15 Swedish research projects

with blood samples and health data available for future research

Version 1.3.

BIOBANK SWEDEN

Preface

Swedish biobanks store samples and data from a multitude of research projects. These samples and data are available for use in medical research. The Swedish personal identity number facilitates the combination of samples and data with data from national health registers and medical records. This makes it possible to study a large number of issues, for example, disease risk factors or signals of incipient diseases in samples obtained before a disease has become apparent.

This report describes 15 Swedish medical research projects that have sample collections stored in Swedish biobanks. These research projects welcome other researchers to use the available blood samples and health data. This is not a complete list, and a more extensive catalogue of Swedish sample collections and cohort studies can be found in the BBMRI-ERIC Directory and the Maelstrom Catalogue, respectively.

The report aims to make it easier for researchers to identify projects that they would like to collaborate with. The project descriptions provide information about what research areas and study designs each research project is most suitable for. The terms for collaboration vary from project to project when it comes to, for example, costs, support functions, ethical review requirements, access to samples, possibility of linkage with other datasets, need for scientific collaboration, and co-authorship requirements upon publication.

We hope that this introduction to a selection of Swedish medical research projects will result in more researchers taking the opportunity to use these often unique and excellent sample collections to a greater extent.

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The report aims to make it easier for researchers to identify projects that they would like to collaborate with.

Aim and method

This digital brochure aims to provide an easily accessible overview of major research projects with sample collections that are available for future national and international research.

Cohorts with sample collections listed under Biobank Sweden's network in the BBMRI-ERIC Directory and/or included in the list of biobank cohorts on Biobank Sweden's website were invited to be part of this compilation.

Between November 2021 and January 2022, 30-minute interviews were conducted with contact persons for each study that had expressed an interest in participating in the brochure. A draft of each summary was written based on the interviews and information collected from the studies' websites. The study contact persons were then asked to edit the draft and approve the final content.

The brochure is available on Biobank Sweden's website. It will also be distributed via Biobank Sweden's Sample Service Coordinators, located at the universities or university hospitals in Umeå, Uppsala, Stockholm, Örebro, Linköping, Gothenburg and Lund, all of which offer enhanced biobanking services.

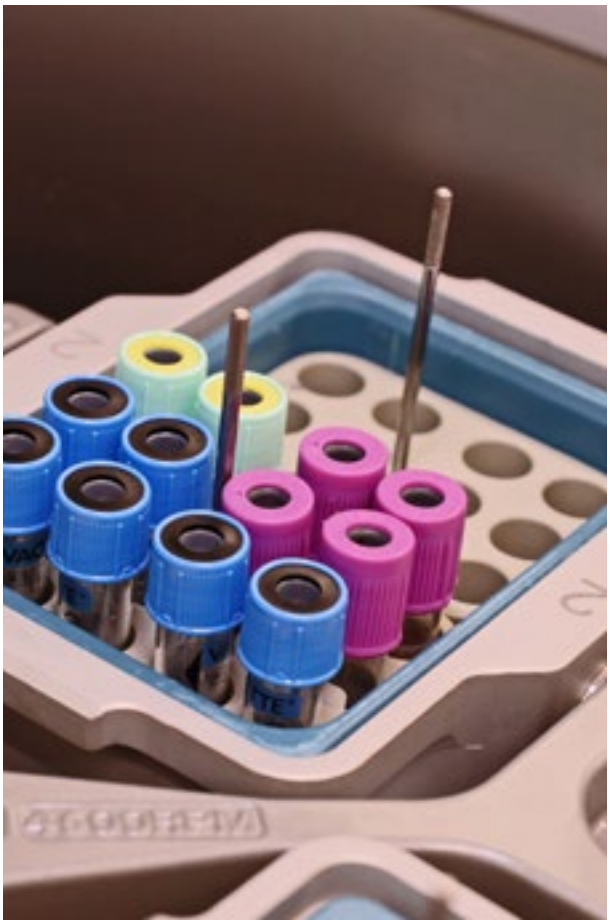
For questions regarding the brochure, please contact Ulrika Morris (Ulrika.morris@umu.se) or Alexander Hertzberg (alexander.hertzberg@regionstockholm.se).

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

List of biobank cohorts

Biobank Sweden's network in the BBMRI-ERIC Directory

The Cohorts.se network in Maelstrom



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Northern Sweden Health and Disease Study (NSHDS)

The Northern Sweden Health and Disease Study (NSHDS) combines three prospective population-based cohorts with questionnaire data and accompanying sample collections. NSHDS includes the Västerbotten Intervention Programme (VIP); Northern Sweden monitoring of trends and determinants in cardiovascular disease (MONICA study in northern Sweden); and the Mammography Screening Project. Protocols for sample collection in these three cohorts are harmonised, as is a large portion of the data from VIP and MONICA.

