

Registry of Dialysis Patients (RDP) – current results and comparison to other European national registries

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on behalf of the Czech Society of Nephrology

Prague, Czech Republic

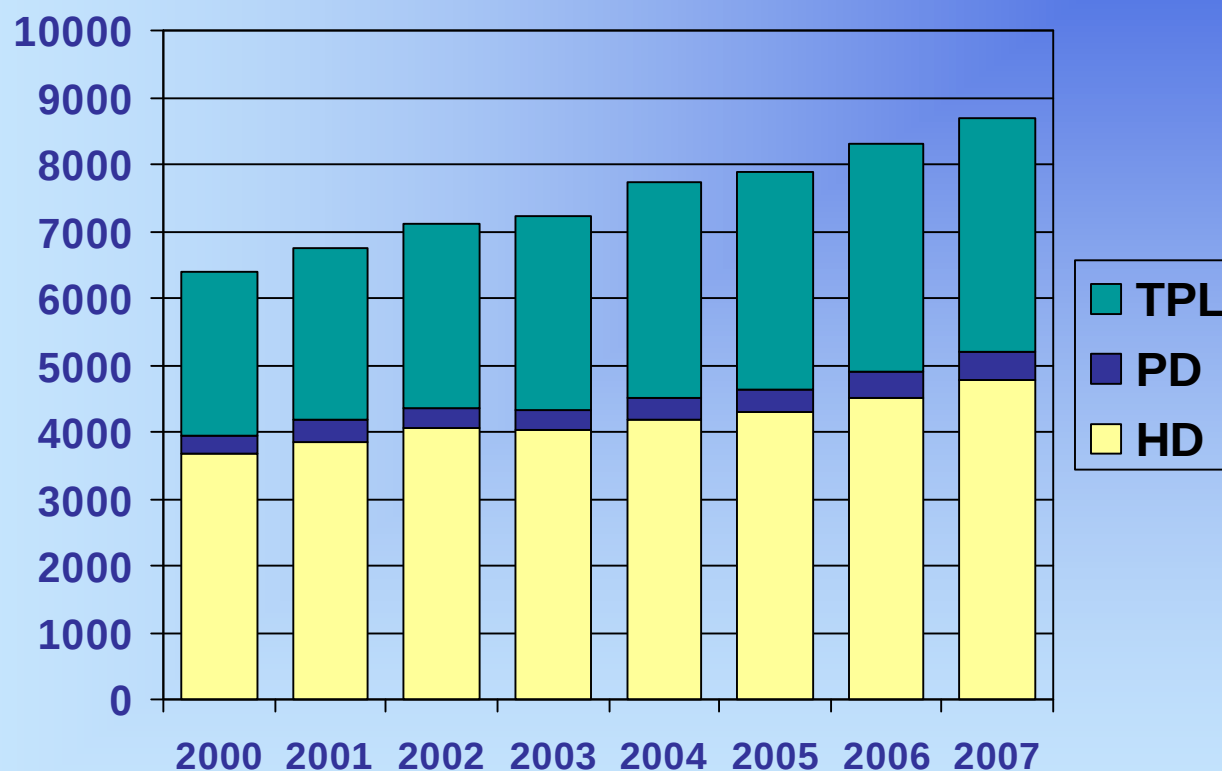


Basic data 2007 – Czech Rep.

- total population 10.3 mil
- 87 dialysis units + 7 transplant centers
- prevalence 31.12.2007:
 - in dialysis treatment 5,190 pts, i.e. 509 pts PMP
 - functioning graft 3,500* pts, i.e. 340 pts PMP
 - **RRT total 8690 pts, i.e. 844 PMP**
- total 710,056 hemopurification treatments
- peritoneal dialysis: 402 patients (7.8%)
- transplanted: 416 patients (incidence 40.4 PMP; cadavers 360, living donors 34, combined Tx 22)

*data in 6/2007

Prevalence - method of RRT

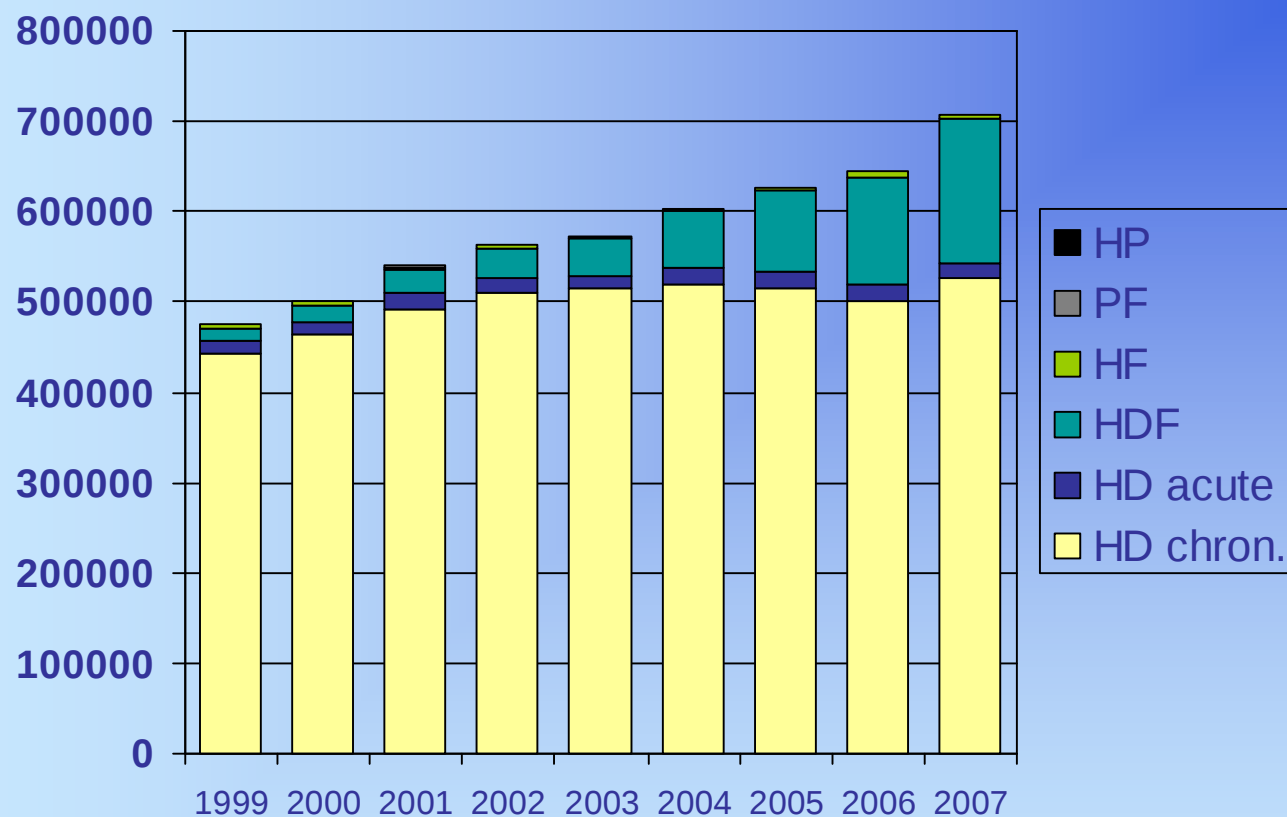


Number of patients - 31.12.2007:

HDP	4788 pts
PDP	402 pts (7,8 %)
Tx	3500 pts*

RRT: 844 PMP

Numbers of treatments

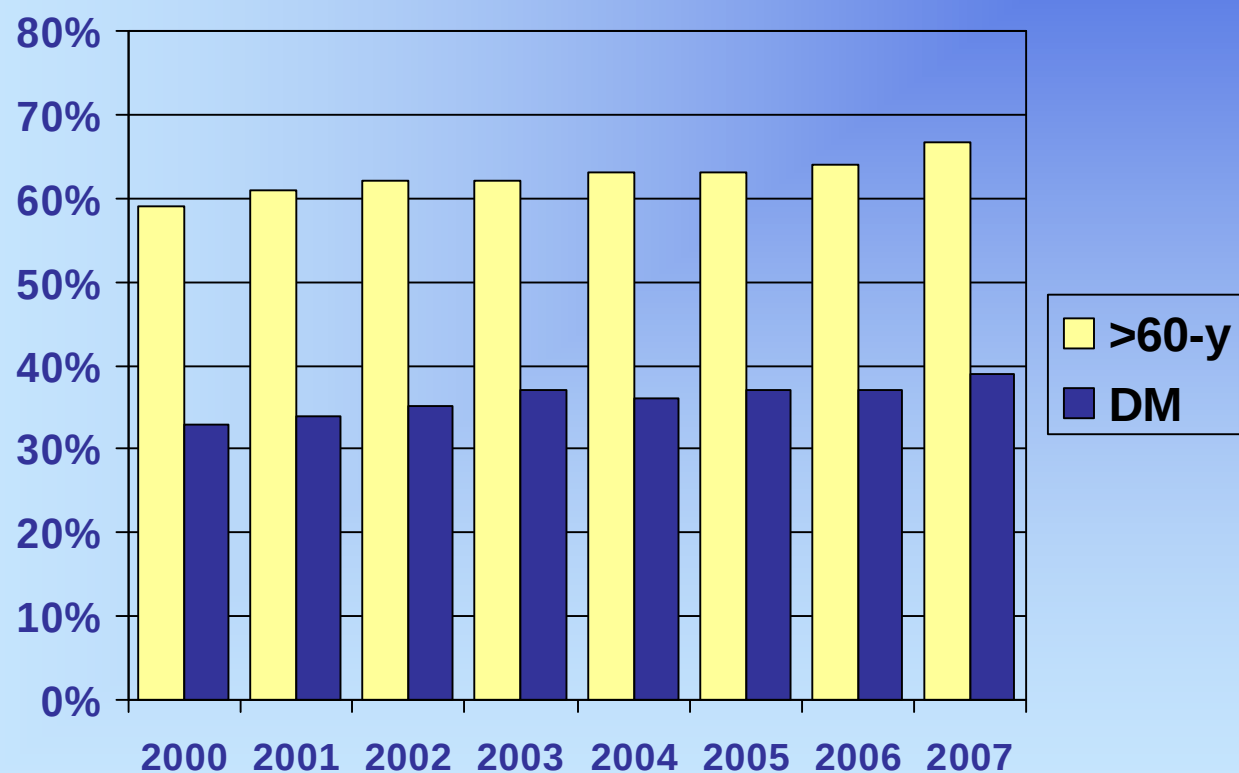


Treatments 2007:

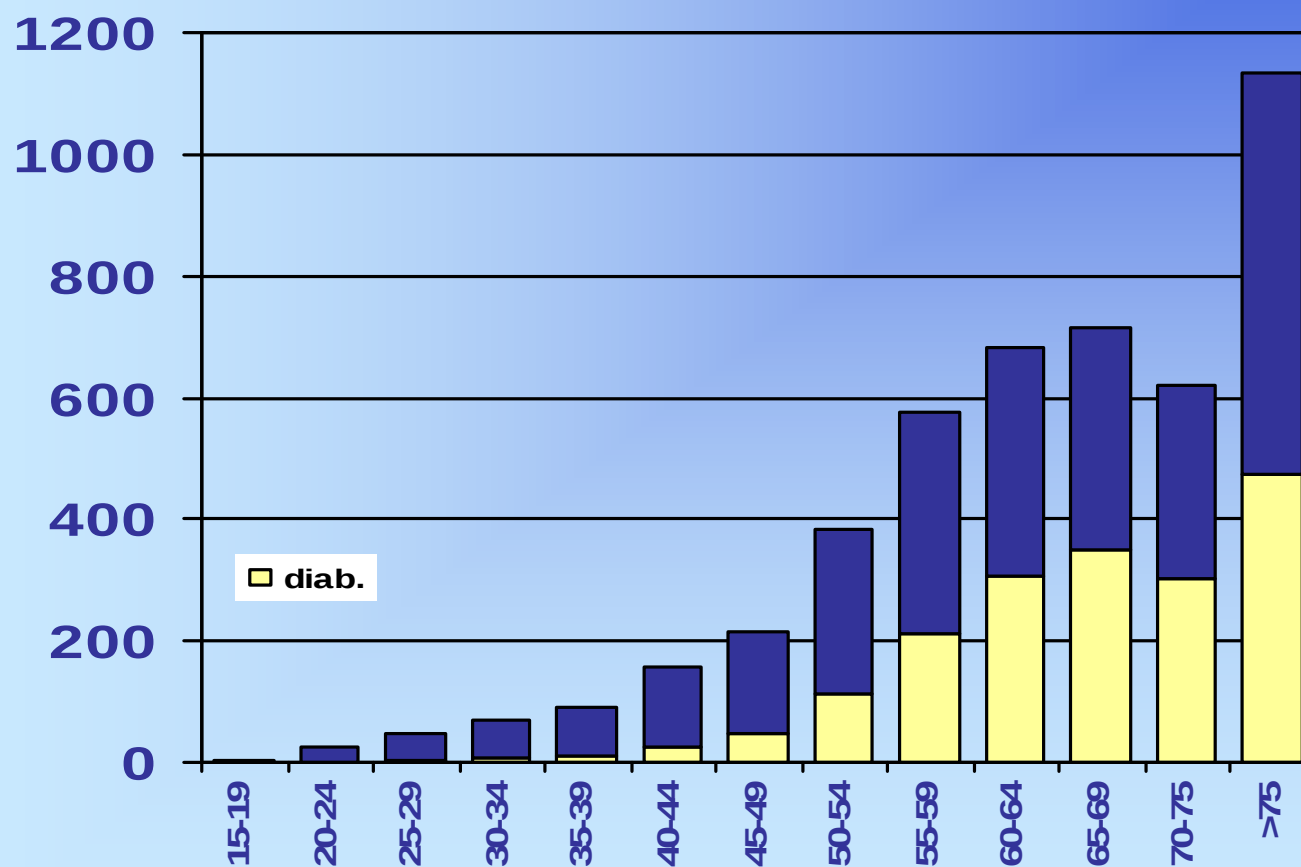
HD 525 709 (acute 3%)
HDF 160 248
HF 3665

