

Table 1 Selection criteria for renal artery angiography.

Category	Definition
Clinical presentation	
1. Hypertension	
Resistant	Systolic BP \geq 140 or diastolic BP \geq 90 mm Hg while on \geq 2 drug classes at \geq 2 defined daily doses
Severe	Systolic BP \geq 180 or diastolic BP \geq 110 mm Hg regardless of drug therapy
2. Kidney dysfunction	
Unexplained	C-G CrCl \leq 50 ml/min without clearly established cause
ACEI-ARB induced	Documented acute renal dysfunction attributable to ACEI or ARB therapy Radiographic grade \geq III and no other recognized cause* and associated with acute hypertension (\geq 160/100 mm Hg) or chronic hypertension
3. Acute pulmonary edema	
Risk factors for severe atherosclerosis	
1. Cerebro-vascular disease	Ischemic or arterial embolic stroke; carotid bruit; causing stenosis \geq 50%; or previous carotid revascularization
2. Severe coronary artery disease	Three territories with \geq 60% stenosis; previous revascularization of 3 territories; or left main coronary \geq 50% stenosis Causing stenosis \geq 50% of diameter; documented
3. Severe atherosclerotic abdominal aortic or lower extremity artery disease	atherosclerotic aneurysm; previous peripheral or aortic surgery; or intermittent claudication with corroborative physical examination

*e.g., ejection fraction \leq 40%, acute myocardial infarction, severe valvular disease; ACEI=angiotensin-converting enzyme inhibitor; ARB=angiotensin receptor blocker; BP=blood pressure; C-G CrCl=Cockcroft-Gault creatinine clearance. Modified from Table 1 in Buller et al. The profile of cardiac patients with RAS. Am Coll Cardiol. 2004;43:1606-1613.

Table 2 Results of renal angiography categorized by severity of RAS.

Severity of RAS	No. (%) of patients*
Any renal arterial disease	309 (37%)
Renal stenosis > 50%	120 (14%)
Renal stenosis > 70%	61 (7%)
Renal occlusion	8 (1%)

*Of the 1149 patients who met one of the criteria, 851 underwent renal angiograms. Modified from Table 2 in Buller et al. The profile of cardiac patients with RAS. Am Coll Cardiol. 2004;43:1606-1613.

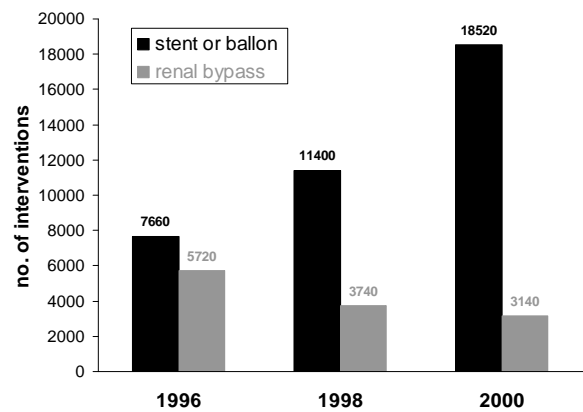


Figure 1 Increase in utilization of percutaneous renal artery interventions by Medicare beneficiaries 1996–2000 (by intervention type). The data are extrapolated from the Medicare population in the USA. Adapted from Murphy TP, Soares G, Kim M, et al. Increase in utilization of percutaneous renal artery interventions by medicare beneficiaries, 1996-2000. Am J Roentgenol. 2004;183(3):561-568.

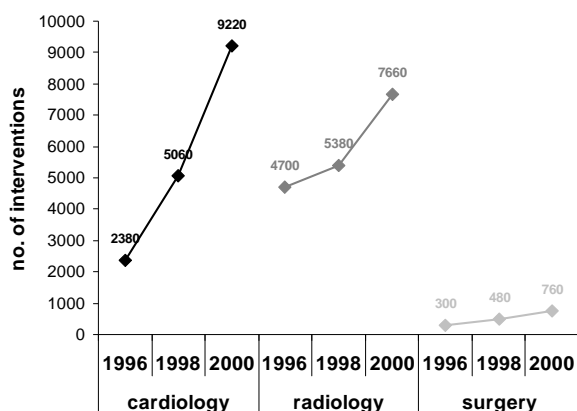


Figure 2 Increase in the total number of percutaneous renal artery interventions by Medicare beneficiaries 1996–2000 (by medical specialty). The data are extrapolated from the Medicare population in the USA.

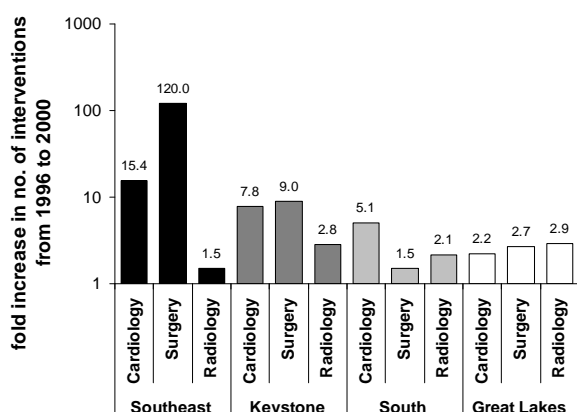


Figure 3 Increase in the total number of percutaneous renal artery interventions by Medicare beneficiaries 1996–2000 (in selected regions, by specialty).

The issues raised by conventional thinking about renal arterial stenting

For years, renal arterial stenting was believed by many to be associated with a high morbidity, mortality, and cost. Furthermore, many experts as well as practicing physicians also believed that there was a lack of data supporting clinical outcome of renal arterial stenting. Therefore, the

above-mentioned studies lead to a concern over whether the use of drive-by renal shooting to diagnose RAS is a good practice and whether renal arterial stenting has been over-performed. These arguments against renal arterial stenting suggest medical or conservative therapy as a preferred choice for the treatment of RAS. However, this conventional view may arise mainly from poor understanding of the natural history of RAS and current existing data about clinical efficacy of renal arterial stenting.

Understanding the natural history of atherosclerotic RAS

There were numerous studies examining the natural history of RAS since 1968.¹⁰⁻²² We would only limit the discussion here on 2 recent most important studies as examples. Caps et al. documented in their prospective study of atherosclerotic RAS progression that overall cumulative incidence of RAS progression was 35% at 3 years and 51% at 5 years. For patients with RAS initially classified as normal, <60% stenosis, and ≥60% stenosis, the 3-year cumulative incidence of RAS progression was 18%, 28% and 49 respectively with an incidence of 6% total occlusion. The risk of RAS progression was the highest among individuals with preexisting high-grade RAS, elevated systolic blood pressure, and diabetes mellitus.²³

In a prospective study of simultaneous renal angiographies performed in cardiac catheterization laboratory at 2 different times, the incidence of normal renal angiography in the study population decreased from 91% to 75% after a mean period of 2.6±1.6-year follow-up. The disease progression in 1 or more renal arteries was seen in 6% of the patients within 1-year follow-up but it increased to 28% within 6 years.²⁴ These and many other studies clearly showed the natural history of RAS is undoubtedly progressive over time.

The association of severity of RAS with loss of renal function and size

The single most important impact of progression of RAS is a reduction in the kidney size and function. Along with the progression of severity of RAS, many studies also showed its association with renal atrophy and dysfunction.²⁵⁻²⁸ A prospective study showed overall cumulative incidence of renal ischemic atrophy defined by a reduction in renal length of greater than 1 centimeter was 16.2% at a mean of 33 months. For patients with renal arterial stenosis initially classified as normal, <60%, and ≥60%, the 2-year cumulative incidence of renal ischemic atrophy were 5.5%, 11.7% and 20.8% respectively.²⁹ In addition, it has been estimated that atherosclerotic renal occlusive disease is the primary cause of end-stage renal failure in 5% to 15% of patients over the age of 50 years who begins dialysis each year.^{30,31}

The impact of RAS on survival

In a study of 1235 patients undergoing diagnostic cardiac catheterization and abdominal aortography, four-year unadjusted survival for patients with RAS was 65% compared with 86% for patients without significant RAS. Among the factors associated with decreased 4-year survival, i.e., the presence of significant RAS, reduced ejection fraction, elevated serum creatinine, and symptoms of congestive heart failure, significant RAS was a strong independent predictor of 4-year survival in that patient population.³²

In summary, the nature of progression in atherosclerotic RAS is that renal arteries with higher degree of stenosis progress faster than those with mild or moderate stenosis and this progression leads to a decrease in size and function of kidney and it is associated with a negative impact on the long-term survival without intervention.