Some facts:

- VIP started in 1985; data and sample collection are ongoing. The cohort includes over 100 000 individuals, mainly aged 40 to 60 years. VIP participants registered between 1992 and 1996 (approximately 25 700 individuals) are also included in the EPIC cohort.
- MONICA is a population-based study on diabetes and cardiovascular diseases. Eight public health screenings have been conducted in Norrbotten and Västerbotten (1986, 1990, 1994, 1999, 2004, 2009, 2014, and 2022). Approximately 13 000 randomly selected 25–74-year-olds have participated so far.
- The mammography screening project includes 28 800 women, of whom 95% were aged 48 to 70 years upon registration. Samples and data were collected from 1995 until 2006 in conjunction with mammography screening in Västerbotten.
- The three NSHDS sub-cohorts contain over 140 000 participants combined. Amongst these, 129 000 have submitted samples, half of which have submitted samples more than once. Furthermore, there is a large overlap with other cohorts such as U-CAN and SCAPIS. Biomarkers can be followed over time and before the onset of a disease. This is currently being developed further by integrating the cohorts into the PREDICT project.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For studies requiring high-quality samples, such as studies involving biomarkers.
- For case-control studies in samples taken before disease onset, and where cases are characterised with clinical information from medical records, quality registers, or tissue analyses.
- For studies requiring a time series, for example samples collected at 40, 50, and 60 years of age.
- For studying trends over time, for example when measuring the presence of substances in biological samples collected from a population over time.

- Samples have been collected following the same standard operating procedures as are used today, with registered fasting status. Plasma, erythrocytes, and buffy coat are frozen within one hour of sampling. Samples are kept for a maximum of one week at minus 20°C, after which they are stored at minus 80°C.
- Data related to lifestyle factors and diet are available. It is also possible to link samples and data to disease registers and clinical files.

Contact information: Interested researchers are asked to contact the The Section of Biobank and Registry Support, Umeå University. Email: info.brs@umu.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

NSHDS

The EPIC cohort

The PREDICT project

MONICA-Northern Sweden

Späth et. al 2024 NSHDS

LifeGene

LifeGene was started in September 2009 and is a population-based prospective cohort study with over 50 000 participants aged 0–95 years. The KI Biobank stores blood, serum, and urine from approximately 30 000 participants. Seven Swedish universities with medical faculties stand behind LifeGene: Karolinska Institutet (host institution), Lund University, the University of Gothenburg, Linköping University, Uppsala University, Örebro University, and Umeå University.

Some facts:

- Those invited to participate in the study were 18–50 years old. Those invited were in turn able to invite family members to participate. Self-registration to LifeGene was also allowed.
- LifeGene baseline data collection comprised two components, an online questionnaire with detailed information about exposures and health status and a health assessment including sample collection.
- The questionnaire was answered annually, whilst the health assessment took place on one occasion at enrolment. Data collection was completed in autumn 2019.
- For certain age groups, the questionnaire data and results from the health assessment have been linked to other registers such as national health registers.
- DNA, whole blood, serum, and plasma were only collected at the start of the study.
- The blood samples were placed in a cold chain within one hour of collection.
- Biological materials have been used to refine the cohort by generating new variables including more genotype data.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- This study is ideal for nested–cohort, case–control studies that benefit from repeated, detailed information that can be used to investigate associations between exposures and outcomes of somatic and mental health.
- Biological samples collected during baseline examinations are available for scientific research in all medical and behavioural science disciplines following project specific ethical approval and scientific review of the application. The biological materials are not available to commercial entities.
- Many epidemiological studies have combined data from LifeGene and EpiHealth, as they have similar study designs but different age distribution.

Contact information: Interested researchers are asked to contact Nancy Pedersen, LifeGene, Karolinska Institutet. Email: nancy.pedersen@ki.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

LifeGene

Almqvist et al. 2011
LifeGene

The Swedish Twin Registry (STR)

The Swedish Twin Registry (STR) is the world's largest population-based twin registry and is managed by Karolinska Institutet. The registry was created in the 1960s and has since formed the basis of several research projects that cover a broad spectrum of public health issues such as allergies, cancer, dementia, and cardiovascular diseases. STR contains data on approximately 107 000 sets of twins born since 1886. The zygosity (identical or fraternal twins) of 87 500 twins is known, making STR an invaluable resource for medical research.

Some facts:

- National questionnaires and telephone interviews regarding self-reported health and exposures have been conducted for different birth cohorts since the 1960s.
- Additional information about diseases and prescribed drugs can be accessed via links to Swedish health registers.
- KI Biobank currently stores DNA from 60 000 twins and serum from 12 600 twins.
- Metabolomics (Nightingale) data, blood pressure, height, weight, BMI, waist and hip measurements and key blood markers such as creatinine, cystatin C, IgA, total cholesterol, HDL, LDL, triglycerides, CRP, glucose, HbA1C, ApoA1, ApoB and haemoglobin are available from approximately 12 600 older twins.