PF 780
HP 15
others 2 591

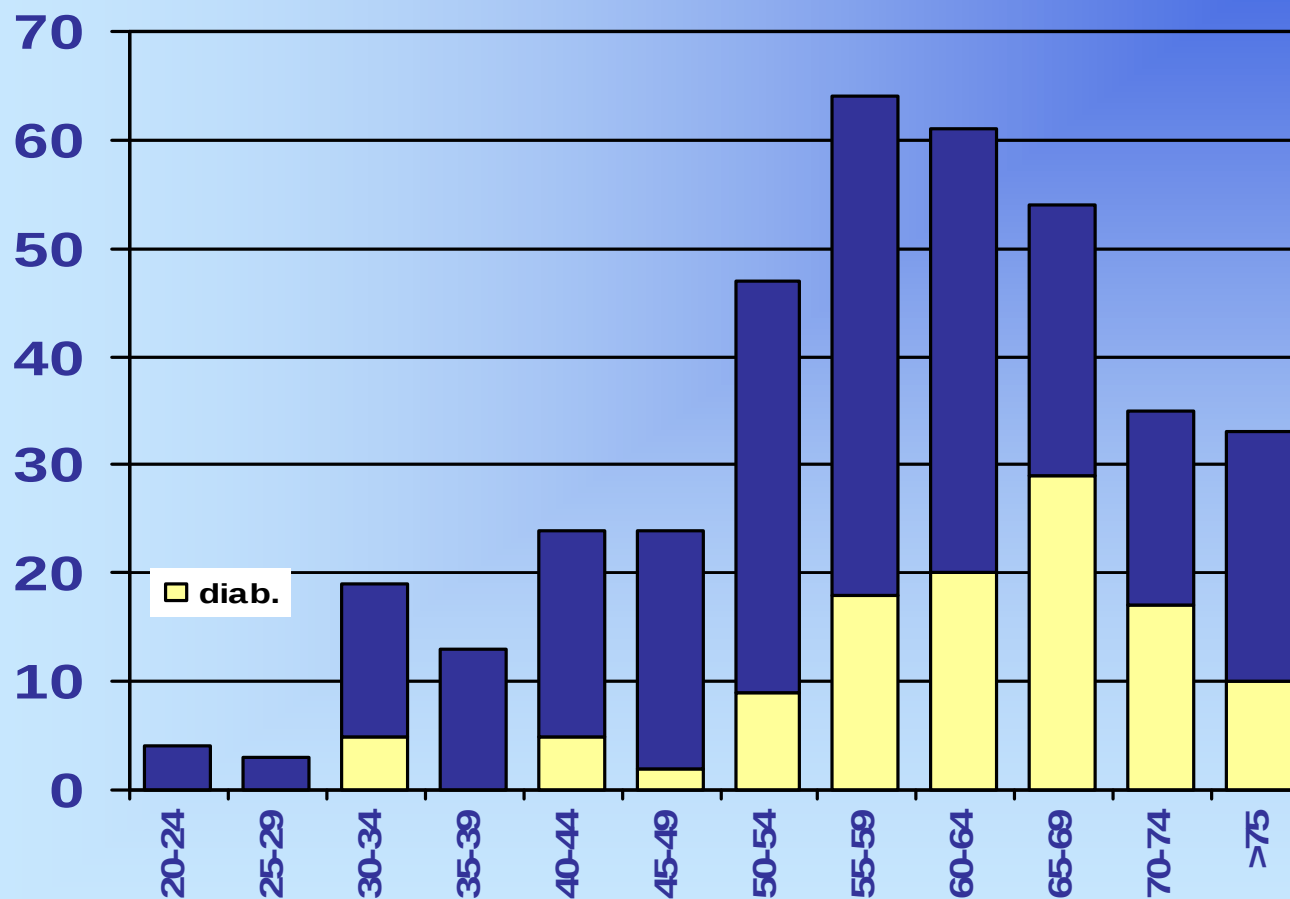
Patients > 60-y and diabetics in HD



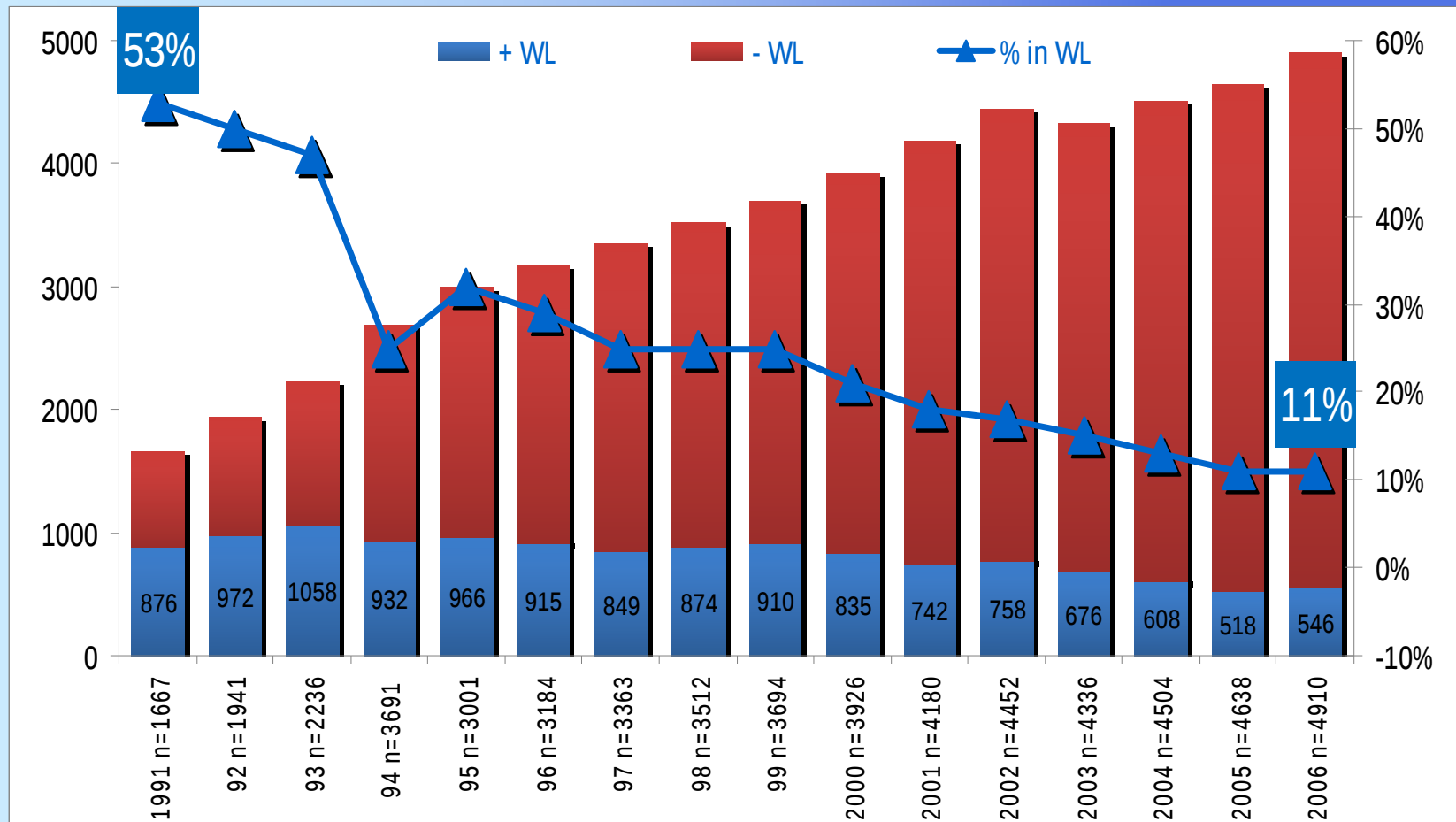
Age distribution - HD (á 5-y.)



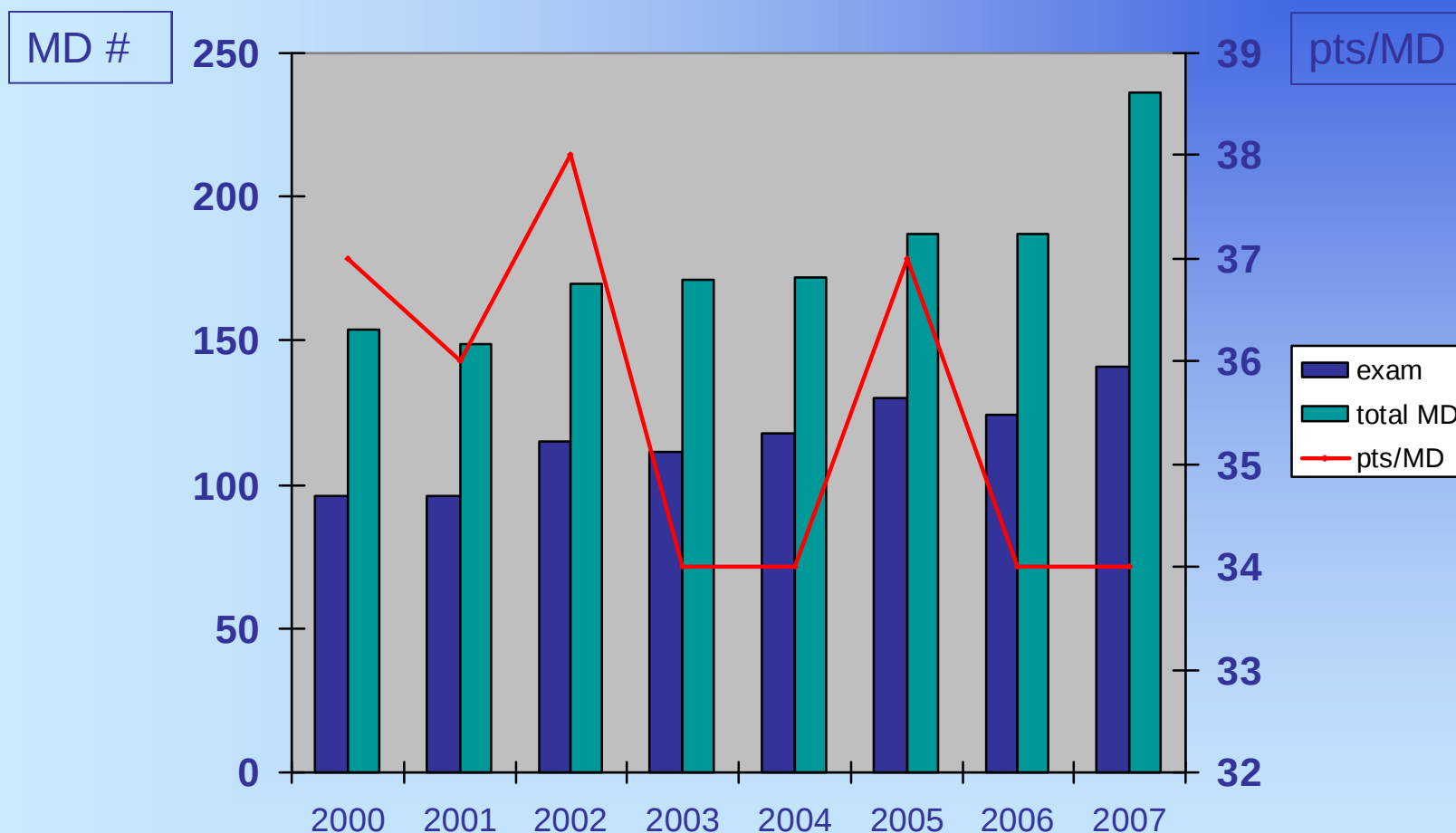
Age distribution - PD (á 5-y.)



Dialysis treatment and waiting list (31.12. 1991-2006)

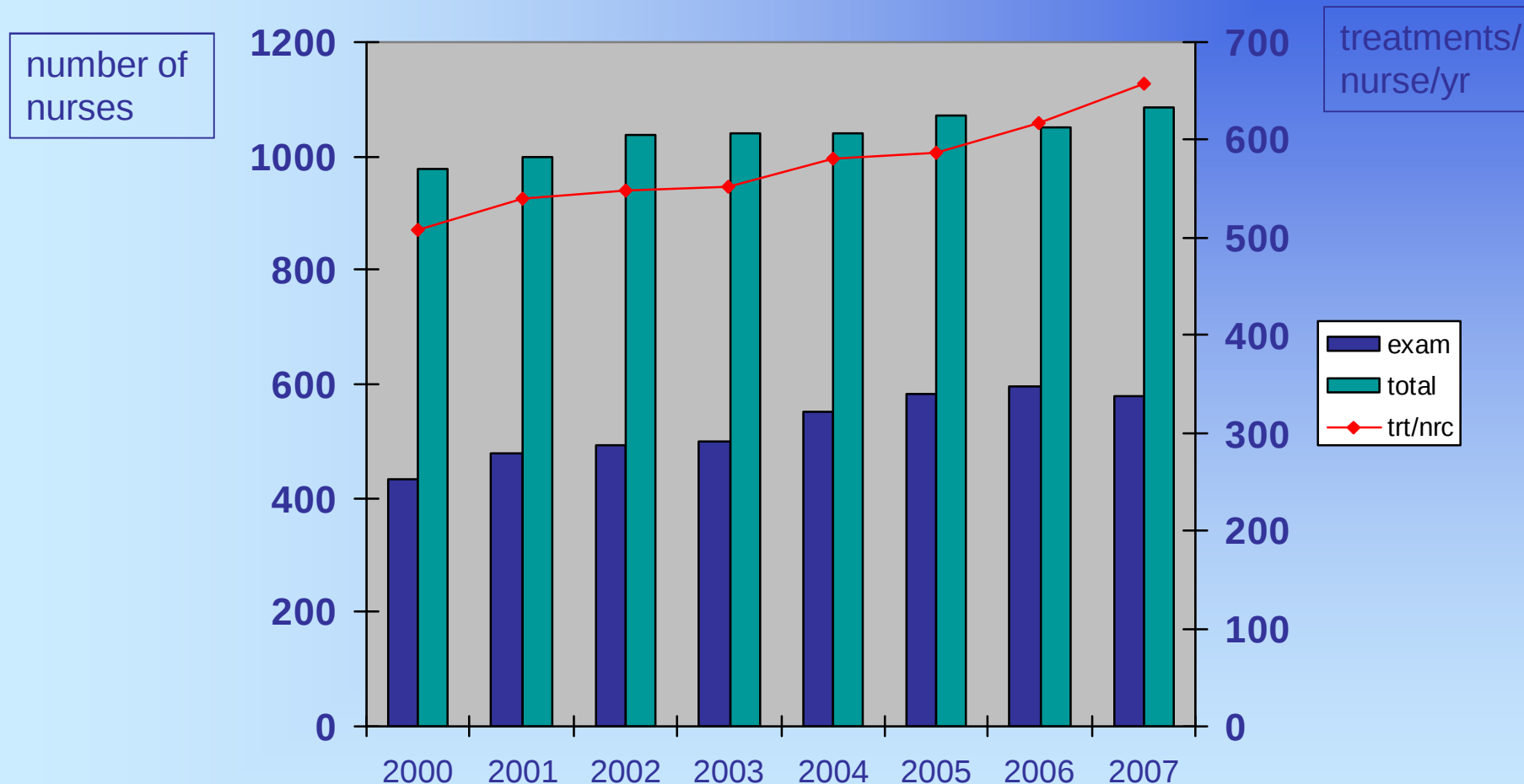


Staff in dialysis units: physicians



2007: Physicians total: 236; → 141 state exam in nephrology (60%)
 number of pts/physician: 34

Staff in dialysis units: nurses



2007: total nurses: 1087; → 579 with exam (53%)
 number of treatments/1 nurse: 658

Up to 2005:

→ National Registry of RRT (since 1991)

- only global data available
- prevalence data reported to 31.12. (response rate 100%)
- no data regarding individual patients
- limited data regarding quality of treatment

Starting 2006:

→ Registry of Dialysis Patients (RDP)

- global data available in the same extend

New:

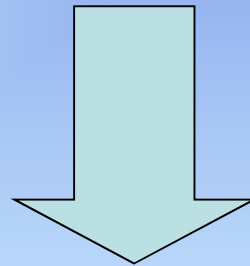
- based on individual data of each patient
- data regarding quality of treatment available

Why RDP?

- **Basic epidemiological parameters**
- **Correlation of treatment parameters and results !!**
 - evaluation of efficacy and quality of treatment
 - regional differences in country
 - continuous **on-line** comparison: unit↔country
 - evidence-based recommendations for CR
- **Better international comparison**

CNS decision → electronically reported data

- requirements:
 - compatibility with local IT systems
 - easy to operate
 - widely accessible software
 - internet access
 - safety transfer and system
 - price



- è system Nefris (Prodos comp. - 64% DU routinely used for everyday clinical + administrative practice)
- è protected net NefPort (owned by CNS+ProDos)

RDP: reported data

- 1. quarterly reported (>70 items)**
- 2. data:**
 - 1. data of dialysis units**
 - 2. basic personal data of patient**
 - 3. periodically reported data - laboratory values**

RDP: status and principles

- **established 2005 as a project of CNS**
- **voluntary data report**
- **financially supported and owned only by CNS**
- **based on individual patient data report**
- **fully registered by state authorities**
- **data report quarterly (trends)**
- **data transfer electronically**

RDP - current status

- certified 87 Dialysis Unit + 3 acute + 3 pediatrics
- regularly reported all data 49 DU $\geq 3x/y$
7 DU 1-2x/y
- entered data: 4288 patients
- i.e. 65% of DU and 61 % of treated patients (= 7056 pts by Statistical Yearbook CNS 2007).