Improving success and risk of the renal arterial stenting overtime

The technology of the percutaneous vascular intervention including renal arterial stenting had evolved very rapidly since percutaneous transluminal angioplasty was introduced in 1978. In 1980s, the success rate of balloon angioplasty of renal artery was below 60 to 90% with a complication rate of 5 to 16%.³³⁻³⁷ Since the introduction of renal arterial stenting in 1990s, the success rate has been reported to be between 90 to 100% with the complication rate of 0 to 4%.³⁸⁻⁴⁰ Zeller et al. analyzed the impact of technical improvements in stent devices and guiding catheters (i.e. reduced device diameter and increased flexibility) on complication rates associated with percutaneous renal arterial interventions. They concluded that the complication rate of renal arterial intervention of atherosclerotic RAS has been reduced significantly during a 5-year period in parallel with the use of more flexible catheters and pre-mounted lower-profile stents.⁴¹ With continuing refinement of balloon and stent technology, currently, renal arterial stenting is no longer a technically challenging procedure with a success rate of >98% and very low complication rate of <1%.⁴²⁻⁴⁵

Abundance of existing studies demonstrating the clinical efficacy of renal artery stenting

There were at least 15 studies including more than 1500 patients demonstrating the clinical efficacy of renal arterial stenting.^{42, 44-57} Among these studies, some of the more important ones are discussed below.

Improving blood pressure control

Dorros et al. described the impact of renal arterial stenting on blood pressure control in their 4-year prospective follow-up of 145 patients who

underwent Palmaz-Schatz stent revascularization of ≥ 1 stenotic renal artery. At the 4-years follow-up, the systolic and diastolic blood pressures significantly decreased from (166 ± 26 mmHg) to (148 ± 22 mmHg) and from (86 ± 14 mmHg) to (80 ± 11 mmHg), respectively. The blood pressure response at 1 year showed that only 1% of patients were cured, 42% were improved, and 54% had no improvement but at 4 years, 2% were cured, 47% were improved and 51% had no improvement.⁵⁷

In another prospective study by Zeller et al., blood pressure (systolic/diastolic/mean) decreased significantly after the intervention from $144/79/102$ mmHg at baseline to $132/72/93$ mmHg at 6-month follow-up. In 46% of the patients, blood pressure control was improved after mean 34-month follow-up; it remained unchanged in 43% and deteriorated in 11%. The numbers of drugs for blood pressure was also significantly reduced from 3.06 ± 1.17 to 2.76 ± 1.16 after mean follow-up.⁵⁸

Blum et al. also demonstrated the efficacy of renal arterial stenting in 68 patients with ostial RAS after initial unsuccessful balloon angioplasty. At a mean 27-months follow-up, cure of hypertension was seen in 16%, improvement in 62% and no change in 22%.⁵⁹

Stabilizing renal function deterioration or improving renal function

In the study by Dorros et al., serum creatinine level decreased or remained stable in approximately two thirds of all patients received successful renal arterial stenting. For patients with unilateral stenosis, two thirds of patients had improved or stable renal function, whereas one third had progression of their renal dysfunction with an increase in their creatinine by >0.2 mg/dl above baseline. In patients with bilateral stenosis, nearly 75% had stable or improved renal function and only 25% had deterioration of renal function.⁵⁷

In 330 patients after successful renal stenting, Zeller et al. also showed a similar beneficial result

with a serum creatinine decreased significantly from 1.45 ± 0.87 to 1.39 ± 0.73 mg/dl in correspondent with an increase of GFR from 59 ± 26 to 62 ± 26 ml/min/1.73 m² of body surface area over a mean follow-up of 34 months. Serum creatinine decreased $\geq 10\%$ in 34% of the study patients, remained stable in 39%, and increased at least $\geq 10\%$ in the rest of patients. Using GFR measure, GFR increased by $>10\%$ was noted in 38% of patients, unchanged in 33%, and a decrease $>10\%$ in 29%. Furthermore, the study also showed improved or stabilized serum creatinine concentrations in 64% of patients with pre-existing normal renal function, 82% of patients with moderate impairment, and 92% of those with severely impaired renal function, suggesting the more severe the renal dysfunction prior to renal stenting, the more the patients benefited from the intervention.⁵⁸

In another study, Harden et al. also noticed the similar beneficial impact of renal artery stenting on progression of renovascular renal failure. In their study, 32 patients underwent renal arterial stenting with a 100% success rate. At 6-months follow-up, improvement in renal function measured by $>20\%$ decrease in serum creatinine was seen in 34%, stabilized in 34% and worsened in 28% with an overall deceleration in the rate of progression of renal failure in 78% of patients.⁵³

In the study of 68 patients by Blum et al., all patients had a stabilized renal function at a mean follow-up of year or months after successful renal stenting.⁵⁹

Improving survival rate

Dorros et al. reported that the cumulative probability of survival was $74 \pm 4\%$ at 3 years, with few deaths related to end-stage renal disease. The survival was good in patients with normal baseline function ($92 \pm 4\%$), fair in those with mildly impaired renal function ($74 \pm 7\%$), and poor in those with elevated baseline creatinine levels (≥ 2.0 mg/dl) ($52 \pm 7\%$). The combination of

impaired renal function and bilateral disease adversely affected the survival in those patients.⁵⁷

In conclusion, there are a large amount of observation studies showing that renal arterial stenting undoubtedly preserves the renal function and improves blood pressure control in a broader spectrum of patients with RAS.

The clinical outcome of medical therapy for significant RAS

Chabova et al. studied the outcomes of atherosclerotic RAS managed medically in 68 patients with high-grade stenosis (>70%) who were followed up for at least 6 months after first angiography. At a follow-up of 38.9 ± 2.8 months, the serum creatinine level rose from 1.4 ± 0.1 to 2.0 ± 0.2 mg/dl and mean blood pressure did not change ($157 \pm 3/83 \pm 2$ vs $155 \pm 3/79 \pm 2$ mmHg), but the need for medication increase from 1.6 ± 0.1 to 1.9 ± 0.1 drugs. Four patients (5.8%) eventually underwent renal vascularization for refractory hypertension (1 patient), for progressive stenosis (1 patient), and during aortic reconstruction (2 patients). One additional patient underwent nephrectomy to improve blood pressure control.⁶⁰

In another study of 45 patients with RAS, Soffer et al. used the renal scintigraphy with iothalamate and technetium pentetic acid to measure for total and single kidney glomerular filtration rate (SK-GFR) to compare the effect of renal arterial stenting in Group 1 (n=17) with medical therapy alone in Group 2 (n=28) on SK-GFR. The result of their study remarkably showed that at 14-month follow-up, SK-GFR was increased in Group 1 by $24 \pm 8\%$ but it was decreased in Group 2 by $11 \pm 5\%$ and the study concluded that renal arterial stenting preserves SK-GFR in patients with RAS, whereas progressive deterioration is observed in medically treated patients.⁶¹

These two studies clearly showed medical therapy of RAS is associated with continuing decline in renal function and a poor prognosis. Therefore,

based on all the up-to-date evidences, renal arterial stenting should be considered as the treatment of choice for significant renal arterial stenosis.

Remaining issues in renal arterial stenting

Indeed, several indeed remain in renal arterial stenting. Even after a successful procedure, 20 to 40% of patients did not improve in blood pressure control and 15 to 20% of patients may have worsening renal function. Therefore, the most important current issues are to identify patients who are most likely to benefit from the procedure and to develop strategies that prevent the worsening renal function after the renal stenting. Currently, there are no useful clinical predictors to select the patients who may respond to the renal stenting procedure. In addition, despite an abundance of data showing the clinical efficacy of renal stenting, there no large scale randomized study to show the benefit of renal stenting over medical therapy although one is now ongoing.

