



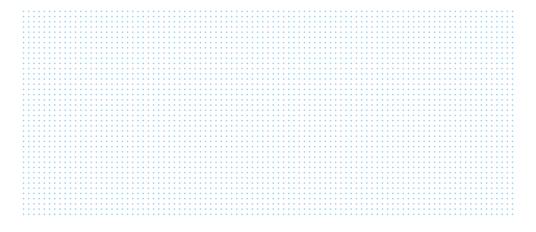




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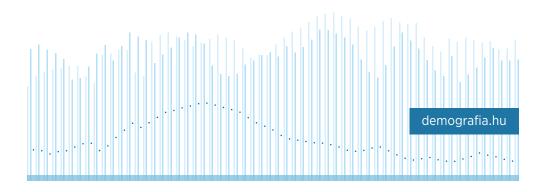
ON POPULATION, FAMILY AND WELFARE



Nº 30

TECHNICAL REPORT
GROWING UP IN HUNGARY
COHORT '18 HUNGARIAN BIRTH COHORT STUDY
PRENATAL RESEARCH, PREPARATIONAL PHASE

Edited by Zsuzsanna Veroszta



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Edited by Zsuzsanna Veroszta

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ABSTRACT

The Hungarian Central Statistical Office Demographic Research Institute launched a Hungarian birth cohort study entitled 'Cohort '18 - Growing Up in Hungary', which follows children born in 2018 and 2019. Data collection began during gestation following approximately 10,000 children born to women who were pregnant at the beginning of 2018. The children will be reevaluated at age six months, one year, and three years within the parameters of the project. The main objective of the study is to provide a comprehensive overview of child development and its influential factors in Hungary. The Cohort '18 Technical Report presents the details of the preparatory work that was necessary to begin the research. It presents the theoretical, methodological and organizational phases and steps prior to the first – prenatal – data collection phase.

Keywords: Cohort '18, birth cohort study, pregnancy, health visitor, child development

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INTRODUCTION

by Zsuzsanna Veroszta

INTRODUCING THE COHORT '18

The Hungarian Central Statistical Office Demographic Research Institute (referred to below as HCSO HDRI) launched a Hungarian birth cohort study entitled 'Cohort '18 - Growing Up in Hungary', which follows children born in 2018 and 2019. The research is financed within the framework of the EFOP 1.9.4. – VEKOP-16 invitation (renewing methodology and informatics in the social sector) issued by the Hungarian Ministry of Human Capacities.

This is a birth cohort study focusing on children born within the same time period (2018/19), forming a joint cohort (generation). Data collection began during gestation following approximately 10,000 children born to women who were pregnant at the beginning of 2018. The children will be reevaluated at age six months, one year, and three years within the parameters of this project. HDRI intends to have the study follow the children until adolescence. The main objective of the study is to provide a comprehensive overview of child development and its influential factors in Hungary. The multidisciplinary study of child development will measure growth indicators, including measures of physical, cognitive and emotional development, as well as health, welfare, academic achievement and social mobility. This research seeks to identify the determinants of growth and to study their impact. Cohort '18 is a longitudinal study, with the intent to track the sample members (children born within the years 2018-2019) for a longer time period, gathering additional information during subsequent waves. The research is based on data collection started during the prenatal period, which is rare in a cohort study. Prenatal and early childhood (age six months) data collection will be conducted by the Hungarian Health Visitors' Network. Facilitating the involvement of the health visitors played a key role in the methodological preparation of the study.

THE COURSE OF RESEARCH

Within the present framework, research plans can extend to 2022. The graphics below summarize the related steps of research.

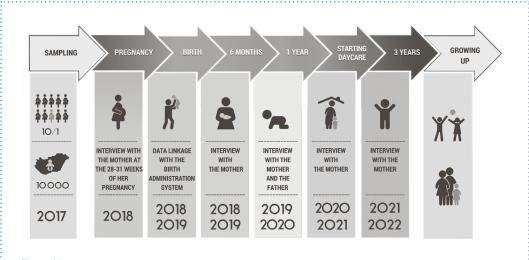


Figure 1.1

Phasing the Cohort '18

AIM OF THE TECHNICAL REPORT

HDRI began to collect data for the Cohort '18 in January 2018. The technical report below presents the details of the preparatory work that was necessary to begin the research. This is primarily for experts and researchers interested in the study. We will present the theoretical, methodological and organizational phases and steps prior to the first – prenatal – data collection phase. The public can learn about the research and continue to follow its results at the Cohort '18 website, www.kohorsz18.hu/en.

The plan will describe the practical steps of identifying the study population, the sample and the methodology. We will then present the base data collection, the technical background work on which the research concept as a whole and the individual data collections are established. We will outline the process of preparing, creating and validating the research materials and measurements, in detail. Finally, we will describe the organizational, structural and logistic processes supporting the launch of the data collection for the study and outline its framework.

THE PREPARATORY PERIOD AND ITS PHASING

The following steps were taken to prepare for the Cohort '18 including the initial preparatory work which began in the spring of 2016 as well as the prenatal data collection period starting on January 1, 2018:

March-November of 2016: preparation of the background studies

November 2016-March 2017: review of former cohort studies and questionnaires

January-March of 2017: review of external databases that may be included

January-March of 2017: establishment of the methodological framework

April-May of 2017: focus group preparatory studies

March-June of 2017: questionnaire preparation

August of 2017: pilot data collection

August of 2017: expert opinion

September-November of 2017: open professional discussions

November of 2017: establishment of the committees

October-November of 2017: preparation and testing of the recording surface

November-December of 2017: preparatory training for the health visitors

December of 2017: data collection logistics

January 1, 2018: launch of the prenatal data collection

THE TARGET POPULATION AND THE SAMPLING

by Balázs Kapitány

The principles and the major steps of sampling the Cohort '18 are outlined below. For brevity, this study report aims to give a general overview, while a detailed description of the sampling process will be included in a separate paper published soon.

THE "FRAMEWORK CONDITIONS" OF SAMPLING

In every survey research in social science, there are externalities that greatly influence the actual sampling practice and the major properties of the sample. These features set up the framework conditions for the actual sampling and are partly based on the demands of the procurer. The most important sample design requirements in the Cohort '18 were the following:

- 1. The realized sample size should be about 10,000 people. This is necessary to allow for a detailed analysis of specific subpopulations, such as smaller social/demographic groups (e.g. large families, single parents).
- 2. The sample should be representative of the whole country. This is not a general requirement for birth cohort studies. However, the nature of fieldwork organization and the need to keep expenses within a realistic budget required territorial clustering in sampling, while maintaining representation on a country level. Reaching groups that are typically remain unobserved in traditional Hungarian questionnaire research (e.g. people who don't speak Hungarian, or those living in institutional households) should also receive specific attention.
- 3. Data collection should start during the prenatal stage. Therefore, sampling should occur among fetuses not yet born. The unit of analysis of the study is the child, while the data provider is, ideally -, the person who is primarily responsible for his or her care. (Therefore, although we collect information from the primary caretaker of the child in the first wave of data collection the pregnant mother in the prenatal stage -, our study focuses on the child at all times.)
- 4. The sample should be formed in such a way that the initial population could serve as the foundation of a long-term follow up study extending even for decades. Given the above sample design requirements, several practical steps have been taken and limitations put into place during sampling. For example, the high selection rate requirement and the demand for territorial clustering of the sample called for a rather lengthy data collection and fieldwork period, since only about 90,000 children are born in Hungary each year.

As there is no up-to-date, online, countrywide record of pregnant women,¹ fieldwork could only be done through the network of health visitors, as they are the only ones who can reach the sampling population. The sampling procedure based on the network of health visitors, however, yielded several practical and methodological issues. For example, because health visitors do not use a unified information technology, paper questionnaires had to be provided, which greatly affected the content and design of the questionnaire.

As a result, the primary sampling unit had to be the district of a health visitor. ² Also, since we have no available data for selection (and validation) within the given district of

¹ Although the law has required health visitors to use a unified information system of local health visitors (EVIR) since 2017, it does not contain much uploaded data and it continues to struggle with technical difficulties. For this reason, we could not rely on it in sample planning.

² Throughout Hungary, each health visitor covers a geographical district and has a specific, local service obligation. Pregnant women are not free to choose a health visitor. The size of population within the districts of the local visiting nurses greatly vary, though regulation 49/V. 21.) issued by the Health, Social and Family Affairs Ministry (changing constantly) puts a limit on the number of people served by a health visitor. An additional issue is that almost 10% of the districts are served by substitutes.

a local health visitor, if a district became part of the sample, then all the pregnant women/fetuses in that district had to be included in the sample. In practice, then, choosing one district of a local health visitor also meant including each of the pregnant women in that district in the sampling.

THE REFERENCE POPULATION

We defined the reference population of the Cohort '18 as children born in Hungary within a one-year period (between April 1, 2018 and March 31, 2019) and their families. In practice, however, the sample design required us to limit the sampling frame to the children of pregnant mothers who sought prenatal care. Health visitor statistics indicate a very high percentage of people seeking this service (approximately 98%, according to official statistics), as this is part of the mandatory national prenatal care protocol and entails financial benefits as well.

Since data collection begins during pregnancy, and the date of birth cannot be determined precisely in advance, we do not know definitively which fetuses will be born between April of 2018 and March of 2019 at the time of the selection. Therefore, instead of the actual date of birth, we rely on what is written under "the expected date of birth" in the so called "prenatal care booklet" (in Hungarian: várandósgondozási könyv) in the sampling.

In light of this, our technical definition of the sampling frame is the following: Seven-month-old fetuses, whose mothers participate in the Hungarian prenatal care system, with an expected due date (according to the prenatal care booklet) within the time period between April 1, 2018 and March 31, 2019. Respondents can be involved as early as the fourth month of pregnancy, but the actual data collection starts at approximately the seventh month of pregnancy. When there is a high risk of premature birth, this can be advanced or even deferred, in the case of a late check-in with the health visitor.

THE MAJOR STEPS OF CREATING THE SAMPLE

Below we will outline how we selected the people who ultimately became part of the sample from the population. In essence, this is how we selected the districts of health visitors included in the sample.

In the first step, we made *three estimates* regarding each of the approximately 4,000 districts of health visitors in the country.

- 1. Based on data from the last few years, we estimated the *expected number of live-births* during the research period in each given health visitors district.
- 2. In the district of each local health visitor, we estimated the *average social status* of each district. To do this, we created a so-called "district-level complex indicator", calculated from 11 relevant indicators from the yearly reports of health visitors (e.g. the proportion of pregnant women requiring enhanced care due to environmental reasons, the proportion of perceived child neglect and child abuse cases).
- 3. Relying on former fieldwork experience, the pilot study and the expert interviews, we also tried to estimate the prospective *level of willingness to respond* (based particularly on the focus group research) within the given type of a district to see what proportion of pregnant women who were asked to respond would be willing to participate in the survey. We estimated this proportion between 62 and 80% for different type of settlements. Naturally, this estimate is rather unsure, leading to the need of a possible subsequent sample correction. In the second step, we ranked the nurse districts into *four spatial strata*, based on their districts/township (in Hungarian: járás): Budapest; agglomeration (10 districts around the capital); large city areas (the eight townships with inhabitants over 150,000 people); other "small and medium districts" *(figure 2.1)*.

