



The Regional Biobank Centers

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Goals

- ◆ To improve the quality, efficiency, accessibility and use of Swedish biobanks for research
- ◆ To protect the integrity of individual sample donors through active ethical guidelines



Regional Biobank Registries

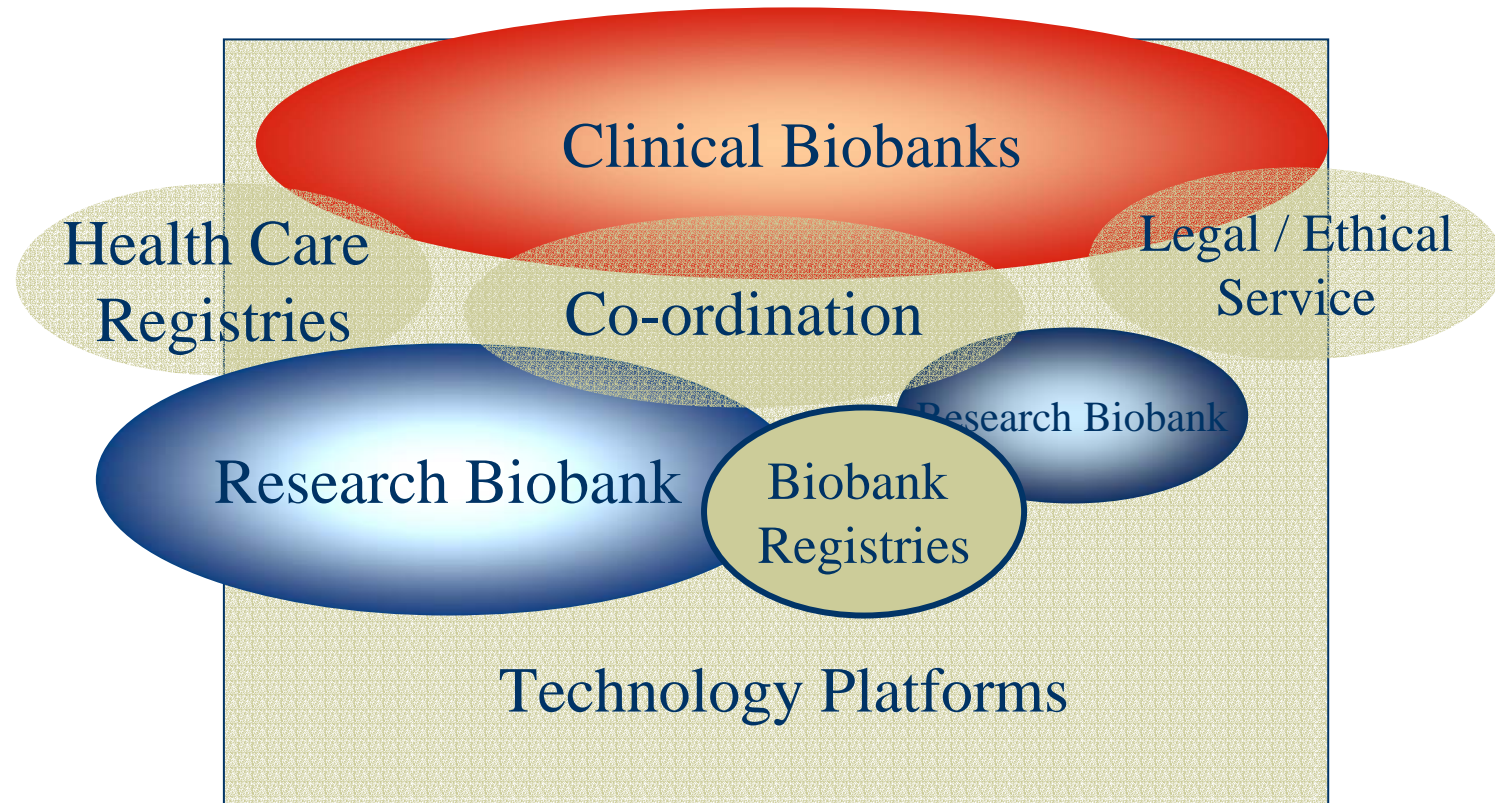
- ◆ Create a complete inventory of all sample collections / samples stored within an entire health care region
- ◆ Document informed consent / dissent
- ◆ Encourage / enforce use of codes and code keys, reducing ethical problems
- ◆ With common national QA processes