RDP data currently available:

3 types of data:

- current on-line data of Czech Rep.
- back-report: dialysis unit data comparison to the mean values of the CR
- other statistics

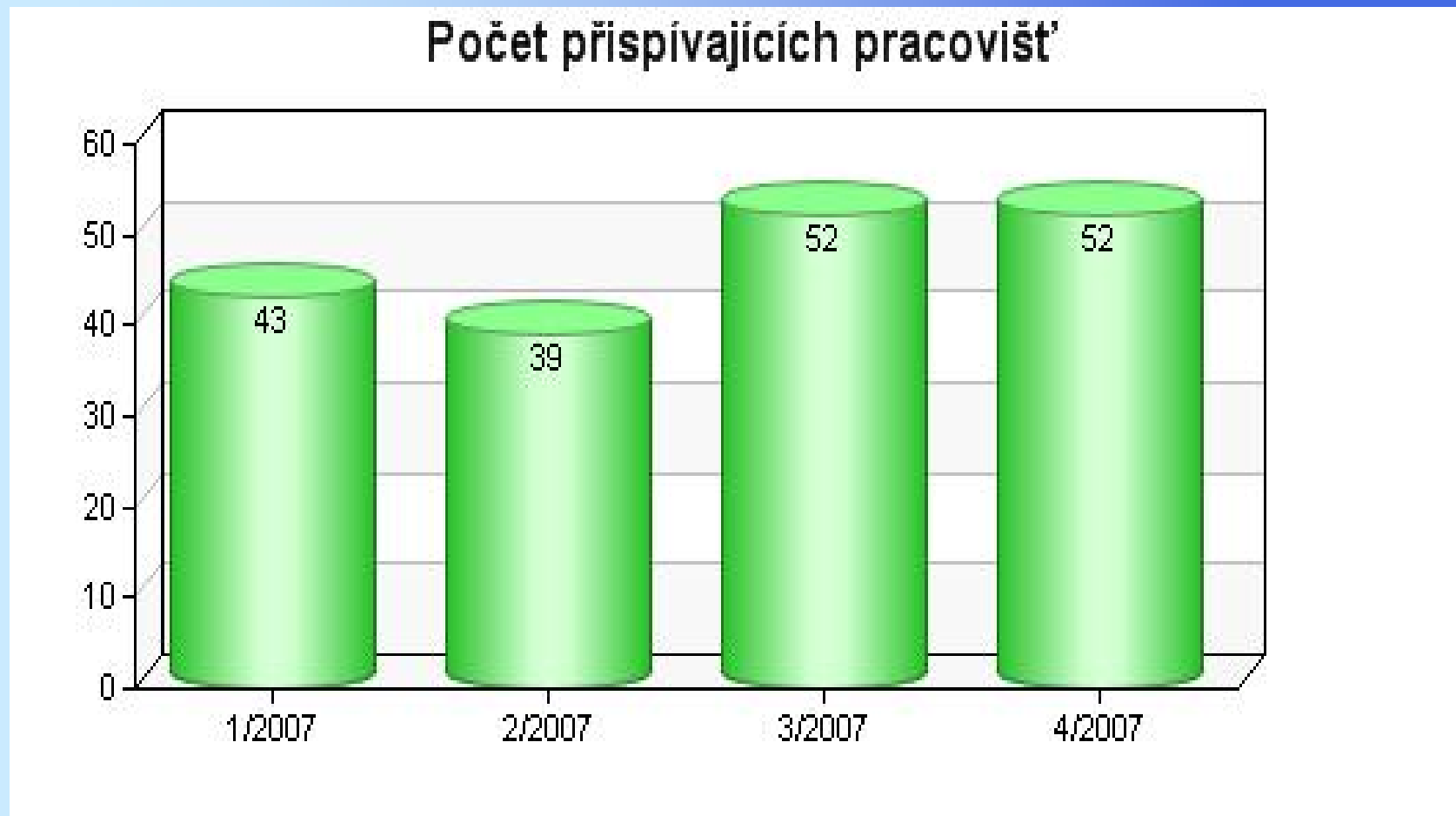
Data currently available:

- current on-line data of Czech Rep.
- back-report: dialysis unit data comparison to the mean values of the CR
- other statistics

On-line data RDP

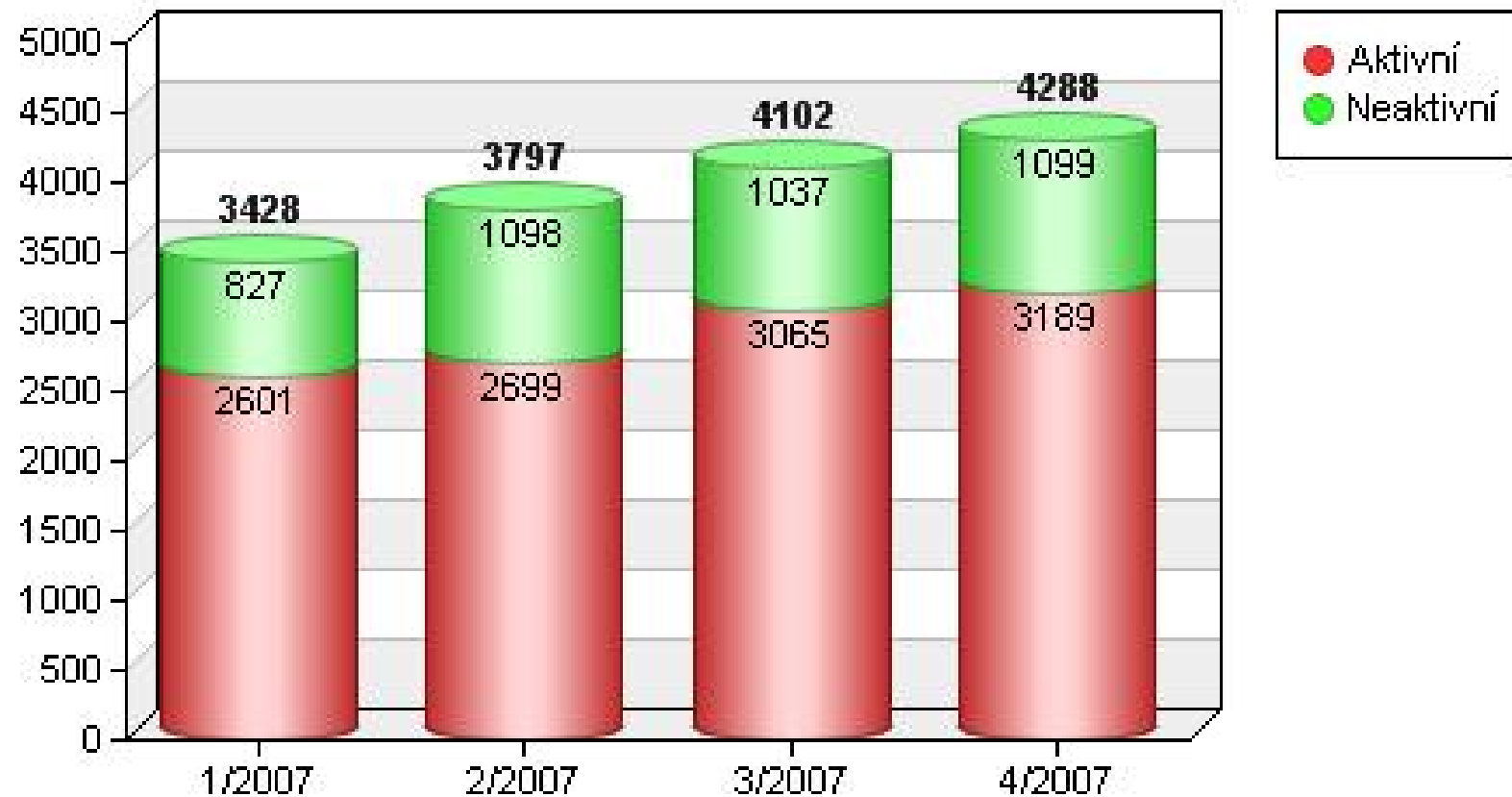
- currently 11 parameters are displayed routinely
- in principle, all combinations of all registered parameters are available

data on-line RDP – number of **reporting units** quarterly, 2007



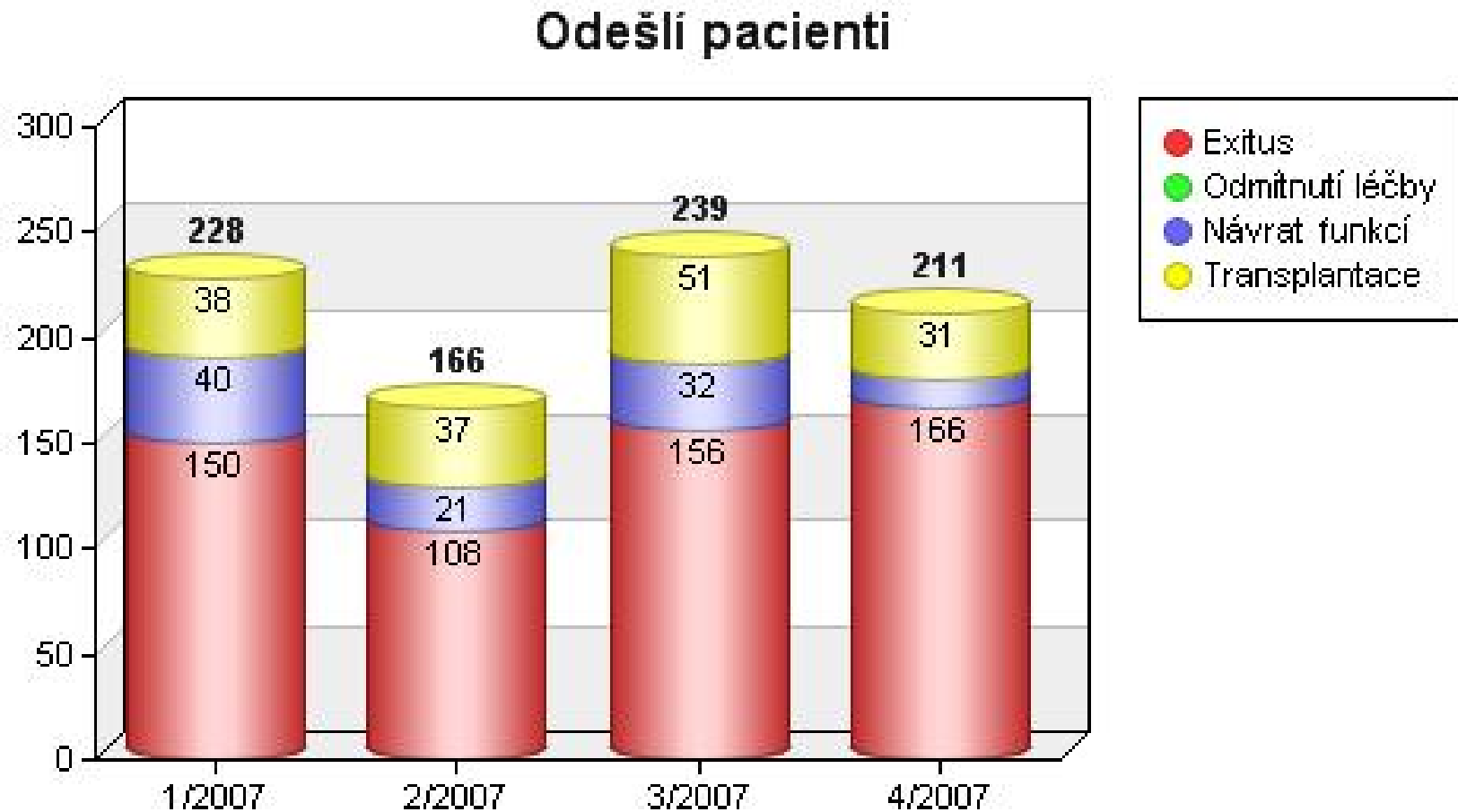
data on-line RDP – number of **registered patients** quarterly, 2007

Registrovaní pacienti



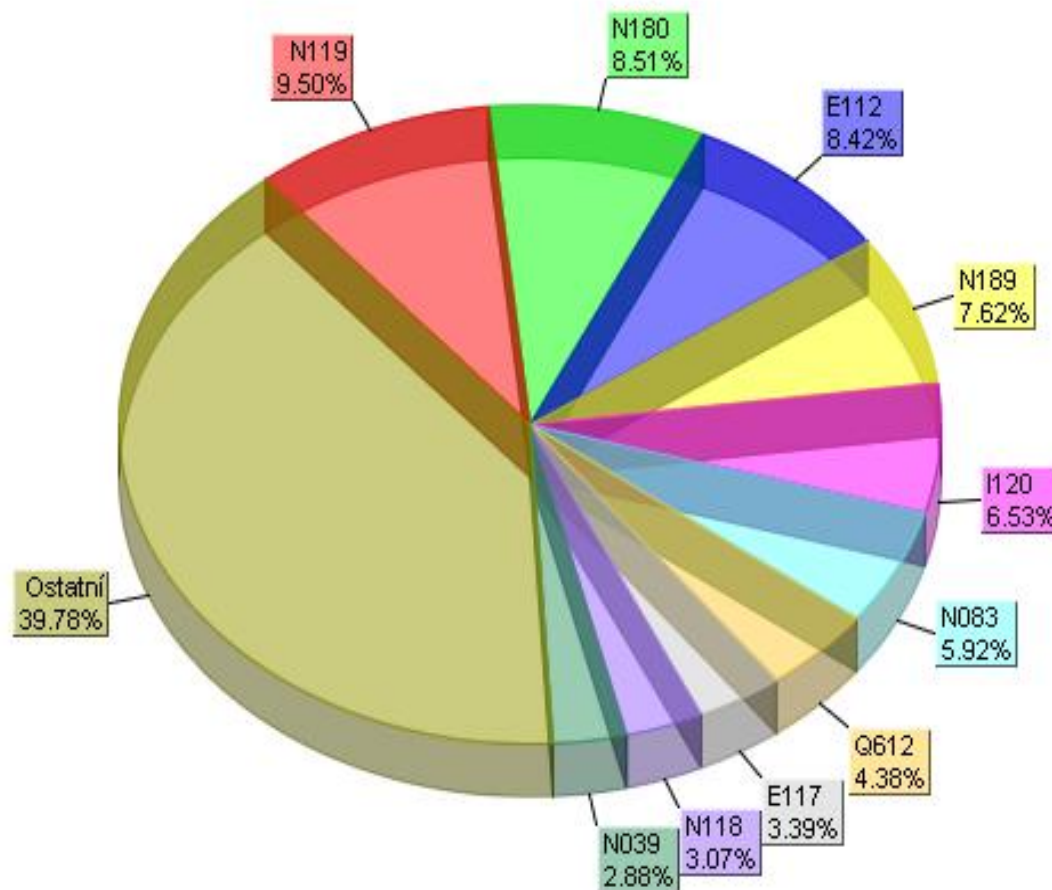
Aktivní pacienti = alespoň jednou vyplněná periodická data za poslední dva kvartály

data on-line RDP – number of **patients ending/leaving dialysis** treatment, 2007



data on-line RDP – **primary renal disease** (using ICD 10)
total entered 3128 pts registered in 12/2007

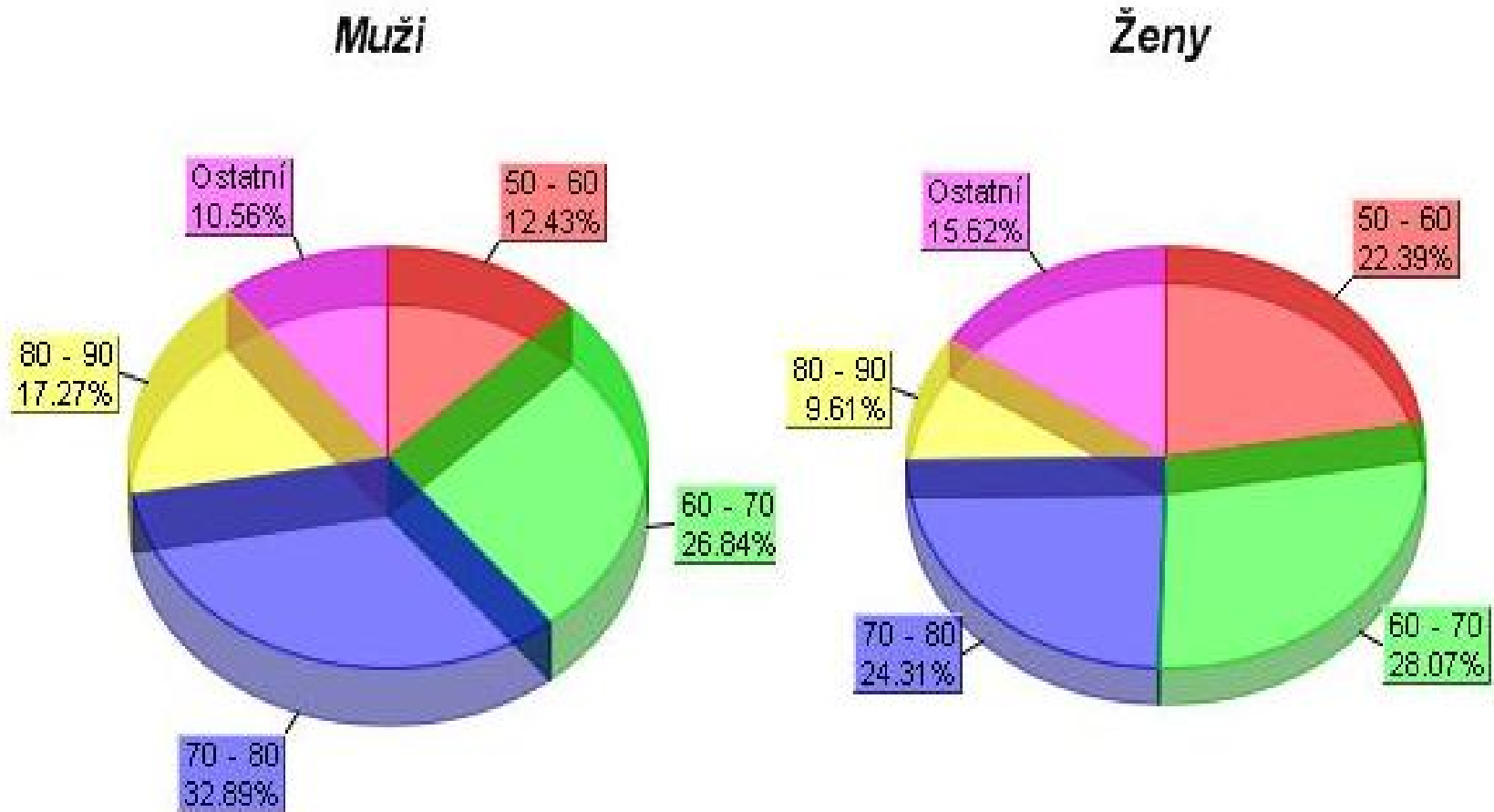
Rozčlenění podle prim. ren. dg.