Lack of clinical predictors for outcome of renal arterial stenting

Several clinical parameters had been proposed to be used in predicting the clinical outcome of renal arterial stenting, but none of these were found to be a standard test.

Renal vascular resistance-index: Based on the theory that the structural alteration in smaller renal arteries or arterioles distal to RAS induced by long-standing hypertension leading to a decrease in the intra-renal vascular surface area and increases in the vascular resistance, Radermacher et al. used “renal vascular resistance-index” measured by Duplex Doppler ultrasonography in their prospective study to predict the outcome of renal revascularization in patients with RAS. They concluded that a renal resistance-index value of >80 reliably identifies the patients with RAS in whom the renal

revascularization procedures (renal angioplasty, stenting or surgery) will not improve renal function, blood pressure, or kidney survival but a reversed outcome in patients with a resistance-index of 80 or less.⁶²

However, the study by Zeller et al. reported a contradictory result in that the resistance index value before renal arterial stenting did not differentiate patients who had or had not improved renal function and/or better control on blood pressure after stenting.⁶³

Serum creatinine and left ventricular function:

Zeller et al. also mentioned in their study that elevated serum creatinine and impaired left ventricular function were independent predictors of improved renal function, whereas female sex, preserved parenchymal thickness, and baseline mean arterial blood pressure predicted the improved blood pressure control after successful renal arterial stenting.⁶³ However, there are no other studies to confirm these findings as yet.

Post-procedural renal dysfunction and its prevention

As mentioned earlier, approximately 15-20% patients have worsening renal function after stenting. The major mechanisms are not clear but are related to the following factors, these are progression of concomitant nephrosclerosis, contrast medium-induced nephrotoxicity, recurrent lesion due to in-stent restenosis and distal atheroembolization. These factors can be minimized by taking preventive measures to reduce the renal injury from the stenting procedures.

To minimize the contrast-induced nephrotoxicity, half-diluted contrast medium, iso-osmolar contrast medium (Iodixanol), oral or intravenous acetylcysteine (Mucomyst), hydration with intravenous normal saline and intravenous sodium bicarbonate infusion were shown to reduce the renal dysfunction.^{64,65} Effective blood pressure control by anti-hypertensive medications, lowering of blood lipid level by statins and effective control

of blood sugar level by insulin and anti-diabetic medications may slow down the progression of concomitant nephrosclerosis.^{66,67} To prevent the in-stent restenosis, drug-eluting stents are currently on the clinical trials but Food and Drug Administration.

Distal embolization of debris after percutaneous renal arterial ballooning and stenting are increasingly recognized as major causes of worsening renal function after a successful procedure.⁶⁸ Not only balloon dilatation and stent deployment can cause the distal embolization but merely engagement of renal artery with a catheter can produce the embolization. Therefore, the strategies to reduce the distal embolization include careful technique in engaging the renal arteries, down-sizing the guiding and balloon catheter and perhaps more importantly the consideration of using distal protection device.

In a study in which a total of 56 hypertensive patients received a distal protection devices during stenting of 65 renal arteries with >70% stenosis, 38 patients had normal baseline renal function but 13 had moderate, and 5 had severe renal dysfunction. The application of the distal protection devices had 100% technical success without serious complications and visible debris were retrieved in the aspirate in all patients with a mean number of 98.1 ± 60 per procedure and a mean size of $201.2 \pm 76.2 \mu\text{m}$. At a mean follow-up period of 22.6 ± 17.6 months, systolic and diastolic blood pressure dropped significantly from $169 \pm 15.2/104 \pm 13$ mm Hg to $149.7 \pm 12.5/92.7 \pm 6.7$ mm Hg. In 10 patients, hypertension were cured, 33 improved, and 13 remained unchanged. At 6-month follow-up, renal function did not deteriorate in any patients, whereas 8 patients with baseline renal insufficiency improved after the procedure.⁶⁹ These preliminary results showed the feasibility and safety of the distal protection devices during renal stenting and it might possibly prevent the post-procedural deterioration of renal function. Of course, large randomized studies are needed to confirm the benefits of distal protection device.

A proposal to increase the clinical efficacy of drive-by renal shooting and renal arterial stenting

Proper strategies of performing selective “drive-by renal shooting” is of paramount importance to avoid over-diagnosis of the RAS. We propose only to perform “drive-by renal shooting” in patients undergoing cardiac catheterization procedure with at least 2 essential criteria instead of just one criterion as used by the study.⁷ First selection criterion is a clinical indication which include at least one of following:

1. drug-resistant hypertension (≥ 2 drugs) and severe hypertension (systolic BP > 180 mm Hg or diastolic BP > 110 mmHg),
2. unexplained renal dysfunction (Creatinine clearance < 50 cc/min) and Angiotensin Converting Enzyme Inhibitor or Angiotensin Receptor Blocker induced acute renal dysfunction,
3. onset of acute Pulmonary Edema with normal left ventricular function and severe hypertension, but without valvular diseases or clinical factors which aggravate or precipitate the congestive heart failure or unstable angina.

The second criterion is at least one risk factor which is associated with a high probability of a significant RAS. These risk factors include one of the following coexisting conditions (Table 1):

1. patients with severe cerebro-vascular disease,
2. patients with severe coronary artery disease,
3. patients with severe abdominal aortic or peripheral vascular disease.

The approach of using at least these 2 criteria to select patients for “drive-by renal shooting” in cardiac catheterization laboratory not only

eliminates the indiscriminative use of this type of practice and increases the yield of diagnosing a significant RAS but also avoid the over-treatment of RAS by providing an indication for treatment.

In addition, defining significant RAS is also very important because it determines the treatment threshold for renal arterial stenting. Although there is no universal consensus on the definition of significant renal stenosis, it is generally accepted that a hemodynamically significant RAS should be at least 50% angiographic stenosis and/or the presence of a significant mean pressure gradient across the lesion (> 10 mm Hg). A more stringent approach in defining a significant RAS may also avoid over-treatment.

Conclusion

RAS is a well-recognized cause of renal function impairment and secondary hypertension. The natural history of RAS is to progress over time, resulting in renal dysfunction, uncontrolled hypertension and finally leading to an increased mortality. Current data clearly demonstrate the clinical efficacy of renal arterial stenting, which should be considered as the treatment of choice for RAS especially in patients with uncontrolled hypertension and/or renal dysfunction. Careful selection of patients for drive-by renal shooting practice and more stringent criteria to define a significant RAS should avoid over-diagnosis and over-treatment of RAS. The issues remaining in renal arterial stenting are the proper selection of patients who may or may not benefit from the procedure, optimal preventive measures to reduce the post-stenting renal dysfunction including the use of distal protection devices and randomized studies to compare with medical therapy.

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Technical Paper ■

Task Force of the European Federation of Medical Informatics Journals: Background, Rationale and Purpose

Delovna skupina časopisov pri Evropski zveze za medicinsko informatiko: ozadje, razlog in namen obstoja

Izet Masic, Josipa Kern, Jana Zvarova, Simon de Lusignan, Gaj Vidmar

Abstract. The paper presents an analysis of how EFMI disseminates new knowledge and of the active medical informatics journals in EFMI member countries, which was carried out as an outcome of the EFMI Council meetings in London 2008, Sarajevo 2009 and Antalya 2009. The analysis identifies eight active major informatics journals and several other publications. Most are subscription-based and published at least quarterly. There is a possibility for the editors to meet regularly and form a community of practice with the aim of further improving their effectiveness in disseminating new knowledge and best practice in medical informatics. It is feasible to share expertise and it may be possible to harmonise several aspects of preparation and submission of manuscripts so that some of the identified barriers in publishing are reduced.