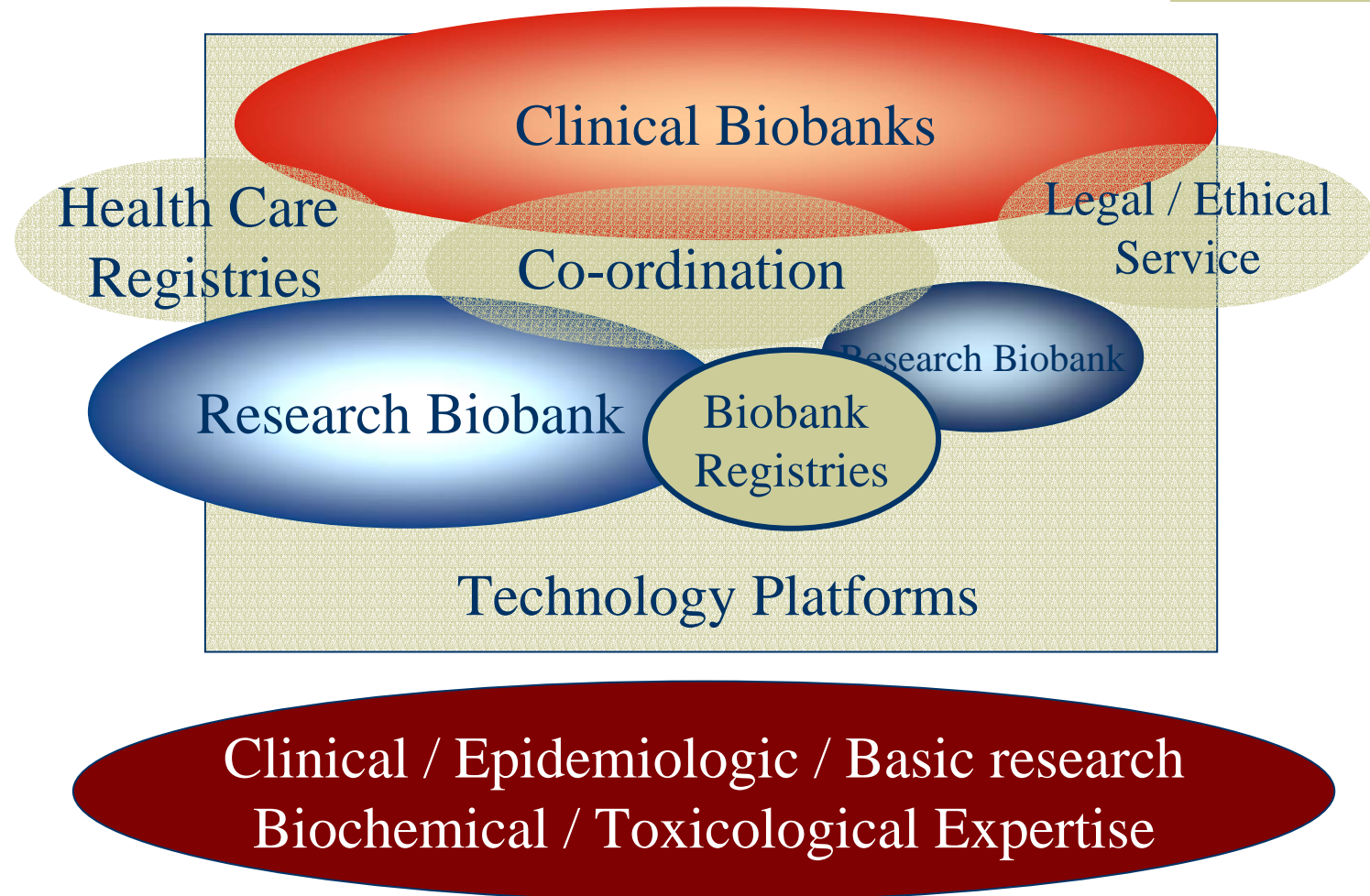
Regional Biobank Co-ordinator

- ◆ Participates in project planning for "new" biobanks
- ◆ Provides advice concerning
 - "informed consent" and ethics applications
 - Study design
 - Practical sample handling

