

Material and methods

”Youth 2004”

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1.0 Background and goals

1.1 Background and summary of our research design

Questionnaire data from a little over 11.000 10th graders (age 15-16 years) from Oslo (UNGHUBRO) and Oppland and Hedmark (UNGOPPHED) was collected in 2000-2002. The response rate to the surveys, which were carried out in school hours, was almost 90%. In UNGHUBRO, two age cohorts of 10th graders participated, respectively 1999/2000 and 2000/2001. In UNGOPPHED, the participants were one age cohort of 10th graders in Hedmark, 2000/2001, and one cohort in Oppland, 2001/2002.

Youth 2004 is a 3-year follow-up study using parts of these youth cohorts – i.e. the cohort 2000/2001 in both Oslo and Hedmark. The survey was partially carried through at school and partially as a postal survey.

The survey is performed in collaboration between the Institute of General Practice and Community Medicine at the University of Oslo and the Norwegian Institute of Public Health. The school survey is supported by Oslo Educational Establishment. There is a project protocol (in Norwegian) with assorted addendums of supplementary information.

1.2 Paramount goals

The paramount goal for the survey was to find factors which may prevent somatic and, in particular, mental illness and complaints in youth. A further goal was to obtain biological material to study the association between disease-producing (or preventing) genotypes and health outcomes now and in the future. Health outcomes will be obtained via new follow-up health surveys and linkage to the Cancer Registry of Norway, the Cause of Death Register and similar agencies after approval from the Data Inspectorate of Norway.

3.0 Design and selection

”Youth 2004” consists of a school survey (in Oslo) and a postal survey (in Oslo and Hedmark) (see flow chart, appendix 1). In the school survey, every final year students (3rd grade) (18-19 years old) in all 32 secondary schools in Oslo were invited (n =

3659). This part may be considered a cross sectional survey, but around 70 % of the students in the school survey also took part in UNGHUBRO in the 2000/2001 school year. These students are a part of the longitudinal part of "Youth 2004"- see below. The school implementation took place from the end of January to the beginning of April 2004. The students from UNGHUBRO (2000/2001) who did not attend in the final year in secondary schools in Oslo, were invited to participate in a postal survey (n = 1085). The age cohort from Hedmark (UNGOPPHED, 2000/2001) was also invited to a postal survey (n=1734). The postal survey in Oslo and Hedmark started in March 2004. The last of two reminders was mailed at the end of May.

5.0 Planning and pilot study

The survey consisted of an information brochure, a questionnaire, a declaration of consent and two buccal cell samples to gather DNA material.

5.1 Developing the questionnaire and pilot testing

A working group developed the questionnaire in the late autumn of 2003. During the work process, people who had participated in the making of the UNGHUBRO questionnaire were consulted.

A pilot survey, focusing on the information planned to be given at the school survey and the selection of wording of new questions in the questionnaire, was carried out. The implementation was made as close to the school situation as possible. After it had been carried out (45 min), the students gave their feedback about the accomplishment of the survey, and then they were asked for replies to the questions they had not fully understood. This pilot study was carried out on 10 students from the 2nd grade at two different secondary schools in Bærum. Afterwards, thorough procedures for school implementation were produced.

The field workers who were to carry out the survey were trained by being sent a detailed procedure description before they were gathered at the Institute of General Practice and Community Medicine to go through the material together. Afterwards, people from the different parts of the project and other field workers visited a

secondary school outside Oslo and implemented the survey in three classes (two technical and one general education).

Field workers (M.Sc. students) were recruited by posting leaflets at the Norwegian School of Sport Sciences, the Faculties of Social Sciences and Education at the University of Oslo. In addition, researchers/scholars from the Institute of General Practice and Community Medicine, who will be using the collected material, participated as field workers. A total of nine persons performed the data gathering.

5.2 Contacting the schools and Oslo Educational Establishment

Early in the planning stage a letter was mailed to the Educational Establishment in Oslo municipality, expressing our wish for a dialogue and the hope that Oslo Educational Establishment would give the project its approval. The first communication to the 32 secondary schools in Oslo (public and private) took place via the head masters. This letter was mailed to the schools a few days after Oslo Educational Establishment had sent a letter recommending that the schools participate. In our introductory letter to the head masters, we asked for the name of a person, a contact person, who could be our contact point in our further planning. Together with the contact, who suggested dates and times suitable for a visit, a detailed plan for the implementation was worked out. The week before the survey, the students were given information leaflets at school.

6.0 Implementation

6.1 Questionnaire

The youngsters were asked to fill in a four-page questionnaire. In addition to many of the same questions that were asked in the main parts of UNGHUBRO and UNGOPPHED, there was an added focus on mental health, physical activity and reading and writing disabilities. The projects dealing with these topics were the main reason for the implementation of Youth 2004. In addition to the topics mentioned, the questionnaire covers the following subjects: self-reported health, stress, coping, social support, education and educational plans, alcohol and smoking habits, antisocial behaviour, nutrition and weight loss, sexual behaviour and use of contraceptives, use of medicines, the utilization of health services and skin problems.

6.2 School survey

Implementation in the classroom was standardised. Materials were packed and distributed from the Institute of General Practice and Community Medicine. Two field workers carried out the survey in each class, with the exception of a couple of small classes.

