



# The Estonian Biobank



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# What is the Estonian Genome Project (EGP)?

- The Goal is develop excellent, prospective, longitudinal, **population based** database with health records and DNA, plasma and WBC samples for research
  - To create a population based collection of health status and biological samples
  - To carry out scientific research in order to find the genes, environmental factors and lifestyle elements that cause and participate in diseases or trait development
  - To implement the results of the genomics research in public health

Currently we have 29 727 GD in the Estonian Biobank.



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# Legal background

## Human Genome Research Act (HGRA)

- Approved by Government on Aug 8, 2000
- Passed by Parliament on Dec 13, 2000 (42 yes, 3 no)
- Enforce since January 08, 2001

## HGRA regulates

- scientific research on human genetics
- the establishment and maintenance of the GeneBank
- the use of genetic information (informed consent, based on principle of open consent)

## HGRA protects

- the confidentiality of gene donor
- the public from the misuse of genetic information
- the gene donor from genetic discrimination

# General Principles of HGRA

- voluntary participation in genetic research studies
- confidentiality of gene donor
- gene donor's right to apply for destruction of his/her identification data (*opt in, opt out*)
- gene donor's right to know or not to know his/her genetic and other data in the database (paternity is excluded)
- non-discrimination by employers and insurers
- the institution of the Ethics Committee and SAB
- EGP Foundation was as a main processor of the EGP from 2001-2007
- from 01. 04. 2007 University of Tartu is as a main processor of the Estonian Genome Project (=Estonian Biobank)



# Estonian Biobank timeline

**The Genome Center Foundation 1999**

**Human Genome Research Act 2000**

**The Estonian Genome Project Foundation → EGeen Ltd. EGeen Inc 2001-2005**

**Pilot Project** September 2002 – March 2003

**Main Project** April 2003 - .....

10 351 individuals in the database in 01.07.2006.

**From 01.04.05. The EGPF was reorganized into a Research Institute of the University of Tartu.**

Research projects are underway, 5 international projects are funded, first publications are out (PlosGenet 2006, Pharmacogenetics J.,2006)

**Funding** – public funding of ca 8M EUR 2006-2010 from government budget, funds for the maintenance of the biobank are foreseen by the HGR Act.



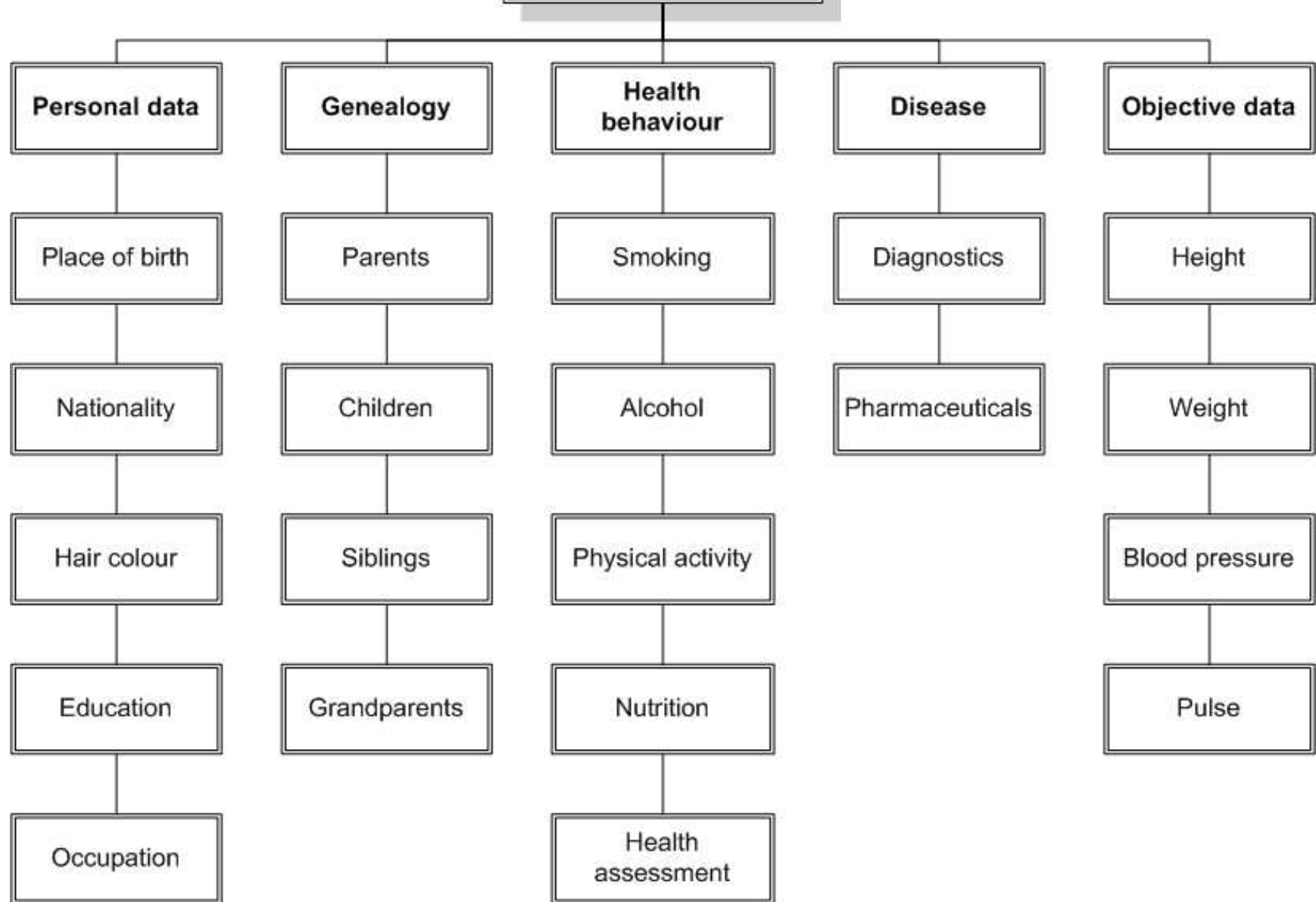
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# Collection of Gene Bank Data

- **Data Collectors** are physicians (GP) and other medical personal in the hospitals - training 20-30h, IT base necessary for the participation, contract, future update of clinical information in database + access to other databases like birth-, cancer-, death-, myocardial infarction- etc. registries
- **Health data questionnaire** – personal data, environment, diet, workplace, lifestyle, clinical data as in ICD-10 plus special disease modules with more clinical data, genealogical data. Takes 60 – 90 min to fill
- **Data monitoring**
- **Logistics and transport** – transport of the blood samples to EGP in 36-48 h
- **Laboratory** – up to 50 ml of blood, DNA and plasma in MAPI straws in liquid N2, lab is 10 people, 300 m2. QC of DNA + PCR
- Electronic health databases and records – special law was passed
- 01.09.2008.
- ISO 9001-2000