Total Biobank Service



High Competence Clinical Research Center





The Scandinavian Goldmine



- ▲ Unique personal identifiers (personnummer)
- ▲ Regional Cancer Registries
- ▲ Swedish Family – Cancer Registry
- ▲ Diagnoses in Hospital Care Registry
- ▲ Twin Registry
- ▲ Multiple generation registry
 - ▲ Regional Biobank registries
 - ▲ Pharmacy registries
 - ▲ Diagnoses in outpatient care

Types of Sample Collections

Health Care Collections

- ◆ Microbiology Departments (> 4 million samples)
 - Maternity cohorts (population based)
 - Risk screening (selection – addicts, dialysis pt.)
 - Diagnostic testing
- ◆ Pathology and cytology (> 50 million samples)
- ◆ The PKU Biobank

Generally small available sample volumes

Little or no standardized information

(Informed dissent)

Large Research Population Studies

- ◆ Malmö Diet and Cancer (30 000)
- ◆ Malmö Preventive Medicine (30 000)
- ◆ Umeå Biobank (90 000)

Up to 32 years follow up with accumulated clinical endpoints

Generally larger available sample amounts

Highly standardized phenotypic information

Participants have given informed consent



Clinical Cohort Collections

- ◆ Botnia Study (Diabetes)
- ◆ Diabetes 2000
- ◆ DiPiS (5 000 of 36 000 screened newborns)
- ◆ STROKE
- ◆ Thrombosis
- ◆ von Willebrand
- ◆ Many, many, many more

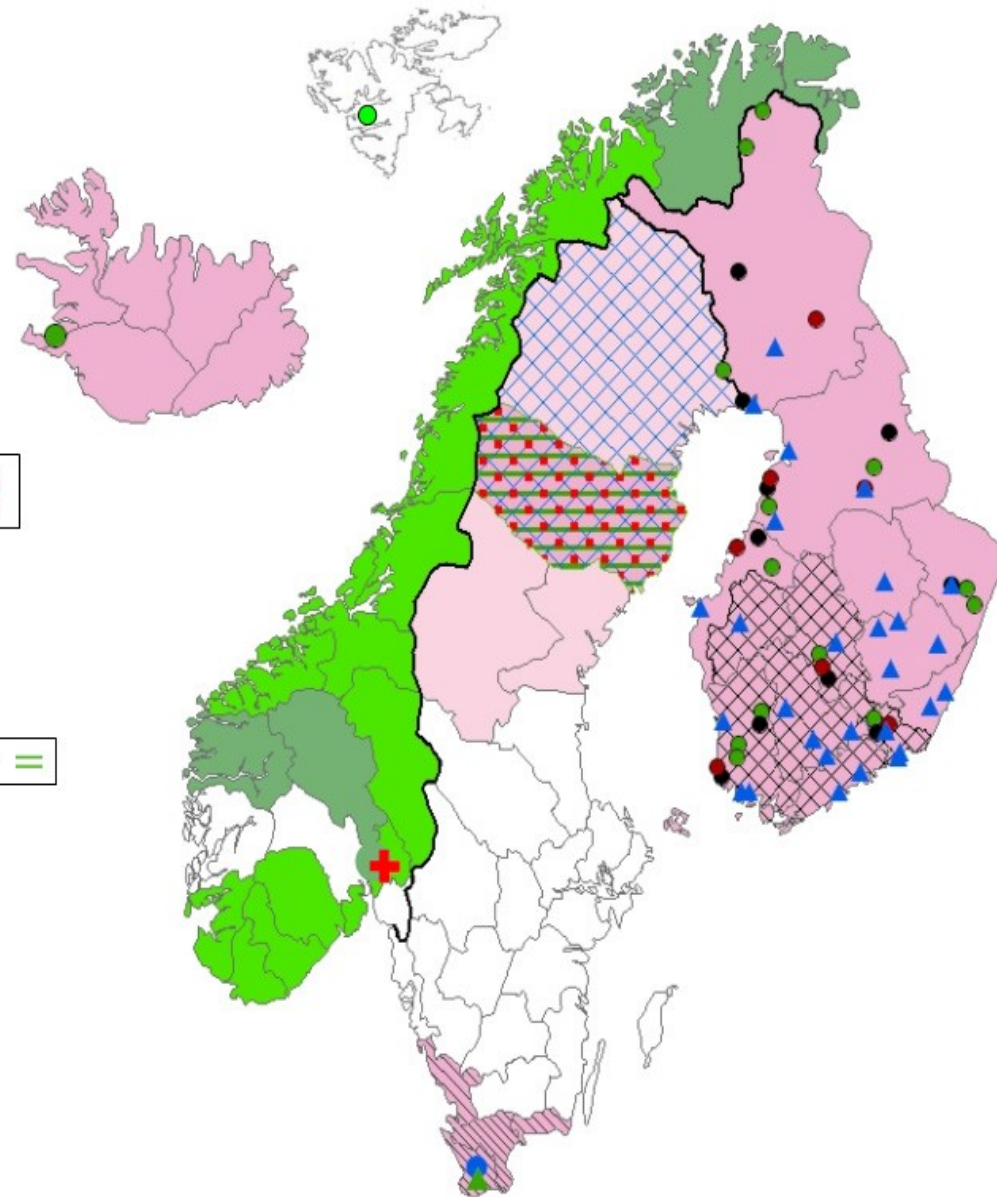
Highly variable quality/quantity of samples and information

