

CCC2000

Access Policy v. 1.0

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Center for Clinical Research and Prevention

The Capital Region Copenhagen

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Contact

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Short summary

The CCC2000 cohort consists of a birth cohort of all liveborn children born in sixteen municipalities in the Copenhagen area, Denmark, through the calendar year 2000, in total N 6090.

The overall aim of the CCC2000 Study is to investigate pre-morbid phenotypes, indicators, and risk factors of mental disorders from birth onwards, and the developing eye from age 11 years.

The cohort has so far been assessed at ages 0-1, 1½ (small subgroup), 5-7, 11-12, and 16-17 years, and regularly followed-up in the Danish national registries.

The CCC2000 is administered research-wise by our steering committee and data-wise by the Centre for Clinical Research and Prevention of the Capital Region of Denmark.

Ethical approval for the CCC2000 study

The CCC2000 is approved by The Danish Data Protection Agency (CSU-FCFS-2016-004, I-Suite 04544) and the Local Committee on Health Research Ethics in Copenhagen (protocol 16023242).

Data policy

In Denmark the European General Data Protection Regulation is applicable.

<https://www.consilium.europa.eu/en/policies/data-protection-reform/data-protection-regulation/>.

All the data collected in the CCC2000 study are defined as sensitive personal data and accordingly cannot be shared publicly. The collected data is uploaded and linked to data from the Danish national registries and analysed through servers at Statistics Denmark (<https://www.dst.dk/en>).

There are limitations on how these data can be shared outside of CCC2000, and outside of Denmark.

Applying for access to data (for researchers only)

Researchers can apply for access to the data in collaboration with CCC2000 researchers by contacting the CCC2000 steering committee.

As such, any requests to access the data must be made following the guidelines described below.

Step 1: If you wish to get access to CCC2000 data for research, you should start by contacting us at bfh-fp-ckff-ccc2000@regionh.dk and very shortly (about 100 words) present your research idea.

Step 2: If your idea is compatible with the purpose of CCC2000, and no similar projects are already planned in the CCC2000-group, you will then be asked to send us a formal short protocol (no more than five A4-pages), which must have clearly stated aims and hypotheses and describe the relevant exposure, outcome and confounders that will be considered, justifying the data you require.

Step 3: Your proposal will then be reviewed by our Steering Committee as soon as possible.

Step 4: If your proposal is approved, you will receive advice on the next stages of the process.

In some cases, approval may be refused due to the lack of relevant data or other obstacles. The Steering Committee also reserve the right to impose additional restrictions as appropriate.

By default, any study using CCC2000 data should include a member of the Steering Committee or a Danish scientist nominated by the Steering Committee.

Charges for access to data

CCC2000 has no basic funding for core activities or research projects.

Currently, we charge a basic fee of 10,000 (ten thousand) Danish crowns per project for use of data to cover administration, data management and costs related to running the database at Statistics Denmark.

Access to data will not be provided until an invoice has been settled or a purchase order number is received by our finance department. VAT will be charged in addition to the table costs, where applicable.

Publication

Any publications and sharing of results from the CCC2000 (i.e. written or orally, scientific or for laypersons) must follow the ICMJE guidelines (<http://www.icmje.org/recommendations/>) and apply to the Danish data legislation in force at any time.

Results should always be presented with CCC2000 participants and cohort members being totally anonymous. Thus, publications must never contain any micro-data through which individual participants could be identified.

It is the senior author's responsibility (together with the primary affiliated CCC2000 researcher) to ensure that any publication of results comply with this policy.

Researchers should inform the Steering committee when a paper is accepted and send through an electronic copy of the final published version.

The Steering committee do not need to see submissions to conferences. However, we request that any talks or posters presented at conferences or other meetings using data from the CCC2000 must include an acknowledgement to the study and the participants along with the CCC2000 study logo.

All press releases on research arising from the CCC2000 must be written in collaboration with the affiliated CCC2000 researcher, and the Steering committee must be informed beforehand.