Contact information: Interested researchers are asked to contact Patrik Magnusson, The Swedish Twin Registry, Karolinska Institutet. Email: patrik.magnusson@ki.se or str-research@meb.ki.se.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For projects where twin studies can be used for increasing etiological understanding. For example:
  - » Heritability, variance partitioning, uni-, bi- and multi-variant analyses.
  - » Co-twin control analyses (causality, check for confounding from genetics and shared environmental conditions when growing up).
  - » Genome wide association studies (GWAS) on individuals and fraternal twins (the latter immunised against confounding by population stratification).
- STR is also suitable for "regular" GWAS, as well as studies on polygenic index that are calculated and available. GWAS have been conducted on approximately 52 000 participants, and the genotypes can be used for analyses of various outcomes such as diseases and behaviours.
- For research questions requiring population-based, longitudinal assessments of questionnaire responses about exposure, health (mental and physical), and lifestyle, or samples collected before illness developed (incident cases).
- For investigations that need the ability to include new questionnaire data in rolling research studies.
- For projects using chromosomal DNA from blood or saliva and/or serum-based measurements.

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

The Swedish Twin Registry

Zagai et al. 2019 STR

Magnusson et al. 2013 STR

Malmö Preventive Project (MPP)

The Malmö Preventive Project (MPP) is a prospective cohort study. In 1974, all men in Malmö, born 1921–1949 were invited to participate in the study. Women born 1926–1949 were later also invited to participate. The purpose was to chart cardiovascular risk factors and alcohol misuse among the local population, and then invite at-risk individuals to participate in an intervention programme. During the follow-up, DNA was used to analyse genetic risk of type 2 diabetes, cardiovascular disease, and certain forms of cancer. When the project ended in 1991, approximately 22 000 men and 11 000 women had participated in the study (71% participation rate).

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For prospective studies for predicting primary onset of disease, that can benefit from a long-term follow up period and the possibility of studying exposure (measured in biological samples) and incidence of disease during the follow-up.

Some facts:

- The baseline examination included a questionnaire that primarily addressed lifestyle and socio-economic factors.
- All participants provided a blood sample and underwent a physical examination where their blood pressure, height, weight, and lung function were measured. Several laboratory parameters were analysed immediately. Plasma and serum were stored at minus 20°C.
- Approximately 6 100 individuals (mainly men) underwent a second examination five to ten years later.
- Between 2002 and 2006, those who participated in the baseline examinations were invited to a follow-up examination. It included a shortened questionnaire and blood sample collection, from which serum, plasma and DNA are stored. A total of approximately 11 500 men and 6 500 women participated in the follow-up examination.
- Each year, MPP is matched against the Swedish Cancer Register, the Regional Tumour Register, Lund, the Swedish Cause of Death Register, Statistics Sweden's population register (for identifying those who have emigrated), the National Patient Register, and local and national stroke and heart attack registers.
- Together, MPP and Malmö Diet Cancer have examined 50 000 of Malmö's residents. This is an open resource, and all researchers are welcome to apply for access to data and biological materials. More than 1000 applications have been received since 2006; fewer than 20 have been rejected to date.

Contact information: Interested researchers are asked to contact Olle Melander, Department of Clinical Sciences, Lund University. Email: olle.melander@med.lu.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

The Malmö Cohorts

References -MPP

Malmö Diet Cancer (MDC)

The Malmö Diet and Cancer Study (MDC) is a prospective cohort with the primary objective of examining the link between diet and the subsequent risk of cancer. In total, 17 000 women (born 1923–1950) and 11 000 men (born 1923–1945) were recruited in Malmö between 1991 and 1996. This is the equivalent of a 40% participation rate.

Some facts:

- The MDC baseline examination (1991–1996) comprised a questionnaire about lifestyle, socio-economic factors, medicines, previous illness, dietary intake measurements, and body constitution.
- All participants provided blood samples that were separated and stored at minus 80°C or minus 140°C. DNA has been extracted from all individuals, and GWAS data is available for almost all participants.
- Approximately 6 000 men and women were examined in the MDC cardiovascular sub-study (1992–1999). The aim of the sub-study was to chart cardiovascular risk factors and early atherosclerosis. The participants provided additional fasting blood samples. Ultrasound technology was used to determine the thickness of the carotid artery.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For prospective studies for predicting primary onset of disease, that can benefit from a long-term follow up period and the possibility of studying exposure (measured in biological samples) and incidence of disease during the follow-up.

- All living participants were contacted during a 5-year re-examination (1997–2001) and asked to complete the survey for a second time. Approximately 22 000 individuals responded.
- Around 3700 individuals participated in a re-examination of individuals in the cardiovascular MDC sub-study (2007–2012). The re-examination comprised a questionnaire, measuring body constitution, blood pressure, oral glucose tolerance test, carotid ultrasound examination, and measuring arterial stiffness, in addition to a blood test.
- The Malmö Offspring Study, MOS, was launched in 2013 to examine the children and grandchildren of previous MDC participants.
- Each year, MDC is matched against the Swedish Cancer Register, the Regional Tumour Registry, Lund, the Swedish Cause of Death Register, Statistics Sweden's population register (for identifying those who have emigrated), the National Patient Register, and local and national stroke and heart attack registers.
- MDC is part of the EPIC cohort that was initiated to examine the relationship between diet, nutrition, lifestyle, environmental factors and the occurrence of cancer and other chronic illnesses. Ten European countries are involved in this study, and data and biological material from approximately 550 000 people are available.