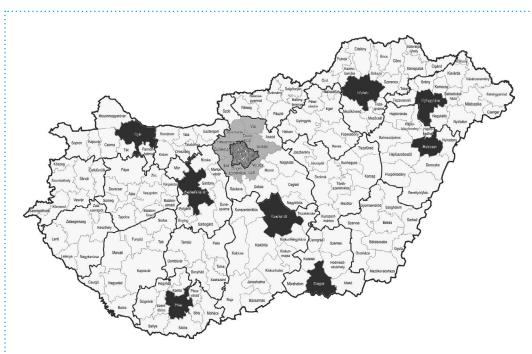


Figure 2.1 Classification of the applied spatial strata in sampling

Table 2.1
Some features of the applied spatial strata in sampling

Spatial strata	Budapest	Budapest agglomeration (10 districts)	Country large city townships (8 units)	Small and medium districts (156 districts)
Share of the number of births in the country (2013-15)	17.9 %	8.6%	15.1%	58.2%
Targeted max. size of the sample at pre- natal data collection (Country total 11,000)	1,966 persons	963 persons	1,664 persons	6,407 persons
Number of live-births (average of 2013–15)	16,045 persons	7,857 persons	13,576 persons	55,278 persons
Number of local health visitor dis- tricts in the stratum (preliminary data, 2016)	488	324	539.5	2,659.75

Then, we selected the local health visitors districts that we wanted to involve in the research, following, in each case, the principle of random sampling, though the method varied within the local divisions.

In Budapest, in the agglomeration and in the large city areas, we arranged the list of local health visitor districts by social standing, and used systematic sampling with simple random starting points in such a way that the prospective number of units in the chosen districts will correspond to its national proportion. This simple selection method was appropriate for these areas because there was no need to cluster the sample based on practical considerations, such as transport difficulty, as this would unnecessarily restrict the sample to only a few districts within the city. In the case of other large city areas with several health visitor districts, district-level selection was also simplified. In addition, the

number of districts chosen this way was large enough from a fieldwork organizational point of view, often reaching the total number of health visitor districts in the spatial stratum of small and medium districts. Arranging by social status before systematic selection ensured the proper representation of various districts of an average social status.

In the spatial stratum of "small and medium districts" - where almost 60% of livebirths take place - fieldwork organization called for clustered sampling. Fitting to the structure of public administration and the network of local health visitors, we decided to use a district/township-level concentration, meaning that certain districts were added to the sample with all of their local health visitor districts. We arranged the territorial districts/townships in this spatial stratum by average social standing and development for the sampling. For stratification by development, we used the so-called "complex indicators" laid out in appendix 2 of Government Regulation 290/2014. (XI. 26), modified by Government Regulation 106/2015 (IV. 23). Then, using systematic sampling with simple random starting points, we randomly selected the districts/townships to include in the sample, making sure that the prospective number of cases in the selected districts/ townships on the whole match the country proportion. (Typically, this led to the selection of 22-24 districts/townships.) We repeated this sampling procedure an additional 100 times. Finally, we took the 100 sample runs, and chose the sample, including 23 districts/townships where the average social standing of the chosen districts and their local health visitors districts was the closest to the average of the social status of the whole stratum according to own complex indicator.

With this complex procedure, a total of 628 districts of local health visitors were selected within the original sampling. We then asked the health visitors (in some cases, substitute health visitors) of the 628 sample districts to cooperate and participate in the research. Due to substitutions, this yielded the involvement of approximately 600 health visitors. In practice, this was in many cases carried out through the chief health visitors of the district/township.

During this time, we also tried to prepare for the challenges of organizing the fieldwork.

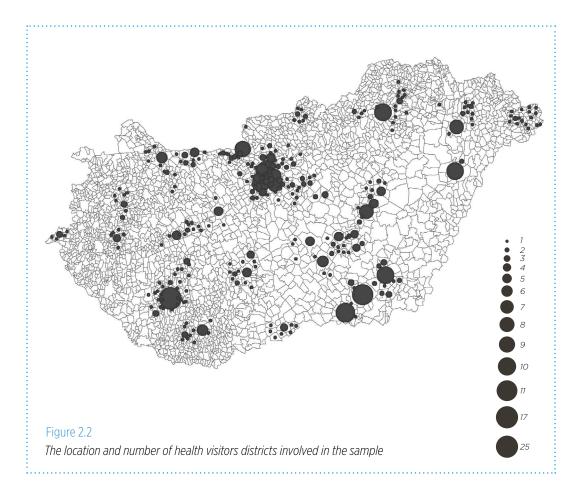
1. For sample districts located in the capital, the agglomeration, and in large cities, we selected replacement health visitor districts matching in size and status to the 'original' district. In a few special cases (e.g. with small districts of a unique social standing), this was not possible, but we managed to find replacement districts for approximately 85% of the districts.

- 2. For the spatial stratum of "small and medium districts/townships", we selected two additional districts/township (which included a total of 18 local health visitor districts) to be involved in the fieldwork, with sufficient diversity to serve as replacement districts in this spatial stratum.
- 3. If the health visitors serving in the given local health visitors district accepted the invitation to participate in the study, the whole district became part of the sample. If the invitation was rejected, we asked the similar replacement district to cooperate.

Of the original 628 districts of health visitors, there were 61 districts in which the health visitor did not cooperate. This means that 90% of the health visitors invited agreed to participate in the research, which, knowing the workload of the network of health visitors, is a very good percentage. Of the 61 missing districts, we managed to substitute 57 with replacement districts. The initial analysis of these districts – although they are rather dispersed throughout the country – indicate that the likelihood of refusing to participate was higher in the outer ring of the agglomeration surrounding Budapest, and in some homestead areas of the Hungarian Plain. By selecting similar replacement districts, we hope to substantially decrease the distortion caused by withdrawals.

After forming the modified sample – upon training and contracting the nurses –, 16 additional health visitors withdrew from or were removed from the research (e.g. because the employer did not support their participation, because they did not show up for

the training, or they did not return the employment contract). As a result, the fieldwork of the Cohort '18 started in 608 districts of local health visitors. One major loss was the withdrawal of all sample districts in a city district in southern Budapest, where there was no opportunity to arrange for a replacement. *Figure 2.2* presents the layout of the districts where fieldwork was actually started within the country.



FUTURE CHALLENGES, OPPORTUNITIES

At the beginning of the fieldwork – when we finish writing this paper –, several important questions that will greatly influence the validity of the initial sample are not yet answered. The following are among the most important of these questions.

We do not now know to rate the general willingness to respond, or the deviations between certain social groups and geographical areas in the future. Inasmuch as data from the first few months of the fieldwork indicate a substantial lack of willingness to participate in certain local districts or social groups, we plan to moderate this distortion by starting additional fieldwork in other replacement districts. Naturally, moderation of the opposite distortion possibility will be enacted as well: If fieldwork in one spatial stratum) indicate that the number of "successfully involved" data providers will exceed 110% of the successful involvements planned by the end of the year, we can stop the data collection in those districts earlier. Still, we will not have accurate data to measure the possible distortions until after finishing the fieldwork gathering of data for six months. We can compare the data we gathered related to babies born and their mothers with the results of demographic data collection in hospitals at the time of birth only. At that time, we plan to record the raw, aggregate data from those refusing to reply.

Also, we predict substantial fluctuation due to health visitors retiring, leaving their profession, or changing districts, which will – due to the length of the fieldwork – affect

the data collection. It is impossible to know beforehand the measure of distortion caused by changes in the health visitor staff during the data collection period in the sample districts. Our current plan is to involve the new health visitors coming to work in these districts in the data collection as well, but it is clear that this will not be successful in all cases, which can affect the representation of the sample. We can correct smaller scale distortions with weighting, of course, but the effectiveness of this measure can be rather limited.

Also, it is hard to estimate the quality of incoming data, as the initial data collection is not done by interviewers, and the majority of data collected will be received from paper questionnaires, not from an electronic source (on the configuration of questionnaires, see chapter 4). This leads to a heightened risk that we will not be able to use (a non-random) part of the incoming questionnaires in the data base. Data cleaning and data correction possibilities will also be limited. These risks particularly affect the self-administered parts of the data collection.

In addition, we do not know the number of dropouts in the data collection waves that will follow the initial (prenatal) data collection. These will naturally distort the initial sample. Dropout, sample deterioration is a constant challenge in longitudinal studies, the two main reasons being refusing to respond, and losing track of data providers who move. In case of a birth cohort study, the possible lack of an "interviewer" adds to the risk, in case the respondent was available, but moved to a place with a local health visitor who would not be able and willing to complete a six-month long data collection. In the ensuing months, in addition to the successful prenatal data collection, our primary aim is to decrease the level of sample deterioration and dropout, which is an interesting task from a methodological point of view. As an example of this type of addition, the possibility came up that between the prenatal and the six-month-old data collection, sample deterioration inevitable due to anonymous adoptions (since we cannot follow the babies adopted anonymously to their new families), could be compensated for by subsequently integrating babies adopted within the sample districts by using special questionnaires. Another challenge will come with the children born very prematurely: cases in which the mother was willing to participate in the study, but the baby was born before starting the prenatal data collection. In this case, providing the possible subsequent addition to the initial sample is also feasible with a special complementary questionnaire.

As a fundamental principle, though, we do not plan to increase the initial prenatal sample, except in the case of a critical measure of sample distortion and dropout.

FOCUS GROUP FUNDAMENTAL RESEARCH

by Gabriella Gresits

Several questions arose in the preparatory stage of the Cohort '18 that called for asking the opinion of health visitors doing the data collection of the pregnant women within the target group. Prior to involving the health visitors in the data collection, it was important for us to learn about the everyday process of prenatal care, such as whether or not there are local disparities in professional procedures, specific answers to these, and the hardships they face in their work. Our most important question was the degree to which pregnant women cooperate during prenatal care. From the pregnant women, we wanted to find out how much they accepted their health visitor as the interviewer, the length of a questionnaire they found to be acceptable, the kind and depth of information about the research they needed to participate in this longitudinal study, and the tools we could use to help them commit to us for the long run. In the spring of 2017, we conducted four discussions to find answers to the above questions which entailed a professional coordination with a group of 10 health visitors and three focus group discussions with pregnant women. Below I will summarize what we learned from these discussions, pointing out the important questions they helped the research group answer in the planning stage.

PROFESSIONAL COORDINATION WITH THE HEALTH VISITORS

The extensive network of the health visitors makes it possible for us to track the development of children born in Hungary from their gestational stage in the 2018 Hungarian Birth Cohort Study. The health visitors service in Hungary provides a quasi-obligatory health service. The one-time state aid given at birth is tied to participation in prenatal care for a given number of times, and if a pregnant woman refuses to cooperate, the health visitor must indicate this to child protection services. Thus, the system has built-in incentives and sanctions, encouraging Hungarian pregnant women to actually participate in the parental care system throughout their whole pregnancy. Social debates about employment and wage policies in 2017 prompted the organization of health visitors to vocalize their interests. A discussion was started about the low wages of professionals working in this field, and the labor shortage of the network. On the country level, about 10% of the health visitor positions are filled by substitutes, which puts a great burden on working health visitors. These facts had a profound impact on the fieldwork and data collection planning, because it was clear from the beginning that the task we are giving the health visitors who cooperate with us is great. We sought to lessen the burden in the two data collection waves in which the health visitors would serve as interviewers by any means available to us. To resolve issues that came up, we established an ongoing cooperation between the research group and the Methodology Department of Health Visitors which is responsible for overseeing the professional work of health visitors. We also coordinated with the local health visitors in daily contact with the pregnant women, by inviting ten of them from various parts of the country to attend a professional coordinating discussion on April 7, 2017 to discuss problems within the development and planning stage.³

The discussion was guided by questions related to the following issues:

- The general process of prenatal care
- The timing of involvement for the pregnant women to the study, and the willingness to respond that we can expect

³ Counties involved: Pest, Nógrád, Borsod-Abaúj-Zemplén, Baranya, Veszprém, Somogy, Szabolcs-Szatmár-Bereg and Budapest. The location of the professional discourse was the conference room of HCSO HDRI. We remunerated the participants with a small compensation and a corporate lunch. Several members of the research group were present at the discussion.