Nordic biological specimen banks as basis
for studies of cancer causes and control
– 2 million sample donors, 25 million person-
years and 100,000 prospective cancers

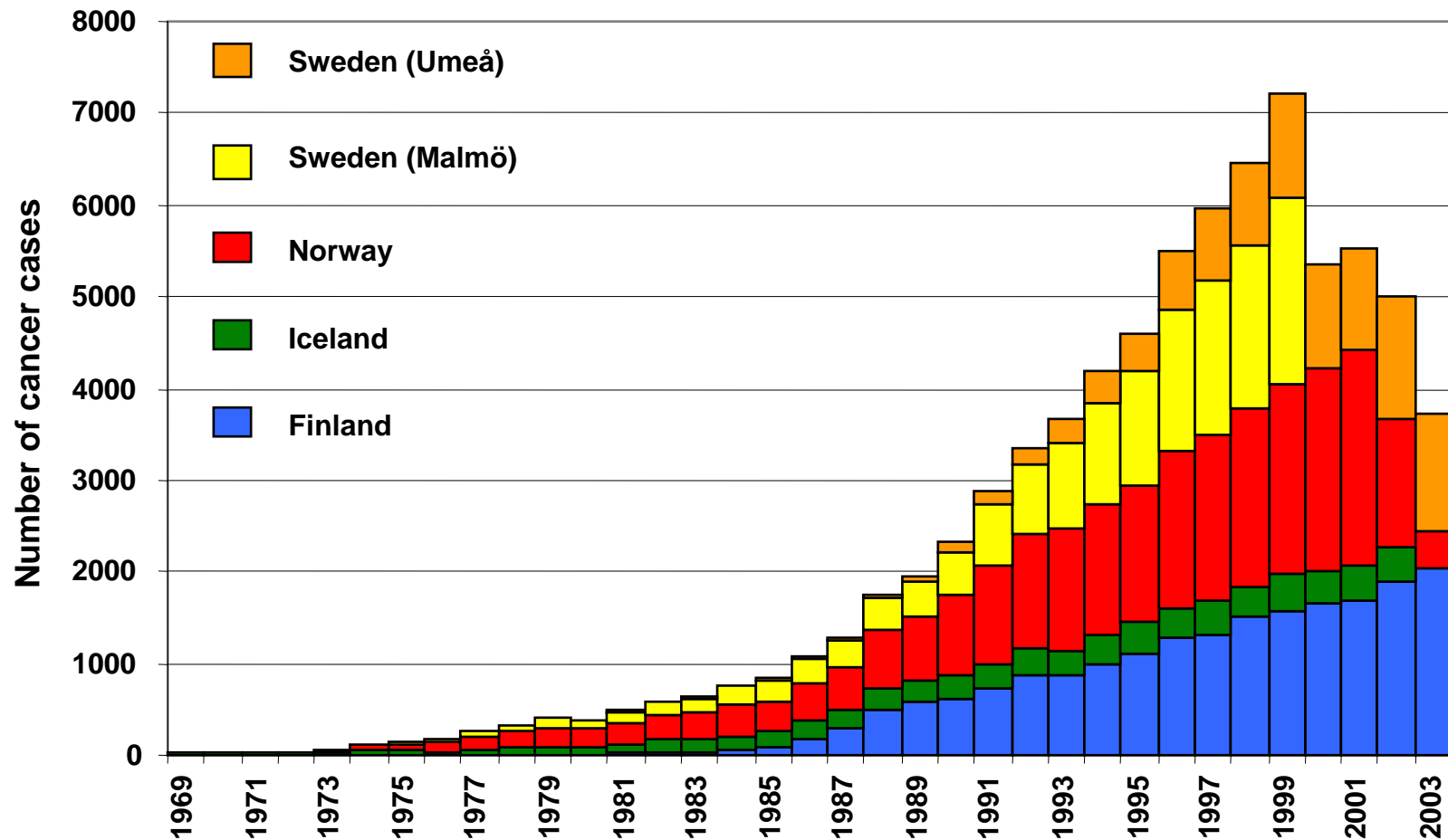


Eero Pukkala^{1,16}, Aage Andersen², Göran Berglund³, Randi Gislefoss⁴,
Vilmundur Guðnason⁵, Göran Hallmans⁶, Egil Jellum⁴, Paul Knekt^{7,8}, Pentti
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Joakim Dillner¹⁷