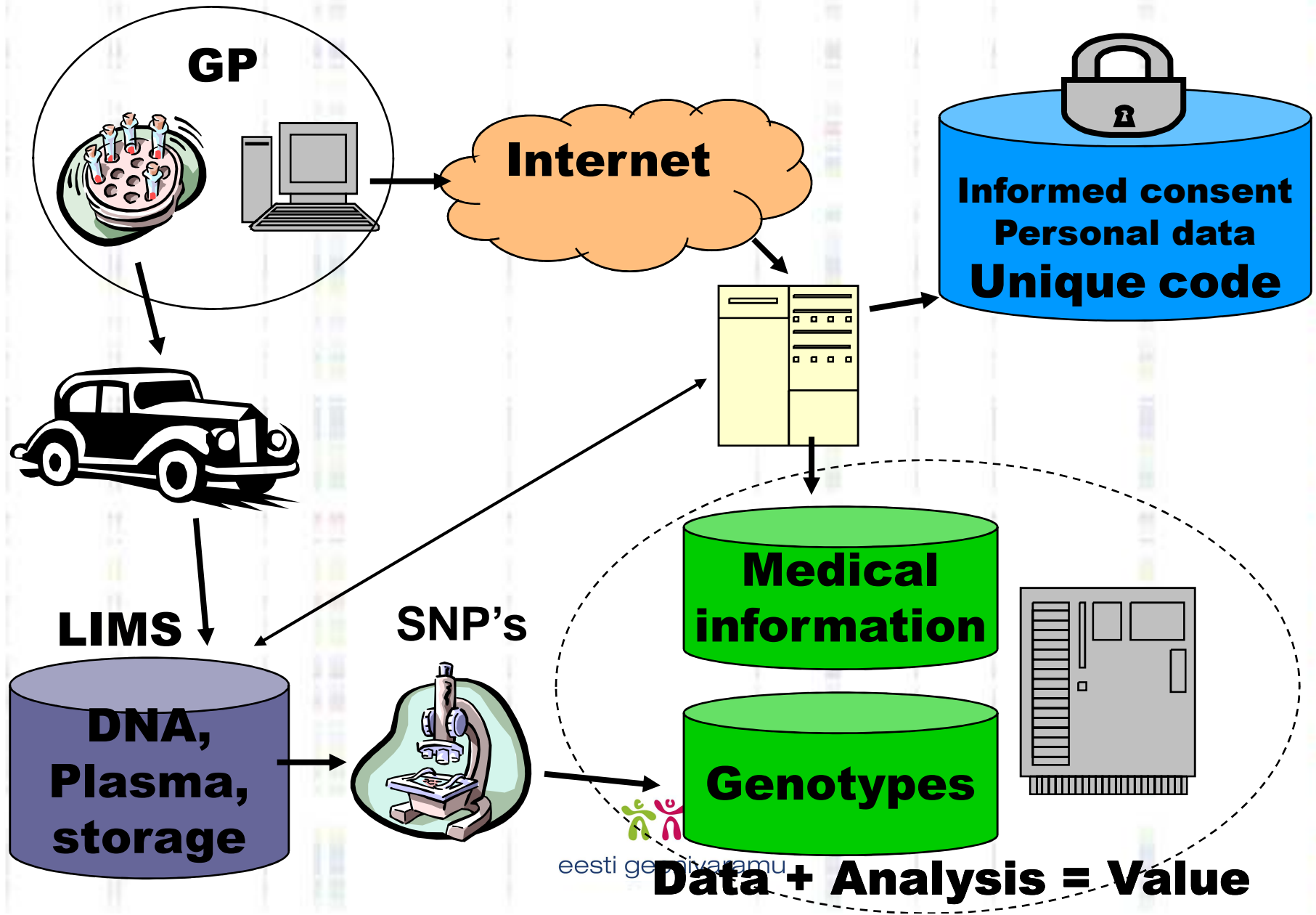


# EGFQ



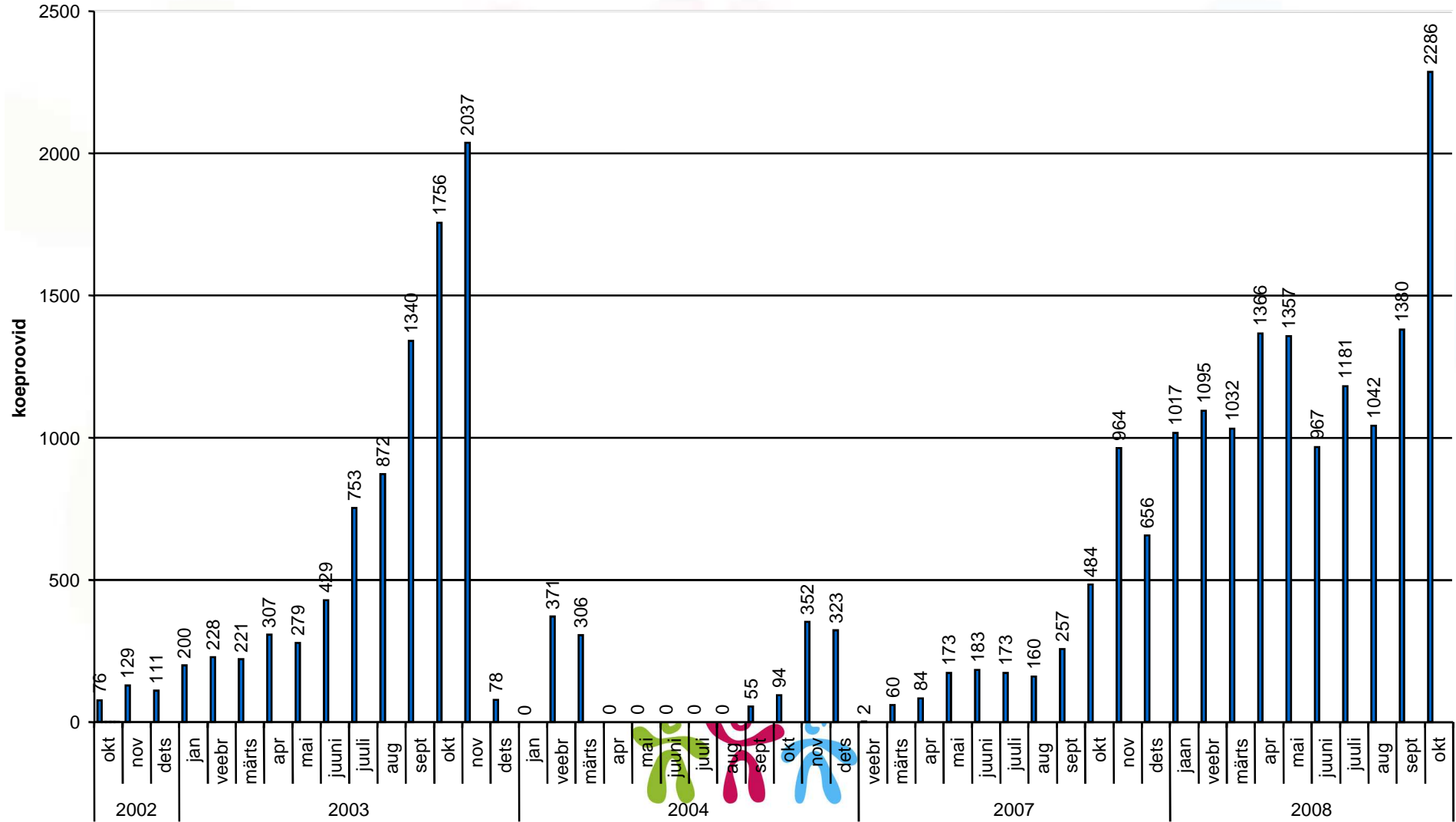


# Process of data collection and handling





# Recruitment 2002-2008



# 50 ml blood sample

- Processing starts at least in 48 hours
- Salting out manual method for DNA
- DNA ~ 1,7 mg - 14 CBS straws (ca 110 µg each)
- Plasma ~ 3.5 ml - 7 CBS straws
- Buffy coat ~ 0.8 ml - 2 CBS straws
- Storage in liquid nitrogen



Vöötкод:

**LIMS**

Teisene код:

Teisene код:

DNA konsentratsioon:

Võtmisaeg:

DNA puhtusaste:

Töötlemise algusaeg:

Töötlemise lõppaeg:

Plasma riknemise aeg:

Plasma riknemise etapp:

Vererakkude riknemise aeg:

Vererakkude riknemise etapp:

DNA riknemise aeg:

DNA riknemise etapp:

Mittevastavaks märkimise aeg:

Mittevastavaks märkimise etapp:

Mitte fraksioneerida

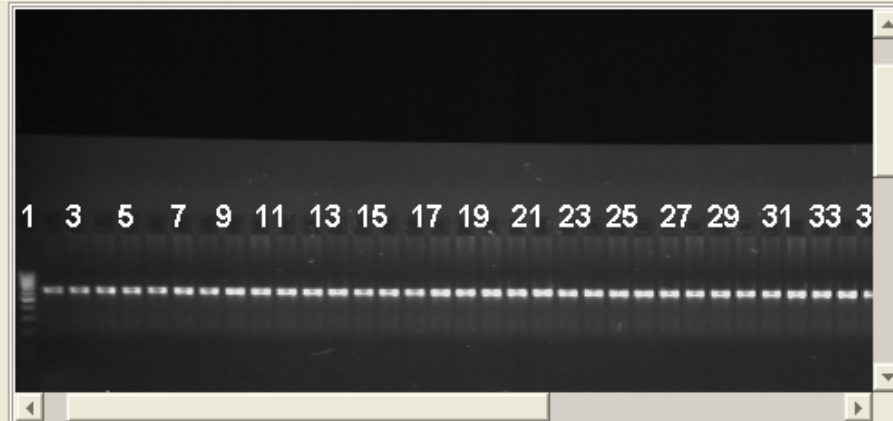
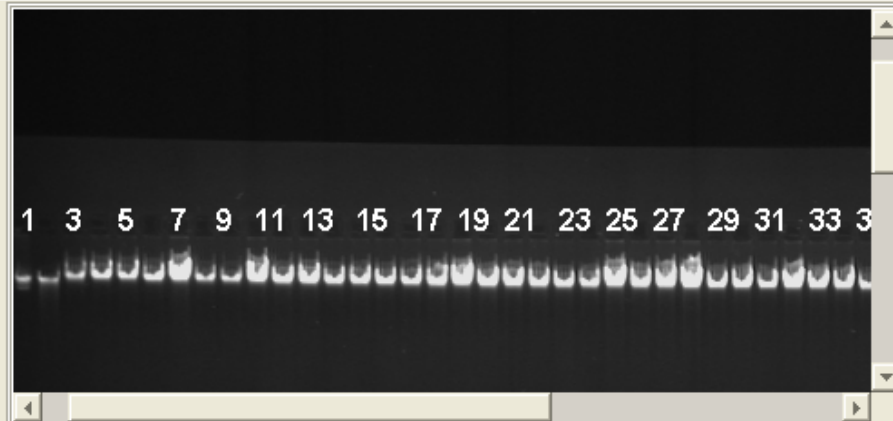
DNA saagis:

Märkused:

Ajalugu | **Komponendid** | Töötlemise staatus | Foto

Elektroforees:

PCR:



Mittevastavus

Positsioon:

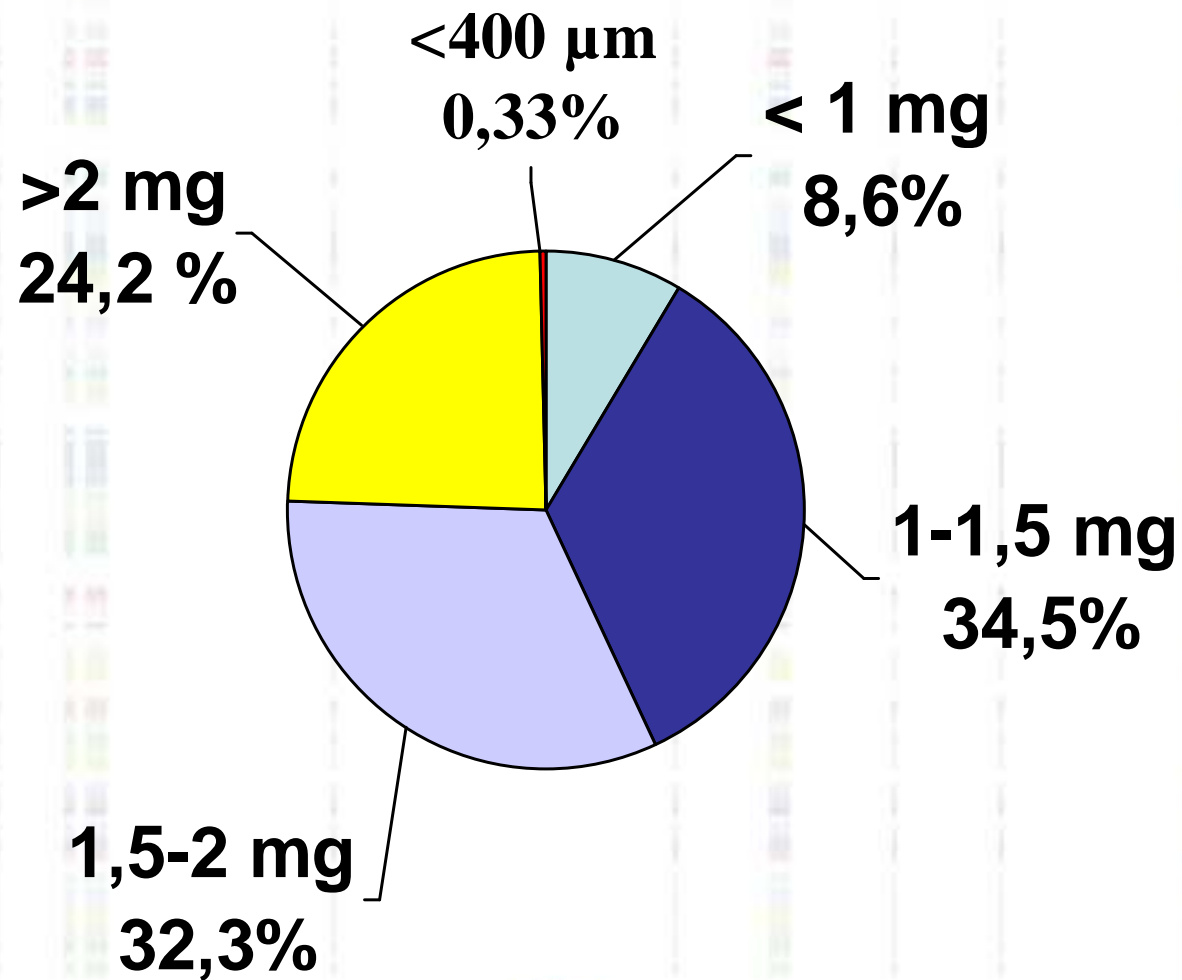
Mittevastavus

Positsioon:

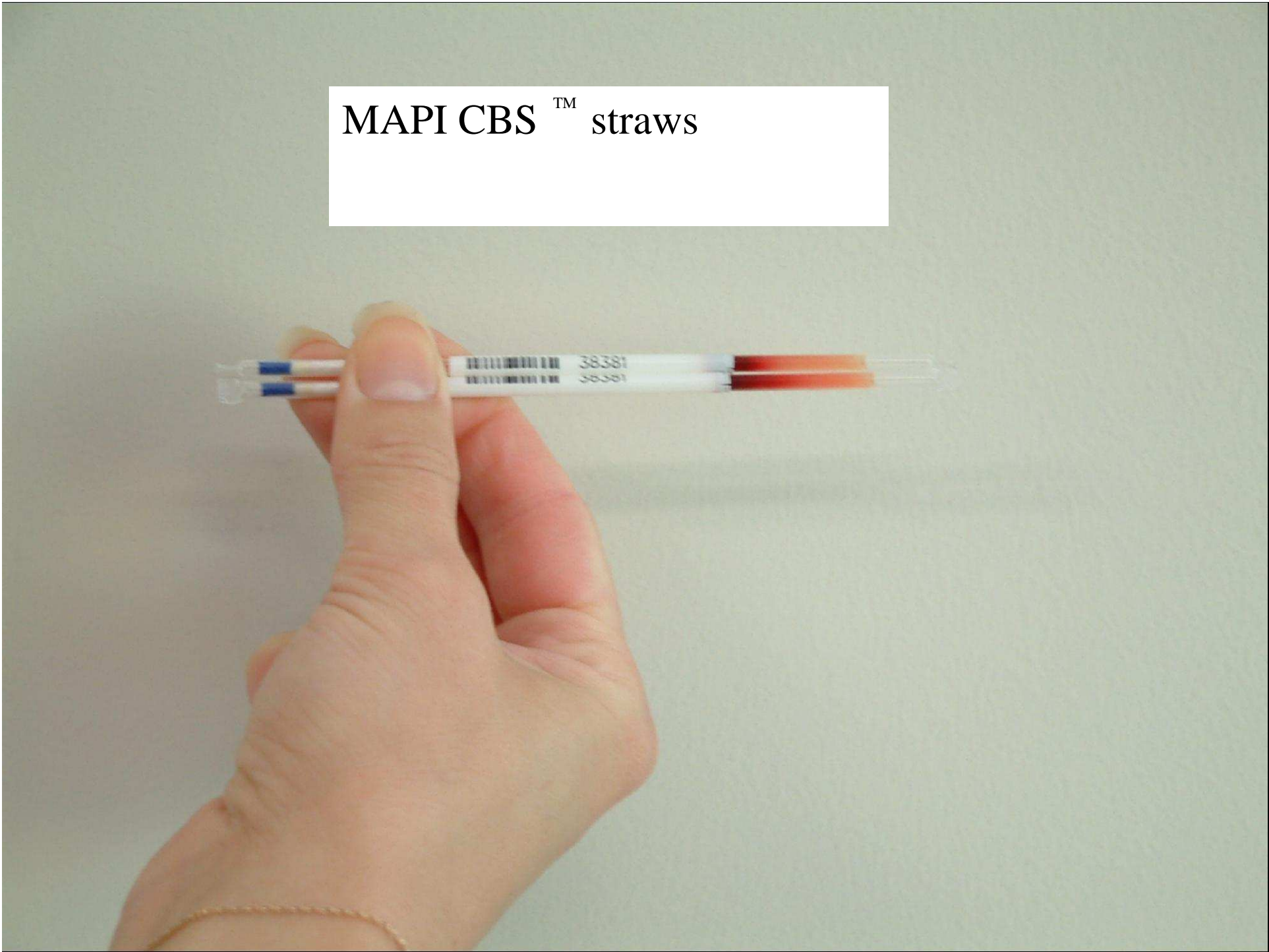
Kommentaar:

Kommentaar:

# Amount of the DNA per gene donor

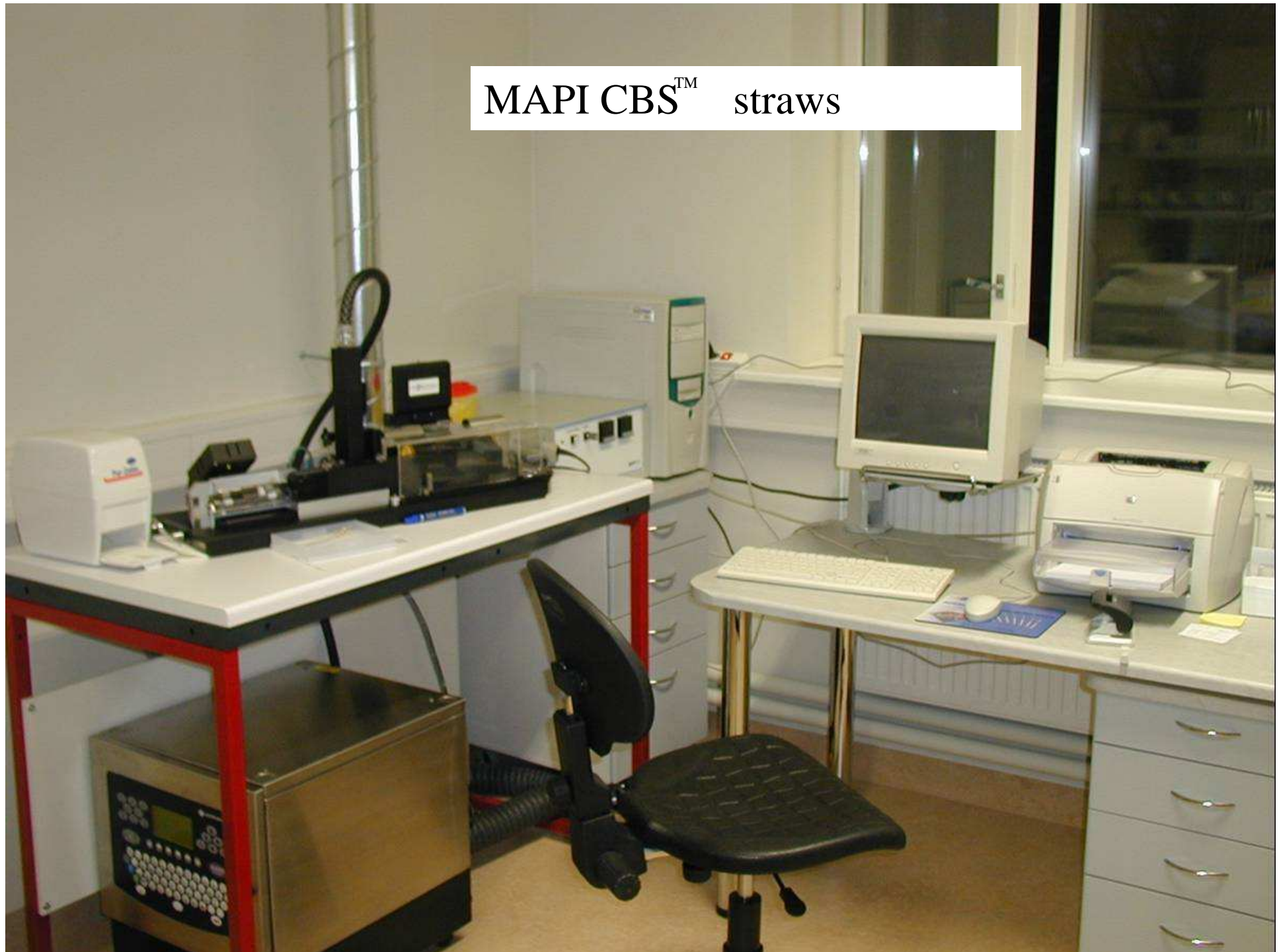


MAPI CBS™ straws





# MAPI CBS™ straws





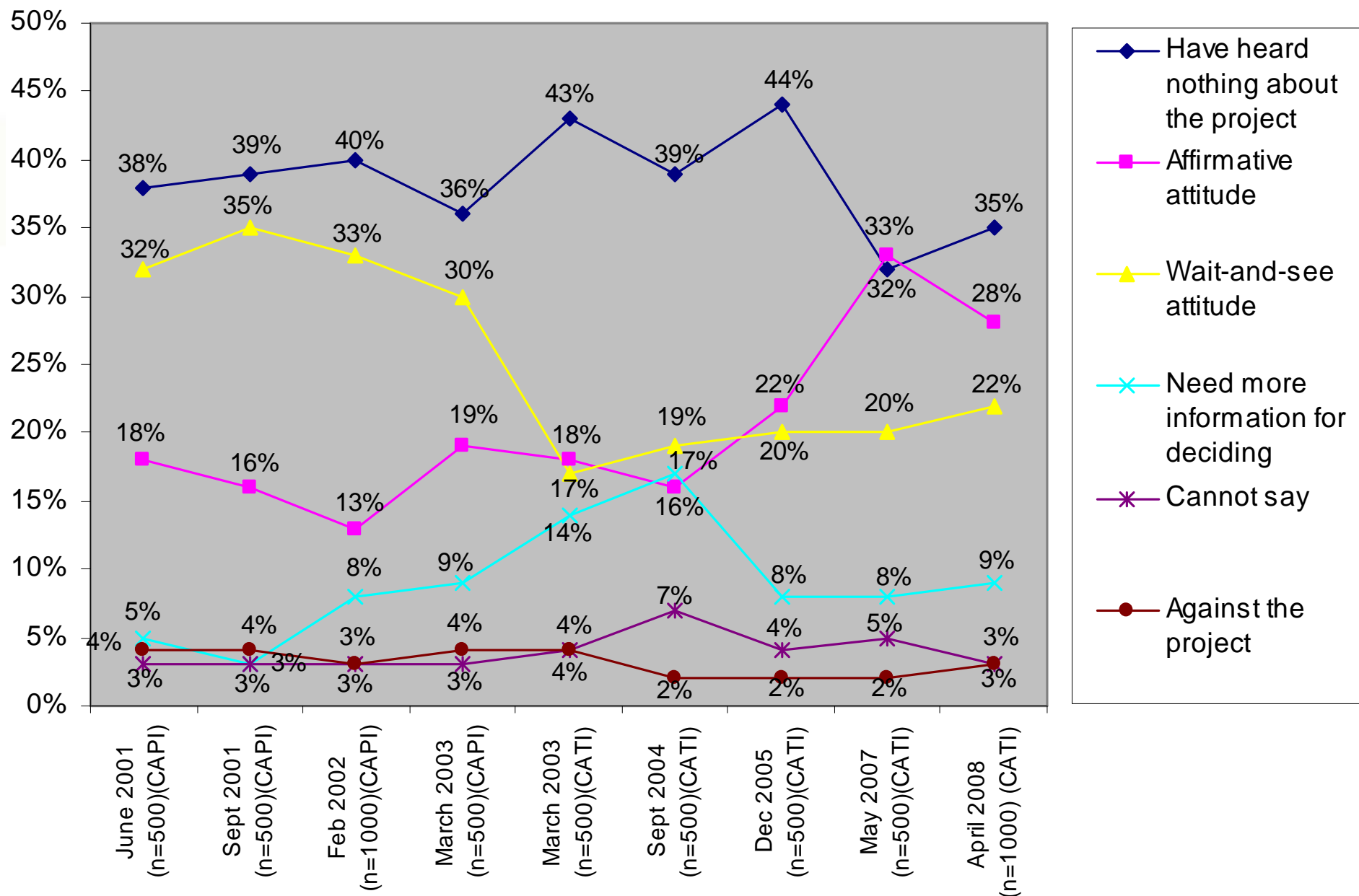




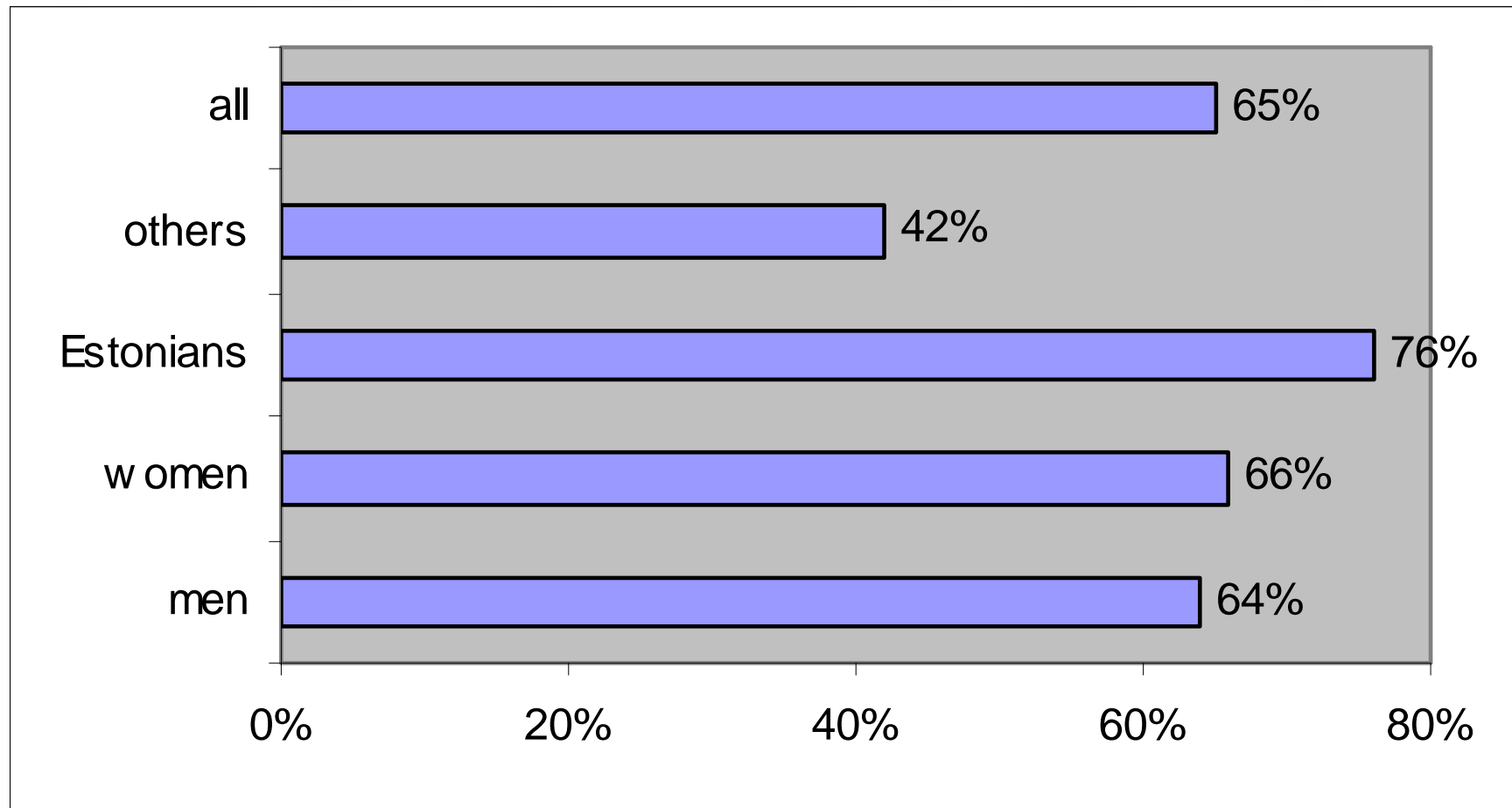