- Information technology questions: Could we plan an online questionnaire? What kind of information technology background would the health visitors consultation rooms have?
- Questions related to the process of interviewing
- Questions related to organizing the fieldwork and the operation of the network of health visitors
- Questions of interest for the health visitors, which we can seek to answer in the study

The local health visitors reported that pregnant women in general check in for care between the 8th and 12th week, but they would not yet involve them in this period. Mothers expecting other than their first child, and women working abroad who want to give birth in Hungary can check in later than that - as late as the end of the last trimester -, so in planning the questionnaires, we had to clearly state that they needed to be interviewed as well. Several health visitors indicated that they also cared for pregnant women in their environment that did not speak Hungarian, and we needed to work out a strategy for those cases, as a one-hour Hungarian questionnaire would not be feasible for these mothers. The projected one-hour interview time seemed to be at the limit of feasibility, as the pregnant women could not tolerate a longer interviewing, and an interview this long could only be done at a separate appointment, not as part of the "regular" prenatal care. This strains the working hours of the health visitors as well. They felt that the fee what we plan to pay them for conducting the interviewing was acceptable. When we asked their opinion on which group of pregnant women would be most likely to refuse to participate, they said educated mothers with higher social standing and those expecting higher-parity births as these women are less cooperative generally in prenatal care. With regard to interviewing, our most important question was whether or not we could plan to do it online. This would require information technology in the consultation rooms of the health visitors in the first place. The computers used by them throughout the country would have to have a stable connection to the internet. The health visitors on the meeting reported several barriers, so we decided on a dual approach of preparing questionnaires on paper and configuring the online interface in such a way that it would resemble the questionnaire on paper, enabling interviewing on the spot if the above conditions were met. An important question relating to fieldwork involved whether there was a central address/building in each area, on which we could rely when organizing the local fieldwork. This was a key question, as reaching the 628 health visitors districts involved in the original sample by post would greatly increase the cost of fieldwork. Generally, they were able to name such spots suitable for logistics, but they also reported several specific cases that required us to assess particularities in all areas concerned. Thus, we designated distribution points, and additional reception points where the local health visitors cooperating with us could most conveniently access the interviewing packages sent to them. In addition to mapping out the difficulties arising in various parts of the country, the professional coordination also revealed that the health visitors participating in the discussion were motivated to cooperate in the study and found it interesting and valuable. This impression was confirmed by the successful involvement of 90% of the health visitors working in the districts chosen for the sample (see chapter 2).

FOCUS GROUP DISCUSSIONS WITH THE PREGNANT WOMEN

As some organizational questions became clear through the meeting with the health visitors in early April, it became increasingly important to ask the opinion of the pregnant women in the target group regarding organizational questions affecting them directly. Our main goal was to discover which tools we could use to assist the participation of

pregnant women in data collection and encourage them to stay in the study long term. To this end, we compiled several documents, based on the work conducted prior to the focus groups. We sought specific feedback on their content. We asked feedback from the pregnant women participating in the focus groups about the information booklet that introduced the study (which we initially planned to be part of the interviewing package to help the health visitors convince the pregnant women). We also sought feedback about the self-administered booklet (which includes psychological questions), the preliminary version of the informed consent, and the list of sensitive issues (at this point, we had not yet decided whether we wanted these to be self-administered or make them part of the questionnaire). To this end, we organized three focus group discussions with 8-9-8 participants in the spring of 2017. The first was held in Salgótarján - the county seat of a struggling region -, the second in Pécs - the center of a disadvantaged but more favorable region -, and the third in Budapest. We organized the discussion in Salgótarján with the help of a local health visitor who previously participated on our meeting in Budapest. The other two focus groups were organized by researchers. In recruiting participants, we sought to find women past their 20th week of pregnancy,4 and compose groups that would be homogeneous enough in terms of educational level for the participants to voice their opinions in front of one another.⁵ The research leader moderated the discussions, with additional (2-2-4) researchers attending: making observations and keeping minutes.

TOPICS IN THE FOCUS GROUPS

In the focus groups, we wanted to get information about the following issues:

- Based on a general orientation presented by the moderator in the introduction, and similar to what they can expect from their own health visitor -, what is the impression of the pregnant women about the study? What is their specific opinion about the leaflet they were given about the study?
- When and in what manner should we inform the pregnant women to be included in the study? What are the circumstances they would need for the interview?
- After being informed about the process of data collection, what questions do they have? How would they feel about their own health visitor interviewing them? What do they think about data linkage?6 Which of the sensitive topics might be better transferred to the self-administered questionnaire?
- What time does filling out the self-administered psychological questionnaire require? In the pregnant woman's opinion, are there any difficulties in filling them out or understanding them?
- How could we motivate the pregnant women to participate in the study? In what form and through which channels should we inform them about the study and its results?
- Which topics are the pregnant women especially interested in regarding the development of their children? Which questions would they like to have answered with the help of the study?

⁴ Altogether, we had two participants in the fourth month of their pregnancies, but one of them was expecting her fifth child, so we could learn from her previous experience as well.

⁵ The groups had the following main characteristics: In the Salgótarján group, we talked with pregnant women with a secondary educational level. Four of them were expecting their first child, and four of them their second. The health visitor assisting in the organization was not present to avoid influencing their answers. In the Pécs group, we talked with pregnant women with a tertiary education. Four of them were expecting their first child, three of them their second, one her third and one her fifth. Most of the pregnant women in the Budapest group also had tertiary education, but some had a secondary level. The majority (4 women) were expecting their first child, two their second, and one her third.

⁶ In order to channel information gathered from the countrywide administrative database into the research database, we asked some personal information from the participants of the study. To make data linkage possible, we needed to ask for their approval when recruiting them.

RESULTS, EXPERIENCES

I will now summarize those parts of the feedback from the focus groups that highlighted a problem or influenced the further planning of the study. They considered the orientation and the information booklet appropriate to the extent that based on the information they received, they were able to decide whether or not they wanted to participate in the study. In our opinion, the pregnant women included in the sample should not be oriented about the study at the first prenatal care appointment, but only around the 20th week. However, the health visitors could give them the information booklet sooner. They agreed that the interviewing should take place at a separate appointment, as the onehour time period exceeds a regular prenatal care appointment. However, they felt that responding could take place either in their homes or at the consultation rooms of the health visitors. In these questions, there was an agreement for the most part between what the health visitors said in former professional discussions and what the pregnant women said now, so we took these into account and finalized our recommendations for involving the respondents and organizing the interviewing. The pregnant women highlighted that finding the right time for an appointment required a flexible coordination process since many of them still worked during the projected interviewing period (between the 28th and the 32nd week of pregnancy). Regarding the interviewing to take place when the child is six months old, they indicated that the one-hour length was too long for the questionnaire, because with the child present, it would be hard to find a whole hour to fill it out, even at home. They were fine with agreeing to data linkage and signing an informed consent. They suggested that we highlight in the text of the informed consent that we use research identifiers to build the research database, which prevents even the researchers to access their personal data, and we complied. In general, they were more concerned about giving out data for keeping in contact than about using their social security number, which is considered sensitive. Regarding the sensitive questions, they indicated that they did not want to answer the following to the health visitor interviewing them: questions about abortion, traumatic life events, family case history, sterility problems, income, religion, or nationality. These topics were either left out of the questionnaire we composed for the pregnant women or moved to the self-administered booklet next to the psychological block of questions. Answering the self-administered booklet took them about 10 minutes, which met our expectations. We had feedback on the wording of some questions and the scale of the measuring instrument. Wherever we could, we changed the scale, replaced the question with another validated version, specified the instructions in the introductory text of the self-administered questionnaire, and brought the possible difficulties of understanding and the possible standard answers to the attention of health visitors while training them in the interviewing techniques of the psychological block. Regarding the channels of information, our three focus groups did not provide convergent answers. Members of the target group wanted to receive news about the study results from a wide variety of channels: baby-mother magazines, forums on the Internet, television magazine shows, newspapers, and the website of the study. They considered it most important for the study to have its own Facebook page⁷. As a result, during the opening conference of the study, the researchers participated in several radio and television shows, and launched the homepage taking advantage of the increased media attention to the study.8 We continue to work to meet these needs.

⁷ Available by typing "Kohorsz '18" in the search panel of Facebook, or directly at this link: https://www.facebook.com/Kohorsz-18-154284575291842/

⁸ See www.kohorsz18.hu/en

One of the most important question topics in the focus group discussions with pregnant women concerning the results of the Cohort '18.9 They listed several questions, which indicated that the pregnant women participating in the discussions liked the study in the first place. We lengthened the questionnaire to include several of their questions regarding breastfeeding, deliberate birth planning, expectations and plans. Naturally, the pregnant women were especially interested in the measuring of factors influencing the complex development of children, which were already part of the research plan. In relation to communicating the results of the study, we plan to compile easy-to-understand information materials regarding the issues above for those participating in the study and for other Hungarian mothers.

⁹ The specific questions included the following: Where do mothers typically get information on questions about caring for their children? What does the development of the mother-child relationship depend on, and what is the role of joint activities in that? How does the use of the computer, the internet and the phone affect the development of children? How do the grandparents and the extended family participate in the life of the child? How deliberate are the mothers-to-be about their preparation for childbirth? How much do the circumstances of origin influence the subsequent life of the child? How much do environmental factors affect the health of the child? How much does breastfeeding and deliberate complementary feeding influence the health of the child? How much does social pressure on women influence the amount of time mothers spend at home before returning to the work force? What is the role of the father in childrearing? How does divorce affect this? How can fathers working abroad participate in the lives of their families? To what extent can a parental pattern be passed down? How does the distribution of work within the family change after the birth of a child? How does the arrival of a child influence a couple's relationship? How much do the parents know about the state aid, the possibilities provided by the social welfare system, and how much can they utilize these? How do parental expectations affect the child, and how much do sacrifices made due to childrearing pay back later?

THE STEPS OF FUNDAMENTAL TECHNICAL WORK

by Zsuzsanna Veroszta

Below we outline the technical preparation of the prenatal research phase, and the steps involved in preparing the questionnaires.

FUNDAMENTAL STUDIES

Prior to launching the project in the spring of 2017, HDRI, in preparation for the Cohort '18, asked several experts for background studies about border areas related to the study that amend the research profile of HDRI. The studies typically aimed at investigating the various research areas of development and health, and the possibilities of data integration. The following professional documents were prepared in the preparatory stage:

- Preparatory material about the development-psychological research issues and the methods of the Birth Cohort Study (Dr. Beatrix Lábadi - Dr. Melinda Pohárnok)
- Measuring the frequency, risk factors and effects of pre-partum depression in the "Hungarian Birth Cohort Study": preliminary plans (Dr. Péter Döme)
- Decision-preparation background material for the Hungarian Birth Cohort Study: The technical requirements for connecting to a DNS database, and the possibilities of a possible genetic/epigenetic application (Eszter Jávorszky)
- Preparatory material for the birth cohort study: Possibilities to measure early child-hood institutional care, related acts and their social effects (Anita Halász)
- Available information systems (Adél Rohr)
- Decision-preparation background material for the Hungarian Birth Cohort Study: Possibilities to integrate register data, based on current practice in Hungary (Zsuzsanna Veroszta)

DATA COLLECTION TOOLS

The data collection tools used by the health visitors in the prenatal interviewing stage are the following:

Questionnaire administered by the health visitors

The questionnaire administered by the health visitors (lasting approximately one hour) will be recorded online subsequent to the interview or directly on the recording interface configured for this purpose, at the discretion of the health visitor. To support the interview, the questionnaire is accompanied by a response booklet.

Self-administered questionnaire

Some variables (e.g. psychological aspects) will be assessed through self-administered paper-pencil tests. These will be distributed by the health visitor to the pregnant women in a booklet after the interview. The health visitor will ask her to fill it out right away (during the interviewing appointment, to avoid late submission). If the pregnant women have visual or reading challenges, the health visitor will read the questions and the possible answers from her own copy. The pregnant women will then mark her answer in a way that the health visitor does not see them. The booklets are immediately sealed in an envelope, and the health visitor makes sure it arrives to HDRI.