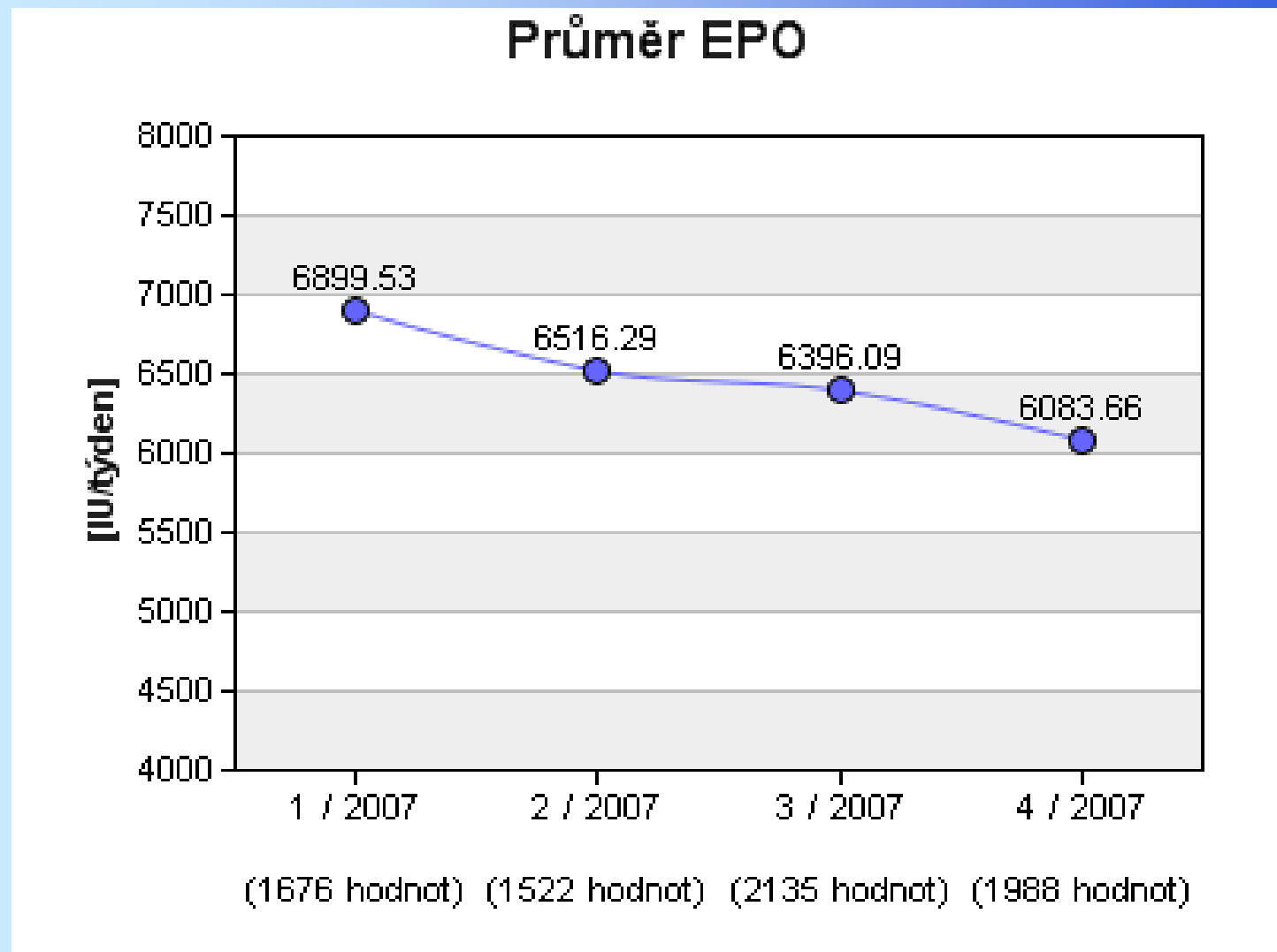
Code dg:
N119-TIN-PN
N180-CHRI n.s.
E112-diabetic nefropath
N189-CHRS n.s.
I120-ICHL
N083-KSW
Q612-PCHL
E117-diab.nefropathy
N118-TIN other
N039-chron.GN

DN-total 17,8%

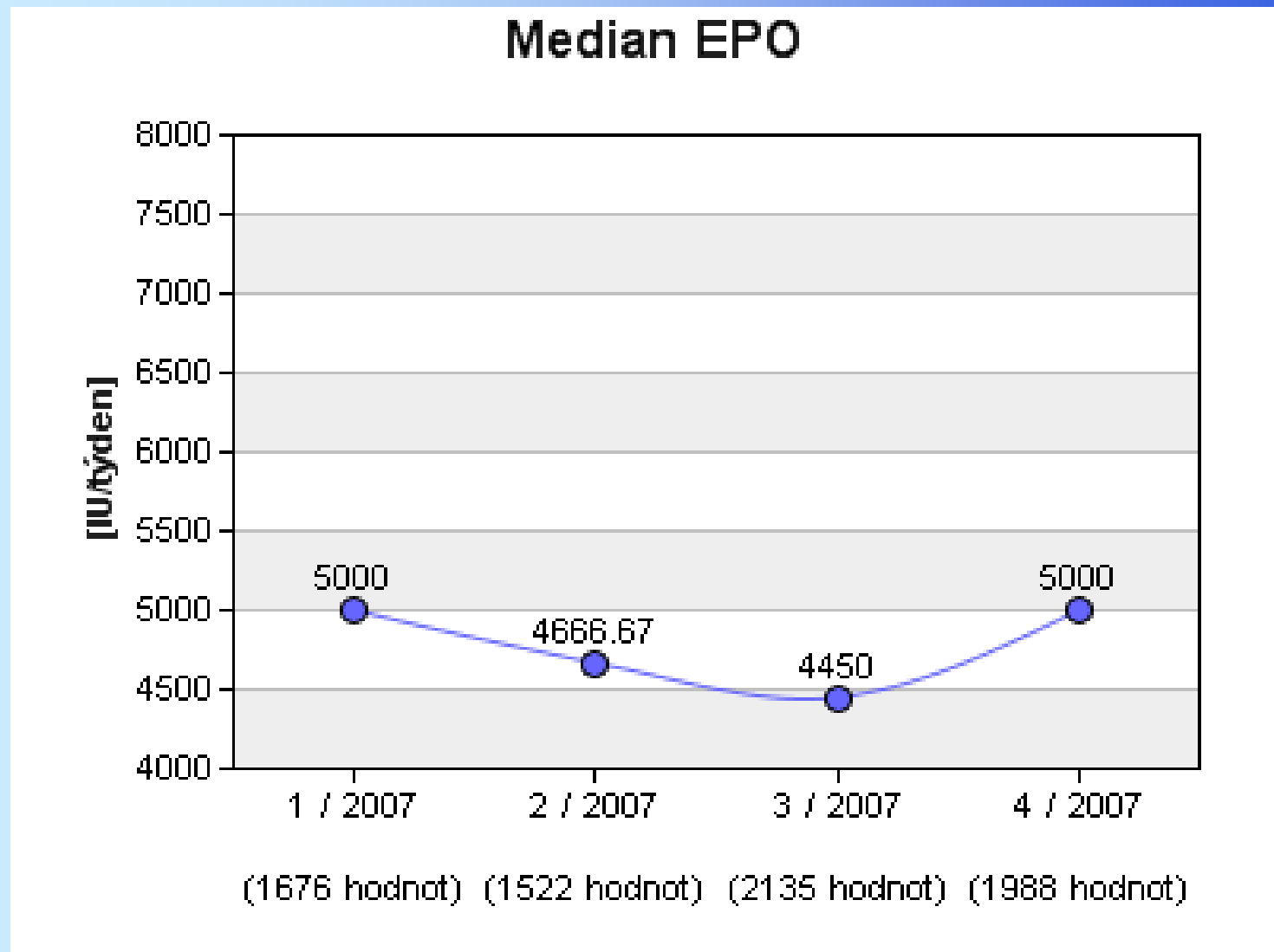
data on-line RDP – **age and gender** (decades, men=2003, women=1533)



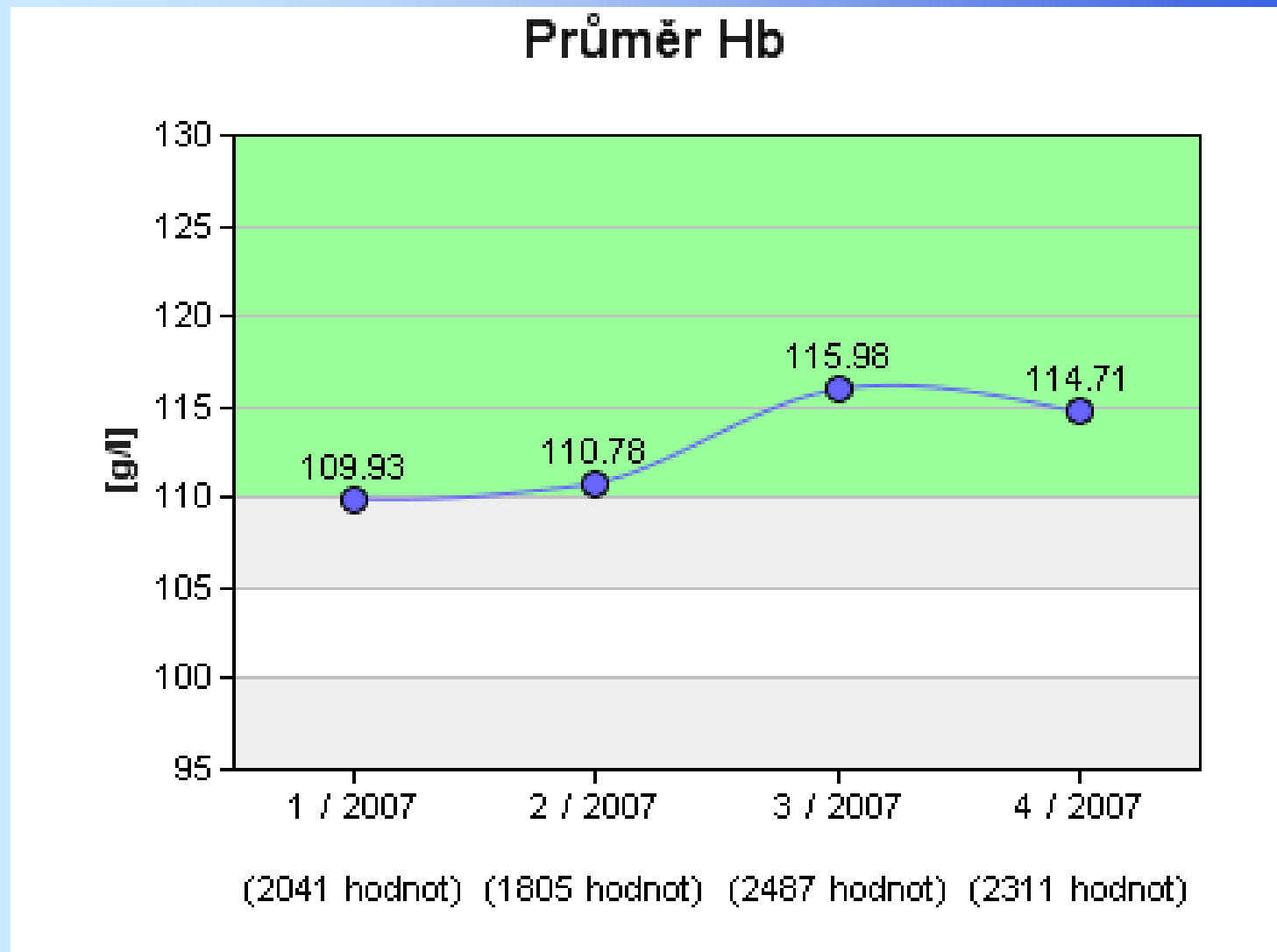
data on-line RDP – **ESA mean dosage:** IU/week (reported quarterly, 2007)



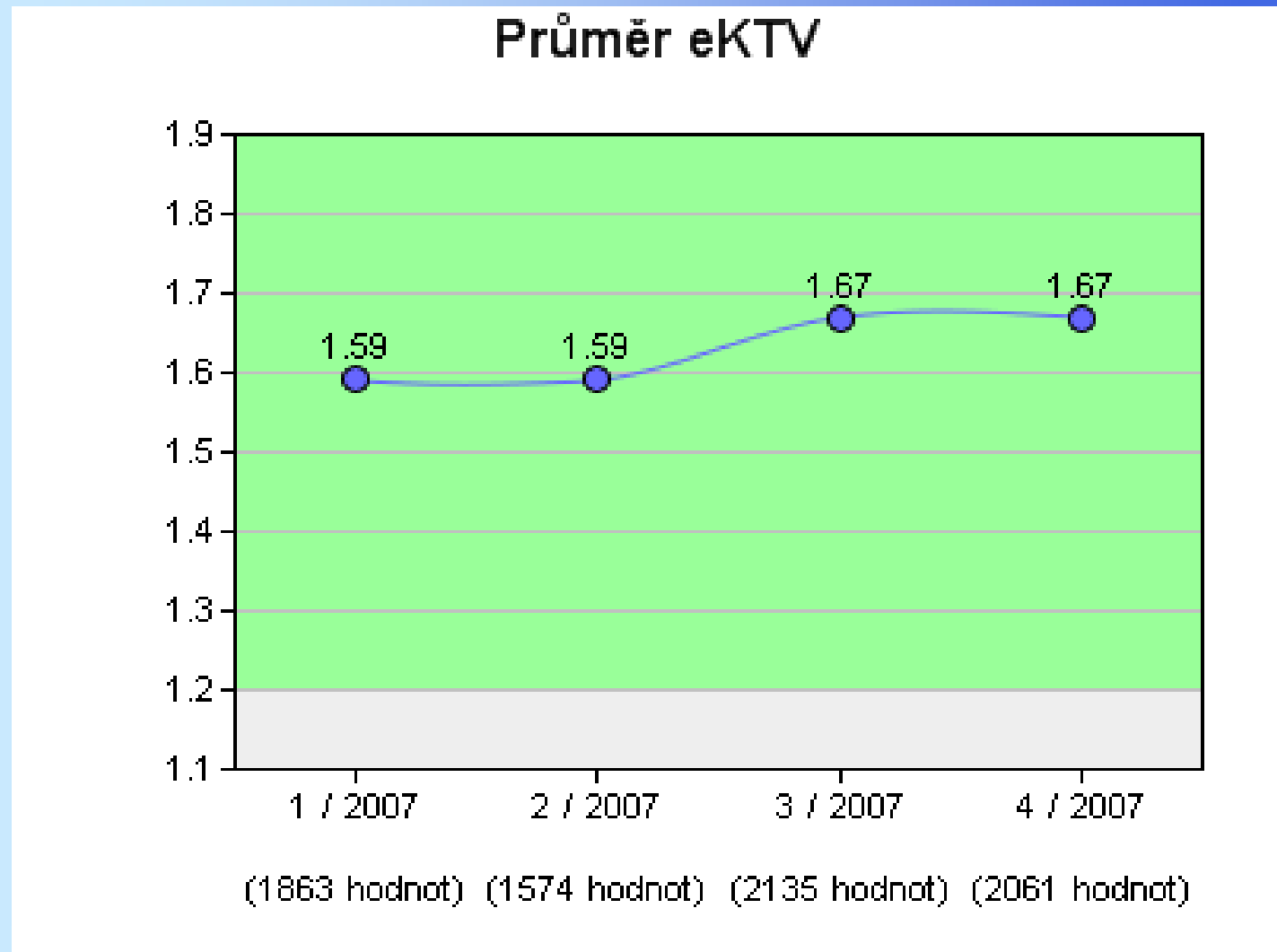
data on-line RDP – **ESA median dosage:** IU/week (reported quarterly, 2007)



