The Czech Registry of Dialysis Patients (RDP)

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on behalf of the Czech Society of Nephrology

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Basic epidemiology data - the Czech Republic 2013

- total population 10.4 million
- 98 dialysis units
- prevalence 31.12.2012:
  - in RRT treatment **10,371** patients, i.e. **988 pts PMP**
  - in dialysis threatment **6,261** patients, i.e. **596 pts PMP**
- total 927,282 hemopurification treatments, 56% out of them performed as hemodiafiltrations
- peritoneal dialysis: 489 patients (8.5%)
- transplanted in 2012: 432 patients (incidence 41.5 PMP), 71 out of them (16%) from living donors and 23 as combined pancreas-kidney transplants

Registry evolution

- development started in 2004 as a project of the Czech Society of Nephrology (CSN)
- primary aims: annonymous collection of individual dialysis patients data to evaluate outcomes of dialysis treatment nation-wide, comparison of the national outcomes with similar data from abroad, comparison of specific parameters from individual collaborating centres with nation-wide means, grant-based national epidemiologic studies, evaluation of specific treatment practices onto treatment outcomes
- solely electronic means of data collection chosen to minimize the workload and to utilize the fact that over two thirds of the Czech dialysis units use the same nephrological information system (Nefris® - Nephrological Information System, devoleped by ProDos, Dobruška, CR)
- for units using the Nefris system, a data exporting utility was developed, for the remaining units simplified Internet-based forms for manual filling-in was established
- data collection started in January 2006, first from the state-owned units, later Fresenius Medical Care and B. Braun Avitum chains joined

Principles

- voluntary data reporting
- financially supported and owned only by the CNS
- based on individual patient data report
- fully registered by state authorities
- data report quarterly (trends)
- data transfer only electronically (via protected protocol)
- electronical data protection - digital signatures and SSL authentication protocol (RSA:Digital signature algorithm; MD5-Hashing algorithm; RC4-Encrypt algorithm)
- IS NEFRIS (HD unit information system) provides per internal function quarterly-data for RDP
- user friendly web based interface

Reported data

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

Outcomes

3 types of data are generated:
  a) global RRT data for the Czech Republic and nation-wide avarage values of selected parameters
  b) back-report: dialysis unit data compared to the mean values of the Czech Republic data
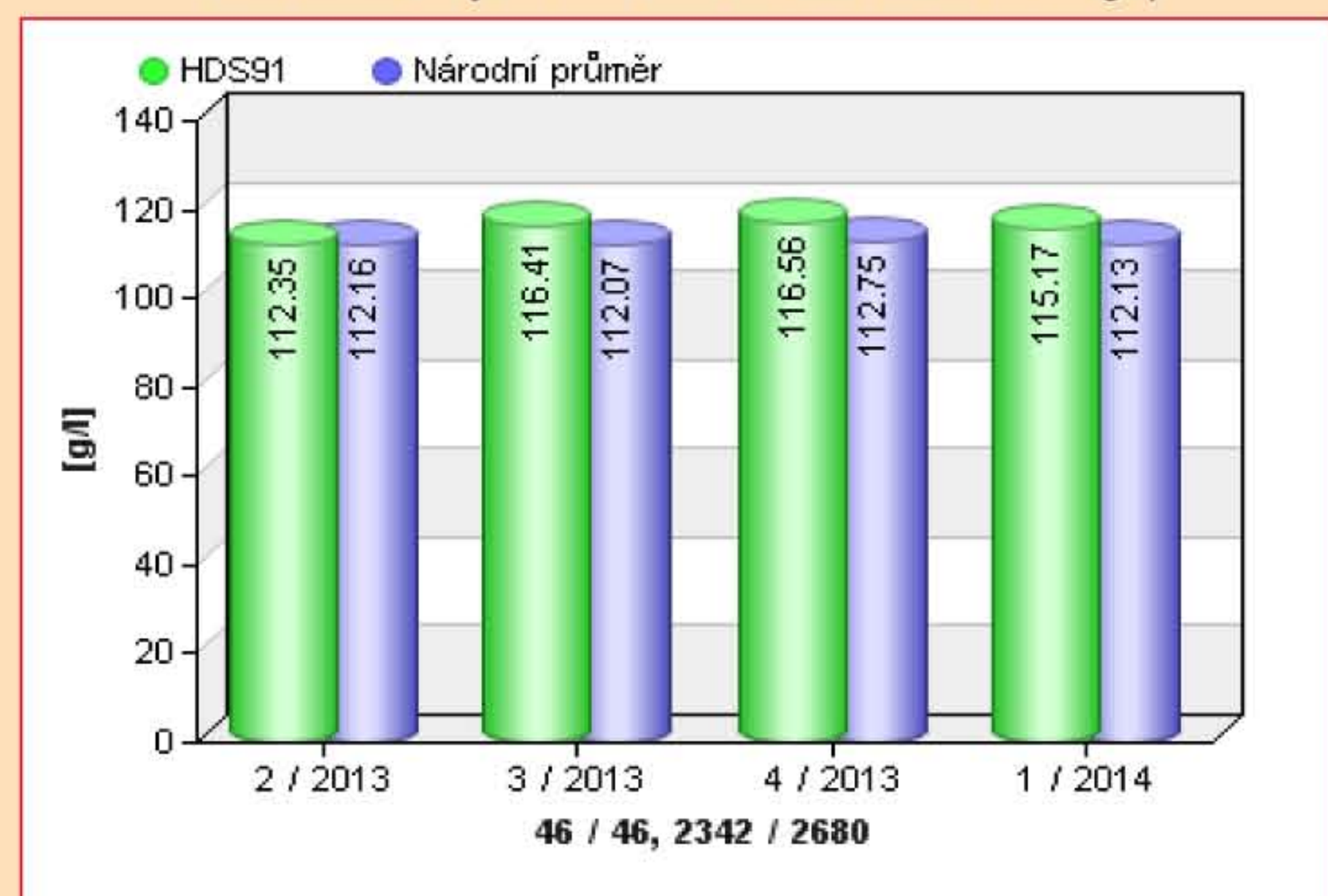 c) other statistics (special ad hoc analyses)

