



## Novosti o Registru bolesnika sa zatajivanjem srca Hrvatskog kardiološkog društva

## Novelties about the Registry of patients with heart failure of the Croatian Cardiac Society

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Sastanak Radne skupine za zatajivanje srca Hrvatskog kardiološkog društva održan je u Kliničkom bolničkom centru Zagreb, dana 25. veljače 2009. godine. Glavna tema sastanka je bila Registar bolesnika sa zatajivanjem srca, s osvrtom na informatički dio.

Sastanku su nazočili: prof. dr. sc. Davor Miličić, prof. dr. sc. Stojan Polić, mr. sc. Duška Glavaš, dr. Branka Jurčević-Zidar (epidemiologinja), dr. Dubravko Tršinski, dr. sc. prim. Mario Ivanuša (portal Hrvatskog kardiološkog društva i *Kardio list*), Lovro Banfić (informatička podrška Registra, prethodni webmaster portala HKD) i dipl. ing. Davor Fanton (sadašnji webmaster portala HKD).

### Zaključci:

1. Registar će se moći i dalje popunjavati direktno preko interneta online (s poveznicom na portalu HKD-a), ali i lokalno offline, nakon informatičke podrške centrima u Republici Hrvatskoj koji nemaju mogućnost online priključka.

2. Informatičku potporu će nam i dalje pružati gosp. Lovro Banfić koji je spreman otići do lokalnih centara i radi dodatne edukacije o registru.

3. Očekuje se da bi sponzor informatičkog dijela Registra i potrebne statističke obrade i dalje trebala biti farmaceutska tvrtka "Merck-Serono", koja se do sada pokazala u najboljem (sponzorskom) svjetlu.

4. U planu je nabaviti novi server Hrvatskog kardiološkog društva, kojeg bi održavao Lovro Banfić.

5. Novosti u sadržaju Registra:

- trebalo bi poboljšati identifikaciju pacijenata, što je od posebne važnosti u opetovanim hospitalizacijama istog pacijenta, u istoj ili nekoj drugoj bolnici;

- bolesnici bi se nastavili pratiti u godišnjim intervalima i poliklinički;

- pri ispunjavanju podataka korištenje pojma "ostalo" trebalo bi svesti na minimum, radi kasnije obrade jednostavnije podataka;

- pojedini "padajući izbornici" bi trebali imati mogućnost istovremenog odabira više podataka;

- otvoriti mogućnost nadopisivanja novih medikamentata.

6. U ispunjavanju Registra mogli bi nam bitno pomoći djelatnici Zavoda za javno zdravstvo (epidemiološka služba — epidemiolozi). Takva suradnja pokazala se izvrsnom u Splitsko-dalmatinskoj županiji (dvije vrijedne kolegice dr. Jurčević-Zidar i dr. Marunica upisale su 70% svih bolesnika u našem Registru!).

The meeting of the Working Group for Heart Failure of the Croatian Cardiac Society was held in the Clinical Hospital Centre Zagreb, on 25<sup>th</sup> February 2009. The main topic of the meeting was the Registry of patients with heart failure focusing on IT segment.

The meeting was attended by: Prof. Davor Miličić PhD, Prof. Stojan Polić PhD, Duška Glavaš M. Sc., Branka Jurčević-Zidar MD (epidemiologist), Dubravko Tršinski MD, Head Doctor Mario Ivanuša PhD (Croatian Cardiac Society web-portal and *Kardio list*), Lovro Banfić (IT support for Registry, previous CCS portal web-master) and Davor Fanton B.Sc. (Engineering) (present CCS portal web-master).

### Conclusions:

1. It will still be possible for the Registry to be filled in directly through Internet, online (with link to the CCS portal) and locally offline as well, after IT support to centers in the Republic of Croatia that lack online connection.

2. IT support will still be provided to us by Mr. Lovro Banfić who is ready to go to the local centers to provide them with an additional training concerning the registry.

3. The pharmaceutical company "Merck-Serono" is expected to continue to be a sponsor for the IT segment of the Registry and required statistical processing that proved to be the best sponsor so far.

4. We are planning to procure a new server for the CCS that is to be maintained by Mr. Lovro Banfić.

5. Novelties in the contents of the Registry:

- We should improve the patients' identification which is especially important in repeated hospitalizations of a same patient in the same or in another hospital.

- Patients would be still monitored in annual intervals and in polyclinics.

- When filling in the registry with data, the use of the term "other" should be reduced to minimum, as to be able to process data in a more simple way later.

- Some "dropdown menus" should have a possibility of simultaneous selection of several data.

- Creating a possibility of entering some new medicines.

6. When filling in the registry with data, the Public Health Institute employees could be a great help to us (epidemiological unit — epidemiologists). Such cooperation proved to be excellent in the County of Split and Dalmatia (two hardworking colleagues Jurčević-Zidar MD and Marunica MD registered some 70% of all patients into our register!).



7. Obavijest o Registru poslat će se u Podružnice HKD-a, gdje se planira imenovanje lokalnih koordinatora koji će pokušati uspostaviti vezu sa epidemiolozima.

8. U planu je i moguća, makar mala, novčana nadoknada kolegama koji ispunjavaju Registar.

9. Na web portalu HKD moći će se pogledati podaci o broju uključenih pacijenata po centrima. *Kardio list* će u svakom broju donositi aktualne podatke o Registru (prvenstveno broj upisanih bolesnika i dr.). Zatražena je ponuda za unaprijeđenje rada, sadržaja i izgleda portala HKD, koji bi trebao sličiti izgledom i funkcionalnošću portalu Europskog kardiološkog društva.

10. Cjelokupni podaci Registra će biti pri HKD-u, a kolege koji ga popunjavaju imat će uvid i raspolagati lokalnim podacima.

7. Notification about the Registry will be sent to the CCS subsidiaries which plans on appointment of local coordinators who will attempt to establish a relationship with epidemiologists.

8. The colleagues filling in the registry with data are likely to be financially reimbursed to a certain extent.

9. CCS will be able to use the web portal to look up the data on a number of included patients in centers. Every issue of *Kardio list* will include actual data on the Registry (mainly a number of registered patients etc.). We have requested an offer for upgrade of work, contents and layout of the CCS portal that should look similar by its appearance and functionality to the portal of the European Society of Cardiology.

10. The overall data of the Registry will be within CCS and the colleagues filling it in, will have an insight in it and will be able to dispose of local data.

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