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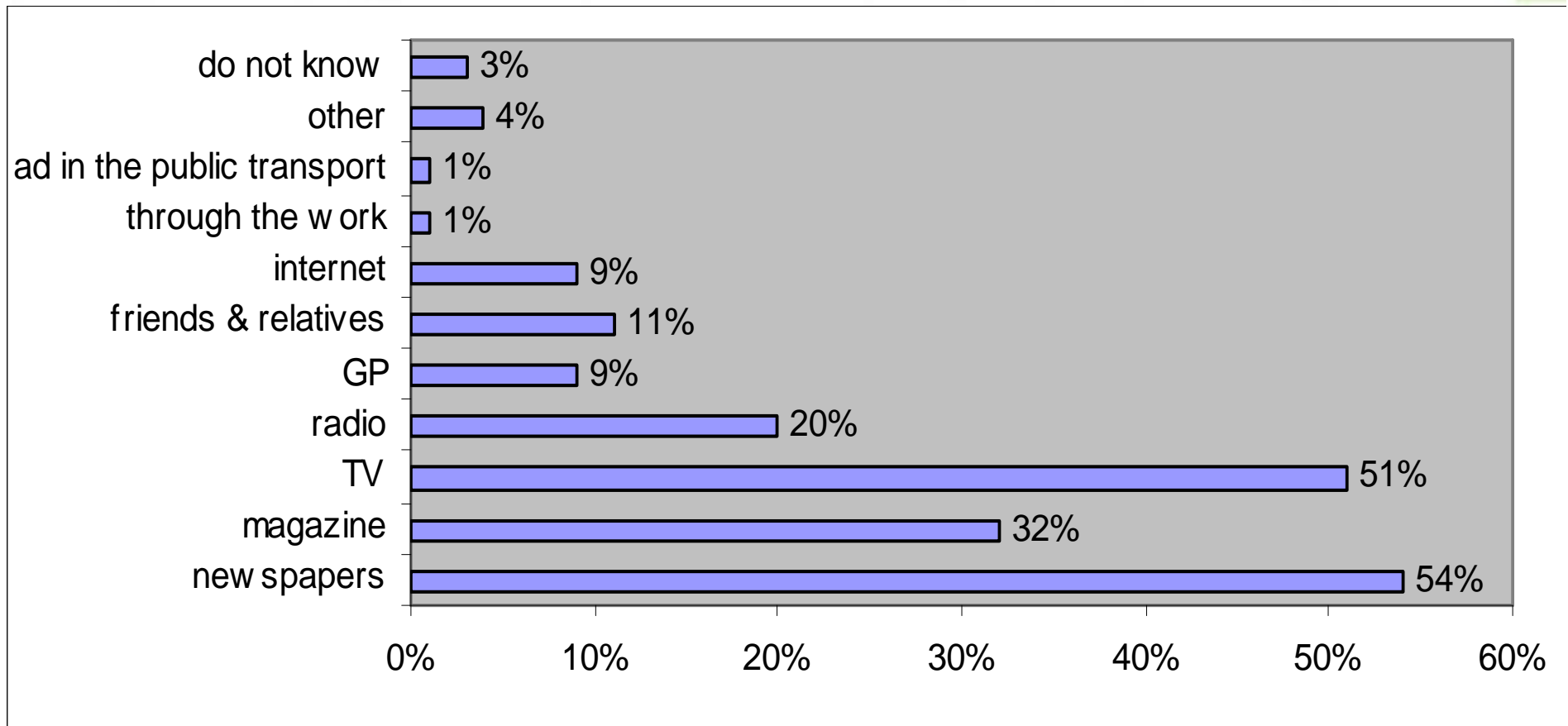
## Awareness and attitude towards the Estonian Genome Project in 2001-2008