Data delivery:
- certified all 98 Dialysis Unit (DU)
- regularly reported data of 60 DU
- in total, **12,651** patients registered as total since 2006, and 3453 patients registered as currently active (i.e. currently quarterly reported data) i.e. 61% of DU and 55 % of prevalent dialysis patients
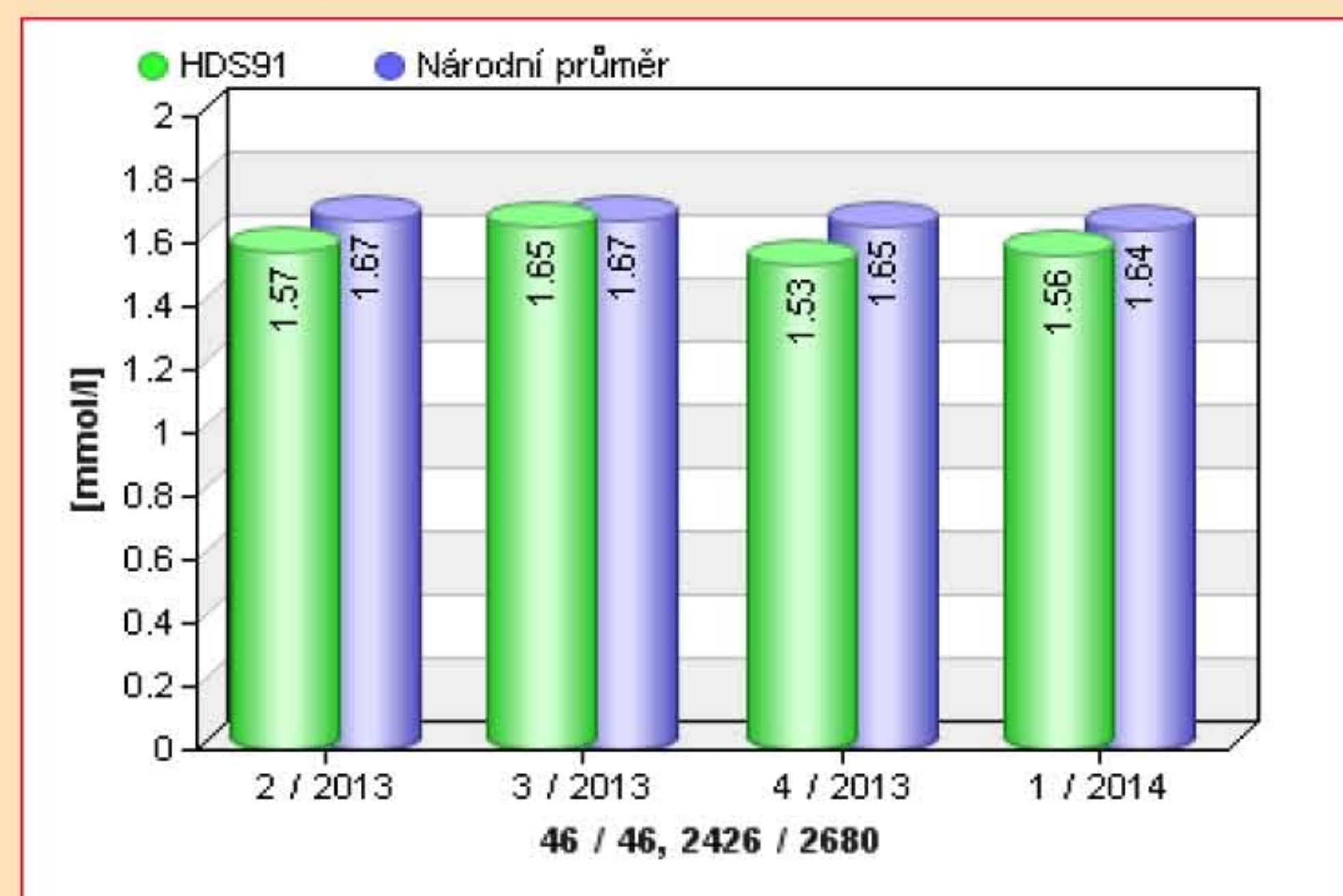
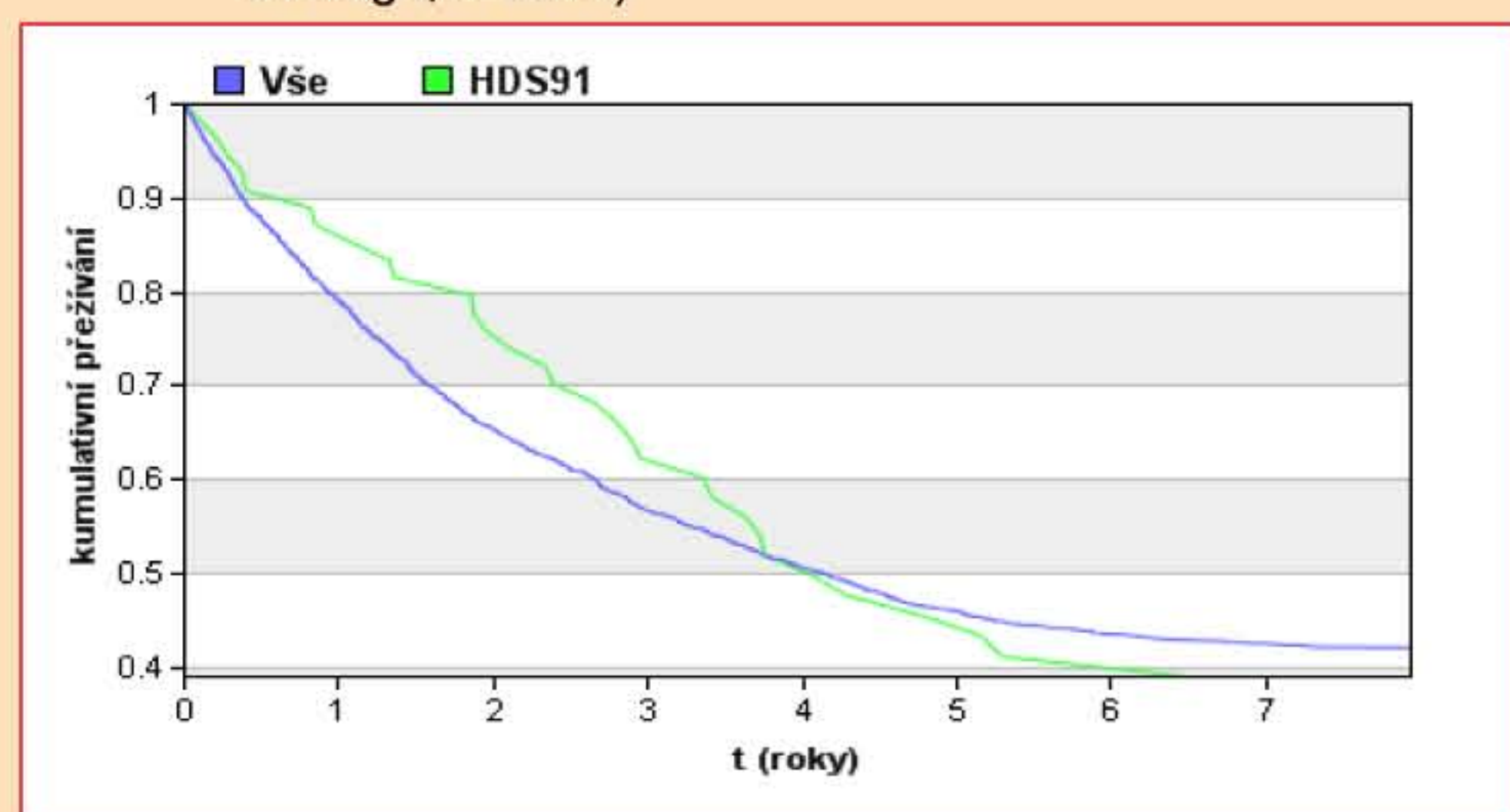## Ad b/ back-report: dialysis unit data comparison to the mean values of the Czech Rep.

examples:

Tab.9: Mean hemoglobin values (n=46/2680 patients; green bars: individual dialysis unit, blue bars: national average)

Tab.10: Mean phosphate levels (n=46/2680 patients; green bars: individual dialysis unit, blue bars: national average)

Tab.11: Cumulative survival rate: Life Table according to Kaplan-Meier method - comparison of diabetic patients who entered dialysis treatment in period 1.1.2006 - 31.12.2013 (green curve: individual dialysis unit, n=55; blue curve: national average, n=2579)