Izveček. Članek predstavlja dejavnost Evropske zveze za medicinsko informatiko (EFMI) in časopise s področja medicinske informatike v državah članicah EFMI. Izhaja iz analize, opravljene na srečanjih v Londonu leta 2008, Sarajevu 2009 in Antalyi 2009. Delovna skupina omogoča redna srečanja urednikov, ki bi olajšala pretok znanja in izmenjavo dobrih praks, poleg tega pa bi se dalo poenotiti številne vidike priprave prispevkov.

■ **Infor Med Slov:** 2009; 14(1-2): 36-41

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Introduction

The European Federation for Medical Informatics (EFMI) is a non-profit scientific and professional organization established in 1976 that today consists of 31 national members.¹⁻⁴ All European countries are entitled to be represented in EFMI by an appropriate national medical informatics society. The term 'medical informatics' is used to include the whole spectrum of health informatics and all its sub-disciplines and allied disciplines. The Medical Subject Headings (MeSH) defines medical informatics as:^{4,5} *'The field of information science concerned with the analysis and dissemination of medical data through the application of computers to various aspects of health care and medicine.'* This definition was introduced in 1987 as a MeSH term.

EFMI operates with a minimum of bureaucratic overhead with each national society supporting the federation by sending a representative to participate in the council. English has been adopted as the official language, although simultaneous translation is often provided for congresses in non-English speaking countries.⁶ EFMI has 16 working groups: Smart Cards in Health Care 'CARDS'; Social Security and Welfare; Education in Health Informatics 'EDU'; Electronic Health Records 'EHR'; Evaluation and Assessment of Health Information Systems 'EVAL'; Informatics for Disabled People and Rehabilitation 'IDR'; Information Planning and Modelling in Health Care 'IPAM'; Libre/Free and Open Source Software 'LIFOSS'; Case-mix and Severity of Cases; Medical Informatics in Transition Countries 'MICIT'; Medical Imaging Processing 'MIP'; Natural Language Understanding 'NLU'; Nursing Informatics in Europe 'NURSIE'; Human and Organisational Factors of Medical Informatics 'HOFMI'; Primary Care Informatics 'PCI'; Safety, Security and Ethics 'SSE'; and Traceability 'TRA'.

To date, EFMI has organized 21 European congresses of medical informatics, including the Medical Informatics Europe (MIE) congresses in

Cambridge (1978), Berlin (1979), Oslo (1988), Glasgow (1990), Vienna (1991), Jerusalem (1993), Lisbon (1994), Copenhagen (1996), Thessaloniki (1997), Ljubljana (1999), Hannover (2000), Budapest (2002), St. Malo (2003), Geneva (2005), Maastricht (2006), Gothenburg (2008) and Sarajevo (2009). The MIE 2011 conference will be held in Oslo. Traditionally, MIE conferences were not held in the year in which the International Medical Informatics Association (IMIA) organises its triennial conference MEDINFO.¹ EFMI has also started a new series of meetings: the Special Topic Conferences (STCs). The STC concept has the following components: a) organization should be done by a member society possibly in combination with its annual meeting; b) EFMI Council meeting should be the integral part of STC; c) topic of the conference should be defined by the organizing member society; d) considering the topic, the relevant EFMI working groups should be engaged; e) contributions should be mostly by invitation; f) STCs are small 2-day conferences with 100+ participants.

The first conference STC took place in Bucharest/Romania 2001, then in Nicosia/Cyprus 2002, Rome/Italy 2003, Munich/Germany 2004, Athens/Greece 2005, Timisoara/Romania 2006, Brijuni/Croatia 2007, London/United Kingdom 2008, and Antalya/Turkey 2009. In 2010, the STC will take place in Reykjavik/Iceland, and in 2011 in Ptuj/Slovenia. The proceedings of these conferences were usually published by Springer in the series 'Lecture Notes in Medical Informatics' and by IOS Press in the series 'Studies in Health Technologies and Informatics'. A selection of the best papers from the MIE conferences were published in a special volume of the International Journal of Medical Informatics and will be published in the Methods of Information in Medicine, while the special proceedings of STCs is published by IOS Press as collection of peer reviewed articles.

Review of medical informatics journals in Europe

Medical informatics scientific and research production in Europe is growing both in quantity and quality. Promoting high-quality research is a major goal of EFMI.^{1,4,6} EFMI has two highly respected official general journals, the International Journal of Medical Informatics (former title: International Journal of Bio-Medical Computing), currently edited by Charles Safran and Jan Talmon, and Methods of Information in Medicine, currently edited by Reinhold Haux. EFMI also publishes several sub-speciality official journals covering the spectrum of medical informatics sub-disciplines. The time-honoured method to disseminate high-quality scientific research is via the proceedings of the MIE annual conference. EFMI also plays a major role in education and in the harmonization of medical informatics sub-disciplines through the organization of STCs. Both MIE and STC proceedings are peer reviewed and published by IOS Press (Amsterdam, The Netherlands). Usually, MIE proceedings are indexed in Medline/PubMed. Most medical informatics journals are published in local languages, but many of them also incorporate English summaries or contain combined articles published in domestic and English language. Altogether, EFMI provides highly effective means for worldwide dissemination of medical informatics research conducted in Europe. However, in addition to the proceedings, journal editors have the opportunity to do more to disseminate knowledge and increase the understanding of our discipline.

Analysis of publishing activities within EFMI members

Most of the information about the EFMI can be found on the official website (www.efmi.org). Furthermore, most of national societies have their own websites providing useful information about publications and meetings in EFMI member

countries. Our analysis is based on the facts generated from EFMI database stored on EFMI website and collected from national representatives of EFMI member countries.

A search of Medline with the search terms 'EFMI' and 'European Federation for Medical Informatics' returns only 21 papers – 18 in medical informatics related journals: Informatics in Primary Care (6), International Journal of Medical Informatics (3), Methods of Information in Medicine (2), Studies in Health Technologies (6); and 3 in non-informatics/non-EFMI journals. Authors of the papers are: Blobel (2), De Lusignan (6), France (1), Horsch (1), McKeon (1), Masic (2), Michalasz (2), Naszlady (1), Tallberg (1), Talmon (1), Trpisovský (1), van Goor (1), and Zvarova (1). Medline search using the term 'IMIA' was performed (for comparison) and 150 papers were found; the search term 'AMIA' resulted in 244 papers found. Most of EFMI papers are related to the activities of working groups – PCI is the most prominent^{5,6} – and relatively few initiatives at the level of the federation. Detailed analysis of EFMI website showed that only 14 of 31 members have their official scientific or professional medical informatics journal or newsletter listed (Table 1). Medical informatics journals have their articles published in English with three published in their national language. There are three journals published only as e-journals.

The frequency of ISSN registered publications varies: one journal is published biannually, two quarterly, one every two months, five journals are published 2–3 times per year, two journals monthly and one journal nine times per year. Medical informatics is the principal subject of all of the journals, but several of them focus on other sub-disciplines and allied disciplines. Most of the medical informatics journals are international publications, though three are restricted to national circulation. Two journals are financed by ministry of health and/or other public institutions, while others use subscription as the way of financing.

