



estonian genome project

Challenge of Secure Biodata Handling – Estonian Genome Project

Erkki Leego

CIO

Estonian Genome Project,
University of Tartu



Erkki Leego – Managing Partner

Background of presenter



Where there is a will there is a way!

- Last 10 years
 - MSc Informatics
 - Office of the President of Estonia, Information councillor
 - Estonian Parliament, Head of IS and Technology department
 - Tartu University Hospital, IT director
- Currently
 - Hansson, Leego & Partner, Managing Partner
 - IT services and data security coordination and consultation
 - Estonian Genome Project, University of Tartu, CIO

Erkki Leego – Managing Partner



- Idea
 - Database of the phenotype and genotype data of the Estonian population
 - Up to 100,000 samples in the database within the next four years
 - Creation of the database is regulated by the Human Genes Research Act
- Goals
 - To create a population based collection of health care status descriptions and tissue samples
 - To carry out scientific research in order to find the genes that cause and influence common diseases
 - To implement in public health the new knowledge of genomics research

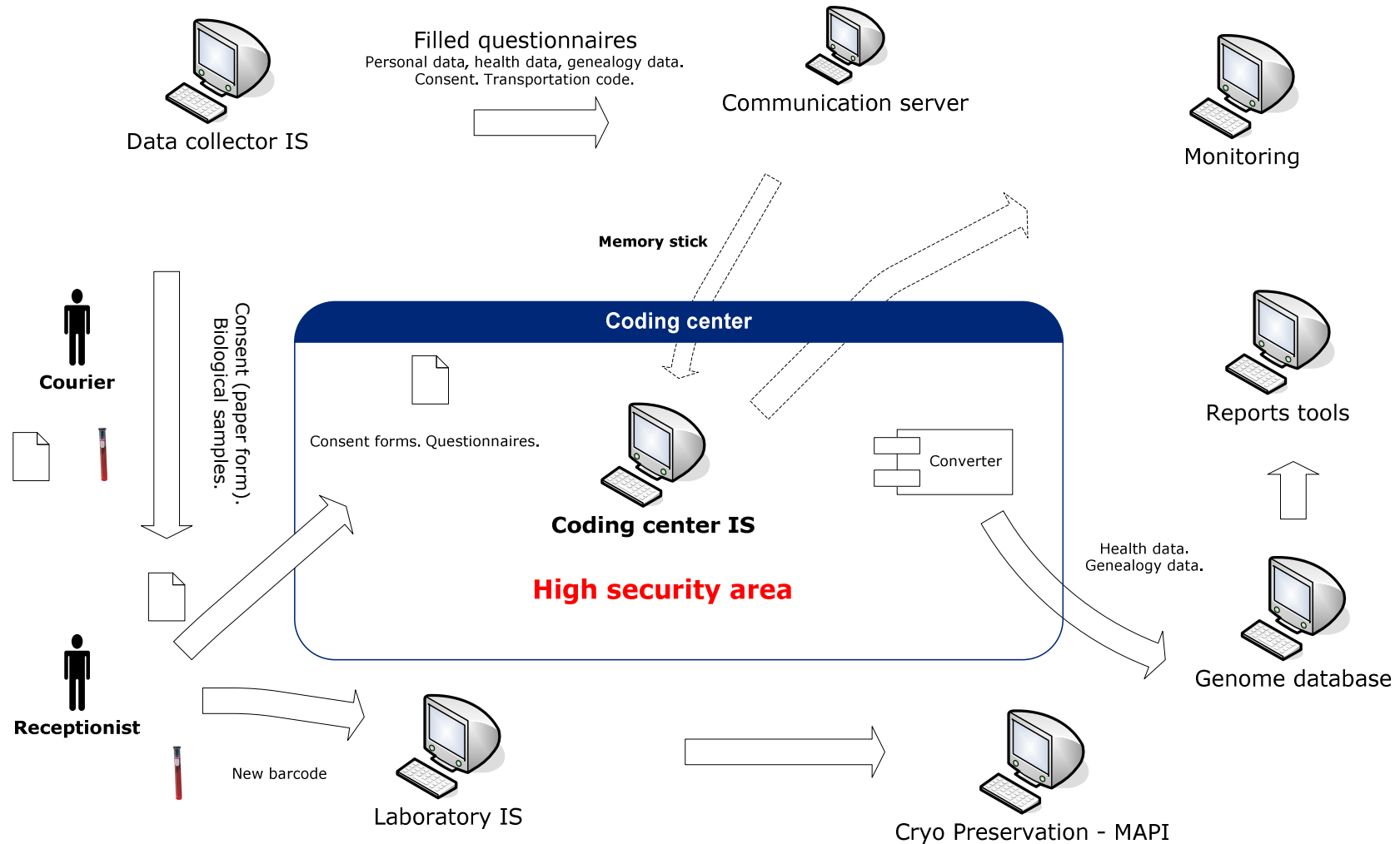
Data to protect

- Health and genealogy data
- Personal data and consents
- Bio samples and genetic information



Data and sample collection

Where there is a will there is a way!



Erkki Leego – Managing Partner

Challenges



- Ensure confidentiality
 - Separate personal data
 - Anonymous health, genealogy and genome data
 - Right to know and right to not know
- Ensure integrity
 - Keep record of encoding and decoding
 - Quality and security control
 - Possibility to withdraw consent at any time and to destruct data
- Ensure availability
 - Data for research - anonymous genealogy, health and genome data
 - Data access by Third Parties (authorities, insurance, employers, ...)

Future challenges



HANSSON, LEEGO
& PARTNER

Where there is a will there is a way!

- 100 000 gene donors (currently 10 400)
- Linkage to national and local health IS's
- Flexible data usage for researchers

Erkki Leego – Managing Partner

Conclusions

- Great opportunities for researchers
- High security demands for genome database
- Challenge – availability and flexibility versus confidentiality and security

Thank you!



Where there is a will there is a way!

Where there is a will there is a way!

Erkki Leego, erkki.leego@geenivaramu.ee, www.geenivaramu.ee



estonian genome project

Erkki Leego – Managing Partner