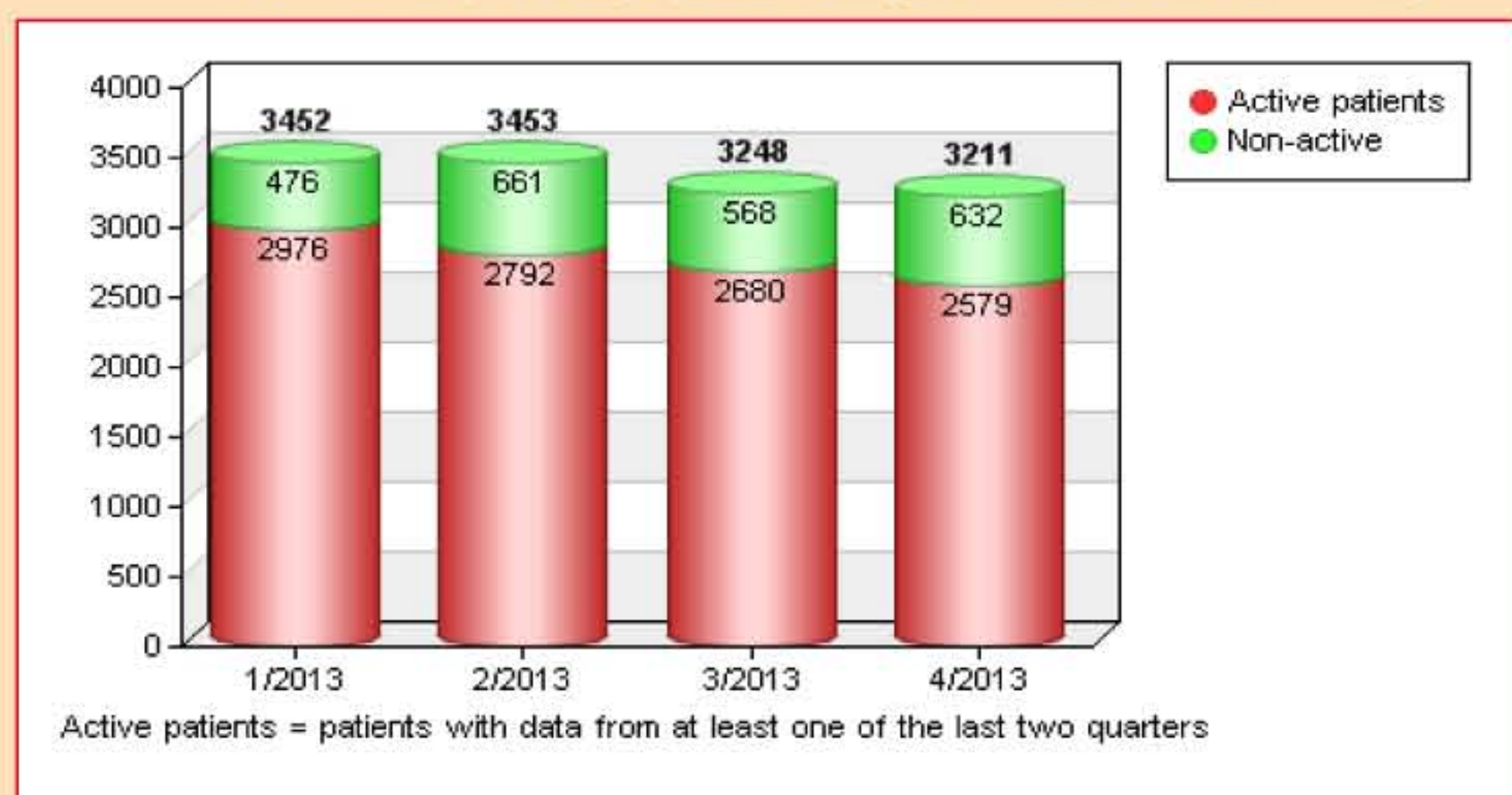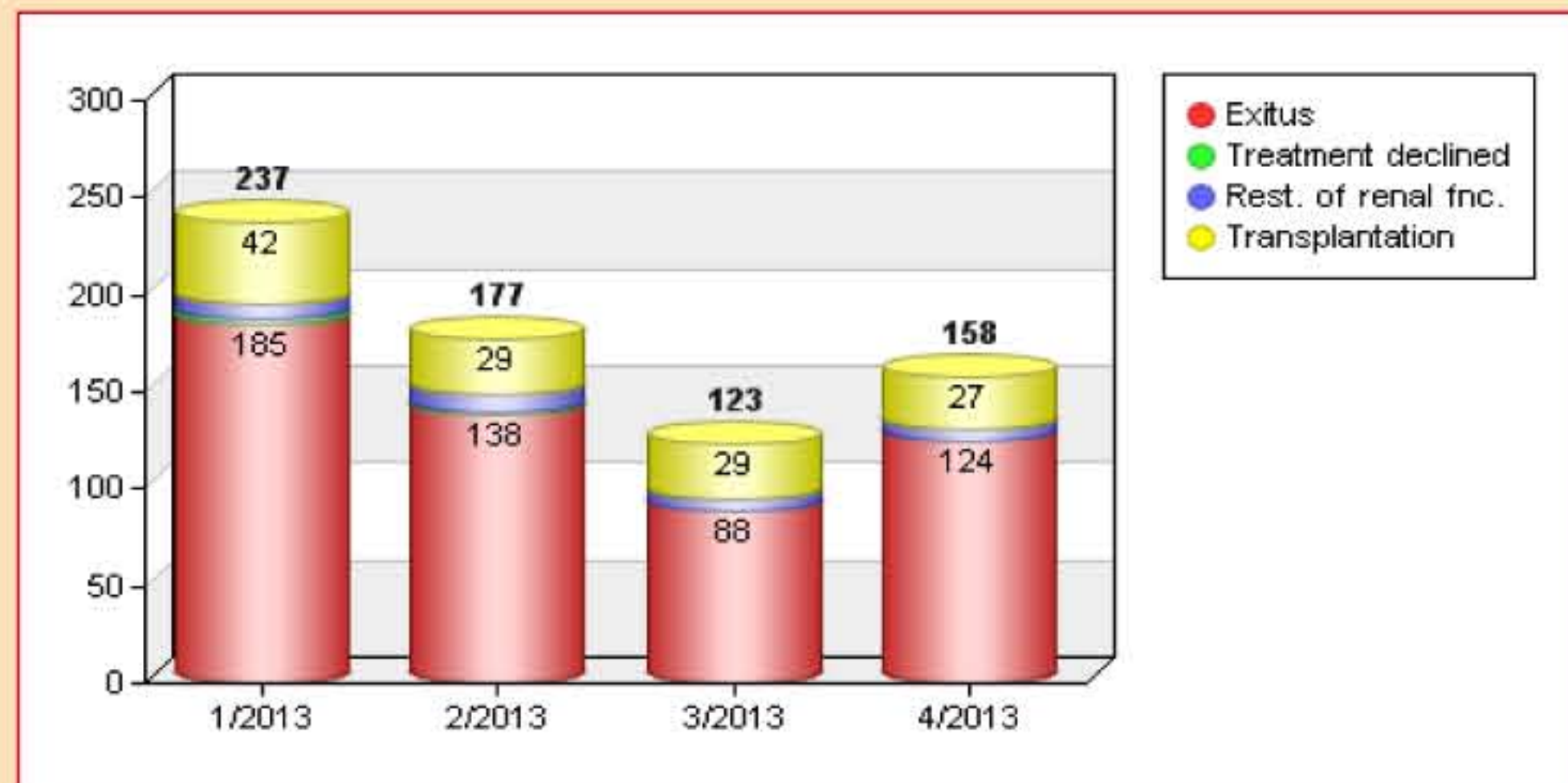## Ad a/ on-line data of the Czech Republic

- in principle, all combinations of all registered parameters are available of the 70 items registered
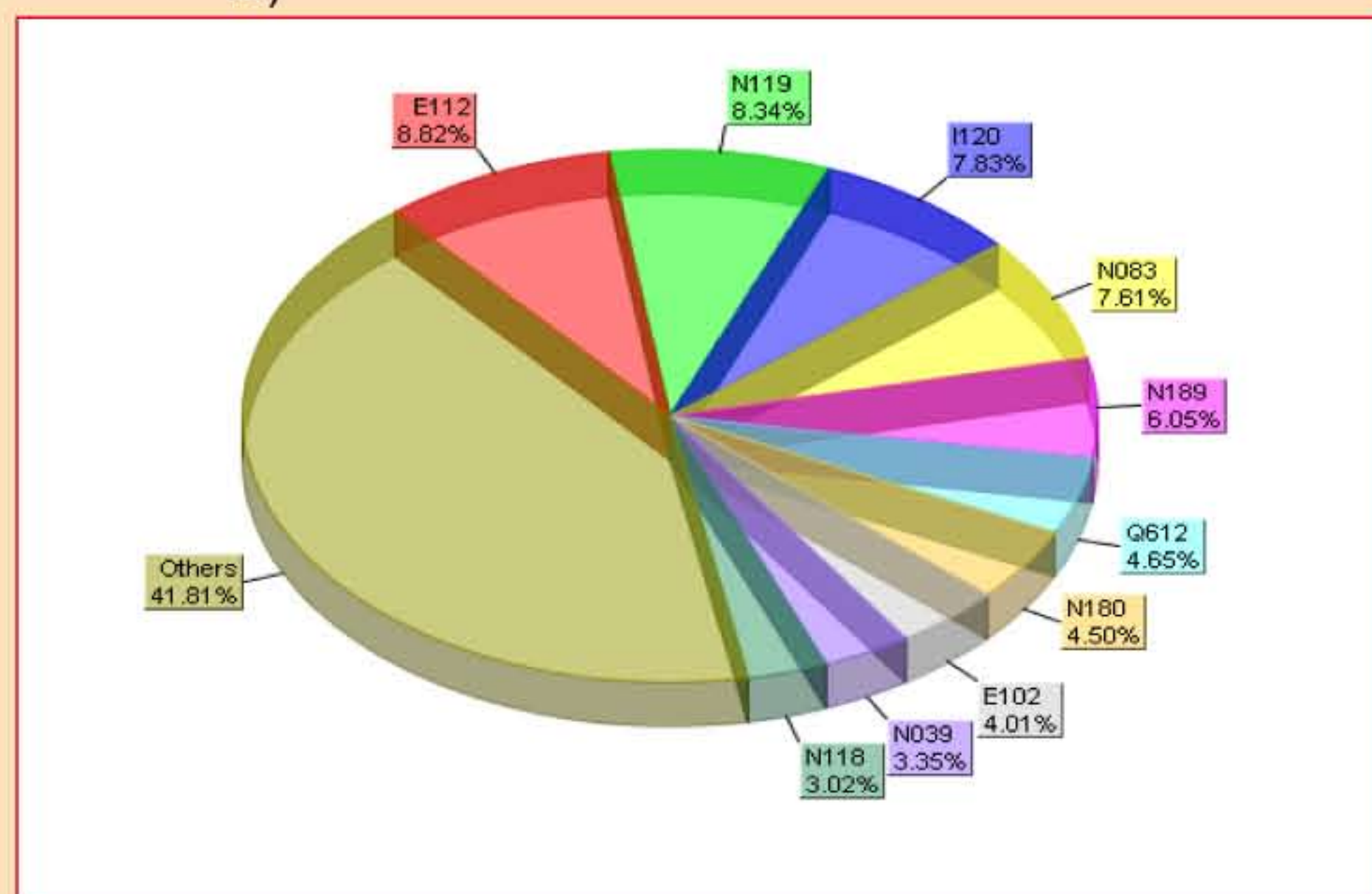
examples:

Tab.1: Patients listed as active, i.e. currently on chronic dialysis treatment (>90 days) according to data report availability

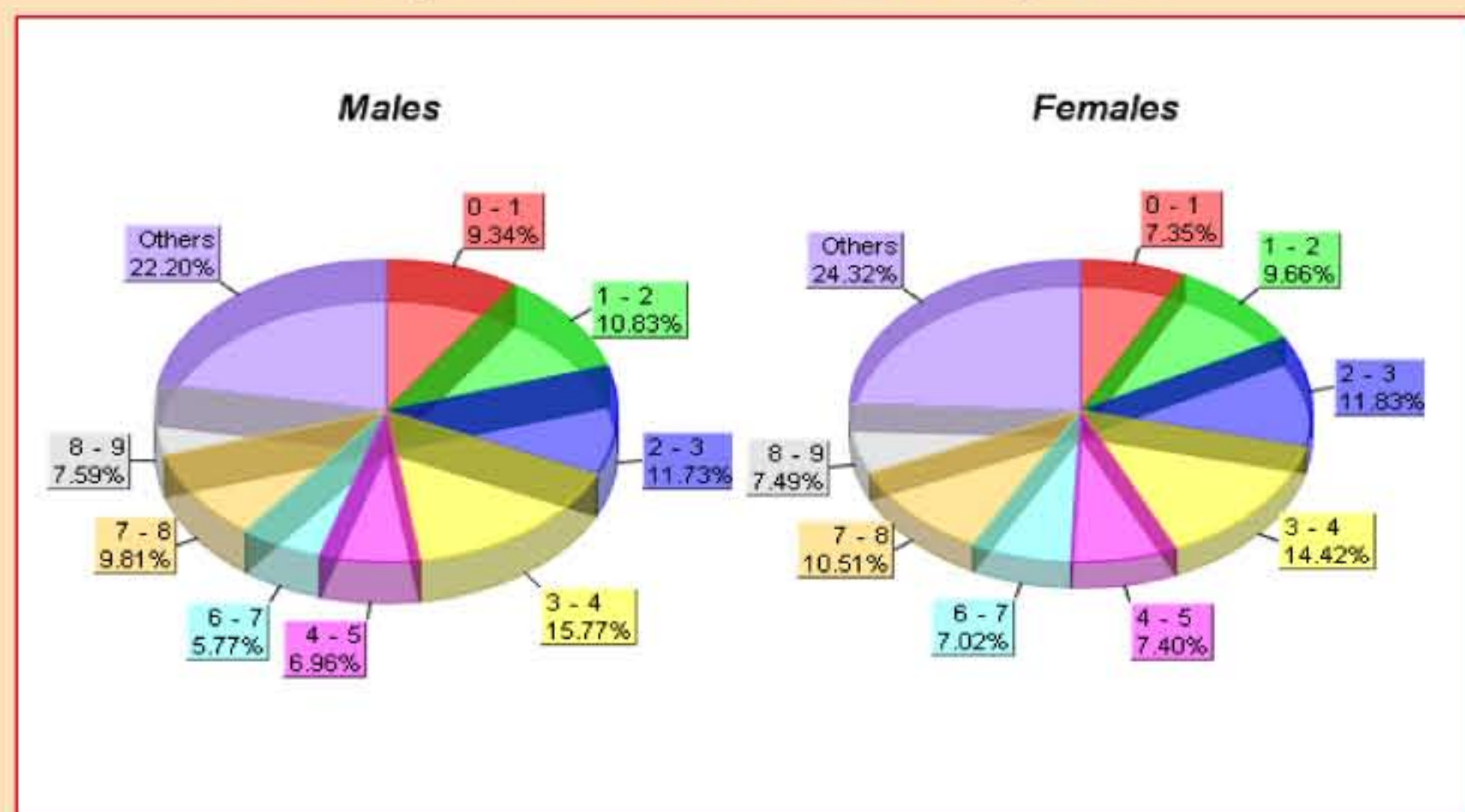Active patients = patients with data from at least one of the last two quarters

Tab.2: Patients registered as having terminated the treatment during the year 2013 (n=695)

Tab.3: Distribution according to the primary renal disease (n=3211 prevalent counts in the 4th quarter 2013; coding system: ICD 10)
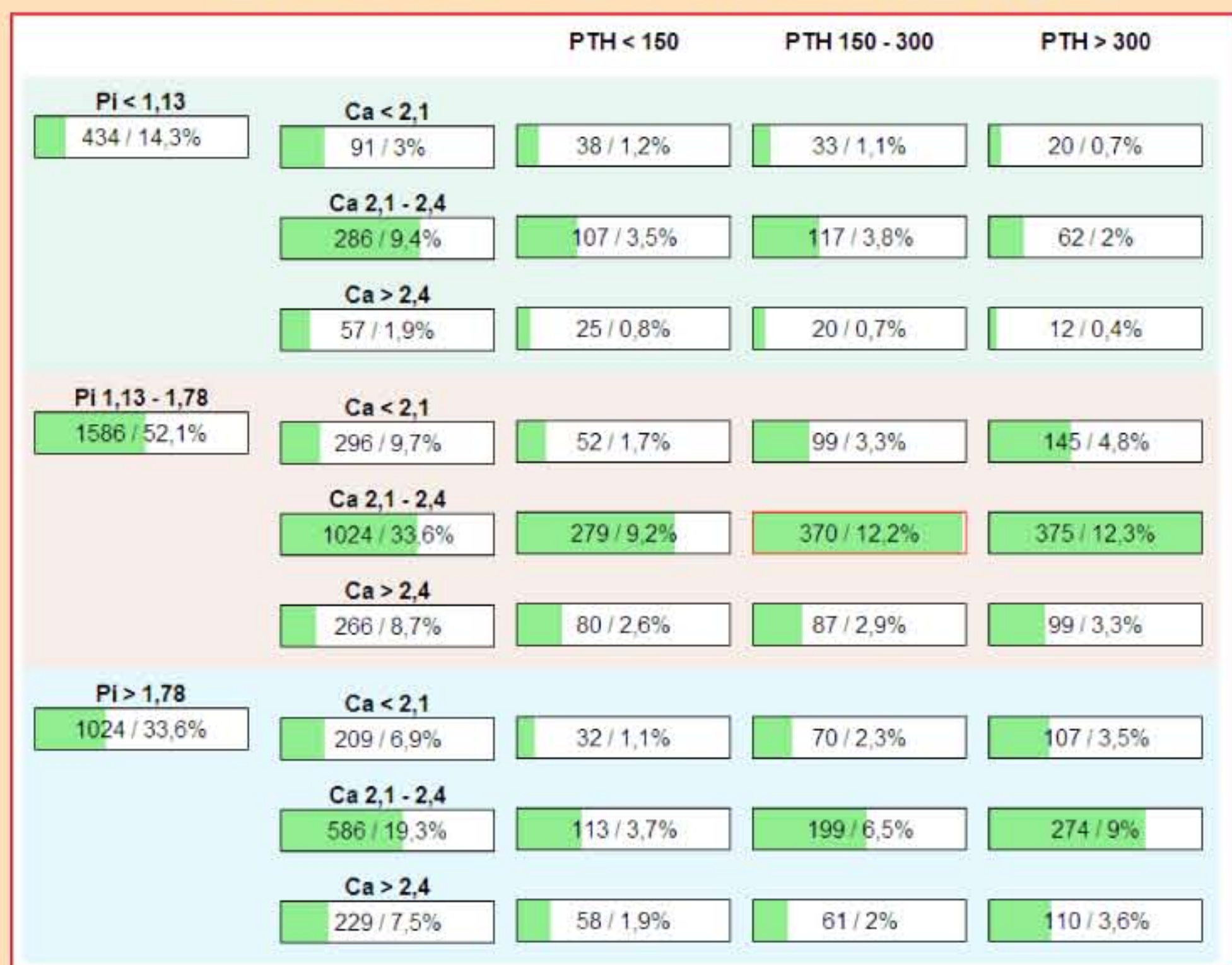