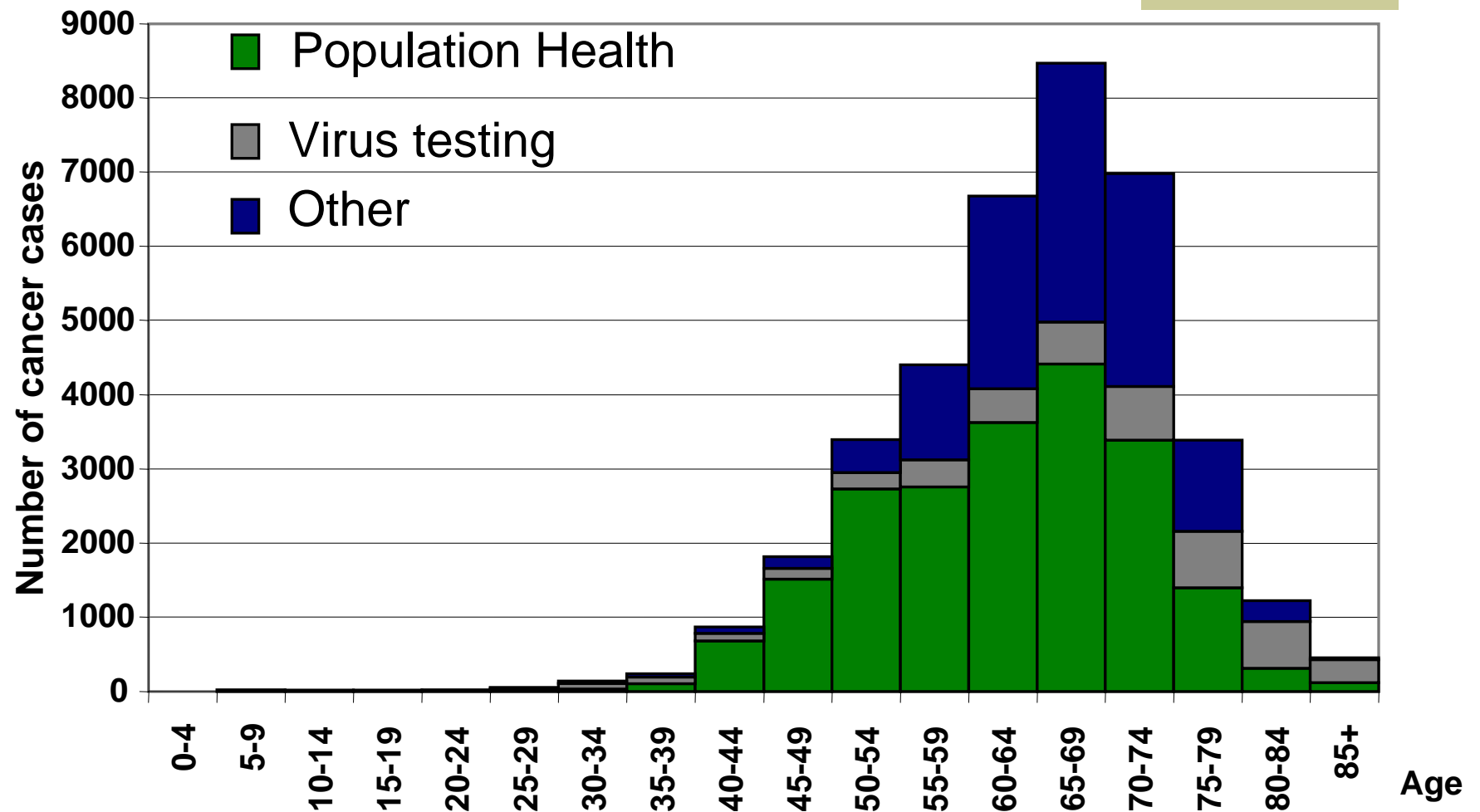
- Mobile Clinic Health Examination Survey 1966-1976 ● rural ● urban ● industry
- Reykjavik Study 1967-1996 ●
- Janus, health examinations (1972-1978) (1981-1992)
- Janus, Red Cross donors 1973-2000 +
- Malmö Preventive Medicine 1974-1991 ▲
- Maternity Cohort, Northern Sweden 1975+ (+ neighbouring areas 1984-1990)
- Maternity Cohort, Iceland 1980+
- Helsinki Heart Study 1980-1982 ▲
- Maternity Cohort, Finland 1983+
- ATBC Study 1984-1988 ✕
- Västerbotten Intervention Program (VIP) 1985+ =
- MONICA 1986/1990/1994/1999/2004 ✕
- Malmö Microbiology 1986+ (1969+) ▨
- Malmö Diet and Cancer 1991-1996 ●
- Mammography screening 1995+ ●●●