Contact information: Interested researchers are asked to contact Olle Melander, Department of Clinical Sciences, Lund University. Email: olle.melander@med.lu.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

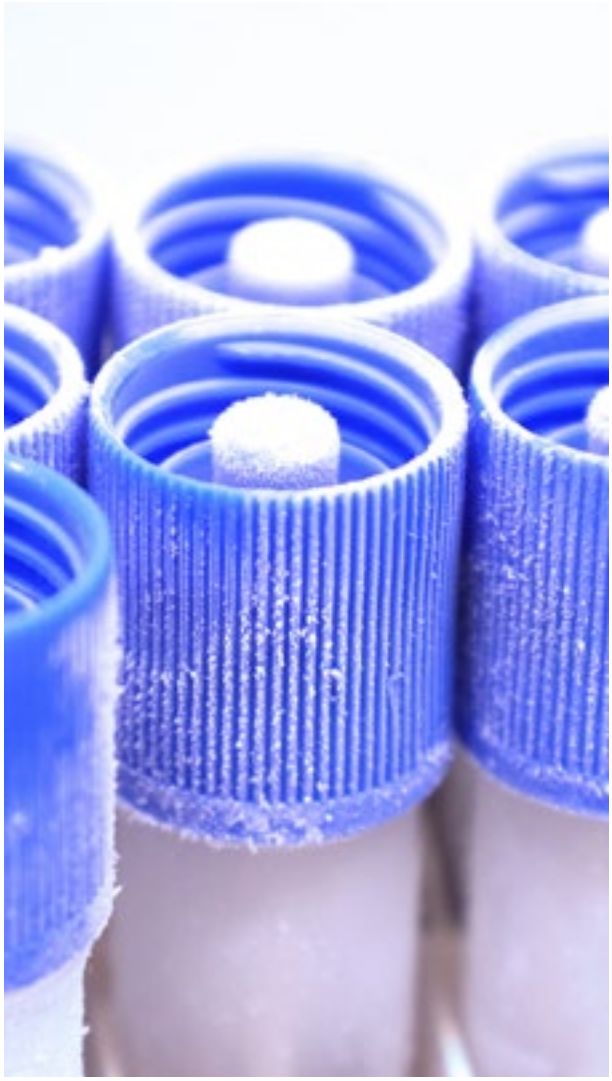
The Malmö Cohorts

The EPIC study

References -MDC

The Malmö Offspring Study (MOS)

The Malmö Offspring Study (MOS) started in 2013 and was completed in December 2021. The study aims to chart family patterns behind major common diseases based on gene–environment interaction. The aim is to provide access to new information about how diseases are spread within families – not simply genetic heritability, but also lifestyle, social patterns, and health habits. The study is a collaboration between Lund University and Region Skåne and is funded by the EU. A total of 5250 individuals have been examined and a mid-way review in 2017 has assured the data quality for 2600 of the participants. The participant rate among the invited children and grandchildren of participants in the cardiovascular Malmö Diet Cancer (MDC) sub-study is 48%.



WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For prospective studies for predicting primary onset of disease, that can benefit from data collected from parents and grandparents as well as the possibility of studying exposure (measured in biological samples) and incidence of disease during the follow-up.

Some facts:

- Health assessments have been conducted as part of the study to chart family patterns, primarily behind cardiovascular diseases and diabetes.
- Participants are the children and grandchildren of index persons (Generation 1) who were previously examined as part of the cardiovascular sub-study in the Malmö Diet and Cancer Study (1992–1996). The children are now 45–60 years old, and the grandchildren 18–40 years old.
- MOS involves a physical examination, questionnaire, blood test, technical examinations, diet registration and urine and stool samples. Samples, including DNA samples for genetic analyses, are stored in Region Skåne's biobank (BD47).
- The technical examinations include carotid ultrasound examination, measuring arterial stiffness, 24-hour blood pressure (central and peripheral) ankle-brachial index, spirometry, cognitive tests, estimate of glucose metabolic control and transdermal advanced glycation end products.

Contact information: Interested researchers are asked to contact Olle Melander, Department of Clinical Sciences, Lund University. Email: olle.melander@med.lu.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

The Malmö Cohorts

Brunkwall et al. 2021
MOS

Swedish Infrastructure for Medical Population-Based Life-Course and Environmental Research (SIMPLER)

The Swedish Infrastructure for Medical Population-Based Life-Course and Environmental Research, SIMPLER, is a national research infrastructure consisting of the prospective, population-based Swedish Mammography Cohort (SMC) and the Cohort of Swedish Men (COSM). It includes approximately 110 000 people born 1914–1952, resident in Uppsala, Västmanland, and Örebro County. Since 2018, SIMPLER has been managed by a consortium of Uppsala University (host institution), Karolinska Institutet, Chalmers University of Technology, and Örebro University, in collaboration with the regions of Uppsala, Västmanland and Örebro County.