Tab.4: Prevalent counts - distribution according to the duration of RRT (years); analysis performed for 2122 females and 3018 males registered at the end of 4/2013 quarter
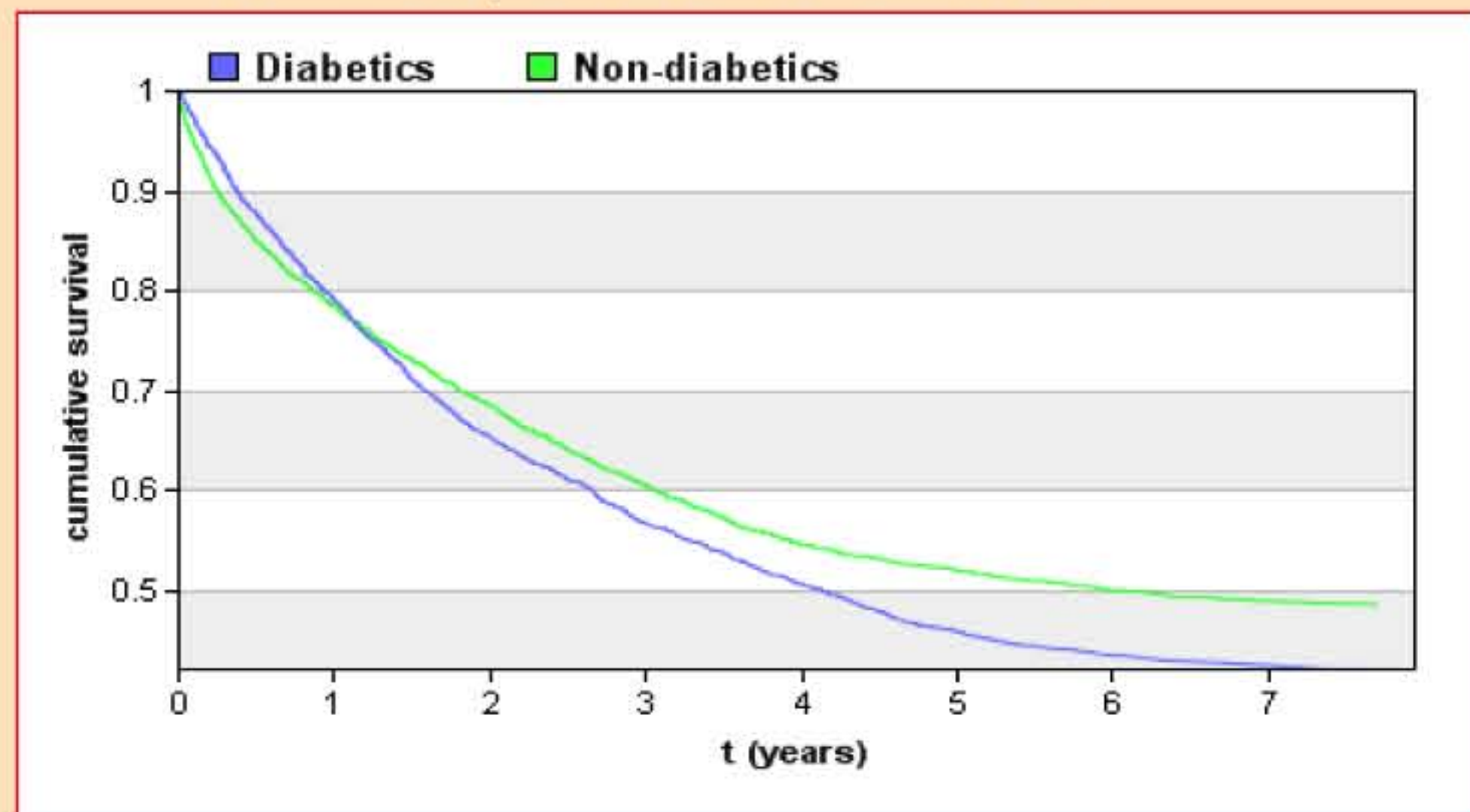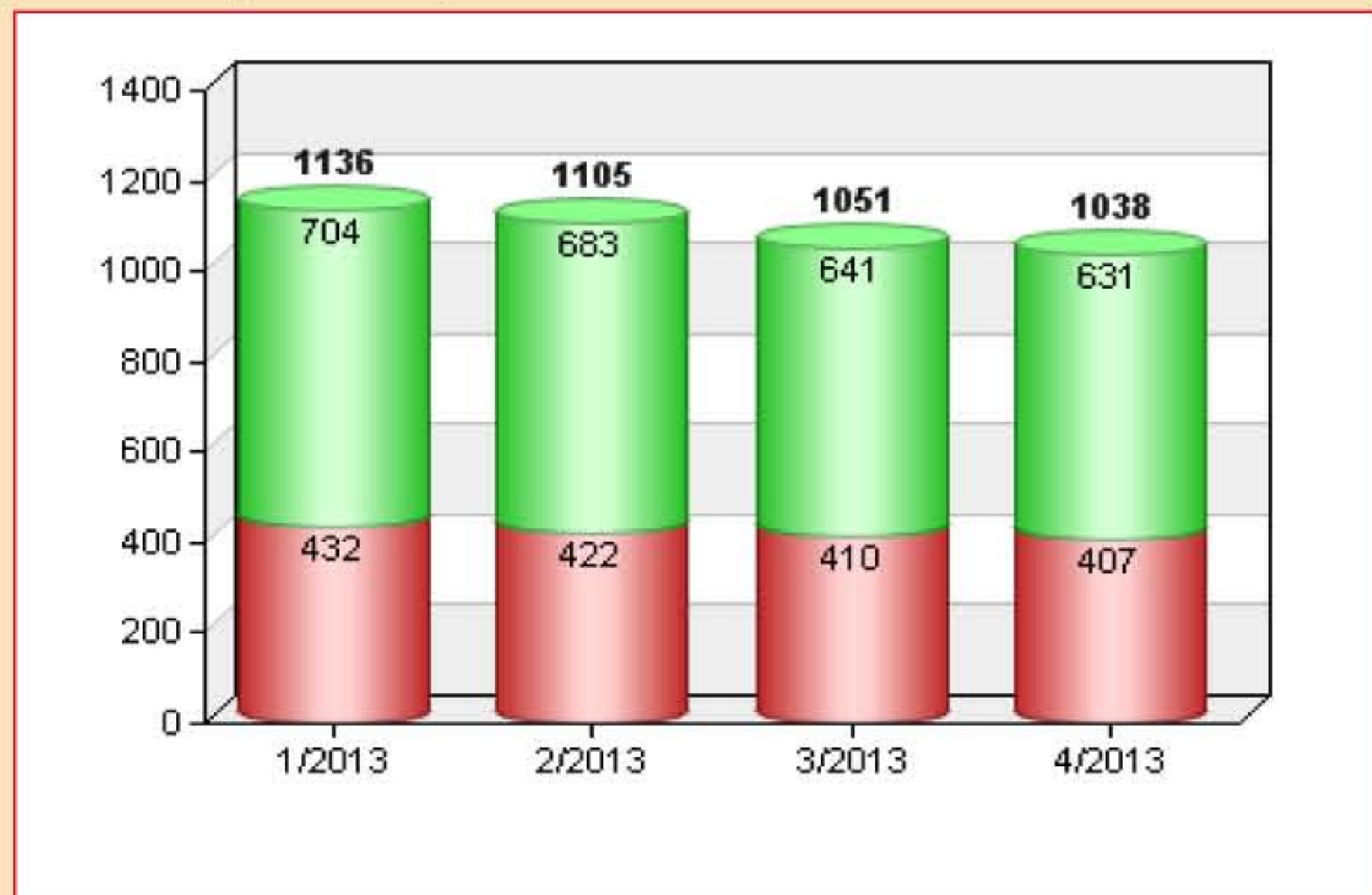