EFMI country	Journal title	Publisher	Editor-in-Chief	ISSN	Estab. year	Issues/year	Submission	Web site	Language	Field	Peer reviewed	Financed by
Austria	Artificial Intelligence in Medicine	Elsevier	Klaus-Peter Adlassnig	1386-5056	1989	9	email	yes	English	MI, other	internat.	subscription
Bosnia and Herzegovina	Acta Informatica Medica	AVICENA, Sarajevo	Izet Masic	0353-8109	1993	4	email	yes	English	MI, other	internat.	subscription
Croatia	Bilten HDMI (Bulletin of the CSMI)	CSMI	Kristina Fišter	1330-0253	1992	2	email	yes	Croatian	MI, other	no	membership in the society
	Medicinska informatika	CSMI	Josipa Kern	1330-1799	1993	2	email	yes	English, Croatian	MI	national	ministry of science, publicity
Czech Republic	Lékař a Technika	SBMILJ	Karel Roubik	0301-5491	1970	4	email	yes	Czech	MI, biomedical engineering	national	public institutions, subscription
	European Journal for Biomedical Informatics	EuroMISE	Jana Zvarova	1801-5603	2005	2	email	yes	English, other	biomedical informatics	internat.	other
Denmark	Newsletter	DSMI	-	-	-	-	-	yes	Danish, English	MI	national	public institutions
France	Informatique et Sante	Springer-Verlag	Patrice Degoutet	-	-	2	email	yes	French, English	MI	national	public institutions, subscription
Germany	Biometrie, Informatik und Epidemiologie in Medizin und Biologie	Urban&Fischer Verlag	-	-	-	-	email	yes	German	MI, other	national	public institutions, subscription
Ireland	Newsletter	-	-	-	-	-	-	-	-	-	-	-
Israel	ILAMI Journal and The Health Screen	-	-	-	-	2	-	-	-	MI, other	-	-
Slovenia	Informatica Medica Slovenica	SIMIA	Gaj Vidmar	print:1318-2129 elect.:1318-2145	1993	2	email	yes	English, Slovenian, other	MI, biostatistics, other	internat., national	MI society (SIMIA)
Spain	I+S	SEIS	-	-	-	6	-	-	-	MI, other	-	-
Sweden	Computer Methods and Programs in Biomedicine	Elsevier	Torny Groth	0169-2607	1985	12	paper, email, online	yes	English	MI	internat.	subscriptions
Ukraine	Clinical Informatics and Telemedicine	UAMI	Oleg Yu Mayorov	1812-7231	2003	2-3	email	yes	Ukrainian, English	MI, other	internat.	public institution
United Kingdom	Informatics in Primary Care	Radcliffe Publishing	Simon de Lusignan	1476-0320	1993	4	paper, online	yes	English	PHC, clinical informatics	internat.	PHCG BCS, subscriptions
EFMI	International Journal of Medical Informatics	Elsevier	Charles Safran, Jan Talmon	1386-5056	1961	12	paper, online	yes	English	MI	internat.	subscriptions
	Methods of Information in Medicine	Schattauer	Reinhold Haux	0026-1270	1962	6	paper, online	yes	English	MI	internat.	subscriptions

Table 1 EFMI member countries medical informatics journals.

Mission statements of task force of EFMI journal editors

Editor-in-Chiefs of medical informatics journals are invited to create a joint mission statement and set out the objective and purpose of all EFMI journals. We believe that the joint statement will foster the dissemination of scientific knowledge and increase our understanding of medical informatics as a discipline. Additionally, we intend to produce and issue a core document stating the fundamental principles upon which all medical informatics journals editors should agree. The common goals will be identified and agreed on the scope and standard of papers that should be published in EFMI medical informatics journals. The reasons for setting out the statement are:

- To promote editorial excellence by enforcing the use of standards and guidelines (International Committee of Medical Journals Editors guidelines; Committee of Publication Ethics; other relevant documents⁷);
- To improve the quality of scientific studies published in EFMI medical informatics journals by imposing same standards for evaluating studies in medical informatics (guidelines already accepted as official EFMI document, but there were no further steps taken to ensure their use);
- To promote scientific publishing excellence by enforcing standards of paper formatting ('camera-ready' manuscript format; Vancouver referencing style);
- To improve diffusion of scientific knowledge through the medical/health informatics area (recognition and diffusion of EFMI research, education, clinical practice guidelines in EU countries should be promoted);
- To increase collaboration among EFMI medical informatics journal editors and schedule regular meetings of the Task Force;
- To explore the potential for using shared pool of reviewers, sharing information on review process and sharing expertise: technical editorial information, experiences, initiatives, publishing resources and tools (such as the open source Open Journal System or commercial/publisher solutions);
- To encourage articles not suitable for medical informatics journals to be published elsewhere and support the communication with editors of such journals;
- To provide a common voice when issues of common interest arise and enhance collaboration between national societies and EFMI bodies;
- To promote European initiatives in stimulating publications and top-quality research.

Acknowledgment

The authors would like to acknowledge the support of Jan Talmon from Maastricht University, Care and Public Health Research Institute, The Netherlands.

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Bilten SDMI ■

Poročilo z letnega srečanja članov SDMI-SIZN na temo Problemi in izzivi v razvoju informatike v zdravstveni negi – kje smo?

Vesna Prijatelj, Boris Žoher, Marjana Jambrovič, Drago Rudel, Zoja Trenz, Boštjan Žvanut

O srečanju

Na Jelenovem grebenu pri Podčetrtku se je že 6. leto odvijalo tradicionalno srečanje članov Sekcije za informatiko v zdravstveni negi (SIZN), ki deluje v okviru Slovenskega društva za medicinsko informatiko (SDMI). Vabilu na dvodnevno srečanje (23. in 24. oktobra 2009), ki je namenjeno tako druženju kot strokovni rasti, se je odzvalo skupaj 50 udeležencev.

V uvodnih besedah je predsednica mag. Vesna Prijatelj predstavila poročilo o delu SIZN v letu 2009 ter plan dela za naslednje leto. V začetku so bili člani seznanjeni z dogajanjem v tem letu, prav tako s poročilom o udeležbi nekaterih članov na kongresih in strokovnih srečanjih (Hrvaškega združenja medicinskih sester – HUIS'09, Nursing Informatics – NI'09, Medical Informatics Europe – MIE'09). Predstavila je tudi plan delovanja za naslednje leto. Ob aktualnih vprašanjih, povezanih s tematiko dela v in za SIZN, se je razvila debata in tvorno sodelovanje.

Pomembna informacija za vse, ki se ukvarjajo z informatiko v zdravstveni negi, je prenovljena definicija pojma "nursing informatics". Zadnja je bila sprejeta avgusta 1998 v Seulu v Koreji: "Nursing informatics is the integration of nursing,

its information, and information management with information processing and communication technology, to support the health of people world wide". Mag. V. Prijatelj je kot predstavnica Slovenije v IMIA-NI aktivno sodelovala pri oblikovanju nove definicije, ki je bila oblikovana in sprejeta na generalni skupščini IMIA-NI julija 2009 v Helsinkih na Finskem: "Nursing informatics science and practice integrates nursing, its information and knowledge and their management with information and communication technologies to promote the health of people, families and communities world wide".

Drugega dne srečanja SIZN so od 10. do 14. ure sledila predavanja po programu. Navajamo povzetke predavanj v vrstnem redu, kot so si sledila.

Boris Žoher (ZZZS): Projekt "On-line KZZ": novosti, spremembe, pričakovanja

Z marcem 2009 se je na področju Slovenije pričela nacionalna uvedba sodobnega on-line elektronskega poslovanja v sistem zdravstvenega varstva in zdravstvenega zavarovanja. Končni cilj

je popoln on-line sistem, v katerem prenovljena kartica zdravstvenega zavarovanja in nova profesionalna kartica ne nosita podatkov, pač pa samo digitalna potrdila, na podlagi katerih je mogoč neposreden, varen in zanesljiv dostop do podatkov, ki se nahajajo na strežnikih ZZZS in prostovoljnih zdravstvenih zavarovalnic. Z uvedbo celovitega on-line dostopa ne bo več potrebe po osveževanju podatkov na samopostrežnih terminalih.

Do konca meseca oktobra je bil on-line sistem uveden že skoraj na celem področju Slovenije z izjemo področja Maribora, ki prične z uvajanjem v novembru, ter področja Ljubljane, kjer se uvedba začne z začetkom naslednjega leta. Seveda je uvedba on-line sistema prinesla določene spremembe v postopkih obravnave pacientov. Bistvena novost je obvezna uporaba KZZ za dostop do podatkov (razen v izjemnih, v naprej določenih primerih). Natančno pa so določeni tudi postopki za primer nedelovanja on-line sistema, ki je po občasnih začetnih težavah postal zelo stabilen. Seveda se on-line sistem vseskozi razvija, dopolnjuje in prilagaja potrebam ter zahtevam uporabnikov. Tako so v načrtu že številne nove elektronske rešitve, kot npr. elektronski recept in druge elektronske listine, nacionalna evidenca cepljenj, nacionalni povzetek elektronskega kartona idr.