Administrative data recording template

Following the interview, the health visitor records the data defined from the prenatal care booklet via the online interface programmed for this purpose.

Health visitor folder

The folder prepared for health visitors includes the main data of interviews successfully conducted during the study, and the subsequent data collection phases planned. In this document, the health visitors also record the number of failed interviews and some of their major characteristics. As the study progresses, the health visitors gather address cards that include the contact and the recruiting information of the respondents.

PREPARING THE QUESTIONNAIRES

The following steps were taken in cooperation with the professional group of the Cohort '18¹⁰ in preparing the questionnaires:

- In the preparatory phase, experiences from the fundamental studies and the earlier international and national birth cohort studies were examined. Overall background materials were prepared, based on the methodology used and the research questions examined.
- Then the data collection's methodological framework was formed in order to plan the proper configuration of the measuring tools.
- In compiling the questionnaires, the method we followed was to draw up study segments from the main research areas – demography, health and development, psychology, sociology, economics – to establish the research concept. These included the theoretical framework of the professional areas, research question proposals, and a broad list of questions written on that base.
- The research questions and the related set of variables were finalized relative to the above background studies, through a series of professional debates, and several selection cycles.
- When compiling the questionnaires, technical work progressed congruently with the above content selection: forming the structure, editing questionnaire items, validating questions/scales, including them, requiring considerations on the part of the interviewer and the respondent, and enforcing time limits.
- The questionnaire items, finalized through professional discussion, were validated through cycles of asking for external expert opinions (described in the following section) and user tests (described in chapter 6). Then, we modified them according to these results.

EXPERT OPINIONS

We asked the opinions of senior researchers of the primary related disciplines regarding the questionnaires prepared for the prenatal data collection phase of the Cohort '18. The professionals had the research concept and the background material introducing the methodology available to them as they prepared their opinions on the questionnaires. Based on the 5–10-page written expert opinions, we modified specific questions of the questionnaire and several of the research questions.

Table 4.1

Researchers participating in the expert opinion phase

List of experts	Affiliation	Focus matter	Specialty
Andrea Andrek	Perinatal psychologist Assistant lecturer, ELTE Faculty of Education and Psychology	Psychology	Perinatal psychology, early attachment
Zsuzsa Blaskó	Senior Research Fellow, HDRI	Society/ Cohort study	Research experience in longitudinal study concepts
Beáta Dávid	Research Chair, HAS Centre for Social Sciences, Institute for So- ciology	Society/ Family	Study of family sociology and social environmental impacts
Zsuzsannna Elekes	University professor, Corvinus University of Budapest	Society/ Deviance	Social background and health, deviance study
András Fogarasi	Chief physician, Head of the Department Bethesda Children's Hospital, Neurology Department	Health and development	Research work in the area of pediatrics and child development
Éva Gárdos	Professional Chief Advisor, HCSO	Health and development	Data collection related to pregnancy, mother-infant health
Kálmán Joubert	Senior Researcher, HDRI	Health and development	Comprehensive measuring of child development
Ferenc Kamarás	Statistical Chief Advisor, HCSO	Demography	Demographic research, family planning, having children
Péter Róbert	University professor, SZE senior researcher, TÁRKI	Society/ Stratification	The theory and measuring of social inequality
Péter Somlai	Professor emeritus ELTE Faculty of Social Sciences	Society/ Socialization	Family sociology, social- ization, social and cultural background research
Károlyné Tokaji	Department manager, HCSO Population and Social Protection Statistics Department	Health and development	Social care system and child protection research and statistics
Júlia Varga	Senior Research Fellow, Hungarian Academy of Science, Centre for Economic and Regional Studies, Education and Labour Economics Research unit	Society/ Labor market	Labor market participation and early investment research
Zoltán Vokó	University professor, ELTE Faculty of Social Sciences, Department of Health Policy and Health Economics	Health and development	Health policy, planning and financing

PROFESSIONAL PUBLICITY

As the study advanced through its planning phase, we continued to guarantee the visibility of the work and the opportunity for the professional public to voice their opinion. Several events were organized to accomplish this, in which the forming concept, methodology and the questionnaire was discussed. The study was presented at the following events:

May 22, 2017 Professional introductory presentation

The purpose of this event was to present and discuss the concept and methodology plan of the Cohort '18 among HDRI researchers.

September 4, 2017 Technical discussion on the prenatal questionnaire

The purpose of this event was to introduce the Cohort '18's prenatal questionnaire to the whole body of HDRI researchers to get their opinions.

September 21, 2017 The inaugural meeting of the Body of Social Policy Experts

The purpose of this event was to introduce the Cohort '18 and the questionnaire (in progress) to representatives in the field and in civil organizations.

November 13, 2017 Opening conference

The concept and the methodology of launching the Cohort '18 were introduced to the broader professional circle as well as the media in a symposium. Experts were invited to give lectures related to the topic of the study at the conference.

BODIES OF EXPERTS

The study will be conducted with the full support of professional bodies throughout the duration. These bodies will be assigned an ongoing consultative role and can voice their opinion throughout the study. In addition, as the preparation of each phase progresses, we will regularly inform them through the use of background materials and events. The following bodies support the implementation of the Cohort '18:

Body of Social Policy Experts

The body was established in September of 2017, by invitation. Its membership includes representatives of the field and civil organizations related to the study.

Its role is to provide an ongoing consulting background for the Cohort '18 to enhance the use of scientific results in social policy. Membership in this body was invited on the basis of institutional and organizational representation, from those fields of state administration and the civil sphere that are related to the study. The membership also included researchers experienced in developing policy agendas.

Body sessions will be connected to the presentation of study reports. In addition, ad hoc sessions may convene to deal with specific research problems, with the involvement of experts on the given topic.

Body of Scientific Experts

The body was established in January of 2018, by invitation. Membership consists of one senior expert per discipline related to the study.

Its role is to provide ongoing scientific and professional background support for the Cohort '18 and enhance the professional integration of the results. The body will have a

consulting role in some planning phases of the study. It can voice its opinion when the research results are presented. In researching ethics questions, the body can turn to the Ethics Committee of the study and receive priority treatment.

Body sessions will be connected to the presentation of study reports. In addition, ad hoc sessions may convene to deal with specific research problems, with the involvement of experts on the given topic. The membership will be invited and given the opportunity to participate at professional events and international conferences to present the research results.

Ethics Committee

The ethics committee supporting the work of the Cohort '18 was established in January 2018. The membership was created by invitation from renown researchers of disciplines related to the study.

Its role is to provide ongoing background support for the Cohort '18 by giving opinion on and validating the research ethical questions of methodological decisions and data use. The committee will be asked to give its opinion in some planning phases of the study, and in ethical questions relating to data management and usage. Coordination will be initiated by HDRI. Statements, approvals, and ethical permission can be requested from the committee in certain ethical observations, and research procedure decisions directly related to the Cohort '18. Statements, approvals, and ethics explanations can be requested by external actors, people concerned, researchers or analysts participating in the study, or other bodies of the study (e.g. the Professional Advisory Body). HDRI will act as mediator. The statements of general application issued by the committee are public and will be uploaded to the homepage of the study.

The work of the ethics committee is case-based. In the case of research related ethics questions arising during the study, opinion requests and ad hoc sessions may occur by involving experts on the related issue. In case of observations received in relation to the study requiring ethical consideration, ad hoc sessions may also convene in addition to requesting a statement. The membership will be invited and given the opportunity to participate at professional events and international conferences to present the research results.

ENSURING THE DATA PROTECTION BACKGROUND

Throughout the study and specifically in relation to individual data collection phases, data protection principles had to be set, and the legal guarantees of data collection and data processing ensured. The following steps were taken to build up the data protection background during the preparatory stage:

- Preparation of an official legal statement about the legal background of the Cohort '18. The document is available in Hungarian and in English at the homepage of the study (www.kohorsz18.hu/en). The official legal statement establishes the foundations of the research by constructing the legal framework and references behind the individual steps and procedures, including the clarification of the legal background in Hungary and the EU on data management and data connection protocols.
- Preparation of a data protection information booklet to inform the data providers
 - the pregnant women. The information booklet provides the foundation for an informed consent (and thus, participation). It explains the conditions of participating in the study, clearly in advance, along with the legal guarantees of data use and data security. The local health visitors provide each of the pregnant women invited to participate in the study with a data protection information booklet prior to their signing the informed consent and the data collection.

Preparation of an informed consent for pregnant women involved in the study. The informed consent is a basic document and requirement of participation, in which the pregnant women – in case of a minor, her guardian – commits to participate in the study, and consents to the use of her and her unborn child/children's data for research purposes. This consent – in a form chosen by the respondent – will also include permission to use data based on her social security number. This is required for administration-based data linkage planned for later research phases. The informed consent includes the personal and contact information of the respondent which enables her identification. Consequently, HDRI will use exceptional care in gathering, recording and using this information, and will ensure that it will be used for research purposes only. The research data base(s) will remain anonymous. Data collection is conditioned upon receipt of an informed consent of the pregnant woman, signed by her, in which the respondent clearly agrees to participate.

SCALE ADAPTATION

by Krisztina Kopcsó

INTRODUCTION

The psychological variables in the prenatal data collection of the Cohort '18 will be measured by self-administered scales. Hungarian translation is available for most of the selected paper and pencil tests, along with their related psychometric data. We will use either their full or – based on former research – a selected set of items with unchanged text. However, because we did not have a concise test to evaluate pregnancy-specific anxiety and couple interactions available in Hungarian, we gave the Hungarian adaptation of the Pregnancy Related Thoughts (PRT) questionnaire (Rini et al., 1999) and the Gilford-Bengtson Scale (Gilford and Bengtson, 1979), along with their reliability and validity tests.

METHODOLOGY

Sample and procedure

We asked members of a several groups on a social networking service established for pregnant women to participate in the study. Participants filled out an anonymous online questionnaire with informed consent. The test battery consisted of demographic questions, self-administered psychology tests, and questions related to pregnancy. We used IBM SPSS Statistics 22 and Amos to analyze the data.

In total, 298 people filled out the questionnaire. We excluded 50 data sequences from the analysis because their answer to the question about the gestational age indicated that they were not pregnant. This reduced the number of participants to 248 Hungarian pregnant women. Their average age was 30.46 (standard deviation=4.94) years old. The youngest participant was 18 and the oldest 42 years old. With regard to gestational age, 30 women were in the first trimester, 62 in the second trimester, and 156 in the third trimester (gestational week 4–40, M [average]=27.90, SD [standard deviation]=9.52). Seven women had up to primary education, 86 women up to secondary, and 155 had tertiary education. In the assessment of their subjective socio-economic status, 6 of them felt to belong to the lower class, 155 to the lower middle class, 84 to the upper middle class, and 3 to the upper class. 238 women (95.9% of the participants) lived with their partners (30.6% in a partnership, 65.3% in a marriage). Seven had partners living apart and three did not have partners. For 185 of the women, the length of partnership was longer than three years, for 50 of the women, between one and three years, and for 10 women, less than a year.

Measurements

In the online questionnaire, we gathered information about demographic characteristics (age, level of education, subjective socio-economic status, parity, partnership status), subjective health condition (very bad, bad, sufficient, good, excellent), current duration and intendedness of pregnancy, the physical symptoms experienced during pregnancy (frequent nausea and vomiting, viral infection, fevers, abdominal pain and cramps, bleeding) and the history of previous pregnancies (assessing the presence of former premature births, low birth weight children, induced abortions, and miscarriage) of the women participating in the study.