# Informed about the EGP (n=1003)



# The sources of the information about the EGP (n=654)

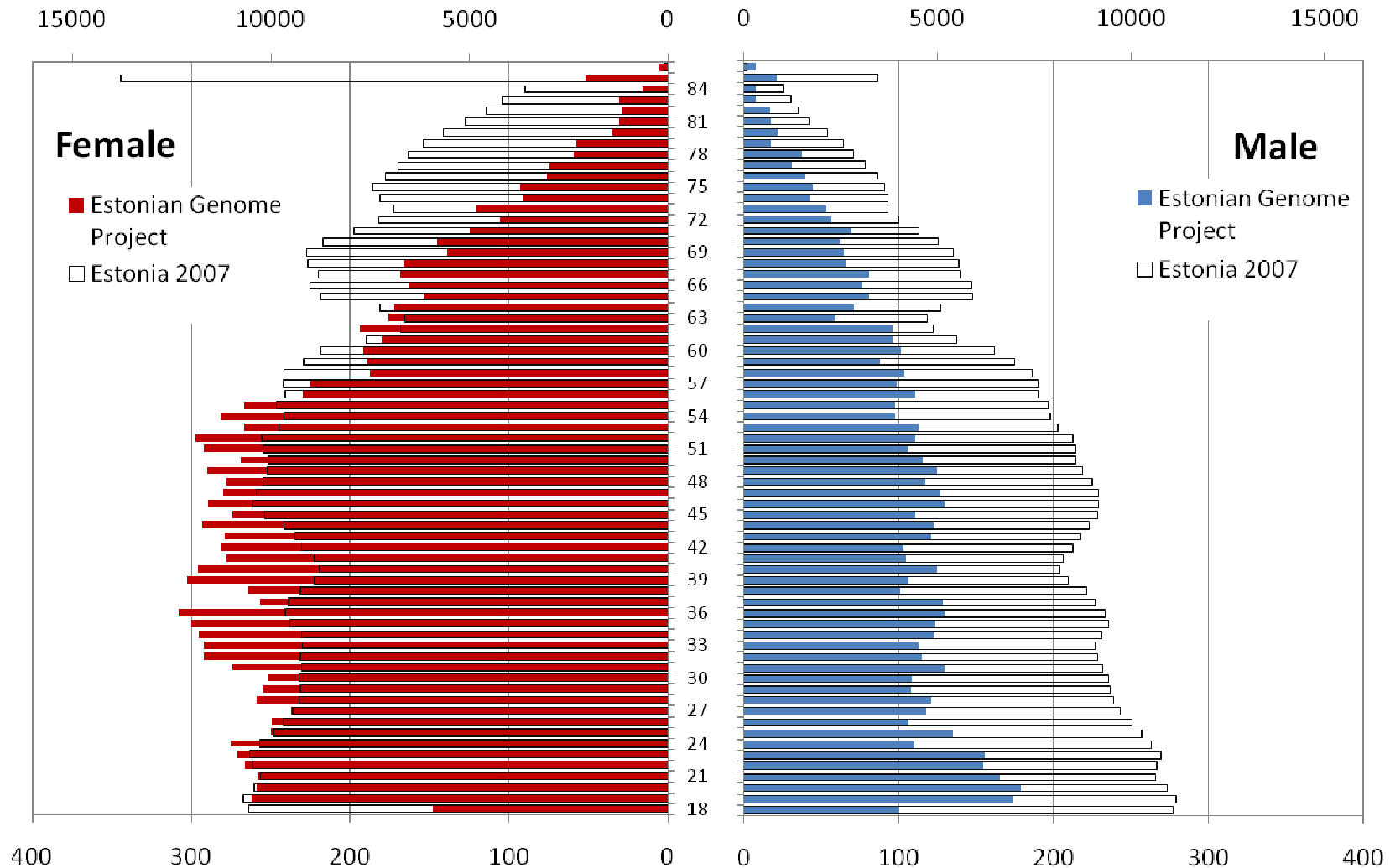


# Estonian media about the EGP

- 2000-2005 more than 500 articles and news were published. Three special issues of the largest newspapers were printed.
- 2006 more than 60 articles
- 2007 more than 100 articles
- 2008 during the first 10 months 134 articles were printed in various newspapers and magazines, 120 min in the TV.
- International media (TV, radio, newspapers and journals/magazines) have reported about the EGP more than 100 times.

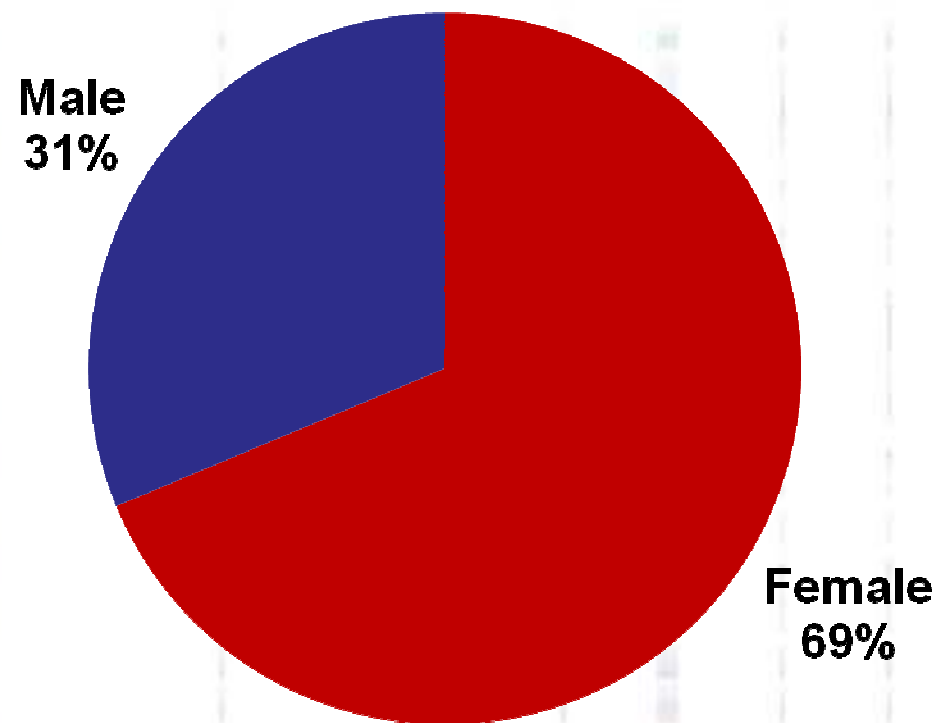
...and still 35% of the population in Estonia have not heard anything!

