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Growing up in Hungary - Cohort '18 Hungarian Birth Cohort Study. Technical report 2. Prenatal wave

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Hungarian Demographic Research Institute 'Cohort '18 - Growing up in Hungary'

Data protection and data management information

1. Introduction

The Hungarian Demographic Research Institute is embarking on a **long-term study called 'Cohort '18 – Growing up in Hungary'**, tracking the development of children born in 2018/2019. This is a unique opportunity to see what it is like to grow up in Hungary today – the kinds of family, social and institutional factors that assist or hinder the healthy development and growth of children. To this end, **we are approaching respondents with questions regarding their children, and the families.** Since growing up and developing depends on many factors, respondents can expect various kinds of questions. Some are psychological, while others have to do with the structure and operation of the family. We are also seeking to gather much information on people's state of health and on how they look after their health. In order to learn about the living conditions of the child, it is important to gain a picture of the family's socio-economic background, habits, values and plans. Also, several questions will touch on the operation and use of the social and healthcare system.

We hope to include over 10,000 respondent mothers in the study. We need to choose them in such a way that they represent the population of the country, as accurately as possible on a small scale. Since data collection starts in the prenatal period, we have used data from the health visitor district system to form the sample. We have selected health visitor districts for the sample from all over the country, and have asked the local health visitors to assist in data collection at the prenatal and the 6-month phases of the survey. In those health visitor districts included in the sample, we would like to involve all pregnant women with a due delivery date between **1 April 2018 and 31 March 2019**, as indicated in their **prenatal care booklet**. The high participation rate enables us to obtain reliable and generally applicable results through the study. Local health visitors invite the pregnant women under their supervision to participate in the study, and they are the ones who provide the women with information. **Participation in the research is voluntary and can be cancelled at any time afterwards. The respondent can quit at any stage of the research and cease to provide information.** The research starts once the informed consent is signed.

Phases of data collection

The proposed research phases involving personal contact are as follows:

- January 2018 – March 2019: health visitor-assisted data collection among the **pregnant women**
- June 2018 – October 2019: health visitor-assisted data collection with the **mother** when the **child is 6 months old**
- April 2019 – April 2020: interviewer-assisted data collection **with the mother when the child is 1 year old**
- 2019–2021: supplementary data collection; contacting **fathers**

- April 2021 – April 2022: interviewer-assisted data collection **with the mother and the child when the child is 3 years old**

This document ‘Data protection and data management information’ aims to inform participants about the structure of ‘Cohort ’18 – Growing up in Hungary’, the process of data collection, and the data management principles and procedures, reassuring participants that the data they provide for the study will be used exclusively for that purpose.

2. Data protection: basic definitions

a) Data manager: the natural or legal person, or an organization not considered a legal person, that specifies the purpose of data management, makes and carries out the decisions regarding data management, or assigns these to be carried out by a data processor. The **data manager** of ‘Cohort ’18 – Growing up in Hungary’ is the **Hungarian Demographic Research Institute** (hereafter: data manager), with the following contact details: electronic contact: nki@demografia.hu; homepage: www.demografia.hu; postal address: H-1525 Budapest Pf. 51; address: 1024 Budapest, Buday László utca 1–3).

b) Respondent: any natural person participating in the present study or supplying data to it, who is defined, identified on the basis of personal data, or identifiable – directly or indirectly – especially a close relative (parent) of the child.

c) Personal data: data that could be associated with a respondent – especially name, identification number, permanent address, contact address, phone number, social security number – along with conclusions that can be drawn in relation to the respondent. Data continues to be regarded as personal so long as it can be associated with the respondent.

d) Assent: voluntary and definite declaration of agreement by the respondent, based on adequate information, providing unambiguous assent to the management of personal data relative to the respondent (either fully comprehensive or restricted to certain procedures).

e) Objection: a declaration by the respondent objecting to the management of personal data related to the respondent and requesting the termination of data management or the deletion of the data being managed.

f) Data deletion: wiping data in such a way that it cannot be reconstituted.

g) Data processing: carrying out technical tasks in relation to data management operations, regardless of the method and tools used to carry out the operations, or the place of implementation.