Marjana Jambrovič (Ministrstvo za zdravje): Kje je zdravstvena nega v projektu e-zdravje?

Projekt eZdravje trenutno predstavlja enega večjih projektov informatizacije javnih storitev. Projekt združuje aktivnosti vpeljave rabe komunikacijskih in informacijskih sredstev na področju zdravstva, s katerimi bo moč zagotoviti učinkovitejše javno-zdravstvene storitve. Rezultati projekta eZdravje bodo omogočili, da se lahko zdravstvena obravnava bolje prilagodi posameznikom, olajša mobilnost in varnost pacientov, zmanjšuje stroške zdravstvenih storitev ter podpre interoperabilnost v državi in prek meja. Izjemnega pomena je

aktivno vključevanje pacientov, zdravnikov, predstavnikov zdravstvene nege in ostalih zaposlenih na področju zdravstva v procese celovite zdravstvene oskrbe.

Trenutno stanje in aktivnosti v teku

Uvodne aktivnosti projekta eZdravje so se začele v septembru 2008, predvideno trajanje projekta je do junija 2015. Za to obdobje je pripravljen akcijski načrt in definirani vsi podprojekti. Do tedaj so na voljo tudi evropska sredstva, skupaj 27 milijonov evrov. Okvirno je program aktivnosti narejen še do leta 2023, ko bo treba vse razvite rešitve vzdrževati in nadgrajevati. Trenutno aktivnosti že potekajo na 12 podprojektih, predvidenih v akcijskem načrtu eZdravja. Podprojekti so tesno koordinirani in vodeni kot celota ter povezani z drugimi projekti.

V teku so trenutno aktivnosti na več različnih projektih, med katerimi so tudi bazični projekti. Med temi sta vzpostavitev varnega zdravstvenega omrežja zNET ter izdelava podlag za izvedbo podprojektov Ogrodje portala zVEM. Poleg bazičnih projektov se izvajajo aktivnosti na osrednjih projektih eZdravja, med katerimi je trenutno v tek podprojekt eNaročanje. Izvajajo se tudi aktivnosti na več vzorčnih rešitvah: varni izmenjavi medicinske dokumentacije med bolnišnicami in mikrobiološkimi laboratoriji ter vzpostavitvi aplikacije za nacionalni čakalni seznam.

Na projektu standardizacije elektronskega zdravstvenega zapisa je v teku podpis pogodbe z izbranim izvajalcem. Objavljeno je bilo naročilo za izdelavo krovnih dokumentov za politiko informacijske varnosti in vzorčnih dokumentov za omrežje zNET. Aktivnosti intenzivno potekajo tudi na področju promocije, prek člankov v strokovnih revijah, sodelovanja na konferencah ter sodelovanja pri mednarodnih projektih Calliope in Callepso. Do konca leta načrtujemo še usposabljanje za vodilne delavce na temo prenove procesov in projektne managementa ter za tehnične sodelavce v javnih zavodih.

Vzpostavitev omrežja zNET

V okviru podprojekta zNET bo vzpostavljeno zdravstveno omrežje zNET, ki je sodobna komunikacijska infrastruktura, tako za centralizirane IT storitve nacionalnega pomena kot tudi za IT storitve, ki jih bodo zagotavljali posamezni akterji v zdravstvu preko certificiranih točk. Omrežje zNET bo zagotavljalo varne in zanesljive povezave med vstopno točko, ostalimi certificiranimi točkami ter ključnimi akterji v zdravstvu. Omrežje zNET mora poleg osnovne storitve (transporta) zagotavljati tudi dodatne storitve, potrebne za zagotavljanje varnosti, kakovosti in uporabnosti omrežja. Omrežje zNET moramo razumeti kot celotno platformo za zagotavljanje omrežne povezljivosti (strojna oprema, sistemska programska oprema, skupek pravil in standardov itd).

Namen podprojekta je zagotoviti izboljšanje informacijsko-komunikacijske povezanosti ključnih akterjev v zdravstvu, povečati zmogljivost povezav in na ta način omogočiti uporabo zahtevnejših storitev eZdravja. **Cilj** projekta je postavitev omrežja zNET, ki bo zagotavljalo varne in zanesljive povezave med vstopno točko, ostalimi certificiranimi točkami ter ključnimi akterji v zdravstvu do leta 2013. **Rezultat** projekta bo vzpostavljeno omrežje zNET, ki vključuje postavitev centralne infrastrukture in priključitev vseh končnih točk v omrežje z ustrezno vzpostavljenimi organizacijskimi in varnostnimi politikami.

Ogrodje portala zVEM

Na področju zdravstva bo predstavljal enotni nacionalni zdravstveni portal zVEM (zdravstvo – vse na enem mestu) sinonim za osrednji zdravstveni portal oziroma osrednje spletno mesto. Na tem portalu bodo lahko uporabniki sistema zdravstvenega varstva in vsi ostali deležniki iskali in izmenjevali zdravstvene informacije in podatke ter uporabljali nacionalne storitve na varen in sledljiv način ne glede na to, kje se bodo podatki nahajali in kdo jih bo pregledoval. Preko zVEM bo potekalo komuniciranje uporabnikov v eZIS, ki

opredeljuje enoten nacionalen zdravstveni portal. zVEM bo tako predstavljal osrednjo točko za sodelovanje, v kateri se bo dostopalo, komuniciralo in uporabljalo informacijske storitve glede na vloge in profile uporabnikov v sistemu zdravstvenega varstva. Portal zVEM je v osnovi zamišljen tako, da že na nivoju ogrodja vključuje tudi nekatere osnovne funkcionalnosti. Poleg ogrodja, na katerega bodo vezane storitve in bo omogočalo izvedbo različnih funkcionalnosti, je v začetni fazi predvidena tudi implementacija iskalnika, spletnega anketiranja, forumov in nekaterih drugih splošno uporabnih funkcionalnosti. Na tem nivoju je potrebno zagotoviti tudi vse predpogoje, ki so potrebni za digitalno podpisovanje in časovno žigosanje dokumentov.

Namen projekta je pripraviti podlago za kasnejši sproten priklop različnih storitev, obenem pa že v tej točki zagotoviti nekatere nujne funkcionalnosti portala zVEM, ki bodo skupne več storitvam. **Cilj** projekta je do sredine leta 2010 vzpostaviti ogrodje portala zVEM, vključno z vstopno točko. To obenem vključuje tudi postopno vzpostavitev ostalih zgoraj navedenih funkcionalnosti podprojekta. **Rezultat** projekta bo vzpostavljena in preizkušena informacijska rešitev, ki vključuje ogrodje portala zVEM z vstopno točko in pripadajočimi funkcionalnostmi.

Vzpostavitev osrednjega EZZ (vključno s PEZZ) in storitev polnjenja, ažuriranja in vpogledovanja

Elektronski zdravstveni zapis (EZZ) je digitalno shranjena klinična in administrativna zdravstvena informacija o celoviti zdravstveni oskrbi posameznika ob zagotovljeni zaupnosti podatkov. Temeljil bo na skupnem nacionalnem jedru – referenčnem nacionalnem zdravstveno informacijskem modelu, ki bo zagotavljal interoperabilnost EZZ, razvoj osrednjega centralnega dela v obliki povzetka EZZ (PEZZ) in bo osnova za večino storitev v okviru zVEM. Razvoj EZZ bo omogočal centralizirano hranjenje bistvenih in po potrebi tudi drugih podatkov, kot

tudi možnost povezovanja delnih EZZ preko določenih kazalcev.