# Comparing to the general population (20 400 GD)



# Gender

(20 400 GD)

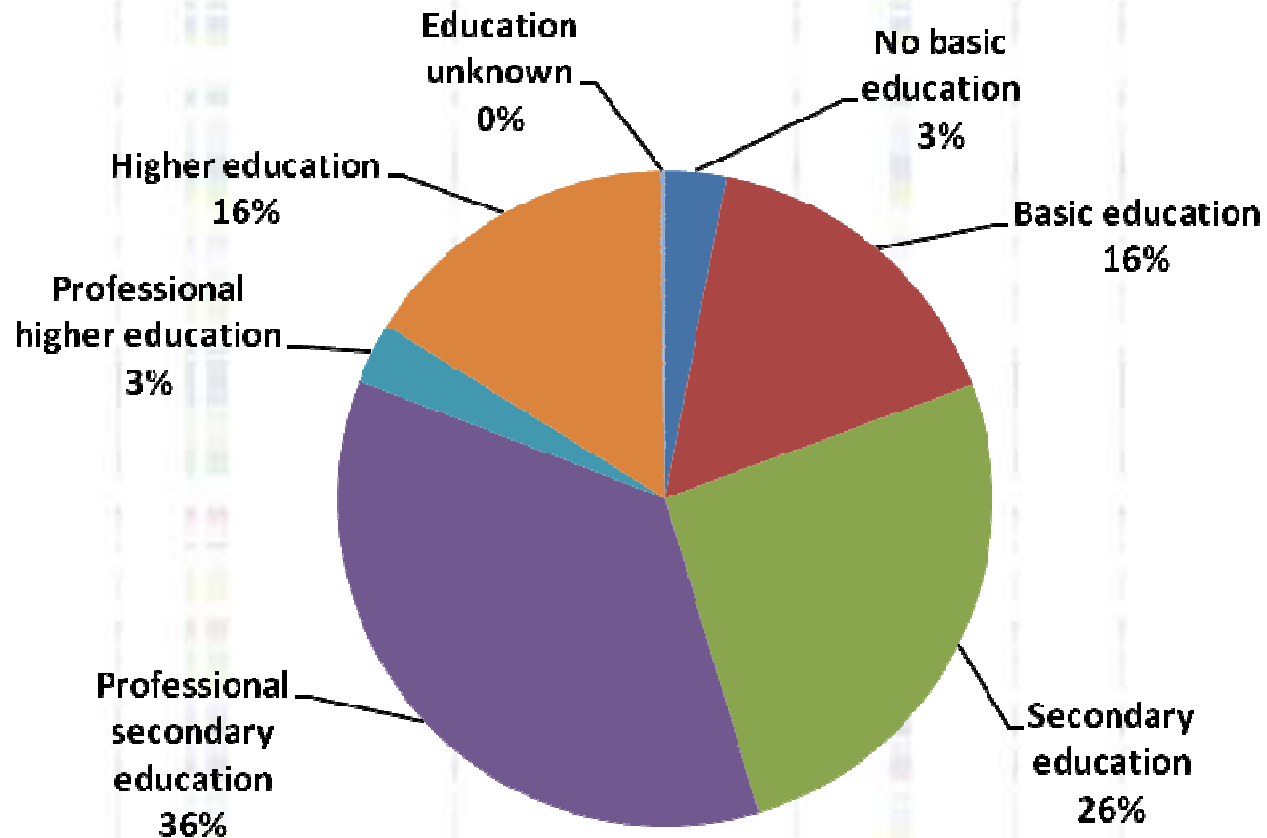


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# Education

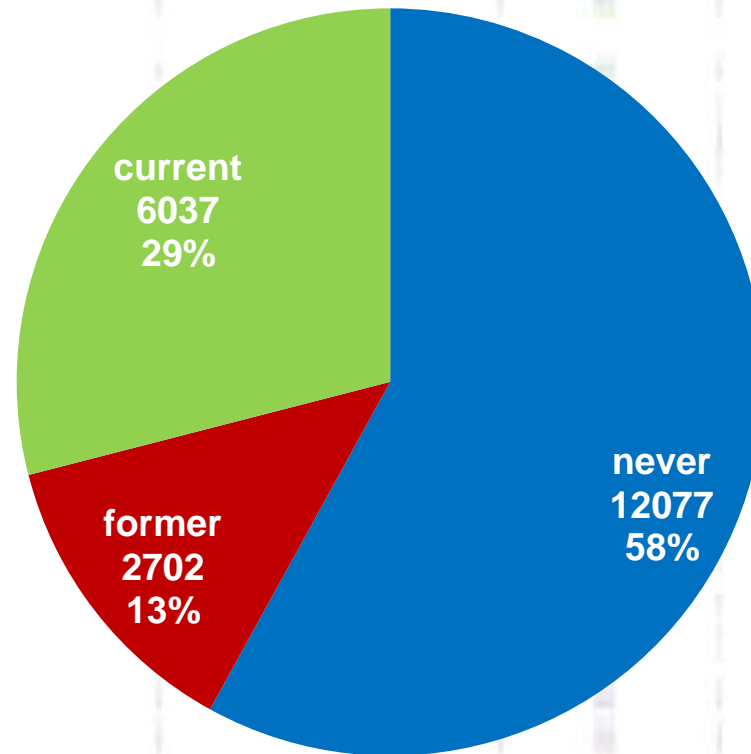
(20 400 GD)



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# Smoking

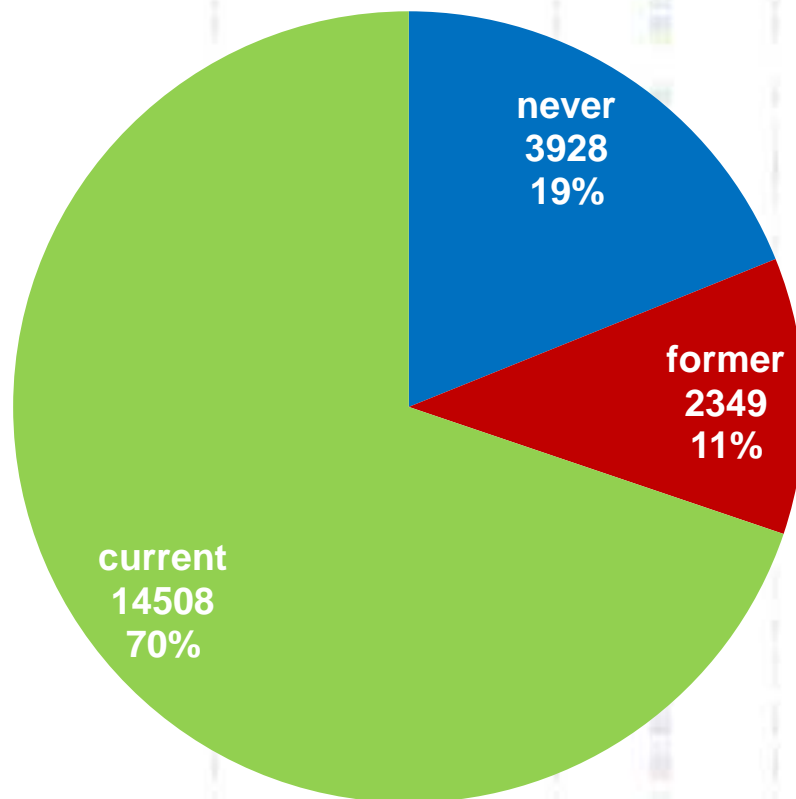
(20 800 GD)



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# Drinking

(20 800 GD)



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[www.geenivaramu.ee](http://www.geenivaramu.ee)



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[www.biotech.ebc.ee](http://www.biotech.ebc.ee)



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