Some facts:

- Between 1987 and 1990, all women born 1914–1948 and resident in Uppland and Västmanland were invited to participate in SMC in conjunction with mammography screening. The first follow-up took place in 1997. The cohort comprises 66 443 participants, with DNA samples from approximately 12 000 participants, and other biological samples from 7654 participants.
- Between 1997 and 1998, men born 1918–1952 and resident in Västmanland and Örebro County were invited to participate in COSM. The cohort comprises 45 906 participants, with DNA samples from approximately 31 162 participants, and other biological samples from 4754 participants.
- Follow-ups of both cohorts took place in 2008–2009 and 2019. The women have answered at least 6 questionnaires, and the men at least 5.
- Clinical sub-cohorts are available for 7654 women and 4754 men where additional samples have been taken and body composition measured.
- The biobank contains blood (serum, plasma, buffy coat), urine, stool, and fatty tissue samples stored at minus 80°C, and DNA samples stored at minus 20°C. The biobank comprises over 800 000 samples and new samples are added continually.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For studies requiring an older cohort with high participation rates, long follow-up period and detailed, repeated measurements of diet and lifestyle factors; repeated matching against national registers, and collection of clinical data and biological samples.
- As the cohorts are divided both geographically and by sex, it is possible to verify findings in other parts of the cohort.
- SIMPLER aims to analyse samples so researchers can access analysis data (i.e., a one-time cost for analyses). At hand is for example GWAS data from approximately 48 000 individuals, and clinical biochemical measurements and proteomic- and metabolomic data from approximately 13 500 individuals. In 2022, microbiome data will be generated for approximately 7300 individuals.
- Studies of high scientific value that include analyses of informative biomarkers in the entire sub-cohort are prioritised in order not to consume the limited samples.

Contact information: Interested researchers are asked to contact Anna-Karin Kolseth, project coordinator of the SIMPLER infrastructure, Uppsala University. Email: simpler@surgsci.uu.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

SIMPLER

Harris et al. 2013 SMC and COSM

Uppsala-Umeå Comprehensive Cancer Consortium (U-CAN)

U-CAN has since 2010 collected blood, tissue samples and clinical information from cancer patients within a wide range of diagnostic areas. This biobank resource for cancer research currently includes material and data from more than 23 000 individuals. Samples are stored in Uppsala Biobank and Biobanken Norr in Umeå. U-CAN's overall objective is to be a resource for research aiming to develop new diagnostic methods, enable early cancer discovery, or to predict the most successful form of treatment at an individual level. U-CAN is a collaboration between Uppsala University, Umeå University, Stockholm University, and KTH Royal Institute of Technology.

Some facts:

- Unique to U-CAN is that samples and data from the same patient are collected over time. Samples and information are typically collected at diagnosis and at multiple time points after various treatments.
- U-CAN collects samples for the following diagnoses: Colorectal cancer, haematological malignancies and lymphoma, brain tumours, neuroendocrine tumours, prostate cancer, breast cancer, gynaecological cancers, lung cancer, oesophageal and stomach cancer, head-neck cancer, cancer in organ transplant patients, and liver and pancreatic cancer. It also contains samples collected in a specific Cancer-Covid study.
- Blood samples are sent to a central laboratory for rapid centrifugation, aliquoting, and biobanking. Genomic DNA, serum, and plasma are available. The time between blood sampling and freezing is generally less than 4 hours and the time from arm to freezer is registered for each sample.
- Un-fixated tumour- and adjacent normal tissue is processed to produce paraffin embedded blocks (for diagnostics), and fresh-frozen tissue blocks for biobanking. All frozen samples are OCT-embedded, frozen, and stored at minus 70°C. Sections from frozen samples are H/E-stained and annotated for use in research. Consecutive preparation of tumor- or tissue-normal DNA and total RNA can be obtained from fresh-frozen sections.
- Nearly 150 research projects have used materials from U-CAN, resulting in 150 scientific publications to date.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For all scientific questions related to cancer and in need of samples and clinical data from cancer patients, especially studies requiring longitudinal samples and in particular follow-up data.
- For example, for questions regarding risk factors for the relapse of cancer, mutations and drug resistance, retrospective analysis of prognostic mutations, or questions related to diagnosis and treatment of tumours.

Contact information: See the U-CAN website (https://u-can.uu.se/om-u-can/kontakta-u-can). Email: u-can@igp.uu.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

U-CAN

Glimelius et al. 2018
U-CAN

Karolinska Mammography Project for Risk Prediction of Breast Cancer (KARMA)

KARMA is a prospective cohort study with the overarching objective of reducing breast cancer mortality and the number of breast cancer cases. The KARMA project is led by a group of researchers at the Department of Medical Epidemiology and Biostatistics at Karolinska Institutet. The project was conducted in collaboration with researchers and healthcare staff at Karolinska Institutet, Södersjukhuset Stockholm, Skåne University Hospital in Lund, Helsingborg Hospital, Unilabs mammography, and the Regional Cancer Centre Stockholm-Gotland.