3. The course of data collection for the study, and the manner of data collection

The respondents in the study are initially pregnant women, and subsequently the children and their parents, collectively called **respondents**. Their participation, the provision by them of data relating to themselves and their children, and the subsequent data management require them to provide so-called ‘**informed consent**’. In the case of pregnant women and mothers who are not yet adults, consent is attested by a legal representative.

Informed consent includes consent to an individual research identification number being assigned to the child of the respondent. Thus, children involved in the research receive an individual **six-digit research identifier** for the entire duration of the study. This is needed because **the research identifier ensures that any information from the research can be linked together in a database without the direct use of personal data. Thus, data connection can be achieved in the research without direct personal identification.**

The health visitors assign and record the research identifiers once the 'informed consent' is signed, during the first data collection. In the event of twin pregnancies, each of the prospective foetuses will enter the database with its own specific research identifiers.

The six digits of the research identifier are made up of the following: the identifier given by HDRI to the health visitor (4 digits) plus the code assigned by the health visitor to the child, based on the interviewing sequence (2 digits).

The following **personal data should be provided** to enable the data to be connected and the respondents to be reached: respondent's name, birth (maiden) name, mother's name, year and place of birth, mother's and child's social security numbers, permanent address, contact address (phone number, email address). These elements are handled separately and do not appear in the research database.

Thus, the research database will not include this personal data. Throughout the research, the data provided under the terms of informed consent will be handled separately. The research identifier will be the only means of identifying the respondent when connecting data in time.

Data collection tools used during the research

Interview recorded personally

In an interview (about 1 hour long) the interviewer (health visitor) records the mother's answers on paper or online. In the research database, answers will be assigned to the six-digit research identifier, which will allow them to be connected in time.

Self-administered questionnaire

A paper questionnaire filled in by the respondent (mother, father) alone. When filled in at the location of the interview, the person conducting the interview (health visitor or interviewer) is not allowed to see the answers to the completed questionnaire. Upon completion, the questionnaire is sealed in an envelope and sent to the researchers. In special cases, where independent completion is not possible (e.g. the respondent is visually impaired or has difficulty reading), the self-administered questionnaire is completed orally, with special emphasis on the voluntary nature of the responses. In the research database, the answers will be assigned to the six-digit research identifier, which will allow the databases to be connected.

Including administrative data

We will include some data available in the state's administrative public service and public administration systems at the individual level. During the research, this procedure may involve data recorded in public education, local government, social security, pension and other systems. The basis of data connection will be the social security number of the mother or the child. In the research database, the administrative data will be assigned to the six-digit research identifier only, separated from the personal data, which will allow the data to be connected in time.

4. The purpose, legal base and duration of data management

We would like to emphasize that the data manager will manage personal data received during the data collection of the research in accordance with the relevant legal regulations, will keep them confidential, and will ensure their security.

The legal basis of data management in relation to all data received is the **voluntary assent of the respondent**, in accordance with the 2011 CXII law on the right of self-determination and the freedom of information (hereafter: Info. Law), § 5, paragraph 1(a).

Thus, data management is allowed only on the basis of the voluntary declaration of the respondent, based on adequate information ('informed consent'). This declaration includes the definite assent of the informed person that, in order to participate in the data collection required for 'Growing up in Hungary – Cohort '18 Hungarian Birth Cohort Study', **specific personal data as indicated in the table below will be provided to the data manager.**

Based on the information material, the following data of the respondent will be managed:

| Data managed | Purpose | Duration |
|---|---|--|
| (Pregnant) woman's name, birth (maiden) name (Pregnant) woman's place and date of birth Name of (pregnant) woman's mother (Pregnant) woman's permanent address, contact address, phone number, email address | Organizing contacting, keeping in contact, and data connection within the research database for the sake of carrying out the data collection needed for the research | We delete data needed for the organization of contacting and keeping in contact right after the collection of data needed for the research is finished |
| (Pregnant) woman's social security number Child's (children's) social security number | We use it exclusively for administrative data connection | We delete it right after the collection of data needed for the research is finished |

The data manager is not allowed to use the personal data outlined in the table above for purposes other than those defined there.