Namen podprojekta je zagotoviti dostop do zdravstvenih podatkov o posamezniku, ki so potrebni za zdravljenje le-tega, vsem pooblaščenim izvajalcem zdravstvenih storitev. PEZZ pa bo zagotovil dostop do bistvenih podatkov, ki so nujni za zdravljenje posameznika. **Cilj** podprojekta je do sredine leta 2011 postopoma zagotoviti izvajalcem zdravstvenih storitev dostop do bistvenih in ostalih podatkov, ki jih potrebujejo za medicinsko/zdravstveno obravnavo bolnika.

eNaročanje na zdravstvene storitve

Podprojekt "e-naročanje na zdravstvene storitve" vsebinsko obravnava problematiko standardizacije in optimizacije procesa naročanja na zdravstvene storitve, kar je eno izmed prioritarnih področij povečanja učinkovitosti delovanja zdravstvenega sistema in strategije e-Zdravje 2010, ki jo izvaja Ministrstvo za zdravje, ter projekta e-Zdravje. Namen tega projekta je vzpostaviti ustrezno informacijsko podporo naročanju na zdravstvene storitve. V sklopu projekta so predvideni naslednji rezultati: opredeljeni (skladno z referenčnim informacijskim modelom) podatki, ki se povezujejo z naročanjem na zdravstvene storitve, vzpostavljeno/delujoče spletno naročanje na zdravstvene storitve, integracija informacijske rešitve za spletno naročanje z informacijsko rešitvijo za čakalne seznane in integracija informacijske rešitve za spletno naročanje z Ogrodjem portala zVEM.

Učinki projekta eZdravje

Rezultati projekta eZdravje bodo v precejšnji meri odločilno vplivali na spremembo, prilagoditev in modernizacijo slovenskega sistema zdravstva. Predvsem bodo velike spremembe skozi različne učinke zagotovljene zaposlenim v zdravstvu, kjer bo z izboljšano informacijsko komunikacijsko infrastrukturo zagotovljen boljši pretok in večja zanesljivost informacij, kar bo vplivalo na izboljšano učinkovitost zaposlenih v zdravstvu in

posledično tudi večje zadovoljstvo zaposlenih v zdravstvu pri njihovem delu. Izmenjava in dostop do informacij bosta v precejšnji meri vplivala tudi na državljane (posameznike) kot uporabnike zdravstvenih storitev, ki bodo imeli od projekta eZdravje največje koristi. Rezultati projekta eZdravje jim bodo namreč omogočali številne koristi, povezane z izboljšanjem zdravstvenih storitev ter višjo stopnjo zdravstvenega varstva, ki temelji predvsem na optimizaciji zdravstvenih procesov. Tako bo posameznikom zagotovljena boljša dostopnost do informacij o njihovem zdravstvenem stanju, postopkih zdravljenja in kakovosti zdravstvenih storitev, s čimer sledimo trendom sodobne informacijske družbe, kjer dostopnost do informacij povečuje kakovost življenja. S tem bo namreč povečana osveščenost posameznikov, kar pomeni, da bodo ti o svojem zdravju bolje informirani in se bodo lažje odločali ter pravilneje in hitreje reagirali v primeru zdravstvenih težav.

Učinki na zdravstvene ustanove in zaposlene se bodo odrazili tudi v učinkih na celotni zdravstveni sistem. Povečanje učinkovitosti zdravstvenih storitev se bo pokazala v nižjih izdatkih za zdravstvo. Izvedba projekta eZdravje bo tudi povečala varnost in zanesljivost pri izmenjavi občutljivih zdravstvenih podatkov (pri tem bo imela glavno vlogo vzpostavitev nacionalnega zdravstvenega omrežja zNET). Poleg tega se bo izboljšal tudi pregled in transparentnost poslovanja na različnih nivojih zdravstvenega sistema, kar bo lahko omogočilo racionalizacijo upravljanja s sredstvi v zdravstvenem sistemu. Uspeh projekta bo v veliki meri odvisen od zaupanja posameznikov in zdravstvenih delavcev v to, da so vsi vidiki eZdravja, ki vplivajo nanje, oblikovani tako, da postavljajo interese dvigovanja kakovosti in povečanja varnosti na področju zdravstva na prvo mesto.

Zoja Trenz (SRC Infonet d.o.o.): Elektronski temperaturno terapevtski list

Projekt izdelave programske rešitve z delovnim imenom "Računalnik ob postelji" predstavlja raziskavo obstoječega informacijskega sistema v bolnišnicah z namenom, da bi se podprlo tudi aktivnosti zdravljenja, opravljene ob bolniški postelji. Ker sta prvi dve od treh generacij bolnišničnih informacijskih sistemov (BIS) sloneli na cenovno dostopnih stacionarni računalniški opremi ter utečenih delovnih procesih, podprtih s papirno informatiko, so tudi računalniški sistemi po bolnišnicah togi in ne podpirajo dinamičnega, terenskega dela zdravstvenega osebja. Podatki se ob bolnikovi postelji zapisujejo na papir, kjer jih večina tudi ostane, zaradi česar niso izkoriščeni tako, kot bi lahko bili. Namen produkta je torej podpreti vse procese, ki so povezani s terapevtskim/temperaturnim listom (v nadaljevanju TT list), od pregleda stanja pacienta, predpisovanja medikamentozne terapije in spremljanje njenega izvajanja, spremljanje vitalnih znakov, zdravnikovega naročila diagnostičnih postopkov, nege in medicinsko tehničnih postopkov in izvedbe teh naročil do posredovanja naročil izvajalcem. Poleg tega bo omogočal povezavo z nadaljnimi postopki v procesu predpisovanja in porabe zdravil (predpis zdravila, delitev zdravil, naročanje zdravil in materiala v lekarno, evidentiranje delitve zdravil), povezavo z nadaljnimi postopki v procesu naročanja preiskav (odvzem materiala, posredovanje naročila izvajalcem, spremljanje statusa naročila, pregled prispelih izvidov), povezavo s kliničnimi potmi ter podporo postopku zdravstvene nege od načrtovanja do evaluacije.

Delovna skupina je že opravila večji del analize delovnih postopkov v sodelujočih bolnišnicah (SB Novo Mesto, SB Celje, KOPA Golnik). Kot glavni ugotovitvi analize sta bili izpostavljeni pomanjkljivo spremljanje opravljenega dela in odsotnost izvidov na viziti, ki sta dve največji pomanjkljivosti sistema. Čeprav se kaže večji interes uporabe v segmentu zdravstvene nege, smo

se v prvi fazi odločili za izdelavo modula z delovnim imenom Elektronski temperaturno terapevtski list. V tem segmentu se namreč kaže interakcija med zdravnikom in zdravstveno nego, saj slednja poleg svojih lastnih dejavnosti izvaja tudi zdravnikova naročila.

Raziskava trga mobilnih naprav je skupaj s postavljenimi zahtevami pokazala potrebo po uporabi ne ene, ampak dveh vrst mobilnih naprav – pocket PC in tablet PC ali notesnikov. Pocket PC (dlančnik) je primeren predvsem za manjše aktivnosti v procesu zdravljenja (beleženje dane terapije, beleženje odvzemov), tablet PC ali notesniki pa ponujajo boljšo preglednost ter ustrezno velikost vmesnika, primerne za vnos podatkov v stoječem položaju in v naglici.