Some facts:

- KARMA links a comprehensive information database to biological samples to enable the identification of individual breast cancer risks with regard to established risk factors such as breast density, genetic factors, and lifestyle.
- The majority of blood samples and questionnaire responses were collected between 2010 and 2013, with over 71 000 women choosing to participate in the KARMA study.
- A blood sample was taken when the women joined the study. DNA, plasma, and whole blood are stored in the KI biobank. Approximately 25% of the women have provided blood samples more than once.
- Mammograms are continuously collected whenever a Karma participant performs a mammography. There is an increase of approximately 25 000 images per month.
- The participants have answered a detailed questionnaire on several occasions and have provided consent for linkage to medical records and national disease registers, such as the Cancer Register, Cause of Death Register, and the Prescribed Drug Register
- Tumour samples are available for a small subset of participant but has not been collected in a coherent way.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For studying factors that influence the risk or prognosis for breast cancer.
- For access to a large number of mammography images for AI analyses.
- For those interested in studying genetic factors and/or biomarkers in plasma associated with breast cancer.
- For self-reported variables regarding quality of life, sense of coherence, diet, physical activity, and other factors that can be related to breast cancer.
- The informed consent only covers studies into the risk and prognosis of breast cancer. The Swedish Ethical Review Authority has granted studies in other areas in a few cases.

- Biopsies of normal tissues have been taken from a selected group of healthy women.
- KARMA is part of the Breast Cancer Association Consortium which includes approximately 100 international research groups, all with the common aim of identifying genetic changes that influence the risk of breast cancer.

Contact information: Interested researchers are asked to contact Per Hall, Karolinska Institutet. Epost: per.hall@ki.se or karmastudy@ki.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

Gabrielson et al. 2017
KARMA

KARMA for researchers

Human Glioblastoma Cell Cultures (HGCC)

Human Glioblastoma Cell Cultures (HGCC) is a collection of well-characterised cell lines derived from surgical samples from patients with glioblastoma. The biobank currently holds 100 cell lines and is an important resource for human glioblastoma cell lines. The HGCC biobank is the result of a collaboration between researchers Lene Uhrbom, Bengt Westermark, Karin Forsberg Nilsson, Sven Nelander and Fredrik Swartling at the Division of Neuro-Oncology, at the Department of Immunology, Genetics and Pathology, Uppsala University.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For studies requiring well-characterised glioblastoma cell lines cultured in stem cell media.
- The cell lines and accompanying data are open resources that facilitate the study of glioblastoma in basic research and drug development.

Some facts:

- HGCC is a biobank effort to provide a panel of recently established and well-characterised glioblastoma cell lines from patient samples.
- It is possible to explore gene expression, copy number variation, and clinical data for the HGCC cell lines on the HGCC website (www.hgcc.se).
- To apply for access to HGCC cell lines, contact the HGCC project manager via mail@hgcc.se. The first stage of the process involves establishing a material transfer agreement with a list of the cells and a brief project description. A distribution fee covers the running costs for maintaining the biobank and distributing the cells.
- So far, the cell lines have been used in collaboration with 50 laboratories in 17 countries.

Contact information: Interested researchers are asked to contact project manager Tobias Bergström, Department of Immunology, Genetics and Pathology, Uppsala University. Email: mail@hgcc.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

HGCC

Xie et al. 2015 HGCC

Johansson et al. 2020 HGCC

The Importance of Migration and Ethnicity for Diabetes Development in Malmö (MEDIM)

MEDIM is a population-based cohort aiming to chart and identify risk factors for developing pre-diabetes and diabetes in adults living in Malmö, born in Iraq or Sweden. Between 2010 and 2012, 2220 residents in Malmö were invited at random to participate in a health assessment where glucose tolerance was tested, and fasting samples were taken. Participants were aged between 30 and 75 at time of registration. Full blood, plasma, and serum samples were collected from the participants and stored in Region Skåne's biobank.

Some facts:

- Study participants were invited to participate in a health assessment with glucose tolerance testing, in order to identify individuals with pre-diabetes who were at a high risk of developing diabetes over the coming years.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For those interested in looking into population data. Cross-sectional data with several variables have been collected, including blood pressure, pulse, lifestyle habits (including physical activity with Actigraph GT3X), family history, and medication.
- For those interested in analysing biomarkers in the general population and/or wanting to compare country of birth and differences in metabolic biomarkers.
- For those interested in data from glucose tolerance testing to examine mechanisms for glucose regulation.

- New diabetes cases detected in conjunction with the health assessment are also included in the All New Diabetics in Skåne (ANDiS) study that stores samples in a separate biobank.
- An intervention study aimed at individuals at a high risk of type 2 diabetes has been conducted in a follow-up to the cohort study, with the aim of studying whether lifestyle programmes can reduce the risk of developing diabetes.
- The MEDIM cohort is thoroughly phenotyped. It represents one of the largest cohorts on glucose tolerance test, fasting samples, and assessment of Actigraphs in middle eastern immigrants and native Swedes.