Personal data – unless directed otherwise by the compulsory force of law – can only be given to third persons or authorities not defined in the present regulation on the basis of either the authority's decision or the preliminary, definite assent of the respondent.

5. Enforcement possibilities for the respondent

1) Contact the data manager with the following complaints

A) Ask for information about personal data management or ask for correction to his or her personal data. On request from the respondent, the Hungarian Demographic Research Institute, as the data manager, provides information on data processed by it or by its assigned processor; on the purpose, legal basis and duration of data management; on the name, address (seat) and data management related activity of the data processor; and on who has received the data and for what purpose. The data manager provides information within the shortest time possible from receipt of the request, but within 25 days at most, in writing. This information is free of charge, provided the person requesting the information has not filed

another information request about the same area in the same 12-month period. In other cases, the data manager can make a charge.

B) The respondent can object to the management of his or her personal data

If:

a) the management and forwarding of personal data is required only to fulfil a legal obligation on the part of the data manager or to enforce the interests of the data manager, data receiver or a third person, except for mandatory data management; or

b) the use or forwarding of personal data is for direct marketing, opinion polling or scientific research,

then the law allows a respondent to exercise the right to object.

The data manager – while suspending data management – must consider the objection within the shortest time possible from receipt of the request, but within 15 days at most, and must inform the petitioner of the result in writing. Should the objection be sustained, the data manager must terminate the data management (including further data collection and data forwarding), lock up the data and inform all those who have already been supplied with the relevant data of the objection and of the measures taken on that basis. Consequently, they also have to take measures to uphold the right to object.

The data manager must delete the personal data, if the data management is illegal, if the respondent requests it, if the purpose of the data management no longer exists, or if the court or the Hungarian National Authority for Data Protection and Freedom of Information orders it.

The data manager must inform the respondent of the correction and deletion, along with all those to whom the data have already been forwarded for data management. This passing of information is set aside if it does violate the legitimate interests of the respondent in view of the purpose of data management.

II) The respondent can go to court

- if his or her rights have been violated, and
- if he or she disagrees with the written decision of the data manager, following the procedure outlined in I(B) after his or her objection, or if the data manager fails to act within the 15-day deadline, then the respondent can go to court within 30 days of receiving the decision or of the deadline.

A lawsuit against the data manager can be filed at the court assigned to the permanent address of the respondent or at the court assigned to the residence of the respondent – as the respondent chooses. The court gives priority treatment to the case.

If the data manager should cause material harm to someone through the illegal management of the data of the respondent or through a breach of the requirements of data security, the data manager is obliged to provide reimbursement.

If the data manager should infringe the personal rights of the respondent through the illegal management of the data of the respondent or through a breach of the requirements of data security, the respondent can demand restitution from the data manager.

The data manager is absolved of responsibility and of any obligation to pay restitution if it can be proved that the damage or the infringement of the personal rights of the respondent was

caused by something falling outside the scope of data management and beyond the data manager's control.

The data manager is not obliged to compensate the respondent for loss, and restitution cannot be demanded if the harm or the injury caused by the infringement of personal rights was due to intentional or grossly negligent behaviour on the part of the respondent.

III) Apply to the Hungarian National Authority for Data Protection and Freedom of Information

Should the respondent not be satisfied with the answer or the procedure of the data manager, or should there be any questions regarding personal data, then he or she can apply to the Hungarian National Authority for Data Protection and Freedom of Information (homepage: www.naih.hu, address: 1125 Budapest, Szilágyi Erzsébet fasor 22/C; postal address: 1530 Budapest, Pf. 5, Tel.: +36 (1) 391-1400, email: ugyfelszolgalat@naih.hu).

Information, contact: www.kohorsz18.hu
 info@kohorsz18.hu