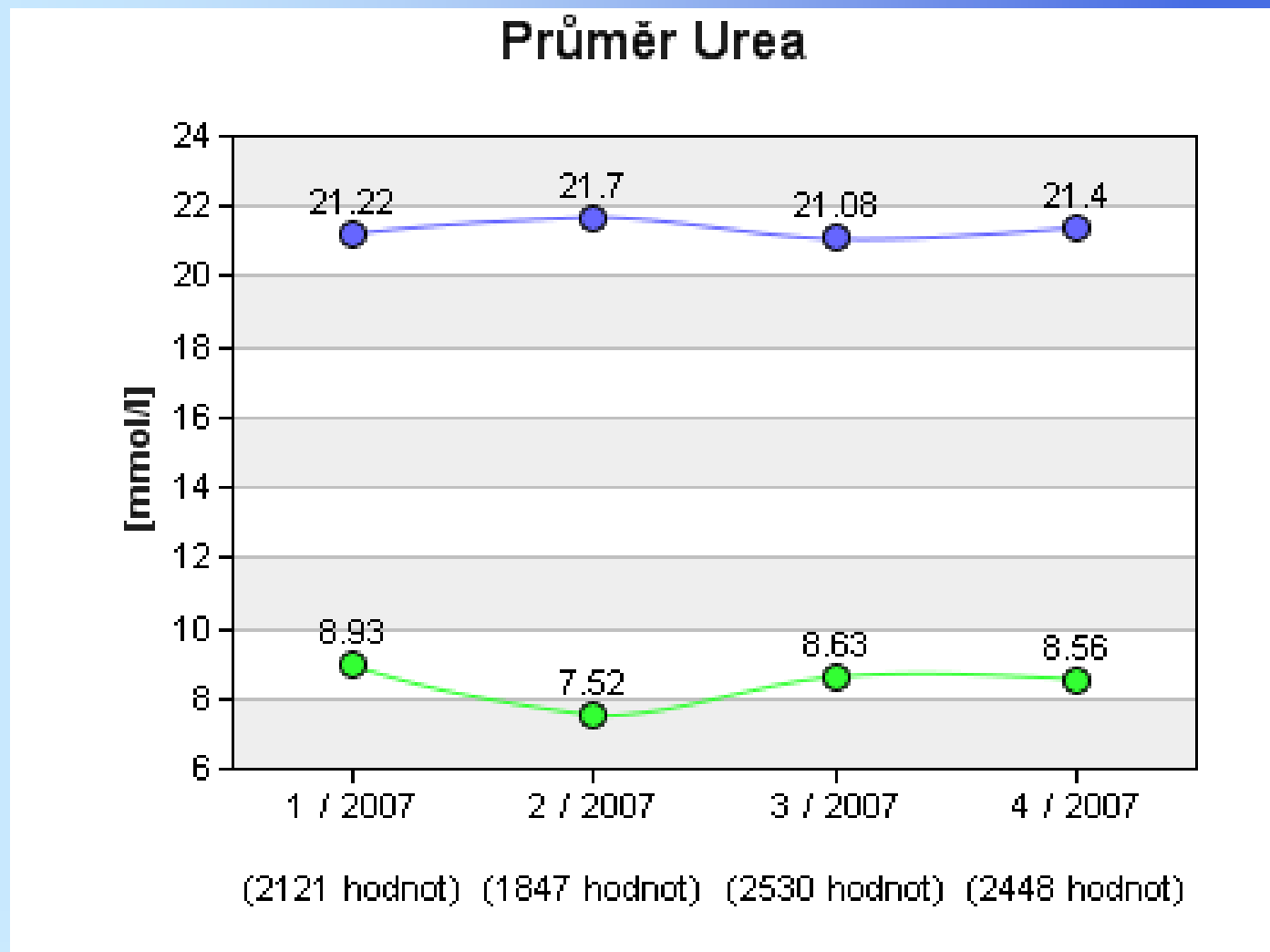
data on-line RDP – **mean hemoglobin** level (reported quarterly, 2007)



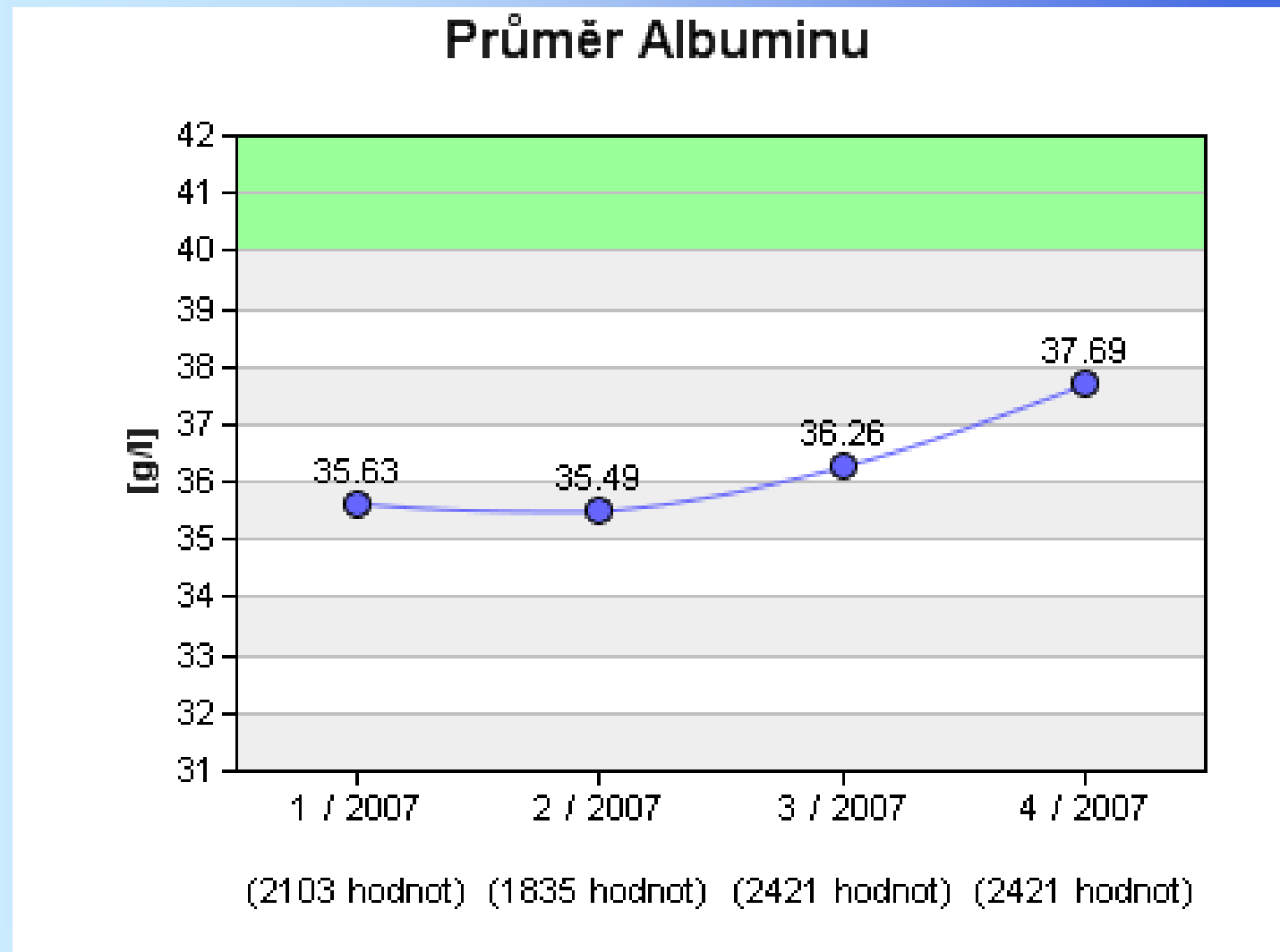
data on-line RDP – **dialysis efficacy** according to eKTV (reported quarterly, 2007)



data on-line RDP – **blood urea nitrogen** levels before and after treatment
(reported quarterly, 2007)

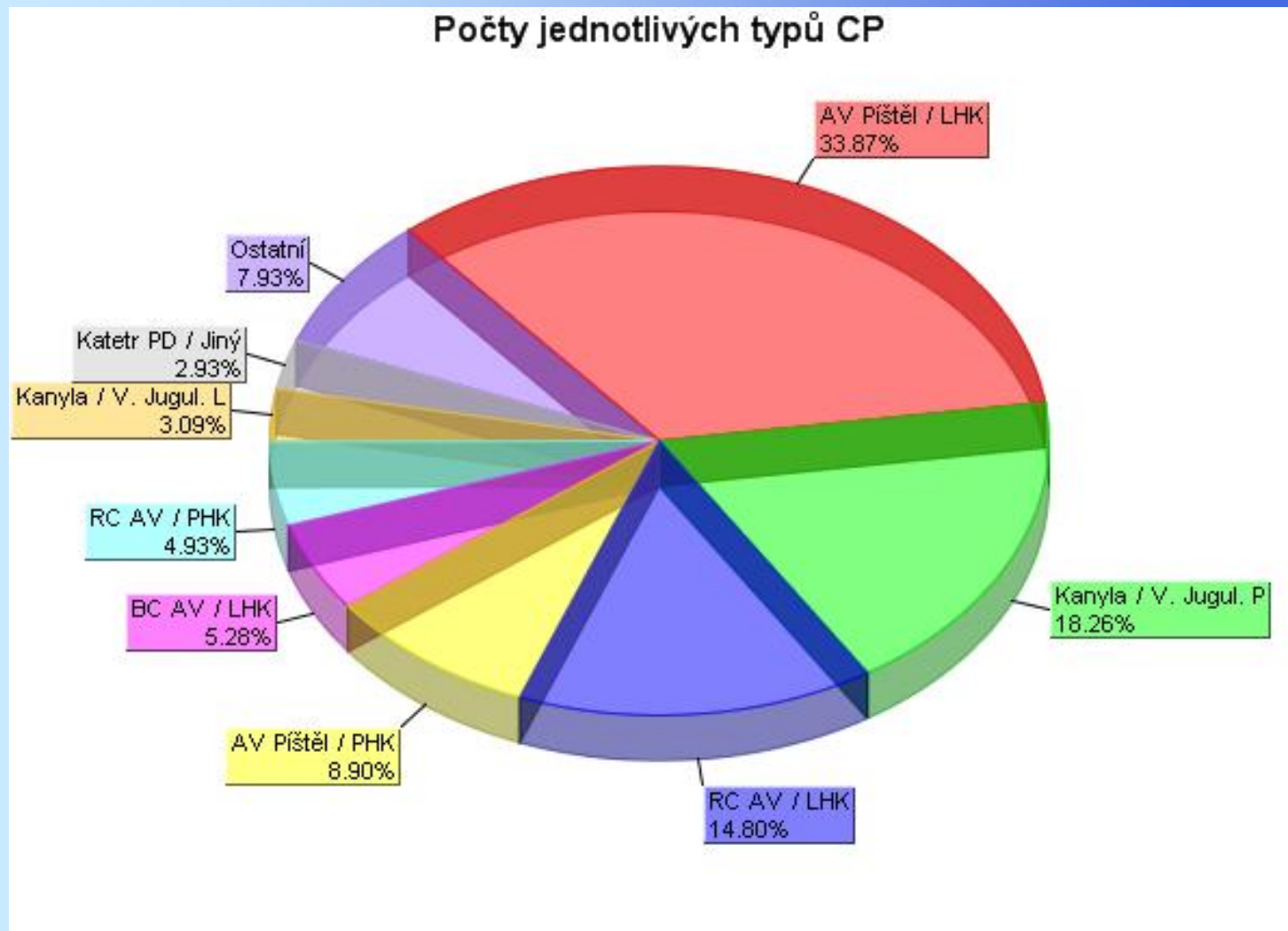


data on-line RDP – nutritional status according to **albumin level**
(reported quarterly, 2007)



Type of vascular access

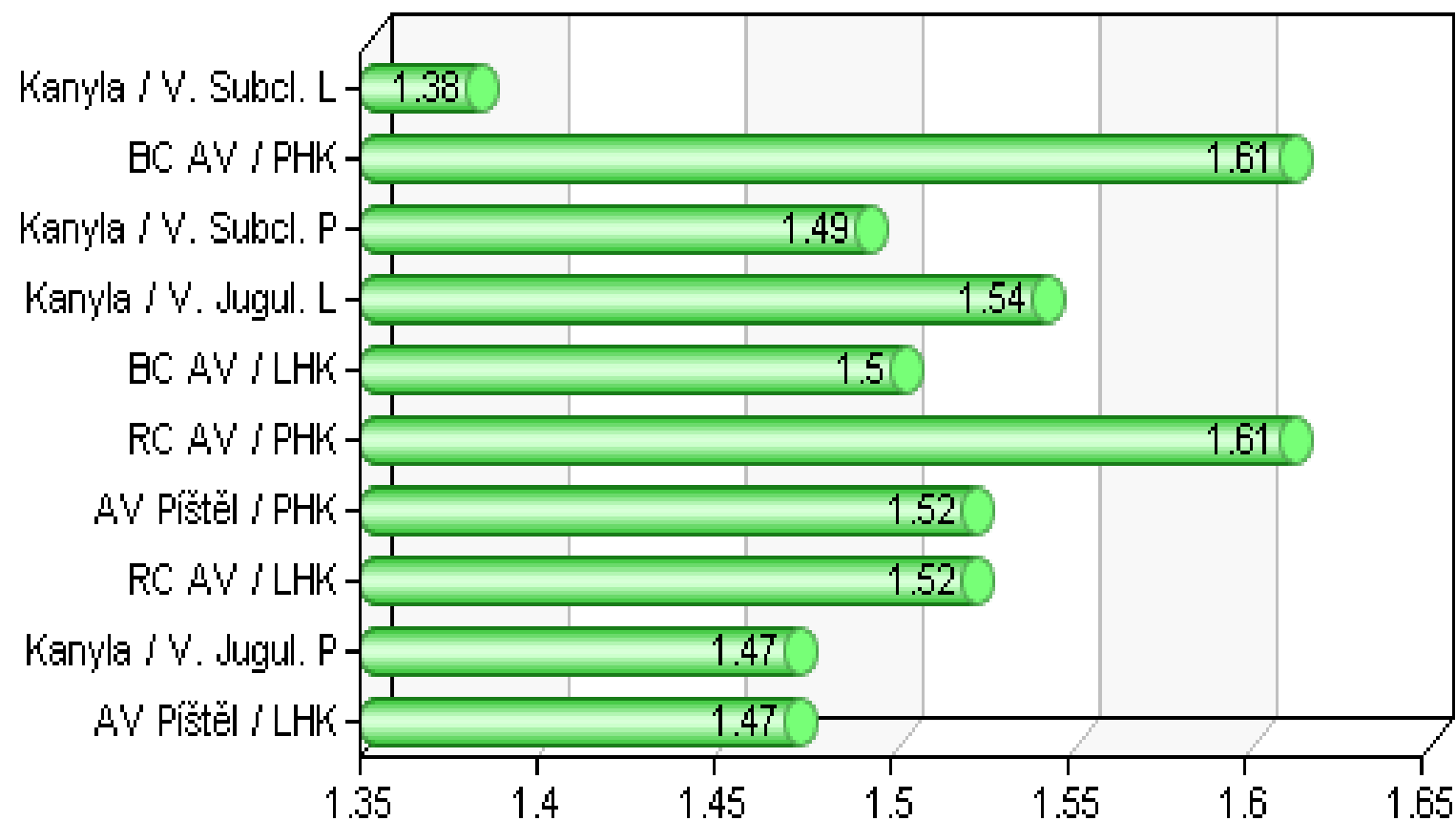
entered 3210 pts registered in 4/2007



Vascular access and eKTV

entered 1777 pts registered 4/2007

Vztah CP a eKTV



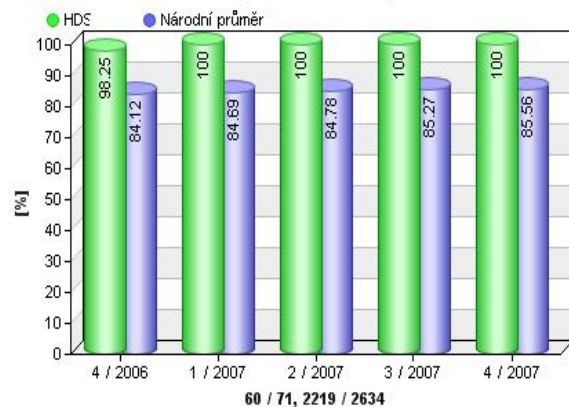
Data currently available:

- current on-line data of Czech Rep.
- back-report: dialysis unit data comparison to the mean values of the CR
- other statistics

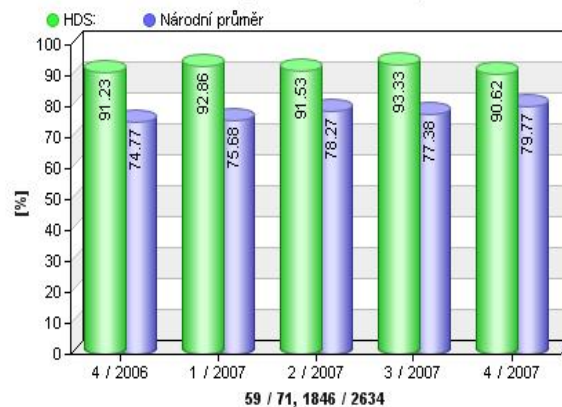
Back-report: dialysis unit data comparison to the mean values of the CR

- data accessible only for each single dialysis unit
- data base structure identical as national

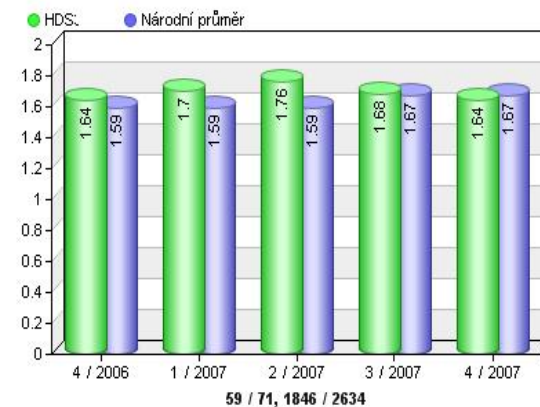
Procento pac. dial. 3x týdně



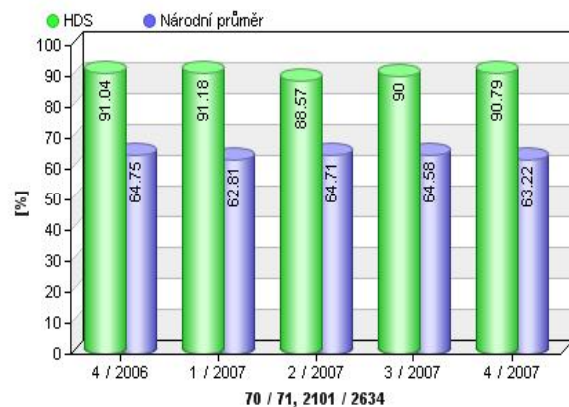
Procento pac. s eKTV $\geq 1,2$



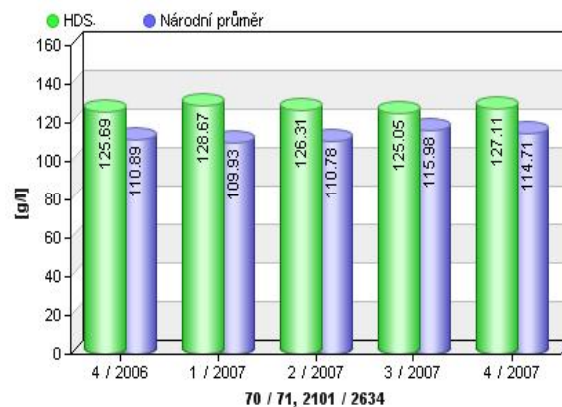
Průměrná hodnota eKTV



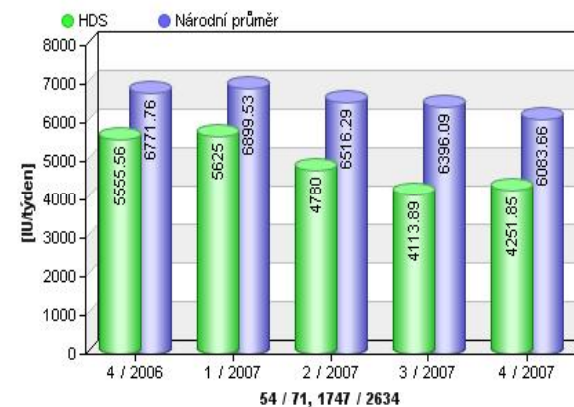
Procento pac. s hemoglob. ≥ 110



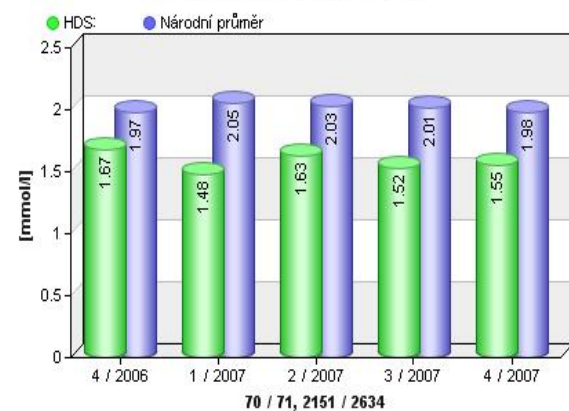
Průměrná hodnota hemoglobinu



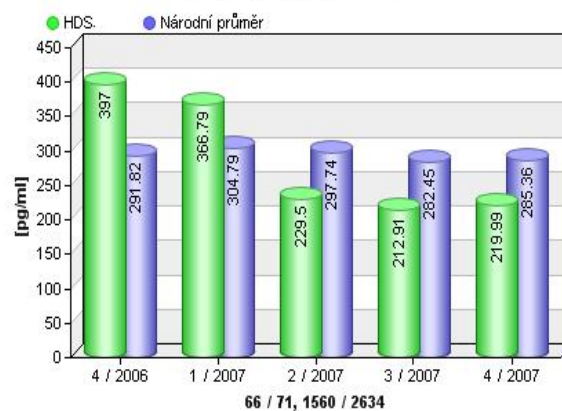
Průměrná hodnota EPO



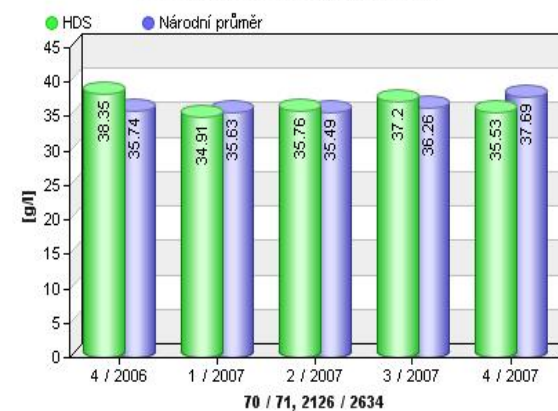
Průměrná hodnota fosfátů



Průměrná hodnota PTH



Průměrná hodnota Albuminu



Data currently available:

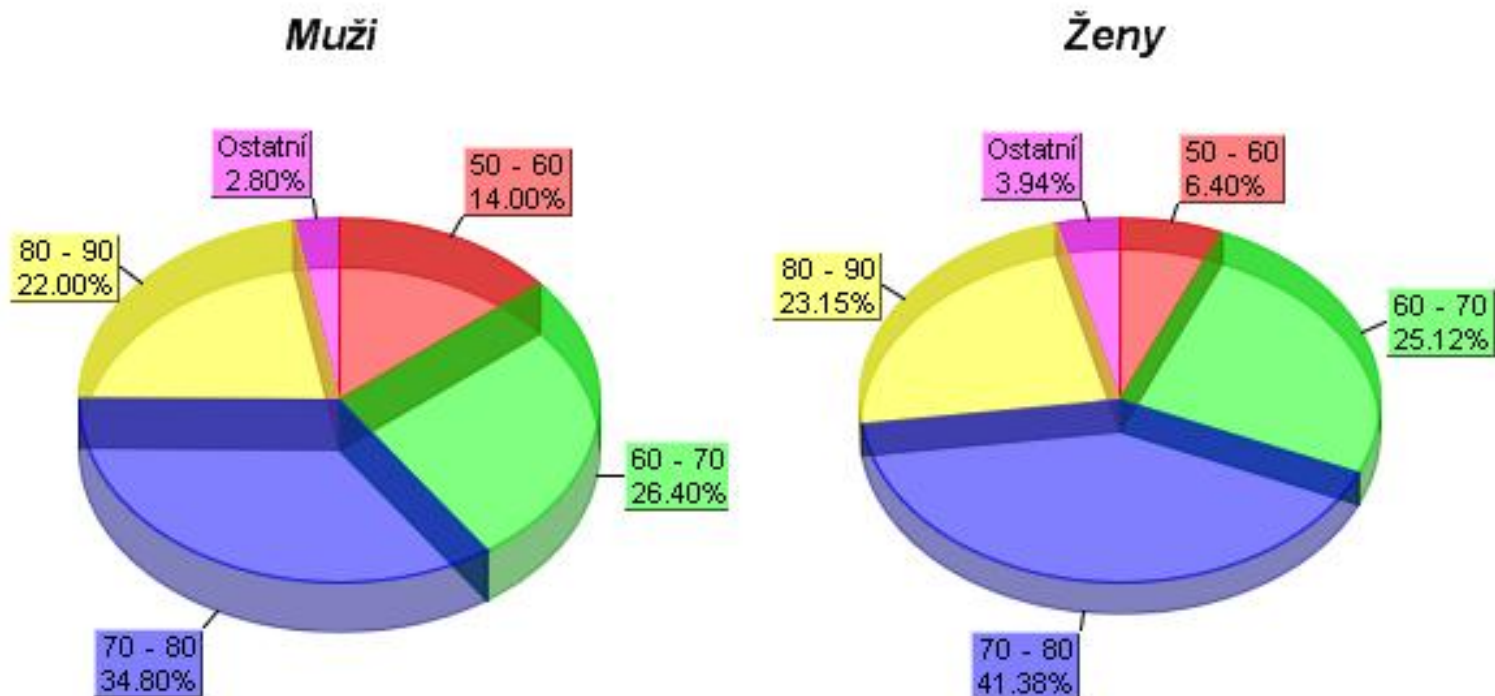
- current on-line data of Czech Rep.
- back data evaluation and comparison to the mean values of the CR
- other statistics

Examples of possible evaluation of RDP data

- Mortality
- Survival
- Ca-P-PTH metabolismus

Mortality rate & age and gender (n=453)

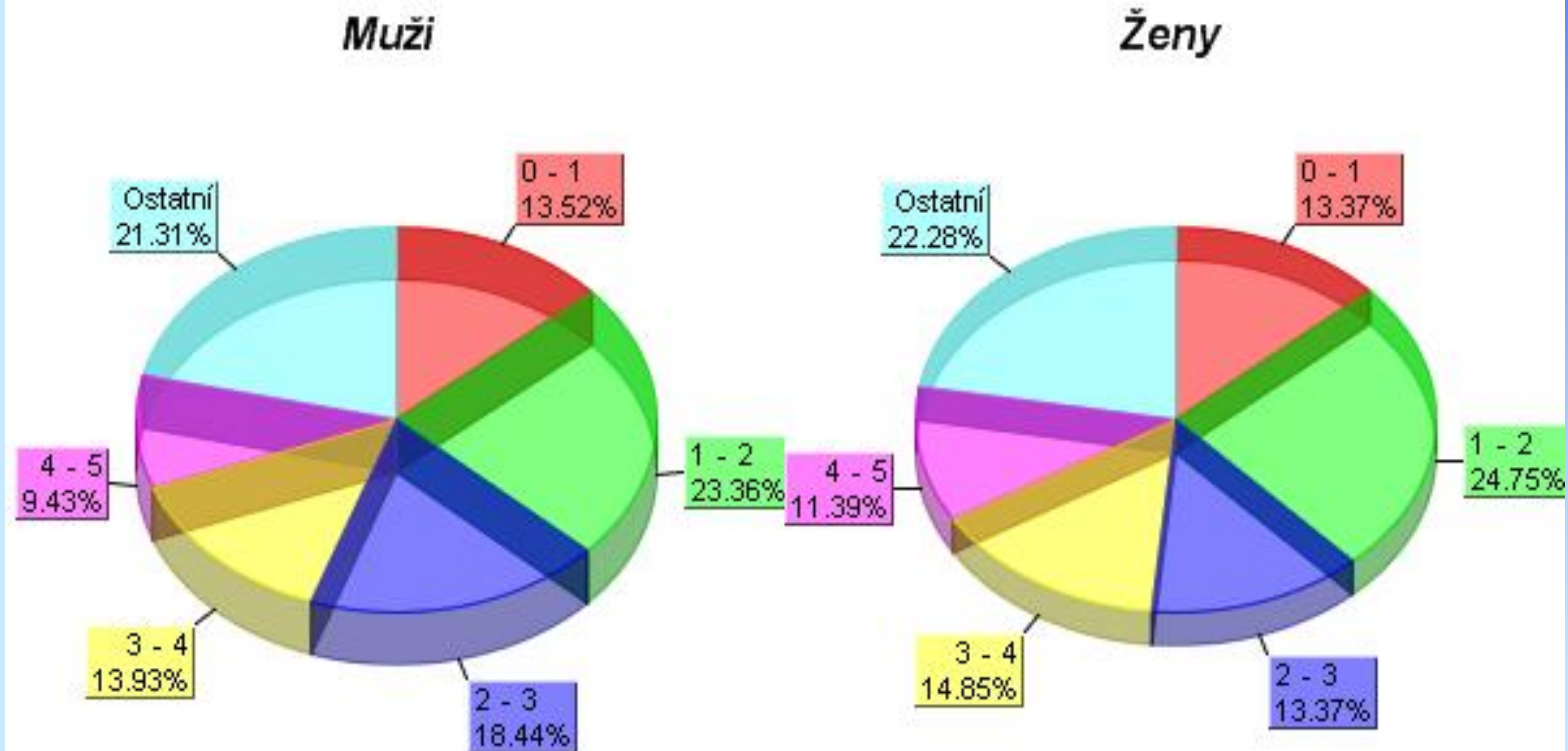
Věkové rozložení



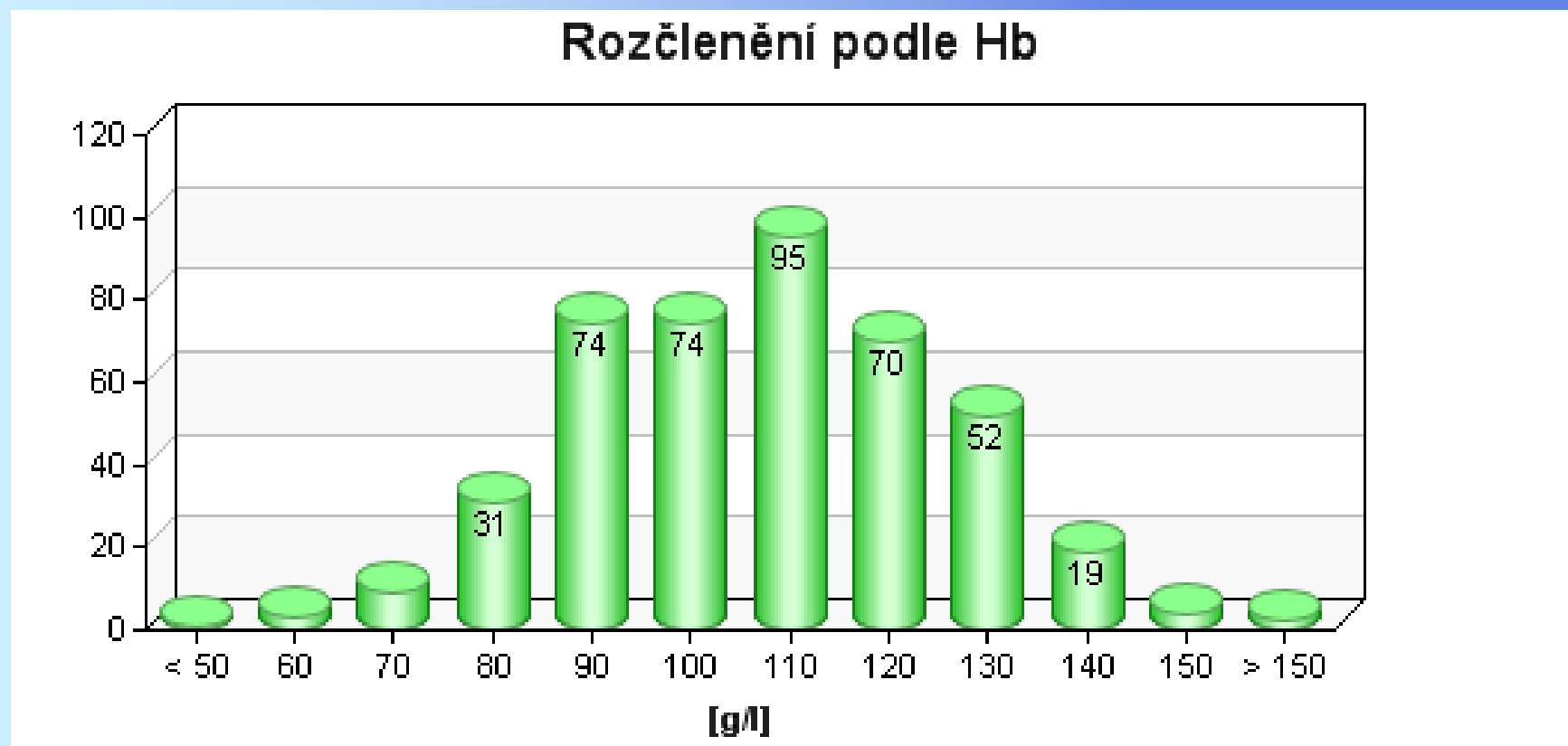
Mortality rate & duration on RRT

244 men, 202 women in 4/2007

Rozčlenění podle délky RRT (roky)