Contact information: Interested researchers are asked to contact Louise Bennet, responsible researcher for the MEDIM-study, Lund University. Email: louise.bennet@med.lu.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

MEDIM

Bennet et al. 2014 MEDIM

The Environmental Determinants of Diabetes in the Young (TEDDY)

TEDDY is an international study focusing on three diseases, autoimmune (type 1) diabetes, coeliac disease, and autoimmune thyroiditis. The study began in 2004 and will run in Skåne, Finland, USA, and Germany until 2025. A total of 8667 children have joined the study, of which 2528 (29%) are from Sweden. As of December 2021, 5285 children remain in the study, of which 1635 are in Sweden. So far, 422 (109 in Sweden) children have developed diabetes and 1414 have exited the study as they have turned 15, thus reaching the age limit of the study. TEDDY is financed by the National Institutes of Health, USA's healthcare authority.

Some facts:

- Enrolment in the TEDDY study took place between 2004 and 2010. Umbilical cord blood sampling was carried out on 60 000 new-born babies and was used for genetic analysis of increased hereditary risk for autoimmune diabetes. The children who participate in TEDDY are followed up until they turn 15 years old.
- Follow-up takes place 2–4 times per year. Each follow-up involves an interview and questionnaire, weight and height measurements, blood test, nasal swab, and urine sample. Once per year, the participant's physical activity levels are registered, and a toenail sample is provided to measure antioxidants and cortisol (long-term stress).
- Diabetes, coeliac, and thyroid autoantibodies are measured using the blood samples. The aim is to determine why some children develop autoantibodies and which hereditary and environmental factors are involved in the disease's development.
- Dietary assessments are also an important component of the TEDDY study. The foods that children do and do not eat are included in several of the theories as to why children develop autoimmune diabetes and coeliac disease. Dietary assessments intend to determine the dietary factors that could increase or reduce the risk of a child developing autoimmunity against their insulin-producing cells, autoimmune thyroiditis, or coeliac disease.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For all research questions requiring access to longitudinal data and samples taken as a child develops.
- All data and samples in the TEDDY study are available upon application to the NIH National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Central Repository. The children participating in the study are at increased hereditary risk of developing autoimmune diabetes. Around 10% of the children have developed one or more autoantibodies and 5% have developed diabetes.
- Blood samples on filter paper are available for research questions related to newborns and have been taken from approximately 70% of all children born in Skåne between 2004 and 2010. Filter paper blood samples are also available for one-third of the children's mothers. The samples can be traced using the mother's personal identity number and are stored at room temperature at the Region Skåne biobank.

- The TEDDY study replaced the Diabetes Prediction in Skåne (DiPiS) study. An advantage of the TEDDY study is that it includes a large number of children from four different countries (Sweden, Finland, Germany, and the USA).

Contact information: Interested researchers are asked to contact Åke Lernmark, Professor in diabetes research at Lund University and responsible researcher for the Swedish part of the TEDDY-study. Email: Ake.Lernmark@med.lu.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

TEDDY-studien

The TEDDY study

The Swedish CArdioPulmonary BioImage Study (SCAPIS)

SCAPIS is one of the world's most extensive population-based cohort studies on diseases of the heart and lungs. Over 30 000 participants aged between 50 and 64 from all over Sweden participated in comprehensive examinations. The aim of the project is to identify individual risks for conditions such as COPD, sudden cardiac death, myocardial infarction, and other heart diseases, and begin treatment before the disease emerges. SCAPIS is lead and run by researchers from the universities and university hospitals in Gothenburg, Linköping, Malmö, Stockholm, Uppsala, and Umeå in close collaboration with the Swedish Heart–Lung foundation, which is the main funding body of the study.

Some facts:

- Between 2013 and 2018, 31 154 randomly selected individuals aged 50–64 participated in comprehensive health assessments involving blood tests, ultrasound examinations, computed tomography (CT) and lung function tests, physical activity and a comprehensive questionnaire and questions on dietary habits. The results have been compiled in a data-, image-, and biobank that is unique in the world.
- In March 2021, SCAPIS opened the data service for all researchers linked to Swedish universities. There are approximately 2500 images of the coronary vessels, lungs, and fat distribution throughout the body for each participant. The assessments have resulted in a collection of 30 million data points.
- During 2022, the biobank will issue a call for applications for access to biological materials. Applicants must analyse all participants in the cohort and the volume of samples must be reasonable in relation to the value of the research. Analysis results are to be returned to the cohort.
- The purpose of the biobank is to enrich the cohort with new data. For example, during 2023, genetic analyses and several biomarker analyses of the whole cohort will be added.
- There are several unique elements to SCAPIS; the size of the study, the broad representation, the choice of examination methods, the depth of data, the advanced image technology, and the possibility to link to Swedish registers.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For access to unique data from a large population-based cohort study for reseach on heart and lung diseases.

Contact information: Interested researchers are primarily asked to visit the SCAPIS website. Researchers who wish to apply for data access or who would like to see which variables are available, please visit www.scapis.org/data-access.

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

SCAPIS

SCAPIS for researchers

Bergström et al. 2015
SCAPIS

BIG3

BIG3 is an open prospective longitudinal cohort study in Skåne. Its name, BIG3, refers to three of the most common and widespread diseases caused by smoking – chronic obstructive pulmonary disease (COPD), cardiovascular diseases, and lung cancer. The overarching objective of BIG3 is to increase the understanding of the mechanisms behind these diseases, in order to develop new treatment methods that can lead to earlier, improved, and safer diagnostics for better and more individual-based treatments. Region Skåne is the sponsor and data controller. The project is a collaboration between Region Skåne, AstraZeneca AB, and researchers from Lund University.