Tab.12: Calcium - Phosphates - PTH leves (n=3044 patients, period 1.1.-31.12.2013; units: Ca and P: umol/l, PTH: pg/ml)
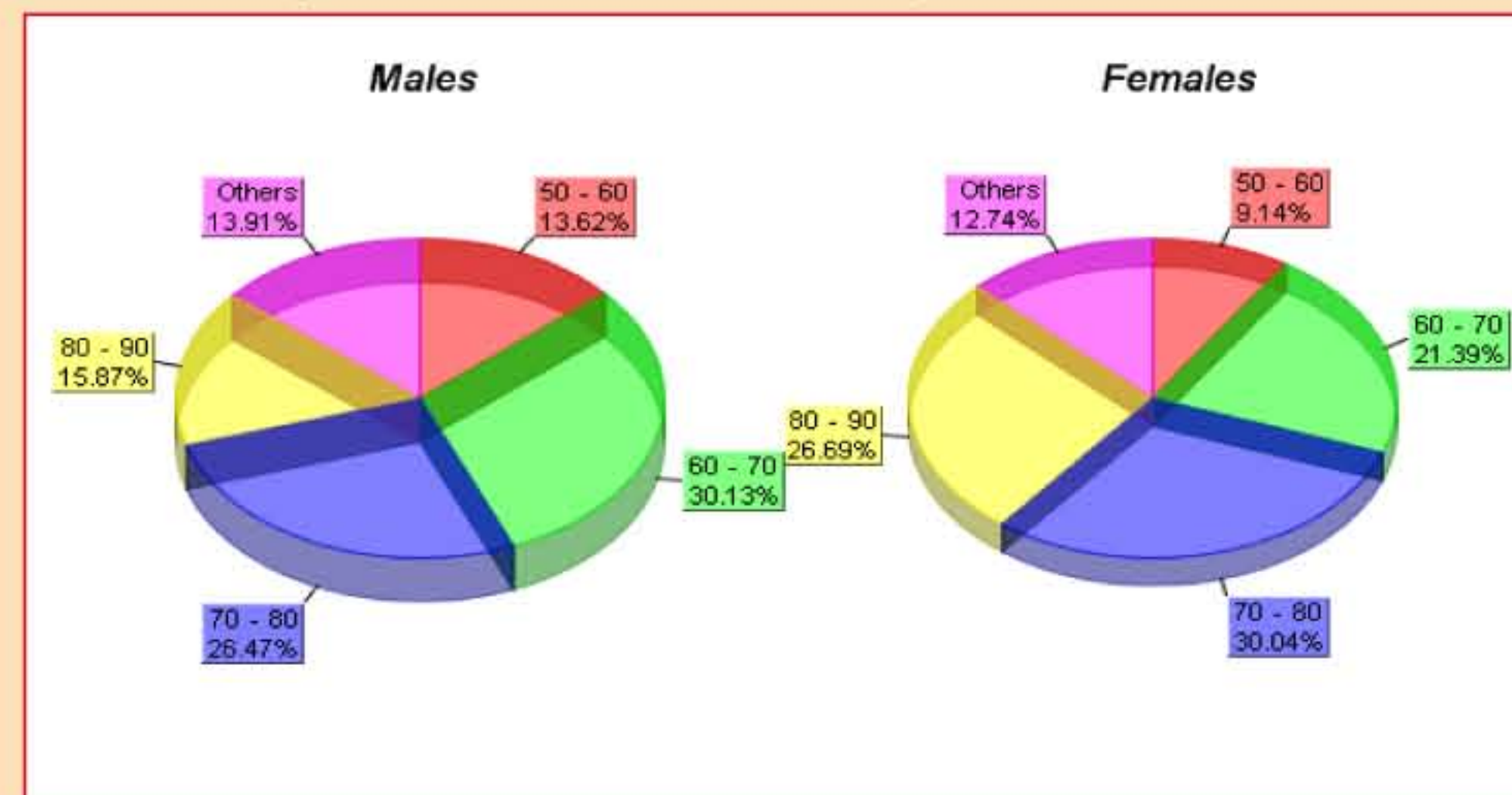

Tab.13: Cumulative survival rate: Life Table according to Kaplan-Meier method - comparison of diabetic (n=2579) versus non-diabetic patients (n=3801) who entered dialysis treatment in period 1.1.2006 - 31.12.2013
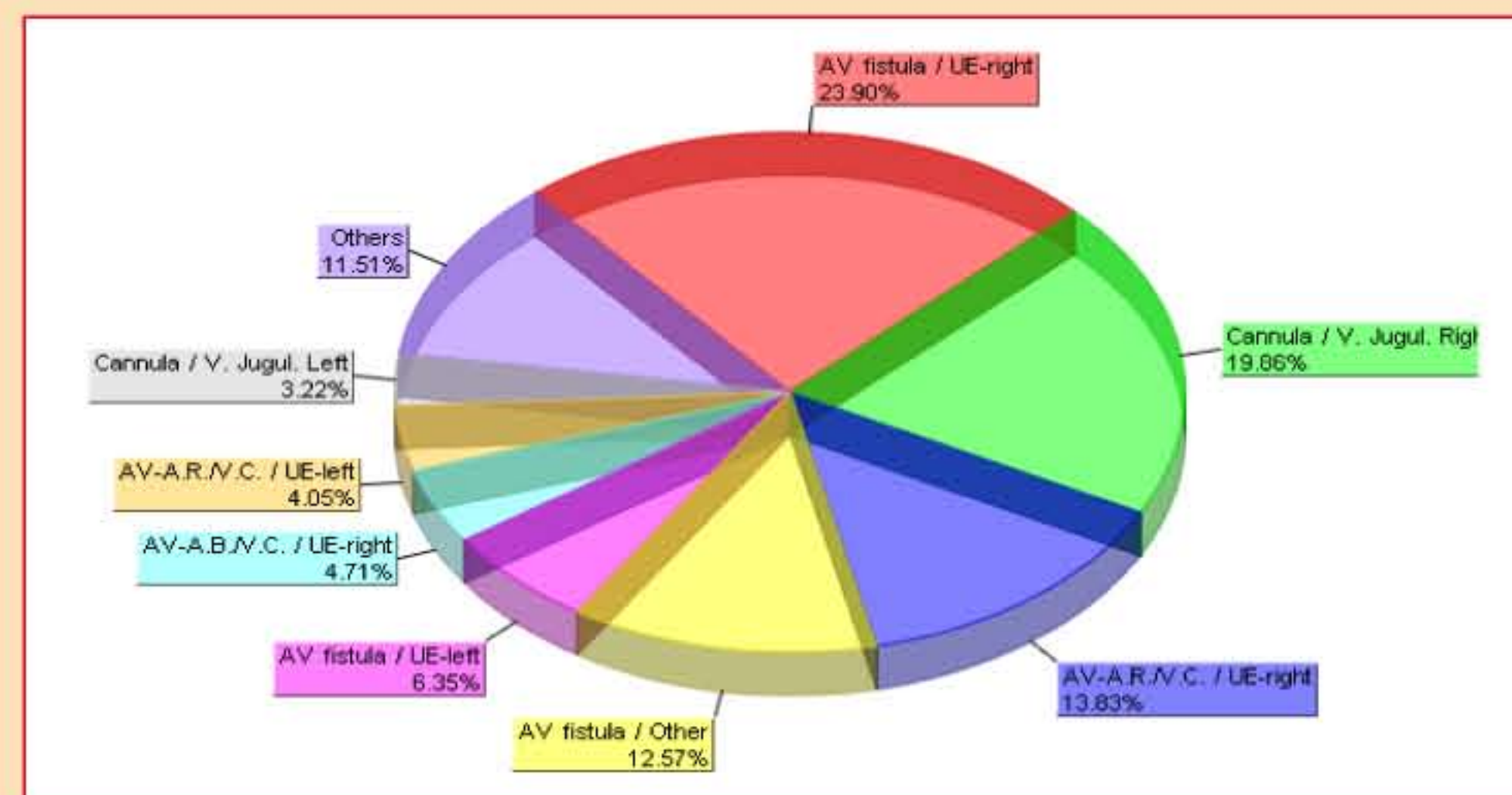

