

# MultiPark Biobank Access Procedures

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## Overview

### The MultiPark biobank collection

The MultiPark biobank sample collection (MPBC) includes three major parts; information from MPBC questionnaires, blood samples and registry data. At entry, blood is sampled and the questionnaire is answered by the participants and later transferred to a database. The design is thus cross-sectional and will include patients at different stages of the disease at a given time-point. Registry data is usually updated annually allowing for future stratification of patients at entry and at later stages during the project. All samples are stored in Region Skåne's biobank BD47, Medicon Village, Lund. Serum and plasma samples are stored in 96-well format, RNA and DNA is collected and frozen in PaxGene tubes and EDTA tubes, respectively.

### Overview of the access procedure

All samples are part of a primary sample collection in the Region Skåne biobank (BD47). To access sub-samples and clinical data, an application is sent to the MultiPark biobank coordinator. The application is reviewed by the steering group. If access is granted, a full application to the Region Skåne should be completed together with the coordinator. This will be signed by the biobank custodian and submitted by the coordinator. Coordinator, custodian and steering group can contribute to study design as well as interpretation of data. Among these, those contributing to design and/or interpretation of data should be considered as co-authors in resulting publications.

- Healthcare principal: Region Skåne, BD47
- MPBC custodian: (SE, provsamlingsansvarig): Oskar Hansson
- MPBC coordinator: Maria Swanberg (maria.swanberg@med.lu.se)
- MPBC steering group: Maria Swanberg, Oskar Hansson, Håkan Widner and Per Odin

### Research requiring re-contact of participants

The MultiPark biobank sample collection does not allow investigators to re-contact any of the study participants. If contacts are necessary, a specific and separate ethical approval is mandatory.

### Access fees

The fee to access samples relates to costs for sample handling, DNA/RNA extraction and data derivation. It will be payable prior to the release of any data or samples. The fees are defined annually by the MultiPark biobank steering group to ensure that they relate to actual costs. Shipping costs are paid by the applicant.

- Cost per DNA sample: 10 SEK (minimum fee 10.000 SEK irrespective of number of samples)
- Cost per RNA sample: 25 SEK (minimum fee 10.000 SEK)
- Cost per serum/plasma sample: 5 SEK (minimum fee 5.000 SEK)

## Application and review process

### Application form

The applicant Principal Investigator (PI) of a research project using MPBC data and samples is required to complete an **Application Form** and the following attachments:

1. Scientific rationale of project (background and any pilot data; experimental details and design; power calculations; expected value of results; relevant references) (max 5 A4)
2. Ethics approval and specification of any ethical or potentially contentious issues related to the proposed use.
3. Required data and/or quantity and type of samples.
4. Proposed timetable (start; duration; availability of results; publication);
5. Details of funding (or applications for funding);

### Material transfer agreement

- An approved ethical permit with applicable appendices must exist, unless the research is not covered by the original permit.
- For samples sent for analysis, the following **must** be observed:
  - The MPBC custodian continue to be legally responsible for the samples.
  - The samples are pseudonymised/coded.
  - The key to personal data remains with the custodian.
  - Remnants of the samples are returned to the Region Skåne biobank *or* destroyed after completed analysis.

### Publication of findings and return of results

The applicant PI is required to publish the findings of any research deriving from the Resource in an academic journal or on an open source publication site. Approval ahead of publications is not required from the MultiPark Biobank, but the applicant PI should submit them to the steering group at least 2 weeks ahead of an expected date of first public presentation or publication in any format (e.g. meeting abstract, on-line report, paper journal).

All publications should include the acknowledgement “This research has been conducted using the MultiPark Biobank Resource”. All results or data analysis that origin from MBBC samples must be shared with the biobank steering group, after publication or latest 1 year after completed analysis).

/Lund, February 2, 2016