We measured pregnancy-related anxiety with the Hungarian translation of the Pregnancy Related Thoughts questionnaire (Rini et al., 1999). In an overview study by Brunton, Dryer, Saliba and Kohlhoff (2015), 60 publications researching pregnancy-specific anxiety were identified. Eight of them used PRT, making it the second most frequently

used questionnaire for this purpose after the State-Trait Anxiety Inventory (Spielberger et al., 1983) questionnaire. The questionnaire was translated from English to Hungarian independently by three staff members of HDRI. An English language teacher verified the conformity of the English back-translation of the agreed Hungarian version and the original questionnaire. The scale originally included 10 statements in which the respondents had to indicate on a four-point Likert scale how much they considered it applicable to them (not at all – very much). Even though PRT sought to reveal several aspects of anxiety during pregnancy, it is more of a one-dimensional questionnaire according to the results of Rini et al. (1999).

We measured the frequency of positive and negative couple interactions with the Hungarian version of the Gilford-Bengtson Scale (Gilford and Bengtson, 1979; Silverstein and Bengtson, 2008), which has been proven to be valid and reliable in the recent past as well (Erol and Orth, 2014). Although the questionnaire was translated earlier (Gödri, 2001), it has not been used. The English questionnaire had been modified in the meantime. As a result, we translated the scale according to questionnaire-adaptation principles from English to Hungarian. The translation was done independently by three staff members of HDRI. We compared the translation with that of Irén Gödri, and back-translated the questionnaire to English. An English language teacher verified the conformity of the back-translation and the original questionnaire. The scale includes 11 items, in which the respondents need to indicate on a five-point Likert scale how often these happened in their own relationships (hardly ever – always). The statements are sorted into two factors: positive couple relationship interactions and negative couple relationship interactions.

In assessing generalized anxiety, we used the GAD-7 questionnaire (Spitzer et al., 2006), a tool of excellent reliability and validity, which has an official Hungarian translation available at the http://www.phqscreeners.com page. The respondents had to indicate on a four-point Likert scale how often they experienced the seven listed symptoms denoting anxiety during the last two weeks.

In assessing depression, we used the Hungarian adaptation (Töreki et al., 2013) of the Edinburgh Postnatal Depression Scale (Cox et al., 1987). For each item, respondents are asked to select one of four responses that most closely describes how they have felt over the past week.

As a reliable indicator of couple relationship quality, we used the Hungarian version (Martos et al., 2014) of the one-dimensional Relationship Assessment Scale (Hendrick, 1988). The scale includes seven questions asking the respondents to indicate their level of agreement on a five-point Likert scale. The test battery also included the Hungarian version (Martos et al., 2014) of the 5-item Satisfaction with Life Scale (Diener et al., 1985) with a seven-level Likert scale.

RESULTS

Structural analysis

We studied the factor structure of PRT and the Gilford-Bengtson Scale with a confirmatory factor analysis. The one-factor structure of PRT did not display a proper fit. The statistical indices of the model fit are the following: CMIN/DF=9.19; RMSEA=0.18 [90% confidence interval: 0.16–0.2], TLI=0.63; CFI=0.71; SRMR=0.12. Based on corrected item-total correlation, we excluded item number nine, as the correlation coefficient (r=0.16) did not reach the required 0.3 value. Analyzing the one-dimensional structure of the 9-item version with confirmatory factor analysis yielded proper values, (CMIN/DF=2.74; RM-SEA=0.08 [90% confidence interval: 0.06–0.1], TLI=0.94, CFI=0.96, SRMR=0.05), considering that the covariance value was rather high between the errors of some items (1., 2., 5., 8.). The original two-factor structure of the Gilford-Bengtson Scale displayed an ac-

ceptable fit (CMIN/DF=2.72; RMSEA=0.08 [90% confidence interval: 0.07-0.1], TLI=0.92, CFI=0.94).

Descriptive statistical characteristics and reliability

Verifying it with the Kolmogorov-Smirnov test, neither the PRT, nor the Gilford-Bengtson subscale scores were characterized by a normal distribution (p<0.05). Thus, we used nonparametric analysis from that point on. We conducted comparisons between the groups with Kruskal-Wallis and Mann-Whitney U-tests and studied correlations between continuous variables with Spearman correlation.

The nine-item PRT (Cronbach's α =0.839), the positive interaction subscale of the Gilford-Bengtson Scale (Cronbach's α =0.885), along with its negative interaction subscale (Cronbach's α =0.755) all displayed proper reliability values. The PRT scores ranged between 9–32 (M=17.68, SD=5.8), the Gilford-Bengtson Scale's positive interaction scales between 6–25 (M=20.64, SD=3.8), and its negative interaction scores between 6–23 (M=10.24, SD=3.1). The two subscales of the Gilford-Bengtson Scale displayed a medial negative correlation (N=245, r_s =-0.497, p=0.000). The study of Fairlie, Gillman and Rich-Edwards (2009) considered the pregnancy-related anxiety of those pregnant women exceptionally high, who chose the "to a great extent" option for at least three questions. Adopting their criteria to the present sample and the 9-item version, 14.9% of the pregnant women experienced a high level of pregnancy-related anxiety.

Validity

There was no significant difference between groups formed according to level of completed education in relation to pregnancy-specific anxiety ($\chi^2(2)=5.82$, p=0.054) and positive couple interactions ($\chi^2(2)=0.41$, p=0.813), while there was a significant difference in relation to negative couple interactions ($\chi^2(2)=7.43$, p=0.024). Those with a secondary education (N=85, Mean Rank=134.74) reported significantly more frequent negative couple interactions (U=5207.5, p=0.010) in comparison with those with a tertiary education (N=153, Mean Rank=111.04). Due to the small number of people in the groups, we merged the lower class with the lower middle class, and the upper middle class with the upper class in terms of socio-economic status, and compared these two groups, which did not display differences along either of the adopted scales. Groups formed according to the length of the relationship did not display differences either on the positive interaction ($\chi^2(2)=0.39$, p=0.825), or the negative interaction ($\chi^2(2)=0.80$, p=0.669) subscale.

In examining PRT validity, we analyzed its association with pregnancy-history and the characteristics of the current pregnancy. In terms of assessed pregnancy-specific anxiety, there was not a significant difference between those expecting their first child and those expecting subsequent ones, or between those expecting a planned or an unplanned child. There was no significant difference related to experiencing frequent nausea and vomiting, fevers and virus infection, or formerly experienced induced abortion and the level of anxiety. However, pregnant women experiencing bleeding or abdominal pain and cramps reported a higher level of anxiety compared to those who did not have these symptoms. *Table 5.1* includes the statistical indicators of the comparative analyses. Of the 248 participants in the group, only eight women had previously had a premature birth (<week 37), six had previously given birth to a child with low birth weight (<2500 grams), and five reported losing their previous child after the 24th week of pregnancy/during/within one week of giving birth. We did not study the impact of these variables due to the small sample size.

Table 5.1

Mann-Whitney U-tests, comparing pregnancy-related anxiety between specific groups

		N	Mean Rank	U	р
Number of	None	139	119.84	6.928	0.247
children	One or more	109	130.44		
Intendedness	Planned	212	121.98	3.281	0.178
Intendedness	Not planned	36	139.36		
Frequent nausea,	It was present	162	126.52	6.639	0.542
vomiting	It was not present	86	120.70		
Fever	It was present	24	131.98	2.509	0.590
rever	It was not present	224	123.70		
Viral infection	It was present	50	131.94	4.578	0.411
viidi lillection	It was not present	198	122.62		
Bleeding	It was present	66	139.92	4.988	0.041*
bleeding	It was not present	182	118.91		
Abdominal pain	It was present	152	132.32	6.107	0.030*
Abdullillai þaill	It was not present	96	112.11		
Previous induced	It was present	34	145.13	2.937	0.071
abortion	It was not present	214	121.22		
*					

^{* =} p < 0.05

In analyzing the correlation between pregnancy-related anxiety and age, gestational age, generalized anxiety, depression, satisfaction with life, satisfaction with couple relationship, and subjective health condition, there was significant correlation with all of these, except for age. The validity of the Gilford-Bengtson Scale is confirmed by a remarkable correlation between both of its subscales and the couple relationship satisfaction, while displaying the expected relations with generalized anxiety, depression and satisfaction with life. *Table 5.2* includes the results of Spearman correlation analyses.

Table 5.2

Spearman correlation between variables

	PRT (N=248)		GBS positive (N=245)		GBS negative (N=245)	
	r _s	р	r_s	р	r_s	р
Age	0.001	0.989	-0.189	0.003**	-0.045	0.487
Gestational age	-0.187	0.003**	-0.043	0.507	0.018	0.661
Anxiety	0.424	0.000**	-0.182	0.004**	0.357	0.000**
Depression	0.473	0.000**	-0.233	0.000**	0.357	0.000**
Satisfaction with life	-0.265	0.000**	0.273	0.000**	-0.241	0.000**
Relationship satisfaction	-0.213	0.001**	0.668	0.000**	-0.604	0.000**
Health condition	-0.245	0.000**	0.126	0.048*	-0.106	0.098

^{*=} p<0.05; **= p<0.01; GBS= Gilford-Bengtson Scale

CONCLUSION

The goal of our adaptation study was to prepare and test the Hungarian version of PRT and the Gilford-Bengtson Scale in order to prepare short measurement tools suitable to measure pregnancy-specific anxiety, and positive and negative couple relationship interactions for the Cohort '18. 248 Hungarian pregnant women participated in our online survey. Upon examining the factor structure of the questionnaires, we left off one item of the PRT questionnaire, keeping a one-dimensional structure. The Gilford-Bengtson Scale appeared to be two-dimensional on the Hungarian sample as well. Both questionnaires displayed proper reliability values. We also analyzed the validity of the questionnaires. The PRT displayed a significant correlation with relevant psychological variables and was associated to certain health problems. The Gilford-Bengtson Scale significantly correlated with couple relationship satisfaction, and also displayed correlations with psychological distress during pregnancy. There was no significant correlation with age and relationship length, but this could be due to the same and special life situation of women in the sample (i.e. pregnancy), and the low age deviation. Limitations of the research include the small sample size, and the fact that the group of participants did not adequately represent that of Hungarian pregnant women. In the subsequent analysis of the Cohort '18 data, it would be worthwhile to pay additional attention to examining the psychometric indicators of the present scales.

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TESTING THE QUESTIONNAIRES: THE PILOT SURVEY

by Laura Szabó

THE AIM OF THE PILOT SURVEY

The aim of the (quantitative) Pilot Survey was to test the main and the self-administered questionnaire. The goal was to determine if the questions are understandable and unambiguous; the sensitive questions are placed in the appropriate questionnaire (in the main or in the self-administered one); the main chapters and questions are located in the proper place; which questions are difficult to answer or require too much time; and if there are any questions that the respondents cannot or do not want to answer. We also tested the various survey documents during the piloting, including the invitation letter, information booklet, and health visitor questionnaire.

The tasks of the health visitors in this phase were to conduct preliminary testing, gather information and to voice their opinion. In administering the pilot phase, the interviewers not only had to ask the questions, but also had to document everything related to the interview in detail. Taking notes was an important part of administering the pilot test because it ensured that each observation, comment and opinion would be available for the researchers. This information later assisted in compiling the instructions related to the process of the main survey and the Interviewer's Handbook¹¹. We further elaborate on that feedback in this chapter.

THE TOPICS OF THE PILOT QUESTIONNAIRE

Topics of the Cohort '18 focus on three areas: health and development, demographic characteristics and social background characteristics. Following this line of the survey, the chapters of our first questionnaire in the prenatal phase are also built on these themes. We compiled the individual chapters of the questionnaire in June of 2017. A full month of daily, ongoing cooperation between the experts and researchers of the Cohort '18 yielded the first draft version of the questionnaire. The health visitors used this questionnaire in the Pilot Survey in August 2017.