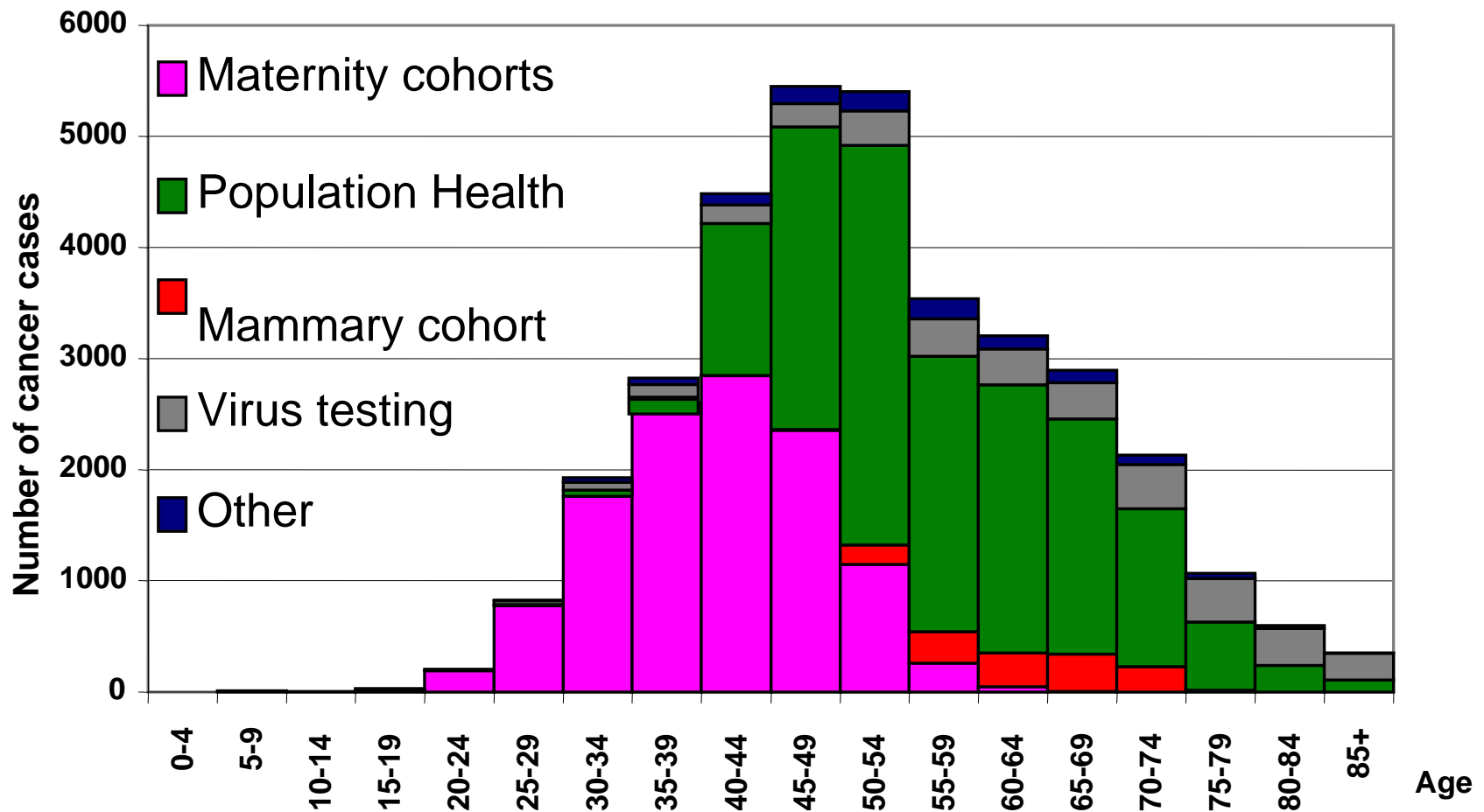
Annual numbers of registered cancer cases among subjects in the Nordic biobanks diagnosed after serum donation, by region.