Some facts:

- BIG3 focuses on smoking-related diseases: Chronic obstructive pulmonary disease (COPD), cardiovascular diseases and lung cancer.
- Over 60 000 randomly selected individuals in Skåne, aged between 45 and 75 years, were asked to participate in the study by responding to a questionnaire about their health, lifestyle, living environment and tobacco habits.
- Among the 18 000 individuals that have responded to the survey, approximately 5500 have participated in examinations at Skåne University Hospital, focusing on cardiovascular and lung function. The examinations included an ECG, lung function assessment and blood sampling.
- Those who participated in the examinations have also responded to a more comprehensive questionnaire.
- A sub-group of approximately 2000 participants also underwent CT scans of their heart and lungs.
- Data collection for this research project is entirely digital. Metadata for sampling, for example the times and temperatures, are well-documented directly in a specially developed laboratory information management system.
- The blood samples were partly analysed directly for a number of markers, and partly stored in the biobank. The time from collection to freezer is consistently below two hours. Blood has also been collected in PAXgene blood RNA tubes and is stored in the biobank.
- Informed consent includes follow-up via registers.
- In November 2019, follow-up examinations began, however these were paused during the COVID-19 pandemic.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- The follow-up of cohort participants is ongoing. As no infrastructure is in place for obtaining the samples, this sample collection is currently unavailable for research collaborations. Nevertheless, the aim is to create an accessible research platform in the future.

Contact information: Interested researchers are asked to contact Ulf Malmqvist, Clinical Studies Sweden – Forum South. Email: ulf.malmqvist@skane.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

BIG3

EIMS, IMSE and other case-control studies and clinical trials in multiple sclerosis

Epidemiological Investigation of Risk Factors for Multiple Sclerosis (EIMS) is a population-based case-control study in 16–70-year-olds. The Immunomodulation and Multiple Sclerosis Epidemiology study (IMSE) comprises 11 prospective pharmaceutical studies. Together with other studies such as Genes and Environment in Multiple Sclerosis (GEMS), and COMBAT-MS, these form a large sample collection with samples from approximately 12 000 patients with multiple sclerosis and 8 000 control subjects. The samples are stored in the KI Biobank.

Some facts:

- EIMS and GEMS have similar study designs. EIMS is a national multi-centre study, where MS patients have been recruited via 40 study centres. Recruitment for GEMS took place using the national MS register. In 2021, data was collected for a follow-up study that included MS patients who had previously responded to the EIMS questionnaire. The aim of the study was to examine how environment and lifestyle habits affect the progression of MS.
- The IMSE pharmaceutical studies involve treating MS patients that fall within the parameters of the IMSE study. Evaluation takes place at the start of the treatment and then once per year in conjunction with the regular doctor's appointment during the patient's pharmaceutical treatment period. Blood tests (plasma and DNA) are taken in conjunction with the first evaluation sessions (0, 12 and 24 months). Control subjects are matched against cases by sex, age, and county of residence. They are invited to complete the same questionnaire about their lifestyle habits and environment and to provide a blood sample.
- COMBAT-MS is a multi-centre prospective pharmaceutical study that compares various treatments as regards to their efficacy, safety, tolerance, and patient satisfaction. The study follows 3700 MS patients over a minimum of three years. Blood tests are taken to measure anti-drug antibodies.
- There is no overlap between MS patients included in EIMS, IMSE and GEMS.

WHEN SHOULD RESEARCHERS TURN TO THIS PARTICULAR STUDY?

- For studies of interaction between various factors (environment and lifestyle habits and genetics).
- For studies requiring high-quality DNA samples. In addition, genotyping has been performed on the main part of the sample selection, and GWAS data is available for researchers.
- DNA and plasma have been collected in all studies; EIMS also includes serum. However, blood samples have been sent by mail which may have affected plasma biomarkers.
- Materials from the control group can be used for all types of research question and are not limited to MS research. For example, they have been used for studies within psychiatry.

Contact information: Interested researchers are asked to contact Lars Alfredsson, EIMS, Karolinska Institutet. Email: lars.alfredsson@ki.se, Tomas Olsson, IMSE, Karolinska Institutet. Email: tomas.olsson@ki.se, Jan Hillert, GEMS, Karolinska Institutet. Epost: jan.hillert@ki.se

FOR MORE INFORMATION (Click on the QR-codes or scan the QR-code with your mobile phone)

EIMS

COMBAT-MS

Hedström et al. 2014
EIMS och GEMS

IMSE

This document is part of our ambition to promote cohorts with sample collections in Sweden. We welcome all suggestions and feedback for future revisions of this document. **Contact information:**
Ulrika Morris (ulrika.morris@umu.se) and Alexander Hertzberg (alexander.hertzberg@regionstockholm.se).

BIOBANK SWEDEN