The questionnaire of the Pilot Survey in the prenatal phase consisted of two parts: the main questionnaire and the self-administered questionnaire (see *Table 6.1*). At the end of interviewing, the health visitors filled out a health visitor-questionnaire and an interviewer observation sheet with eight questions, evaluating each interview situation, and documenting the comments of the pregnant women related to the interview instruments.

¹¹ The questionnaires and the technical materials supporting the fieldwork will be available online after the prenatal research phase closes in January of 2019, at the homepage of the study: www.kohorsz18.hu.

¹² We did not test the structure of the questionnaire prepared for gathering the data from the pregnancy care book.

The content of the prenatal questionnaires of Pilot Survey administered by the health visitors

The content of the main questionnaire, Pilot Survey	The content of the self-administered questionnaire, Pilot Survey
DEMOGRAPHIC BLOCK	PSYCHOLOGICAL BLOCK
1. Introductory questions	General anxiety
2. General opinion and attitudes about family life	Pregnancy-related feelings
3. Having children - feelings and attitudes related to the current	State of mood
pregnancy 71 Prognancy evaluation	Social support
3.1. Pregnancy evaluation	Personality
3.2. Special life-situations	Maternal-fetal attachment
4. Fertility history and planned children	Couple relationship quality
4.1. Own children*	PARENTHOOD BLOCK
4.2. Adopted children* 4.3. Plans for having children	Plans for giving birth
5. Partnership history**	Intentions on breastfeeding
5.1. Actual partner5.2. Natural father (living elsewhere)	Intentions on parental behavior
SOCIAL BLOCK	SOCIAL BLOCK
6. Household	Food deprivation
6.1. Household composition*	Nationality
6.2. Household division of labor	Religion
6.3. Household's financial situation	
0.3. HOUSEHOIU S IIIIdHCIdI SILUdLIOH	
7. Social and work force position	
7. Social and work force position	
7. Social and work force position7.1. General questions: subjective strata placement	
7. Social and work force position7.1. General questions: subjective strata placement7.2. Educational level, profession and job	
7. Social and work force position7.1. General questions: subjective strata placement7.2. Educational level, profession and job7.3. Plans and satisfaction	
7. Social and work force position7.1. General questions: subjective strata placement7.2. Educational level, profession and job7.3. Plans and satisfaction9. Information collection	
 7. Social and work force position 7.1. General questions: subjective strata placement 7.2. Educational level, profession and job 7.3. Plans and satisfaction 9. Information collection HEALTH AND DEVELOPMENT BLOCK 	
 7. Social and work force position 7.1. General questions: subjective strata placement 7.2. Educational level, profession and job 7.3. Plans and satisfaction 9. Information collection	
7. Social and work force position 7.1. General questions: subjective strata placement 7.2. Educational level, profession and job 7.3. Plans and satisfaction 9. Information collection HEALTH AND DEVELOPMENT BLOCK 8. Health condition 8.1. General health condition	

8.5. Resorting to the health care system

8.6. Reproductive health: circumstances of conception

^{*} Questions relating to own children, adopted children and household members were repeated according to the number of children and family members mentioned by the pregnant women.

^{**} Questions relating to the partner varied depending on whom they referred to: spouse, cohabiting partner or a living apart partner (LAT).

THE SAMPLE OF THE PRENATAL PILOT SURVEY

The Cohort '18 population consists of babies born in Hungary between April 1, 2018 and March 31, 2019. However, our primary sampling units are the health visitor districts within the whole territory of Hungary – where the mother of the child is cared for. The health care visitors taking part in the Pilot Survey did not take part in the main survey as their districts were not sampled for it. Following the final configuration of the sample of the prenatal Pilot Survey, we included the health visitor districts displayed in *Table 6.2*, with 26 local health visitors. Each health visitor recruited and interviewed two pregnant women from her district, a total of 52 people.

Table 6.2 Health visitor districts participating in the prenatal Pilot Survey

From the Szombathely area Kőszegszerdahely Nurse Service Nemesbőd Bük 1.	From the Salgótarján area Salgótarján 4th district Salgótarján 7th district Salgótarján 12th district	From the Kecskemét area Local health visitor district 8/14. Local health visitor district 1. Local health visitor district 2.
From the Gyula area	From the Kisvárda area	BFKH, Budapest (4th, 5th, 8th city districts)
Gyula 4th district	Ajak 1st district	5th vaccination circuit
Kétegyháza 1st district	Ajak 2nd district	18th vaccination circuit
Sarkad 2nd district	Mándok 1st district	
From the Balassagyarmat area	From the Nyírbátor area	BFKH, Budapest (10th city district)
Szügy Nurse Service	Nyírvasvári	21st vaccination circuit
Dejtár Nurse Service	Pócspetri	6th vaccination circuit
Balassagyarmat 4th Nurse Service	Nyírbátor	10th vaccination circuit

At the time of the interviewing, the pregnant women were between their 26-34th weeks of pregnancy, 29.5 weeks on the average. They were 20-44 years old, with an average of 31 years. Two of them were expecting twins. 28 women were pregnant with their first child, 19 with their second, 3 with their third, and 2 with their fourth. 22 were single, 26 married and 4 divorced, but their actual partnership situation was living in a relationship. 26 in marriage, 25 in a cohabiting partnership, and 1 with a living apart partner. Eight of the pregnant women did not have high-school diploma, more than half, 28 women, had completed secondary education, and 19 had at least a college degree. Thus, the number of participants with a lower level of education was relatively low in the pilot study. 10 women still worked, 38 had worked previously but were no longer working, and 4 women had not had a job up to the time of the interviewing. Half of the pregnant women answered our question about the income of their household, listing their household income between 120 thousand HUF and 800 thousand HUF, their average net income being 320 thousand HUF. Many of the pregnant women participating in the pilot study lived in Budapest (9 people; see Table 6.3), but the majority lived in other large or smaller cities (17 and 16 people), and the fewest lived in villages (6 people).

Thus, in summary, the majority of pregnant women participating in the prenatal Pilot Survey were from a city and had completed secondary education. The average age was 31 years old, all lived in relationship, half of them were expecting their first child, and the average number of their weeks of pregnancy was 29.5.

Table 6.3

The distribution of pregnant women participating in the prenatal Pilot Survey according to place of residence

City	Nr of pregnant women	City	Nr of pregnant women	City	Nr of pregnant women
Bakonyszentlászló	2	Dévaványa	2	Kecskemét	5
Balassagyarmat	4	Esztergom	2	Mándok	4
Békéscsaba	2	Göd	2	Mátraszele	1
Budapest	9	Gyula	2	Nyíregyháza	2
Bük	2	Helvécia	1	Sarkad	2
Csenger	2	Karancskeszi	2	Záhony	2

FIELDWORK, INTERVIEWING

The fieldwork of the prenatal Pilot Survey took place between August 7–31, 2017. The materials and documents needed for the test were sent to health visitors in early August. Two of Cohort '18 researchers held a training for interviewers on August 11, 2017 in 12 health visitor districts (those participating in the prenatal Pilot Survey, belonging to the Salgótarján, Balassagyarmat, Kisvárdai and Nyírbátor areas). This training and its feedback was highly valuable to compiling the training materials used by the local health care visitors participating in the main research later. The health visitors administered most of the interviews on August 14th and 15th, managing to recruit pregnant women to participate in the study rather quickly. We did not have any constraints in the recruitment. The pregnant women volunteered to participate in the Pilot Survey, and we did not give them any gifts or incentives. However, the regional leader health visitors received remuneration.

The documents included and tested in the prenatal Pilot Survey were:

- The questionnaires of the Pilot Survey: the main questionnaire, the accompanying response booklet and the self-administered questionnaire.
- We prepared an invitation letter for members of the pilot sample which briefly outlined the aim of the research. We indicated clearly the areas in which we needed their help, and provided the contact information of colleagues in charge in case they had any additional questions.
- We also showed them our 8-page information booklet about the study. This booklet gives a concise overall introduction to the cohort study: its goal, the participants, what comes with participating and why it is good for the pregnant women, when the interviewing will be scheduled, and that it is not compulsory. We also provided detailed contact information. Both the invitation letter and the information booklet already had been finalized, making it possible for us to test how they are received by our target population.
- We prepared detailed information materials for the health visitors as well, in which
 we outlined their specific assignment, and in what form we would like to receive
 their feedback. We provided a short technical guide for administering the questionnaire and informed them about whom they could turn to for additional help with
 their questions and observations.

 Using the health visitor questionnaire and the interviewer information sheet, the health visitors were able to record their comments about the questionnaire, about specific questions, about other study materials, and about the study, in general, online and send their responses to the researchers.

We tested only the Hungarian version of questionnaires in the prenatal Pilot Survey, but based on feedback from the health visitors, we started to gather information at district-level about which foreign languages we will need to translate the questionnaires into.

THE MAIN RESULTS OF THE PRENATAL PILOT SURVEY

General observations

On the whole we came in contact with health visitors who were open and kind, fully comprehending the significance of the survey. They knew it is an important study for many reasons, but they were afraid of the length of the questionnaire, the size and variety of documentation, and the online recording of the feedback. Even so, almost all of them described the interviewing experience as having a cheerful, friendly and calm atmosphere, with the participants in good spirits.

There were some complications in administering the Pilot Survey. In five cases, small children were present during the interview. In these circumstances, the pregnant woman was impatient, and stood up multiple times to do something with the child (feeding, changing diapers, giving water, playing with them). In one case, the health visitor did not ask certain questions because the child was present, and in another case the partner of the pregnant woman answered some questions instead of her.

Almost all respondents found the questionnaire to be long, but some thought it was manageable. We emphasized that this was a pilot stage, and this version was much longer than the final questionnaire would be. Despite emphasizing this, there were still complaints about the questionnaire's length. The health visitors suggested the questionnaire to be asked in several sections; and to merge the administrative data to the information we got from the surveys, if possible.

Half of the interviews took place in the home of the pregnant women, the other half in the consultation room of the health visitors, and in two cases in the office of the pediatrician. Whenever the interview took place in the consultation room of the health visitor, the interviewers did all they could to provide a suitable environment: they told their colleagues in advance not to interrupt them, they muted their phones or turned them off, and prepared some water for the respondents.

The majority of the pregnant women (37) filled out the self-administered questionnaire by themselves. In two cases, the pregnant women asked to take away the self-administered questionnaire to fill it out later for lack of time and return it later. While the pregnant women filled out the self-administered questionnaire, the health visitors either looked at their own copies, checked the main questionnaire they had already administered, or went back to their work. One health visitor mentioned that it was uncomfortable to wait.

The comparatively positive feedback was most likely due to the fact that health visitors asked those pregnant women with whom they were already in good relationship to participate. Probably because of this, it was difficult for health visitors to imagine how they could separate their professional role and responsibilities from the behavior we asked of them as interviewers. That is, we had to stress that, instead of explaining and interpreting the questions and clarifying the possible answers, they should simply read them word by word.

Participation

Since the pregnant women who were invited to participate did so voluntarily in the prenatal Pilot Survey, we could not test the non-cooperation and refusal rates. In two cases, the health care visitors indicated that the pregnant woman was initially reluctant to participate in the interview, but finally they became interested and cooperative. One pregnant women indicated at the end that she did not wish to participate in filling out additional guestionnaires.