Mortality rate & mean hemoglobin level (n=434)



Examples of possible evaluation of RDP data

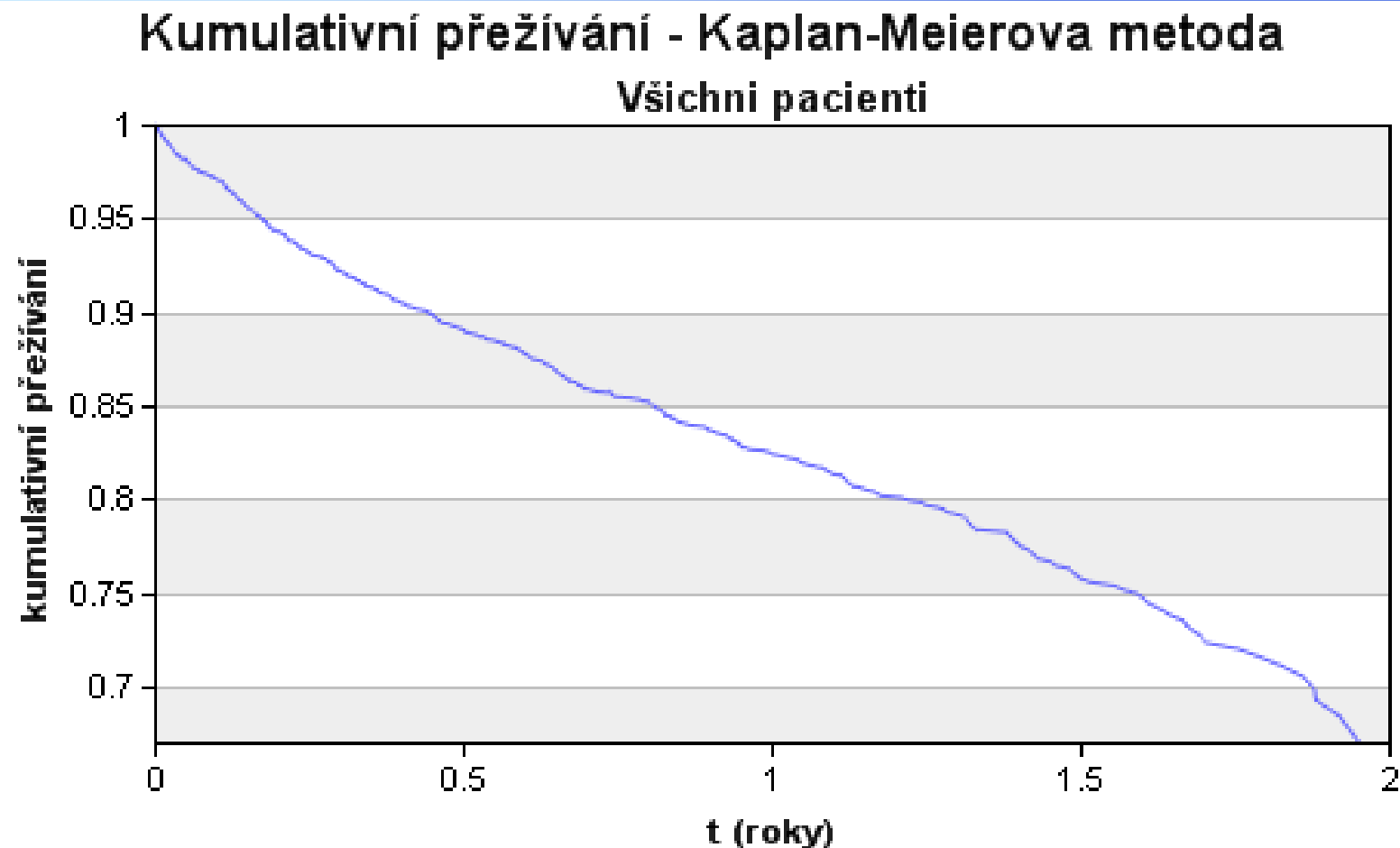
- Mortality
- **Survival**
- Ca-P-PTH metabolismus

Cumulative survival

- calculated acc.to Kaplan-Meier method
- available on line
- adjustment possible according to:
 - period
 - method of dialysis
 - diabetes mellitus

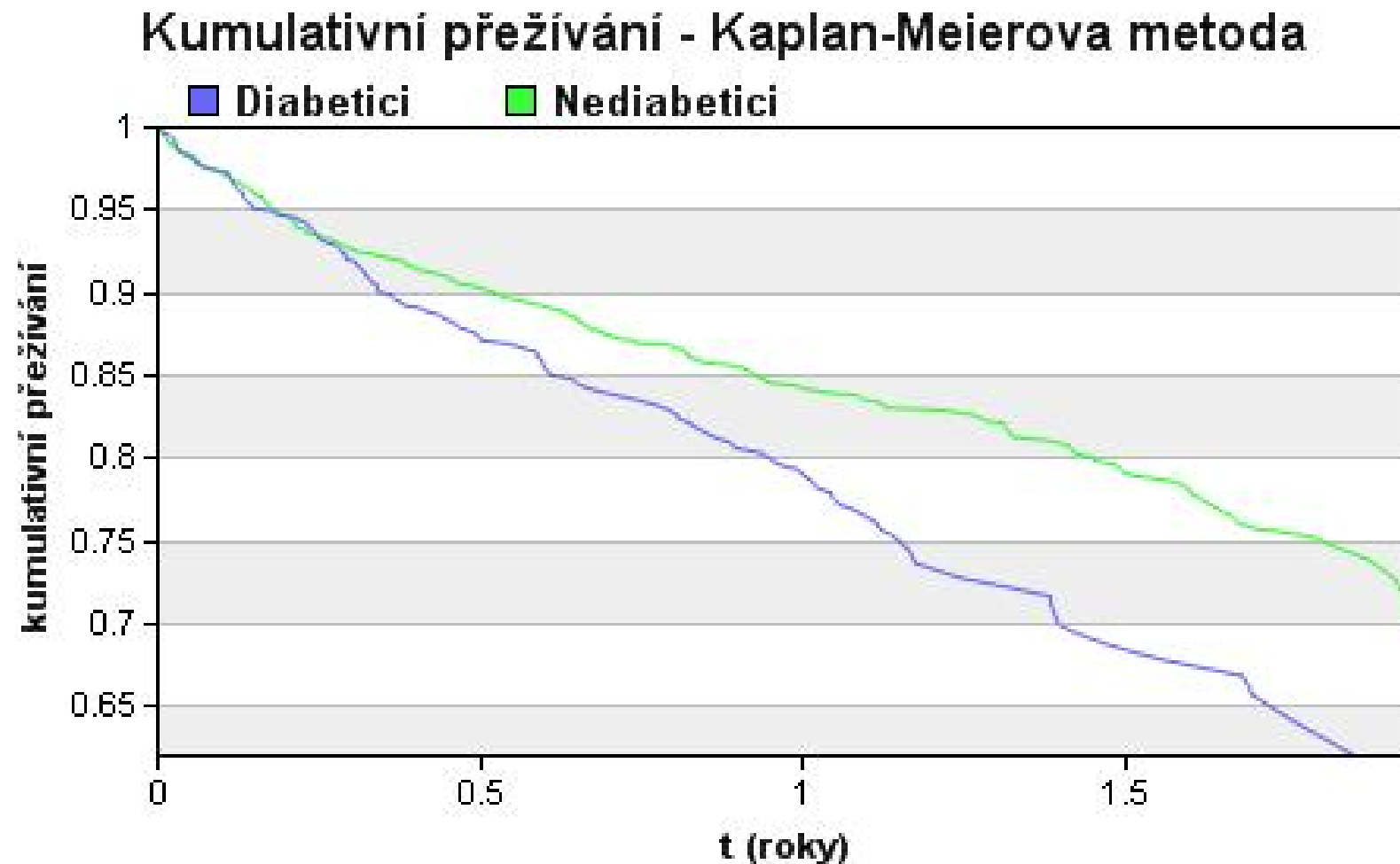
Cumulative survival – all patients

Period 1.1.2006-31.12.2007, total 2473 pts entering dialysis treatment, lost of evidence 23%

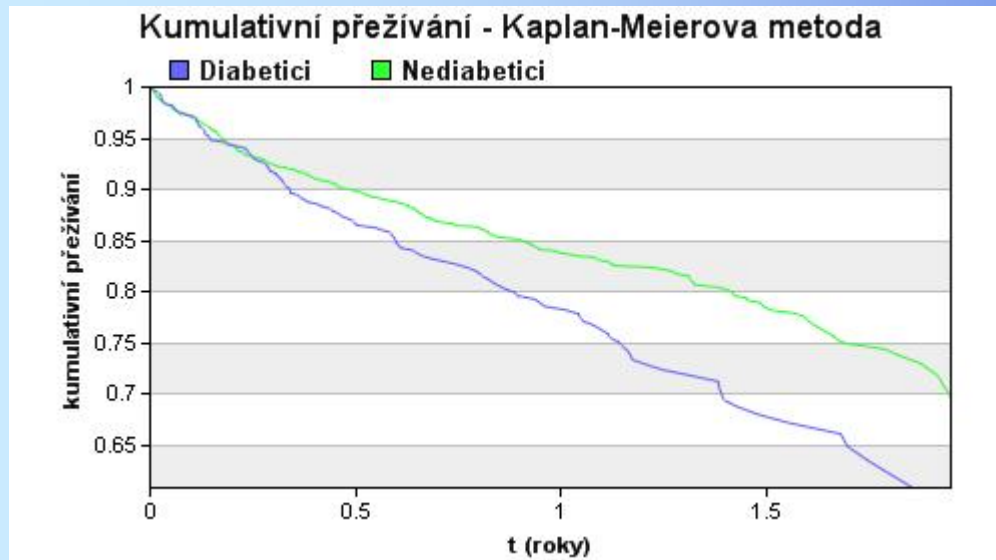


Cumulative survival – DM vs. non-DM

Period 1.1.2006-31.12.2007,
600/1873 pts entering dialysis treatment,
lost of evidence 18% vs. 25%



Cumulative survival: HD vs. PD



HD:

entered 570/1782 pts

lost 18/26%

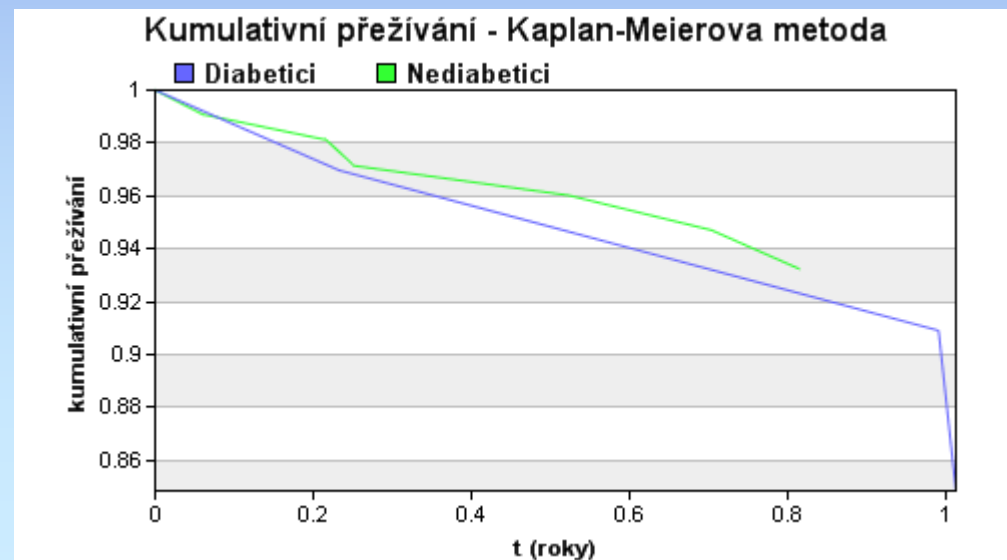
period 1.1.06 – 31.12.07

PD:

entered 35/112 pts

lost 8/15%

period 1.1.06 – 31.12.07

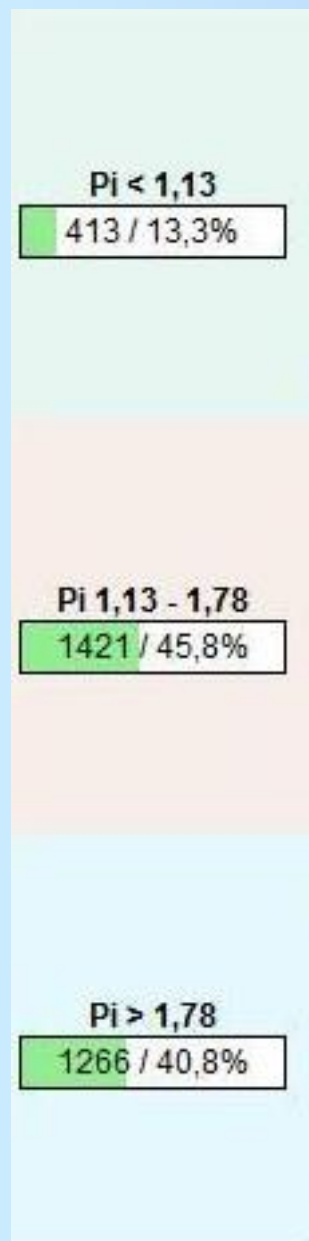


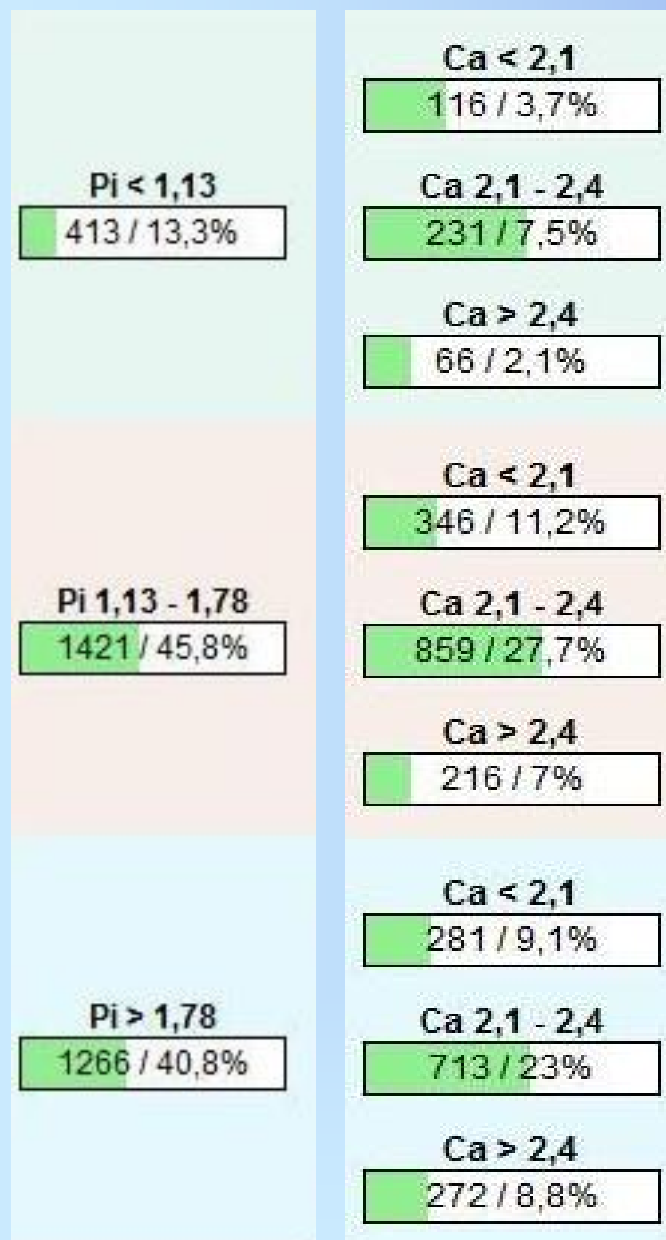
Examples of possible evaluation of RDP data