Tab.14: Numbers of diabetic patients: distribution according to primary renal disease leading to ESRD: diabetic nephropathy (red bars) versus non-diabetic renal disease (green bars)
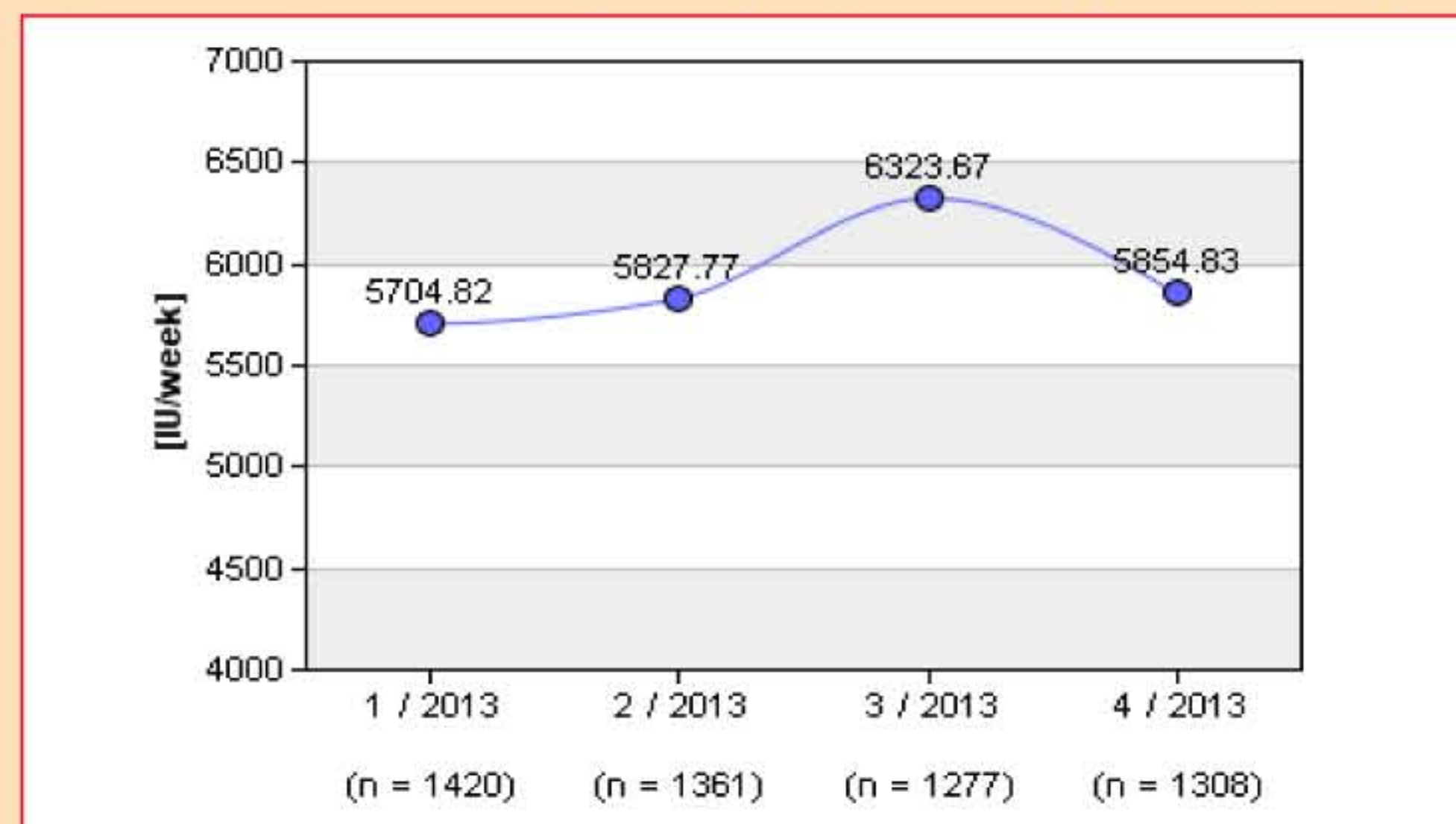
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Tab.5: Distribution according to the age (years) and gender; analysis performed for 2473 females and 3415 males registered at the end of 4/2013 quarter
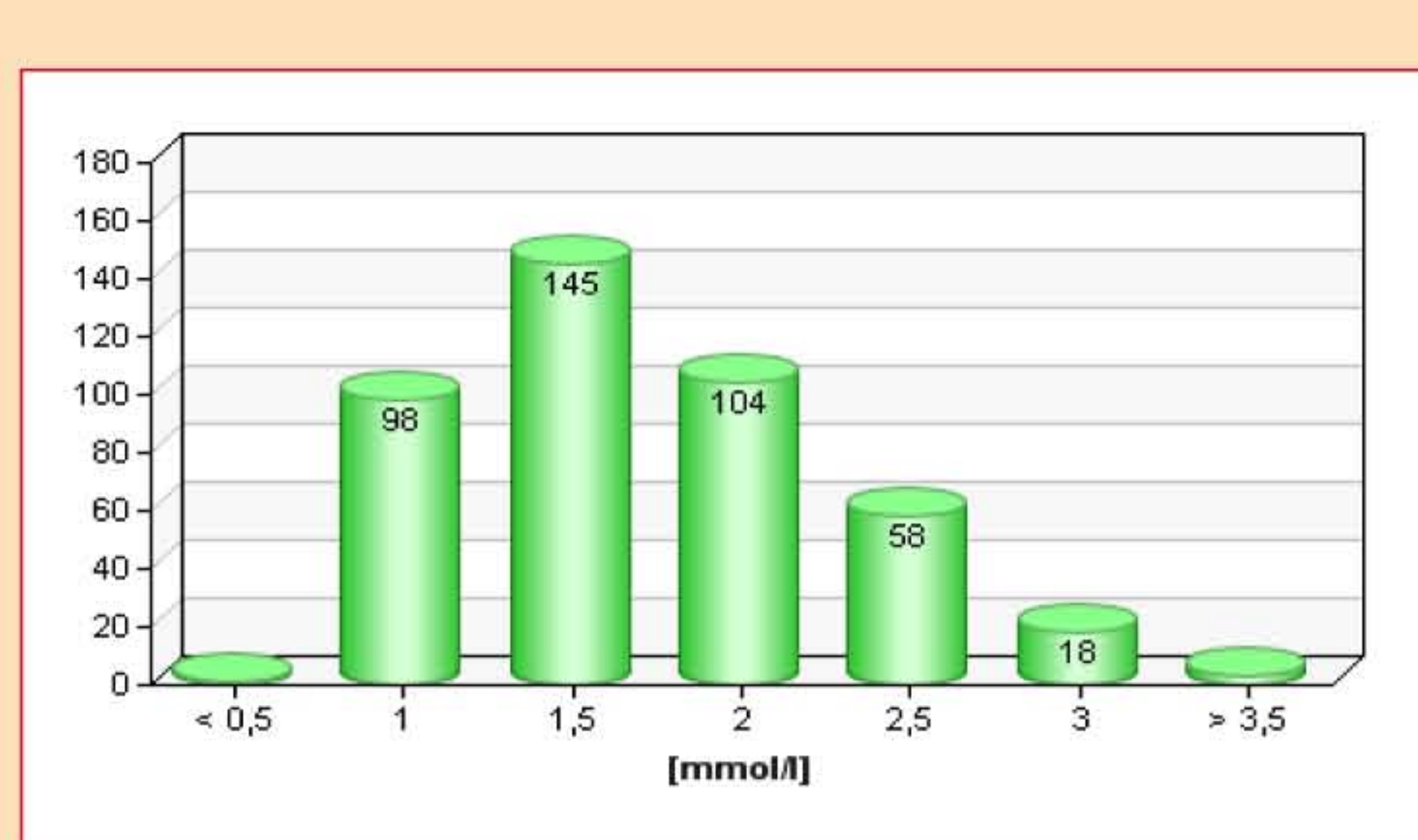

Tab.6: Distribution according to the type of vascular access; data filled-in for 5432 patients registered at the end of 4/2013 quarter
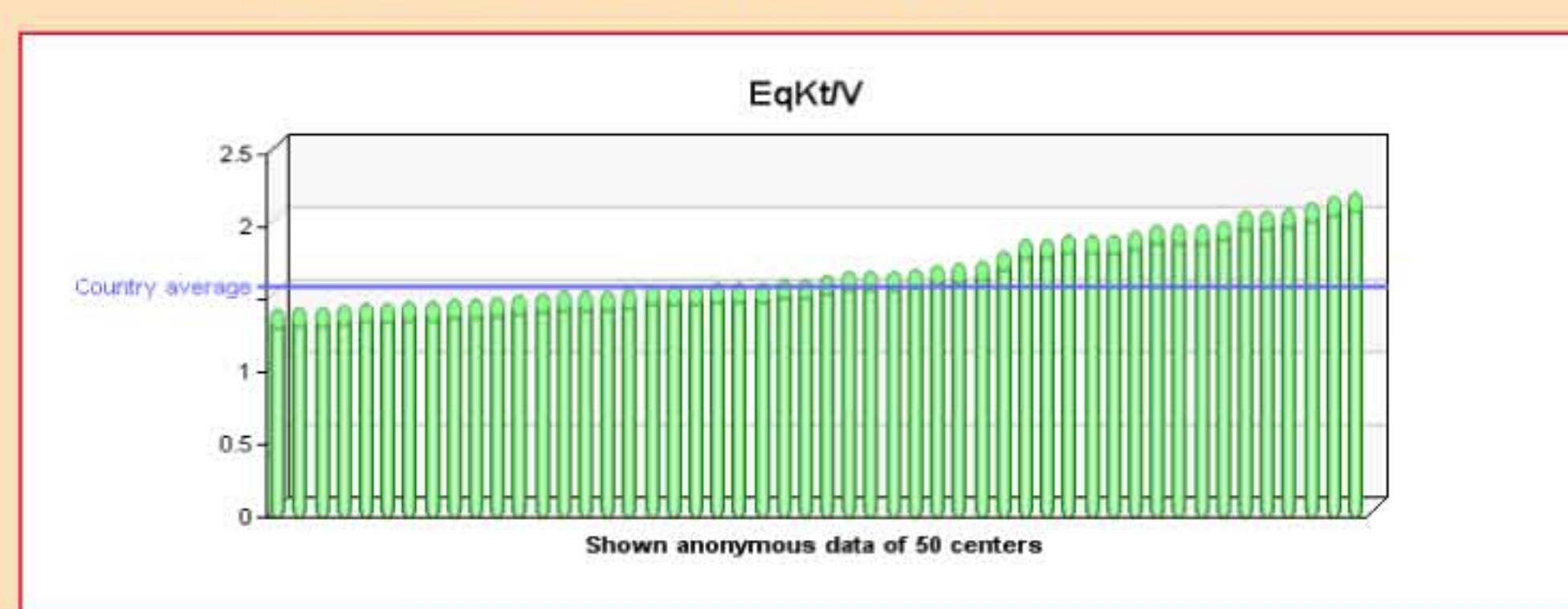