Identifiers

In different documents, we asked for different identifiers from the health visitors. For example, on the pilot questionnaire cover page they had to write down the identifier of the respondent (of the pregnant woman) and the week of pregnancy. On the Interviewer Observation Sheet the health visitors had to mark the interview-identifier. This caused some confusion, because the health visitors were not sure which identifier we were asking for. We noted this after the feedbacks of the prenatal Pilot Survey and clarified the question of identifiers. Consequently, in each of the documents (main questionnaire, self-administered questionnaire, informed consent, address cards recording the fieldwork progress, and all other documents), we asked only for two identifiers for each member of the sample of the cohort survey (i.e. the fetus): (1) the identifier of the child(ren) to be born (which is derived from her own health visitor's district identifier), and (2) the identifier of the health visitor's district.¹³

Content of the questionnaires

Regarding the questionnaires, we highlight two opinions that are crucial. The first has to do with the length of the questionnaire. Several respondents felt that the questions were repetitive ("we talk over the same thing again and again"), and some of them were hard to interpret, especially for people with a low level of education. Having to read them again and again increased the interviewing time. In eight cases, the health visitors indicated that questions will be hard to interpret for people with a low level of education. However, this was only a general observation, not specific to people they interviewed (as we have already seen, very few pregnant women had elementary education in the prenatal Pilot Survey). In fact, the one interviewee with an elementary education was able to answer the questions easily ("Since the mother had elementary education only, I thought the interviewing would take more time, but it didn't. The mother was very cute. I learned a lot about her through the questionnaire.").

Another significant consensus was related to the questionnaire's sensitive questions. Nine health visitors went into details and emphasized that it was very troublesome to ask these questions: those about income, sexual life, or alcohol and tobacco use ("Even if it is anonymous and confidentiality binds me, it was awfully uncomfortable to ask certain sensitive questions and have the pregnant women answer these to me. Basically, I learned everything about her and about her family life, though I was not interested in the smallest details."). Apart from these opinions, most of the health visitors (32 of them) indicated that the pregnant women were interested, and answered the questions gladly and thoughtfully, with good attitudes and effort. ("The pregnant woman was very excited, she enjoyed the interview very much, regardless of its length, and really thought about the questions"; "The pregnant woman enjoyed the experience, gladly answered, and was happy to talk a bit about things like these as well.") Except for two, the majority were interested as well, but wanted to get it over with ("She sought to get it over with and wanted to do it for only as a favor to me.")

¹³ In addition, we asked for the pregnancy week at the time of the interview, and whether the pregnancy was with one fetus, with twins, or with three or more. These pieces of information we continue to use as identifier data.

The respondents were mostly interested in questions related to the topics of pregnancy and of children they already had. Besides the sensitive questions about sexuality, income, etc., there were other topics regarded as uncomfortable: those about the subjective social stratification/class situation (two mentions); those about the anticipated relationship between the child and their father living not with family (one mention); and those asking the women whether or not the actual partner was the father of the child being born (two mentions). We developed the final structure of the questionnaire by taking these comments into account, leaving out the questions about sexual life and subjective social stratification situation. We decided to move some questions (about personal and household income, and the use of drugs) into the self-administered questionnaire. One respondent complained about the order of the questions, feeling that we were bouncing between topics.

Opinions varied about the response booklet attached to the questionnaire, which contained the response options for longer questions. These have to be shown to the respondents to aid in comprehension and responding. However the majority considered it useful (33 mentions). Others used the booklet only in part or not at all. This called our attention to the need to emphasize at subsequent trainings and in the Interviewer's Handbook that for the sake of the unified interviewing situation everyone must use the response booklet.

Questions in the self-administered questionnaire were not considered difficult. Only five health visitors indicated that the pregnant women asked for help in interpreting them. Still, several complained about certain questions (e.g. related to mother-fetus bonding and parental behavior) and did not understand why certain questions were needed (e.g. about being religious). The question about food deprivation was also thought to be "strange" (two mentions). The number of mentions with a somewhat negative content was 13–14. The pregnant women and the health visitors themselves suggested to place some sensitive questions from the main questionnaire to the self-administered questionnaire. Taking these comments into account, we restructured the questionnaires. Since the self-administered questionnaire became considerably longer, we had to leave out some questions from it as well (e.g. those about religion and nationality), having in mind that they should be asked in subsequent data collections.

Length of the interview

As we have already mentioned, a significant point in the opinion of the pregnant women was the length of the questionnaire. 31 out of 48 pregnant women indicated that this was too long and tiresome for not only the respondents but also the health visitors. Several indicated that the respondent started to get tired halfway through the questionnaire (11 people) or while answering the questions about health towards the end (9 people). At the same time, in 11 cases the health visitors did not perceive the pregnant women becoming tired during the interview at all.

The length of the main questionnaire and the self-administered questionnaire of the prenatal Pilot Survey was 100 minutes on the average, with a 90-minute median value. The shortest interviewing time was 49 minutes, the longest 180 minutes. 11 out of the 52 interviews exceeded two hours. Filling out the self-administered questionnaire took 20 minutes on the average. Interviewing required 114 minutes on the average with the 8 pregnant women with elementary education, and 100 minutes on the average with the 24 pregnant women with a high level of education. The more children the pregnant women had, the more time interviewing required (with no children: 96.7 minutes; with one child: 102.4 minutes; with two children: 111 minutes; with four children: 128.5 minutes). Interviewing also took longer for those living in a cohabiting partnership (112 minutes)

than for those living in a marriage (89.9 minutes). ¹⁴ There was no difference in the length of the interview in relation to whether it took place in the home of the pregnant women or in the office of the health visitor (97.4 and 97.1 minutes).

Despite the length of the questionnaire and the tiredness of the interviewees, the majority of the respondents did not object to having to fill out the self-administered questionnaire as well. Five women complained, but they ended up filling it out as well. ("It was the self-administered questionnaire that really piqued her interest. Several questions came up on the part of the pregnant woman, so I said we would talk about these at the end, when we are done with the interview. It was a very good, thought-provoking questionnaire. It would be beneficial to go through it with the rest of those I take care of as well.")

Feedback about the information booklet

The pregnant women gave an overall positive evaluation on the information booklet. 25 out of 48 pregnant women considered it especially nice and informative, containing all necessary information. 12 pregnant women took a neutral stand ("Mother read it and said it contained only what I already told her."). Opinions with a negative content had more to do with the length of the information booklet (five mentions) or its incompleteness (four mentions): did not present the questions in detail, "in depth", and did not give information about the types of health data needed later. There were similar opinions on the invitation letter as well: 31 mentions had positive content ("appropriate", "understandable", "contains all information"); four pregnant women indicated that it should be shortened, and one pregnant woman was disturbed about the fact that the leaflet presented information on both the Pilot and Main Surveys.

USING THE RESULTS OF THE PRENATAL PILOT SURVEY

The pilot study with 52 people has proven to be exceptionally beneficial for redrafting the final form of the questionnaires. They convinced us that both the main questionnaire and the self-administered questionnaire had to be shortened, and we received some points of reference as to which questions to leave out. Another important aspect came to light through the pilot study: how could the format of the questionnaire be changed to make it easier to handle? Thus, we rearranged our questions from the table format and inserted introductory notes before chapters with different topics.

PROVIDING INFORMATION TECHNOLOGY BACKGROUND SUPPORT

by Adél Rohr

The Cohort '18 is unique in the sense that we cooperated with the network of health visitors during the first phase of the fieldwork, asking them to help the research as interviewers for the first two waves of interviewing. This creates a unique situation in terms of the information technology system since, unlike the faculties of a network of interviewers, the health visitors did not have a uniform information technology system used by them all, nor a uniform set of hardware. Therefore, our task was to create a data collection and data recording method that would be available and manageable for all of the health visitors joining the study.

SELECTING THE PROPER DATA RECORDING METHOD

As the preceding chapters outlined, upon preliminary needs and possibilities assessment we decided to give each health visitor the choice between either using a paper question-naire to administer the interview (PAPI data collection method) or using a computer with Internet connection to record the answers directly electronically (CAWI data collection method). Since we did not have the opportunity to install an offline software fit for the interviewing on the computers of each of the participating health visitors, we had to configure an online questionnaire available to anyone.

Compared to the usual online questionnaires, the Cohort '18 questionnaire is very long and has a complicated structure. Even though a variety of free, subscription-based and purchasable software programs are available on the market, selecting the right one took time.

An important criterion for the software was that one could fill out the questionnaire only with a unique identifier originating from HDRI. The reason for this is that during the study, all children (fetus to start with) included in the sample will receive their own research identification number, which will remain constant throughout the study. We were looking for a software that made it possible to access and fill out the questionnaires only when possessing an identification number, and we wanted these identification numbers to serve as entry IDs for filling out other online questionnaires later. The prospective number of respondents also limited our options because we expect to receive over 10,000 online questionnaires in the prenatal phase which exceeds the capacity of several of software programs. Since the majority of health visitors would use paper questionnaires during the interview, and later record the answers electronically, our goal was to have, as much as possible, the same structure and look for both questionnaires. To do this, we looked for a program with an extended text editor mode. The benefit of this was to allow us to create a uniform marking system that could be used by both those who work with a paper questionnaire and who record the answers directly online. Furthermore, we did not want to lose the benefits of electronic recording, particularly the use of answer-based skip logic function and data verification functions. Also, the length of the interviewing and data recording periods required that filling out the questionnaires must be able to be interrupted, to be saved and continued at a later time. In addition to all of our technical requirements, keeping the online survey's user interface simple and easy for everyone to use remained an essential aspect. We finally chose the software online-kerdoiv.com from among the many foreign and domestic options. Although it did not have several of the functions described above, it has proven generally to be adequate. The developers of the software committed themselves to improve the system with the functions necessary to the Cohort '18 questionnaire and the fieldwork by the time the research starts, as well as to prepare the online questionnaires.

THE STRUCTURE OF ONLINE QUESTIONNAIRES

We created two separate online questionnaires, one for the main prenatal questionnaire, and one for recording data taken from the prenatal care booklet. 15 Both questionnaires can be accessed with the individual identification number of the child. This will enable us to connect databases with the help of this identification number.

	VÁRANDÓS KÉRDŐÍV
	25/6
	GYERMEKVÁLLALÁSI TERVEK
C04.	Tervezi, hogy az elkövetkező <u>három éven belü</u> l a hamarosan megszületendő gyermeken túl újabb gyermeket vállal?
0	1 - igen, mindenképpen
•	2 - inkább igen
0	3 - inkább nem
0	4 - semmiképpen sem
0	86 - nem tudja
0	99 - nem kivlim válaszolmi
3104	Andrew C. Tare
	Feltéve, hogy a következő három éven belül nem születik gyermeke - a jelenleg úton lévőn kívül -, <u>valamikor később</u> tne még gyermeket?
•	1-igen
0	2 - nem
0	2 - nem 86 - nem tudja
0	86 - nem tudja 99 - nem kirán válaszolni
0	86 - nem tudja 99 - nem kirán válaszolná A Jelenleg várt és az eddig megszületett gyermekeivel együtt Ön hány gyermeket szeretne összesen?
0	86 - nem tudja 99 - nem kirán válaszolni

Sample page about the user interface of the prenatal questionnaire

The online survey has a linear structure for both questionnaires. Switching between blocks is not possible, only continuous progression, and moving back between pages. The system considers a page acceptable and allows moving on to the next page only if all the questions are answered. We wanted to avoid data absence due to recording error by making all the questions required. To reduce the errors, we added several controls to the questionnaire, defining the range of acceptable answers and values. These controls make it possible to see data errors and contradictions simultaneously during the interview if the interviewer records data directly on the online form. Also, during recording, the health visitors can keep in contact with the respondents to correct these errors. The system considers a questionnaire accepted only if it is free of errors and fully completed. Naturally, a database can have several more difficult, complex problems that cannot be

¹⁵ Recording of the self-administered questionnaire attached to the main questionnaire, and foreign language questionnaires is not done by the health visitors. These items will arrive to HDRI on paper and will be subsequently recorded.

checked in the online survey, so there will surely be a need to subsequently clean the database.

TESTING AND FINALIZING THE ONLINE SURVEYS

Testing the recording surveys took place in several cycles. During the pilot interviews in the preparatory phase, we asked the participating health visitors to record their experiences with interviewing and the questionnaire in a form-like survey created at online-kerdoiv.com. We used this to test the individual entry identifications, because, after the administration of each paper questionnaire, the identification received from HDRI had to be used to enter the online form and record the experiences. This phase further enabled us to use several new developments of the software and receive feedback from the health visitors about its working, usability, and visualization needs.