- Mortality
- Survival
- **Ca-P-PTH metabolism**

Ca-P-PTH metabolismus

- analysis performed for 3.100 pts
- period 1/2007 – 4/2007
- available on-line





		PTH < 150	PTH 150 - 300	PTH > 300
Pi < 1,13	Ca < 2,1	116 / 3,7%	81 / 2,6%	30 / 1%
	Ca 2,1 - 2,4	231 / 7,5%	141 / 4,5%	63 / 2%
	Ca > 2,4	66 / 2,1%	41 / 1,3%	19 / 0,6%
Pi 1,13 - 1,78	Ca < 2,1	346 / 11,2%	140 / 4,5%	116 / 3,7%
	Ca 2,1 - 2,4	859 / 27,7%	400 / 12,9%	280 / 9%
	Ca > 2,4	216 / 7%	106 / 3,4%	52 / 1,7%
Pi > 1,78	Ca < 2,1	281 / 9,1%	116 / 3,7%	80 / 2,6%
	Ca 2,1 - 2,4	713 / 23%	267 / 8,6%	206 / 6,6%
	Ca > 2,4	272 / 8,8%	103 / 3,3%	65 / 2,1%

Analýza byla provedena pro 3100 pacientů z dat z období 1/2007 - 4/2007

International comparison of National & local renal registries



HOME

ABOUT US

♦ objectives

♦ staff

♦ contact info

♦ committee

♦ data collection

♦ technical details

NATIONAL/REGIONAL
REGISTRIES

♦ contributors

♦ information

EVENTS

REPORTS

♦ published papers

♦ posters

♦ presentations

♦ annual reports

♦ newsletters

EDUCATION

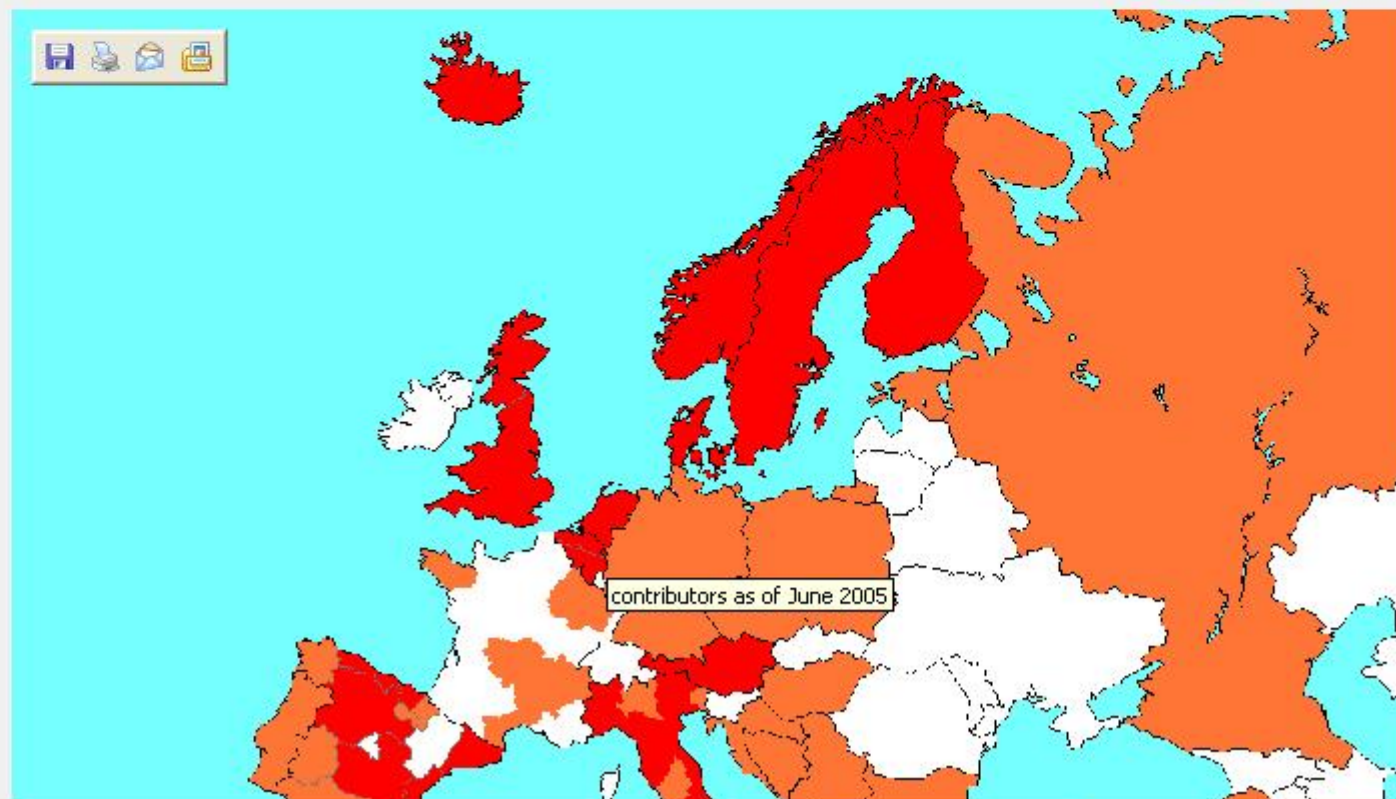
♦ epidemiology basics and beyond

LINKS



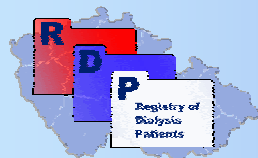
Contributors

The following national and regional registries contributed data as of June 2005.



Questionnaire for representatives of European Registries

- **Aim: to perform the international comparison in basic parameters of National & local renal registries**
- **Distributed during meeting of representatives of European National and local renal registries ERA-EDTA Congress, Barcelona, June 2007**
- **printed version
electronic version**



Registry of Dialysis Patients (RDP) Czech Republic

Questionnaire for representatives of other Registries

ERA-EDTA Congress, Barcelona, June 2007

Registry name:
Country (region):
Web-site:
Contact name/address/email
Registry owned by:
Registry run by (e.g. owner, a hired computer company, Ministry of Health).....
Registry is financed by Yearly running costs
Percentage of covered: centres(%) patients(%) (absolute counts)
Percentage of patients covered by the Registry (%).....
RRT patients covered (tick all that apply):..... pre-dialysis HD PD TX
Data are provided (tick one possibility)on voluntary basis.....obligatory
In voluntary data provision, how are the centres motivated (supported)
Frequency of data collection
Methods of data collection (tick all that apply):
manual electronic (web application, file transfer) direct export from hosp. info systems
Data format and protocol used in electronic data transfer
Data collected (tick all that apply, add those not given):
Centre ID, size, data on water treatment, staffing data, RRT methods provided, schedules
Patient ID, primary cause of renal failure, data of entry to RRT program, vascular access
type, vaccinations, date of change in RRT modality, treatment schedule, dialyser type/size
Treatment performance (QB, eKT/V, CD_{Na} , CD_{HCO_3}) and biochemical data (urea, creatinine,
Ca, P, B2M, PTH, CRP
Regular registry outputs
External access to data (tick): possible yes/no limited to

Thank you for providing the data, on behalf of the Czech RDP

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Questionnaire – results:

Number of answers: 17x

1. Austria (OEDTR)
2. Belgium – Dutch-speaking (NBVN)
3. Belgium – French-speaking (RNCFB)
4. Bosnia a Herzegovina
5. Czech (RDP)
6. Denmark
7. Finland
8. France (REIN)
9. Germany (Quasi-Niere)
10. Macedonia
11. Scotland (SRR)
12. Slovenia
13. Spain – Andalucia (SICATA)
14. Spain – Catalonia (RMRC)
15. Spain – Valencia (REMRENAL)
16. Tunis (TDR)
17. United Kingdom (UKRR)

Registry owner

Soc. of Nephrology	8x
State structure (Min.of Health)	2x
Non-state (private) organization	6x
Other	1x

Coverage of country

Coverage (%) of participating centers in country

100%	14x
>90%	2x
70%	1x

type of pts.	RRT (HD+PD+Tx)	14x
	RRT+predialysis	2x
	HD+PD	1x

Number of registered patients

1.	Austria (OEDTR)	3,000
2.	Belgium – Dutch-speaking (NBVN)	7,100
3.	Belgium – French-speaking (RNCFB)	
4.	Bosnia a Herzegovina	
5.	Czech (RDP)	3,500
6.	Denmark	4,000
7.	Finland	5,000
8.	France (REIN)	55,000
9.	Germany (Quasi-Niere)	
10.	Macedonia	1,200
11.	Scotland (SRR)	
12.	Slovenia	1,800
13.	Spain – Andalucia (SICATA)	7,500
14.	Spain – Catalonia (RMRC)	
15.	Spain – Valencia (REMRENAL)	5,000
16.	Tunis (TDR)	7,000
17.	United Kingdom (UKRR)	42,000

Data delivery

On voluntary basis	9x
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motivation	- back relation	3x
	- payment/pts	2x
	- „none“	4x

Obligatory	8x
------------	----

Frequency and method of data collection

Frequency

– on-line	1x
- quarterly	3x
- twice yearly	1x
- yearly	12x

Method

– manually	4x
- electronically	7x
- combined	6x

Type of data collection

Global epidemiological data	17x
Individual pts history data	15x
Individual pts laboratory data	10x
Center's Data (water treatment, staff etc)	2x

Registry outputs and data accessibility

Year report	15x
Other types of reports	6x
Data access for external subjects	
- yes	2x
- limited (after agreement)	5x
- no	10x
- data provided to ERA Registry	7x
Registry web-site	14x

Financial expenses (EUR)

	total	per 1 pts
Large Registries		
- Germany	1.000.000	
- France (part)	1.000.000	18.-
- UK	800.000	19.-
Comparable Registries		
- Belgium – French	20.000	
- Belgium – Dutch	100.000	14.-
- Denmark	40.000	10.-
- Finland	90.000	17.-
- Scotland	70.000	
- Valencia	80.000	16.-
- Bosnia-Herzegovina	2.000	
- RDP	25.000	5.-

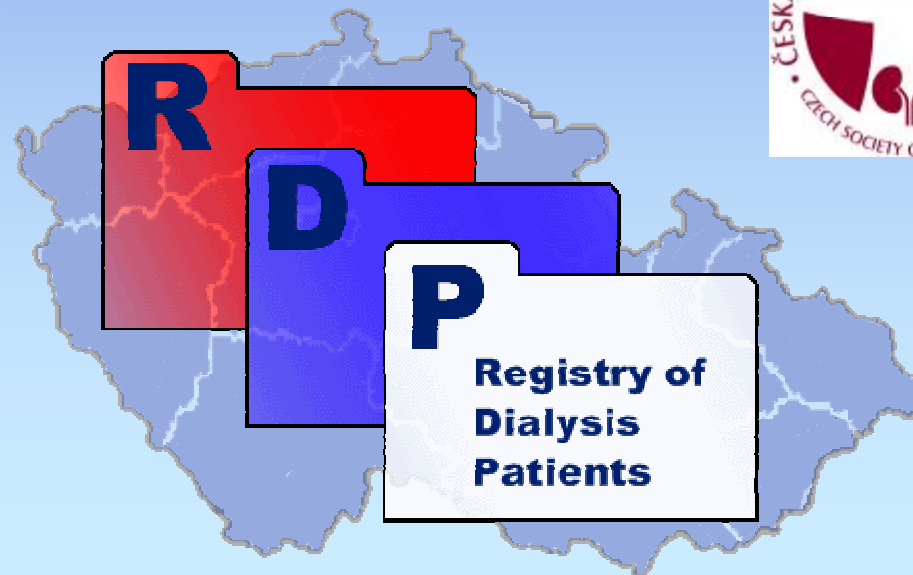
Summary

- RDP
 - fully comparable with other European registries
 - certainly the most detailed Registry of EEC
- What is better ?
 - frequency of data delivery (trends)
 - extend of data (and is possible further enlarged)
 - economy (cheaper)
- What is worse ?
 - coverage (2/3 of the Czech population)
 - presentation of our data (web)
 - not yet individual data delivery for ERA Registry

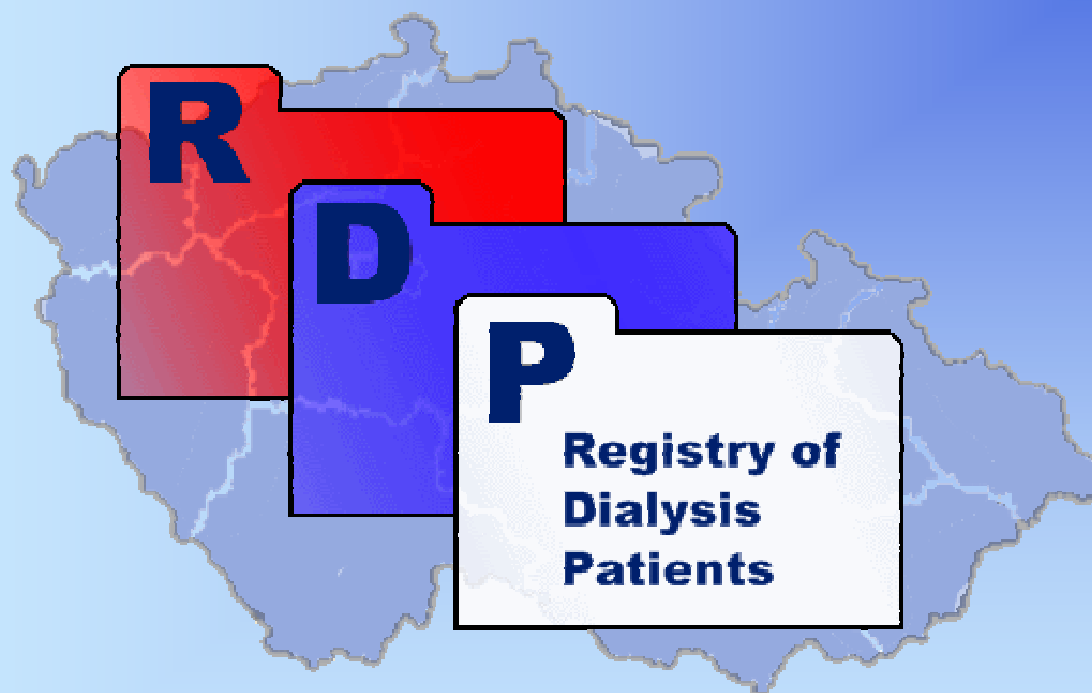


**Ntl' Theatre (1878):
Nation to itself**

**RDP: CNS to itself
(and about itself)**



Thank you



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