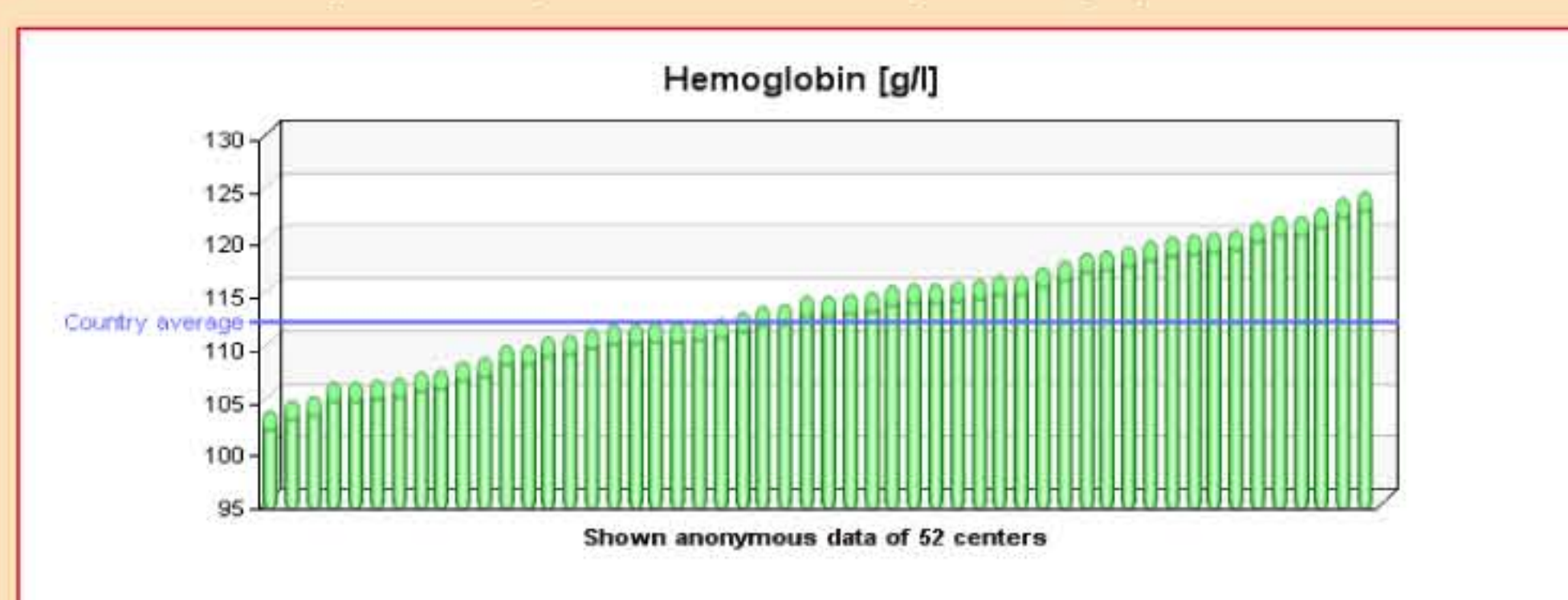**Tab.7:** Mean ESA dosage during the year 2013 (quarterly data)

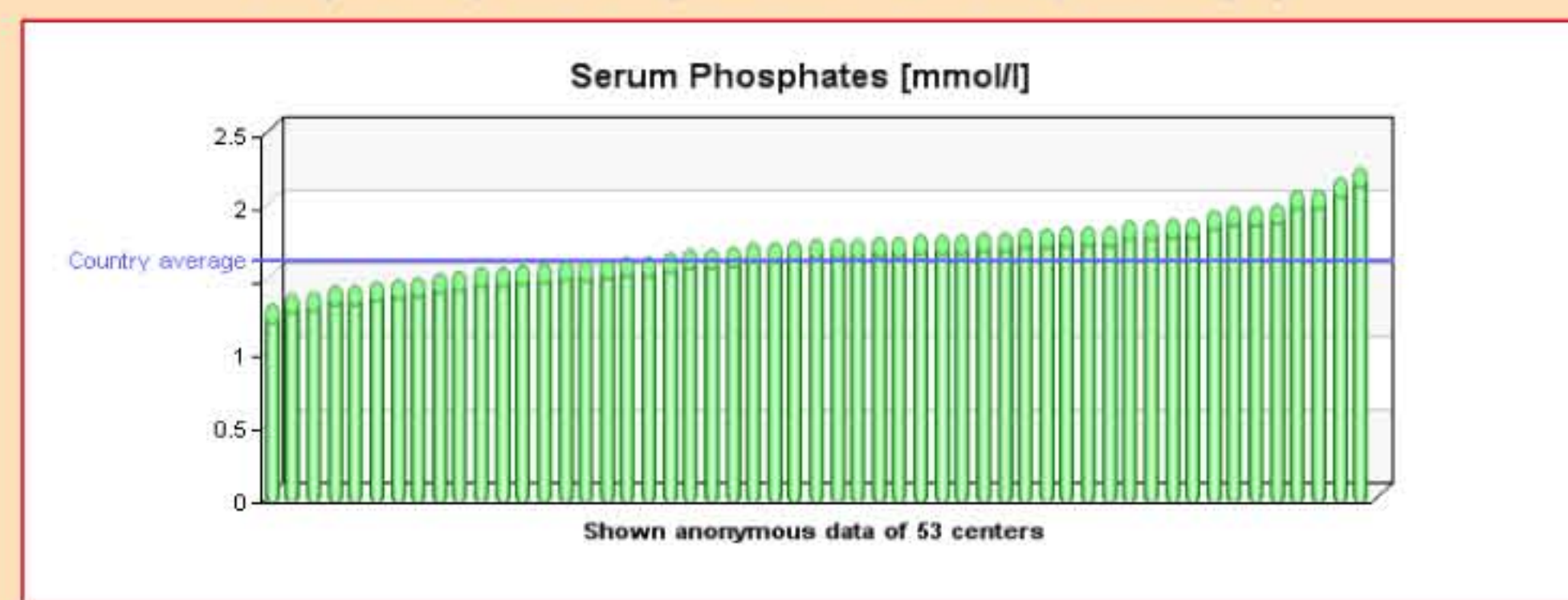**Tab.8:** Deceased patients in 2013 (n=427) - distribution according to the phosphate levels

Ad c/ examples of other statics for the national-wide data based on individual-patient reported data

Tab.15: Histogram of mean values of EqKtV of each single dialysis unit (blue line = country average)

Tab.16: Histogram of mean values of hemoglobin of each single dialysis unit (blue line = country average)

Tab.17: Histogram of mean values of serum phosphates of each single dialysis unit (blue line = country average)

Summary and conclusions

- After 8 years since the start of the Registry, 52 dialysis units (60% of nation-wide count) joined, covering 69% of prevalent dialysis population in the Czech Republic
- Solid database with nation-wide and unit-mean values of selected patient- and treatment-related data (e.g. Hb level, Kt/V, EPO dose) created
- Review of primary renal diseases leading to ESRD in nation-wide setting
- Feedback to the participating units well established
- The first true survival analysis (Kaplan-Meier method) performed
- Inter-units comparison in different parameters can be made
- Persisting problems in obtaining data from non-computerized units (manual data filling of the Internet based forms too laborious) or from units using computer system other than Nefris (cooperation between local IT company or system in development of an interface usually very difficult)

Publication of annual report:

- Statistical Yearbook of Dialysis Treatment, issued by CSN (www.nefrol.cz)
- Czech RDP: www.nefro.cz:
  - public access
  - on-line data restricted only for dialysis units who reported data