Following the testing period, software development continued. The final state was reached by October of 2017. The prenatal questionnaire and the recording form of data taken from the prenatal care booklet were created by the end of October. Cohort '18 researchers then tested the two questionnaires for a month. After making corrections, health visitors participating in the study were able to test the system one month before starting the fieldwork. Experiences gained this way were also built into the questionnaire, which reached its final form before January 1, 2018.

DATA RECEPTION AND CORRECTION

In the course of fieldwork, we can monitor the progress daily and the database itself. As a result, designing and cleaning the database can start in line with the fieldwork, and inconsistencies that are not noticed by the system can be corrected. Our intent is to have most of the errors corrected by Cohort '18 staff members on database level, only asking for specification from the health visitors doing the interviewing when needed. In case of serious errors, we will allow the health visitors to correct the questionnaires.

We are still working on how fieldwork progression will be monitored and on the process of database cleaning.

TRAINING SESSIONS AND THEIR BACKGROUND MATERIALS

by Julianna Boros

To maximize willingness to participate and ensure data quality, it is essential for the interviewers responsible for data collection to have a thorough knowledge of the theoretical background of the survey and its practical aspects as well.

PLANNING THE TRAINING SESSIONS

Taking into account that the first two questionnaires of the Cohort '18 will be administered by health visitors, the majority of whom have no experience as an interviewer, we tried to put together training material that includes general information on interviewing techniques in addition to specific issues. Our initial concern was confirmed by the two training sessions held on August 11, 2017 in Salgótarján and Nyíregyháza, prior to the pilot study. These sessions revealed that even though the health visitors had a great deal of administrative experience, the majority of them had never filled out a survey questionnaire as an interviewer.

In planning the training sessions and the necessary materials, we had to take several other factors into account. One of these was the timing of the training sessions. Because the survey launched on January 1, 2018, we had to get the necessary knowledge to everyone by that date. However, we also wanted to avoid training too early and have the knowledge gained forgotten by the time the study started. Because the time period immediately preceding the study fell on the month of December, when many people are on vacation because of the holidays, we agreed to start the training sessions in November of 2017.

Another time limitation was the proposed length of the training. Since the health visitors were participating in the study in addition to all the tasks of their regular job, it did not seem feasible to hold a two or three-day training as is common with international cohort studies. We had to plan the curriculum in a way that the most important information could be transmitted, and the questions answered within a four-hour block, without losing any of the information needed. To this end, we prepared an Interviewer's Handbook that covered all of the training material, which the health visitors could use right after the training or refer back to after the fieldwork started if they had any questions.

Human resource limitations had to be considered as well. There were only nine staff members (researchers participating in the study and other colleagues) available to train the nearly 600 health visitors. Since we sought to hold the training sessions in a more manageable group size, our preliminary agreement was not to exceed 25 participants in each group. We were not always able to hold to that in practice, but in cases in which we had groups larger than that, as a compromise, we were able to have two or three trainers present. The smallest training group had 3 participants, the largest 38, and the average number of participants was 16.

TRAINING LOCATIONS

Health visitor training sessions took place between November 6 and December 1, 2017, in 36 locations (see *Figure 8.1*).

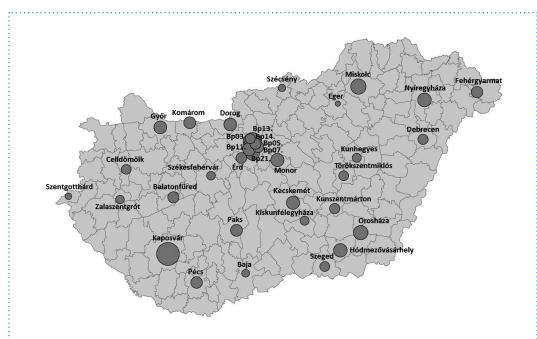


Figure 8.1

Health visitor training locations of the Cohort '18

Note: The size of circles in the figure indicate the size of groups in those locations.

Training locations were arranged by the leaders coordinating the local health visitors. In several locations, they were hosted by government offices, local government offices, or the consultation rooms of the health visitors. The majority of the locations had adequate technical equipment, though in some cases the trainers themselves had to take a projector and/or a laptop in order to show the training material.

PREPARING THE TRAINING SESSIONS

Prior to the training, we prepared a training package for each participating health visitor, which we delivered to the site. The health visitors received these only at the beginning of the training. We also discussed the possibility of distributing these materials to the health visitors earlier to allow them to study the materials before the training sessions for a more efficient use of the time available. Finally, we decided against this because it carried the risk that without the necessary background knowledge the size of the training materials would discourage the health visitors and make them reconsider whether they were able or willing to do this.

Developing the syllabus of the training and preparing the specific training materials (the Interviewer's Handbook and the Power Point presentation used at the training) took place in several stages of teamwork, with cooperation between the researchers and the fieldwork experts. To ensure a standard level for the training sessions, we held a practice training with the participation of all trainers before starting the training sessions. Here we finalized the materials for the presentation, based on their observations and suggestions.

Even though the training sessions were conducted individually (except for the few

cases when more trainers traveled to a location), teamwork was incorporated throughout the training period. Each trainer wrote a report immediately following each session held, which was then shared with everyone to make sure that the problems, questions and suggestions that came up could be addressed in subsequent sessions.

THE STRUCTURE OF THE TRAINING SESSIONS

The training sessions, in accordance with our prior discussions, followed this syllabus in each location:

- Introduction, distribution of the materials
- Introducing the study, the role of the health visitors
- The course of the study, steps and deadlines
- Data collection guide
- Data recording guide
- Administration: signing the contracts, distributing identification numbers

At the beginning of each training session, each of the participants received their training package arranged in a folder, which included the materials they were to use throughout the study. To provide them a better overview, it also contained sample materials from interviewing packages they would receive later (these arrived to the distribution points right before the fieldwork started).

The training package¹⁶ included the following:

Finalized materials:

- Health visitor folder (with a table)
- Interviewer's Handbook
- Poster
- Postcard
- Response booklet

Sample copies:

- Invitation letter
- Information booklet
- Informed consent and address card
- Data protection and data management information sheet
- Questionnaire
- Self-administered booklet

The training consisted of lecturing for the most part (the scope of which, and the inclusion of interactive items being dependent on the size of the group). To utilize the time available most effectively, we asked the health visitors to not look through the training packages themselves, but to look at each document only when presented by the trainer. The brief introduction to the study included the aim of the study, the features of the population and the target group, the major phases of the longitudinal study, and the role of the health visitors.

We then presented the steps of the interviewing work during the prenatal study in detail, starting with participation at a training session, and going through to the research materials being submitted to HDRI. We then discussed the next major task of planning and conducting the six-month interview, the time frame of which will overlap with filling out the prenatal questionnaires. At each major step, we emphasized what the interviewing packages will contain and how these will get to the health visitors. We also explained how and when to encourage the pregnant women in the target group to participate in the study, the materials available to assist in this (poster, postcard, information booklet, invitation letter), and how the interview should be organized, (in an environment with no unnecessary distractions, and with a proper duration). During the training, each of the health visitors received their own identifiers, and a detailed explanation about how the identification numbers of the babies participating in the study should be created (touching on the case of twin pregnancies as well), and where these identification numbers should be used. They also learned about the use of the informed consent form and the closely related data protection and data management information, along with the use of the address card.

When talking about the initial steps, we gave a brief summary of the tasks related to filling out the questionnaire and the self-administered booklet. We also instructed how to record data from the prenatal care booklet, along with how to keep data about successful and unsuccessful recruitment in the health visitor folder.

In the second half of the training session, we looked through the data collection and data recording guides. Since the shortage of time did not allow us to discuss the questionnaire thoroughly, question by question, we decided to first provide an overview the topics covered by the questionnaire and the self-administered booklet, and then to present the formal aspects of the questionnaire. These aspects included how the questions the interviewers should read out loud without modification are separated from the instructions for the interviewers themselves, and how to mark skipping, emphasis, and the "does not know/does not want to answer". We talked about using the response booklet, which can be a great resource in the case of repeated answer categories and questions containing a lengthy list. We then looked through the question types: simple one-answer questions, simple multiple choice questions, number inscription and open-ended questions, along with the various matrix-table questions.

Following the technical/formal introduction of the questionnaire, we presented a hypothetical case (that of "Example Eve") and used interactive methods to call their attention on how questions requiring most specific attention (such as clarifying the couple relationship, household income, employment or profession) should be handled. Of course, this instruction should not supersede a thorough knowledge of the questionnaire, so we asked all of the health visitors to closely study the questionnaire and the Interviewer's Handbook which contains the explanation of the questions before starting the actual fieldwork. We suggested possibly even doing a test administration to see if the health visitor has questions or interpretation problems, which would give us the opportunity to clarify these before the interviewing itself (they could contact the researchers or the colleague responsible for fieldwork through e-mail or by phone).

In the last chapter of the training session, we presented information on data recording. Since we only had an online survey in the testing phase during the training period, the health visitors could not try recording on the spot themselves, but we gave them detailed guidelines. We told them that the online survey could manage direct (during the interviewing) online recording as well as subsequent data recording in case the interview was administered on paper. We presented access to the recording surface, the method of entering, the question types, comparison with the paper questionnaire and possible deviations, how to handle error messages, and tasks for saving, closing and submitting. In closing, we told them how they could test the online survey following the training.

Again, we requested that all of the participants try data recording before starting the fieldwork.

During the training sessions, there was time and opportunity to clear up questions that arose. In that regard, the level of activity on the part of the participants varied by location. It was brought up in several locations that they considered the questionnaire very long, the health visitors asking for motivational help to convince the pregnant women to participate in the study. All of them thought that incentives were the best solutions, if not in the prenatal phase, then at the six-month interviewing for sure. Some indicated that there were many problematic pregnancy cases in their districts – due to social conditions, disability or speaking a foreign language –, so they expected a lower participation rate.

The health visitors also called our attention to several possible organizational difficulties. Several districts are not covered at the moment and are presently served by substitution. Also, we could expect some health visitors to leave due to retirement, having children or other reasons. We would need to provide training for the incoming health visitors.

SUMMARY

From feedback given at the training sessions and after, we learned that the majority of the health visitors were satisfied with the organization of the training, and with the training and other materials that they were given. The motivational level of groups in various parts of the country varied greatly, however. Complaints about being generally overwhelmed by their job was the main reason for this.

THE STEPS OF STARTING THE RESEARCH

by Ildikó Fábián

The figure below summarizes the organizational steps taken to lay the foundation of launching the first, prenatal data collection phase of the Cohort '18.

Designating the health visitor units to be included in the sample (March–June 2017)

Determining the population

Ranking the wards

Stratifying and random sampling

Selecting 628 wards

Informing and inviting chief health visitors to participate (May–Nov 2017)

Preliminary professional coordination

Presenting the research at a meeting of chief health visitors

Official letter of support from the Cabinet Office of the Prime Minister to heads of government bureaus.

Designating the tasks of chief health visitors

Contracting with 52 chief health visitors of certain areas

Informing and inviting local health visitors to participate (July–Nov 2017)

Organizing focus groups discussions

Preparing information materials

Designating the tasks of local health visitors

Health visitor training sessions in 37 locations

Contracting with 608 local health visitors

Developing a contacting/change management system (June–Dec 2017)

Building up the database

Gathering contact data, developing e-mail lists

Research website development, starting a health visitor channel

Setting up the administration of the work done by health visitors

Configuring the online interface of change notification

Delivering the data collection materials (Dec 2017)

Designating distribution points

Assembling and distributing interviewing packages

Delivery

January 2018: Data collection starts

Figure 9.1

The major steps of research organization

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