Drago Rudel (MKS Elektronski sistemi d.o.o.): Kako vključiti storitve na daljavo v dolgotrajno oskrbo – izkušnje "rdečega gumba"

V prispevku so predstavljene lastne izkušnje v 18-letnem prizadevanju za uveljavitev storitve "varovanja na daljavo" v Sloveniji. Pot od tehnične rešitve ter zasnove poslovnega modela sodobne storitve, ki temelji na informacijskih in telekomunikacijskih tehnologijah, do dejanske vzpostavitve storitve za dolgotrajno oskrbo, je dolga. Vso pot uvajanja in uveljavljanja storitve, od potrditve izvedljivosti, pilotne uporabe, do nastopa na trgu je potrebno tlakovati z denarjem investitorjev. Avtor meni, da prav zaradi tega storitev na zdravstvenem in socialnem področju ne morejo biti zgolj stvar podjetniškega investiranja. V uvajanje se morajo že prej vključiti drugi deležniki, predvsem zdravstvene zavarovalnice in resorna ministrstva. Prihaja namreč do absurdnega stanja, ko prav te institucije pričakujejo, da bodo nove storitve za dolgotrajno oskrbo kar same od sebe dosegljive na celotnem teritoriju Slovenije, vse bodo strokovno preverjene in potrjene ter seveda na razpolago po nizki ceni. Izvajanje

načrtovanega zakona o dolgotrajni oskrbi namreč predvideva, da bo nosilec zavarovanja za dolgotrajno oskrbo zgolj "pobral" izvajalce v javnem in zasebnem sektorju ter "upravičenim" podelil koncesijo. Samorastniške poslovne pobude na področju, kjer o tem, do katerih storitev je upravičen prejemnik dolgotrajne oskrbe odločata zdravnik ali socialna delavka, prav gotovo ne morejo uspevati. To potrjujejo številne še neuveljavljene storitve, ki so nadgradnja storitve "rdeči gumb" (detektor padca, delilnik tablet, detektor epileptičnih napadov itd), kot tudi telemedicinska storitev prof. Boruta Geršaka "mobilink" za analizo EKG v urgentnih primerih. Moderne telemedicinske rešitve podjetja Hermes Softlab npr. za prenos podatkov o krvnem sladkorju in krvnem tlaku s pomočjo mobilnega telefona prav tako ostajajo zgolj tehnične rešitve še nekaj let daleč od storitve, ki bi bila na razpolago bolniku.

Vesna Prijatelj (SB Celje): Zdravje na daljavo – etična vprašanja in dileme

Telemedicina je ena najmlajših, a pomembnih vej medicine. Kljub uporabnosti in razvitosti po svetu in v Evropi je premalokrat uporabljena, kar bi lahko pripisali tudi etičnim vprašanjem, ki se pri pomembnih odločitvah porajajo v glavah vsakega izmed nas, predvsem zaradi njenega vpliva na odnos med pacientom in zdravnikom. – Ali je varovana zasebnost pacienta? Ali zagotavljamo zaupnost informacij? Ali spoštujemo pacientovo avtonomnost? Ali so jasni pravni okviri zdravljenja? – To je le del množice vprašanj, na katera moramo dobiti odgovore uporabniki storitev telemedicine. Le malo držav EU ima za telemedicino jasn pravni okvir. Ni jasno opredeljenih mednarodnih okvirov za reševanje primera odgovornosti v primeru nepravilno postavljene diagnoze. Ni mednarodnih pravil, ki regulirajo predpisovanje zdravil. Ni mednarodnih pravil, ki bi omogočala preverjanje resničnosti podatkov. Ni mednarodno priznanih postopkov za

pridobivanje zdravniške licence za telemedicino. Pomanjkanje pravne jasnosti, zlasti v zvezi z izdajanjem dovoljenj, akreditacijo in registracijo telemedicinskih storitev in delavcev, jamstvom, vračilom stroškov in sodno pristojnostjo, je glavni izziv telemedicine, zlasti teleradiologije. Čezmejno zagotavljanje telemedicinskih storitev zahteva dodatno pravno jasnost glede zasebnosti.

Spoštovanje zasebnosti in zagotavljanje varnosti sta glavna vidika pri spodbujanju zaupanja v telemedicinske sisteme. Pri zbiranju in obdelovanju osebnih podatkov, zlasti zdravstvenih podatkov, je treba spoštovati pravice in temeljne svoboščine, kot sta temeljna pravica do zasebnega življenja in varstvo osebnih podatkov. Kot vsako posredovanje osebnih zdravstvenih podatkov, lahko tudi telemedicina ogrozi pravico do varstva osebnih podatkov (razkritje zdravstvenega stanja ali diagnoze lahko odločilno vpliva na zasebno in poklicno življenje posameznika). Varstvo podatkov je treba pri uporabi telemedicine vedno sistematično proučiti. Potrebno je povečati zaupanje v telemedicino in vplivati na njeno sprejemljivost pri pacientih in zdravstvenih delavcih v smislu varnosti in oskrbe. Telemedicina se mora razvijati tako, da koristi oskrbi pacientov, hkrati pa zagotavlja zasebnost in najvišje standarde za pacientovo varnost.

Boštjan Žvanut (VŠZ Izola): Problemi in izzivi v razvoju informatike v zdravstveni negi – okrogla miza

Na okrogli mizi je bila predstavljena problematika izobraževanja študentov in dijakov zdravstvenih šol na področju informatike. Udeleženci okrogle mize so se vprašali, ali so dijaki po zaključenem usposabljanju ustrezno informacijsko usposobljeni. Mag. Vesna Prijatelj in dr. Boštjan Žvanut sta opozorila na problem nezadostne informacijske pismenosti, s katerim se srečujeta pri študentih prvega letnika zdravstvene nege. V praksi to pomeni, da je potrebno v prvem letniku prve

stopnje študija nameniti veliko število ur laboratorijskih vaj za pridobitev osnovne informacijske pismenosti (npr. spoznavanje orodij za urejevanje besedil, preglednic, iskanje gradi v po svetovnem spletu).

Udeleženci okrogle mize so izpostavili tudi pomen vsebin s področja informacijskih sistemov, saj je po mnenju obeh predavateljev nepoznavanje tega področja lahko vzrok za težave pri projektih informatizacije zdravstva. V povezavi s tem pa je bila posebej zanimiva predstavitev ge. Marije Trenz in mag. Vesne Prijatelj o pomenu kliničnih vaj na področju informatike v zdravstveni negi. V okviru kliničnih vaj so si novomeški študentje ogledali informacijske podsisteme novomeške bolnišnice. Na podlagi ogleda so ugotovili probleme s področja poslovnih procesov v zdravstvu in predlagali nekatere rešitve. V seminarskih nalogah so tako predstavili opredelitev poslovnih zahtev za informacijski (pod)sistem s poudarkom na optimizaciji poslovnih procesov. Predlagane rešitve so pokazale številne probleme ne področju informatike, kar se je po mnenju ge. Trenz izkazalo kot koristno tudi za samo bolnišnico. Znanja o opredelitvi poslovnih zahtev za informacijskih sistem posredujejo študentom tudi na Visoki šoli za zdravstvo UP. Ker pa tam v obstoječem študijskem programu prve stopnje klinične vaje iz področja informatike niso predvidene, se ta znanja podajo zainteresiranim študentom v procesu priprave diplomskih del ter podiplomskim študentom pri predmetu Dokumentiranje v zdravstveni negi in Simulacije negovalnih aktivnosti.

Navedenemu je sledilo ključno vprašanje okrogle mize, ali je znanje, ki ga medicinske sestre in zdravstveni tehniki pridobijo na dodiplomskem študiju, zadostno. Ker pa se medicinske sestre pri svojem delu pogosto srečujejo s potrebami po informacijski pismenosti in opredelitvi poslovnih zahtev, je smiselno definirati obseg potrebnih znanj s tega področja. Nekateri udeleženci so celo predlagali, da bi tako informacijsko pismenost kot znanja potrebna za opredelitev poslovnih zahtev za informacijski sistem vključili med kompetence medicinske sestre. Natančna opredelitev teh kompetenc in njihova umeščenost je gotovo lahko predmet nadaljnjih razprav.

Okroglo mizo je vodil dr. Boštjan Žvanut (viš. pred. na VŠZ Izola) v sodelovanju z mag. Vesno Prijatelj (viš. pred. na VŠZ Novo mesto), go. Elizabeto Pikovnik (pred. na SZŠ Ljubljana) in go. Marijo Trenz (vodja informatike v SB Novo mesto ter mentorica klinične prakse pri predmetu Informatika v zdravstvu in ZN).

Zaključek

Zahvaljujemo se Slovenskemu društvu za medicinsko informatiko, ki je podprlo naše srečanje. Tudi naprej se bomo trudili, da našim članom omogočimo tovrstna druženja z namenom boljšega medsebojnega spoznavanja, izmenjevanja izkušenj, oblikovanja novih idej in prijetnega druženja.

■ **Infor Med Slov:** 2009; 14(1-2): 42-48