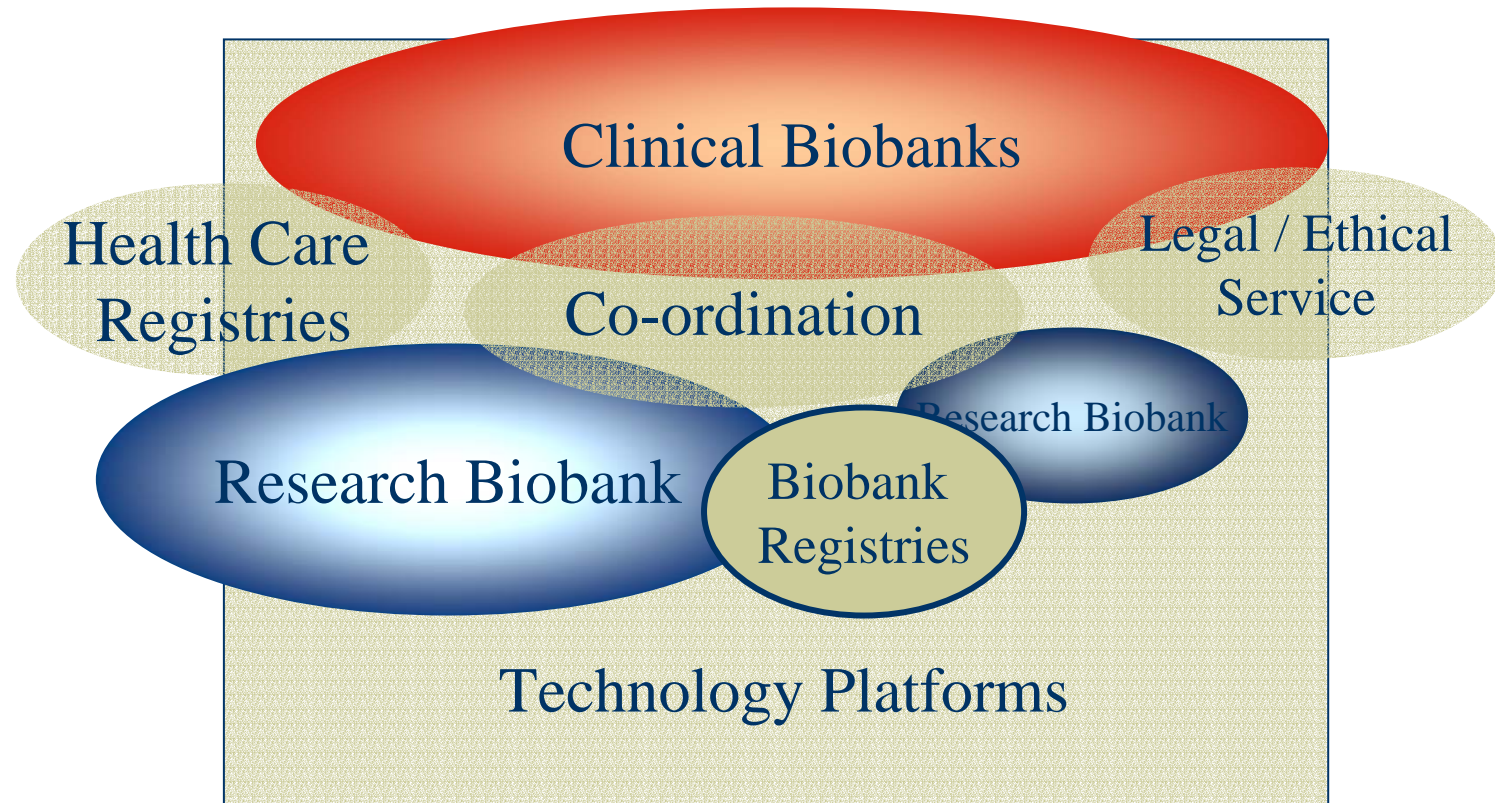
Number of male cancer cases among blood donors in the Nordic biobanks



Number of female cancer cases among blood donors in the Nordic biobanks



The Regional Biobank Center



Regional Biobank Co-ordinator

Provide advice concerning:

- Ethical approval
 - Consent forms (broad general consent, etc.)
- Registration of new biobank
- Study design linking to
- Available registries
- Available samples in existing biobanks
- QC processes, e.g coding of samples

Technical Materials and Services

- ◆ Produce project specific referral forms
- ◆ Sample tubes, labels, storage containers
- ◆ Robotic (traceable) sample handling
- ◆ IT registration and documentation of sample flow
- ◆ QA'd limited access storage facilities at room temp, +4°C, -20°C, -80°C and -140°C

Research strategy

- ◆ Is my favorite disease inherited?
 - Twin register,
 - Multigeneration register

Search for cases and/or controls

- Cancer register,
- Diagnosis register

Research strategy

- ◆ Identify biological samples from cases/controls
 - Biobank registries
- ◆ Retrieve coded samples / information
 - Perform biochemical / genetic tests using available technical platforms

Research strategy

- ◆ Recruit participants to a prospective study
 - Standardized questionnaires
 - Standardized phenotypic studies (BP, BMI, etc.)
 - Standardized sampling and storage of aliquots
- ◆ Research on all participants / subpopulations
 - Perform biochemical / genetic tests using available technical platforms
 - Statistical and epidemiological methods

Thank you

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Eero Pukkala FCR, SPH



Region Skåne

access, quality, security