Students, who did not wish to take part, were asked to be present while information was given– and then, possibly, refuse to take part. Materials for students who were absent at the time of the survey, was placed in an envelope along with a stamped return envelope and an extra information brochure. The name and class of the student were written on the outer envelope, which was handed to the contact teacher. After visiting all classes at a school, it was decided whether we should come back or leave the distribution and gathering of forms from the absent students to the contact teacher. The decision made in each case was based on dialogue with the contact teacher. In most cases, we returned to the school. The contact teacher then helped us fetch the students from their classes. We returned to almost every single school several times. If we were unable to meet the student, the contact teacher handed over the envelope and asked the student to fill in and return the questionnaire in the enclosed pre-addressed envelope.

At most schools, the contact teachers were very positive and cooperative. But at a few schools, this was not the case – this is partially reflected in the participation rates at the schools in question. At some schools, we were only allowed to enter the class rooms in a non-scheduled lesson – which turned out to be voluntary at some schools. The contact teachers were given a fee of NOK 1000 for the extra work this survey led to. In a few large schools the contact teachers were in addition given a gift voucher for NOK 500. In the information brochure the participants were informed that they by filling in the questionnaire were taking part in a prize draw of three prizes of NOK 15 000. The prize draw procedures are described in the protocol (in Norwegian only).

6.3 Postal survey in Oslo and Hedmark

Invitation letters, brochure, questionnaire, consent (at the back of the information letter), buccal cell sample with description of procedure in a padded, stamped return envelope were sent to all the invitees in the first week of March 2004 (week 9). The invitees were all who had participated in UNGHUBRO and UNGOPPHED

(Hedmark) in 2000/2001, who had not declined further contact and who were alive and still living in Norway – and not approached through the Oslo school survey. The first reminder was mailed 4 weeks after the first mailing, in week 13. After another 4 weeks, week 18, another reminder was mailed. The reminders did not contain buccal cell sample

Around 300 returned the questionnaire and, in some cases, the buccal cell sample without returning the consent form or signing the consent form. These people were reminded consecutively.

6.4 Biobank

Two buccal cell samples per consenting student have been stored. Where the student has declined to take part in the buccal cell sample, any samples have been destroyed. The registration of the samples took place at the Institute of General Practice and Community Medicine Institute. The samples have later been stored in the biobank at the Norwegian Institute of Public Health.

When DNA has been extracted from the buccal cell sample, guidelines for access to the DNA will be formulated.

7.0 Participation

In the school-based part of the study in Oslo, approximately 90 % of the invited students participated. In the postal survey in Oslo the response rate was lower - 43 %. In Hedmark around 55 % participated. In total, over 4700 young people participated in the survey in Oslo and Hedmark. Among the adolescence in Oslo who in 10th grade (spring 2001) agreed to be contacted again, 72 % took part in “Youth 2004” (the follow-up survey), and 67 % accepted linkage between the two surveys. The equivalent figure for Hedmark was 55 % and 44 %.

8.0 Access to data

A common steering group for all youth surveys (UNGHUBRO, UNGOPPHED, UNGTROMSØ 2002 and Youth 2004) has been established – with participants from

the University of Oslo and the Norwegian Institute of Public Health. Guidelines for access to data and procedures for approval of projects, etc, have been established.

9.0 Protection of privacy and Ethics

9.1 Official approvals

The survey has been approved by the Regional Committee for Medical Research Ethics and approved by the Data Inspectorate. The survey is supported by Oslo Educational Establishment.

9.2 Linkage to other registers

The Norwegian Institute of Public Health has applied to the Data Inspectorate for permission to link the data from Youth 2004 to the Medical Birth Registry and Statistics Norway.

9.3 The principles for protection of privacy in Youth 2004

The participation in the survey was voluntary, and refusing to do so was fully accepted. It was possible to take part in or decline to take part in the whole survey or parts of it. Nobody has had to explain why he/she chose not to participate.

9.4 Information

One goal was to give good information concerning the survey, i.e. about purpose, contents and implementation of the different parts of the project. The intention has been to present the results in popular articles and scientific journals, as well as in the media.

9.4.1 School survey

Information leaflets were sent to the schools for the teachers to distribute the week before our appointment with the classes. The fieldworkers spent the first 10 - 12 minutes of the lesson in giving information and, where needed, replying to questions. All the fieldworkers informed according to a standardised method approved by the project manager and the Regional Committee for Medical Research Ethics.

9.4.2 Postal survey

Information leaflets were mailed along with survey materials. Both the accompanying letter and the leaflets contained the phone number and e-mail address of the manager.

9.5 Consent in writing

Each participant signed a declaration of informed consent. It was possible to abstain from taking part in parts of the survey.

9.6 Withdrawing from the survey

After implementation of the survey, each individual may at any time withdraw from the survey, and also demand that all information about the individual be erased and the buccal cell sample destroyed. One may withdraw from the survey at any time, i.e. even after many years.

9.7 Confidentiality

All personnel working on Youth 2004 have signed a confidentiality agreement concerning personal matters that may come to their attention in their work, in the same manner as other health personnel.