

Older cohort

The Older Twin Cohort

The older Finnish Twin Cohort study started in 1975 with follow-up questionnaires in 1981 and 1990. There has been registry-based follow-up, and numerous clinical and intensive studies on smaller numbers of twin pairs as described earlier (Kaprio & Koskenvuo, 2002). For the past ten years, our focus has been on registry-based follow-up, reporting on studies in which data collection has been completed, and participation in multicentre studies.

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The study

[The Family Study of Nicotine Dependence](#) is part of an international consortium led by Dr Pam Madden, and primarily funded from 2001 to 2005 by NIH to address the genetics of nicotine dependence. The study sample consists of families ascertained for heavy smoking in at least two siblings, who have been sampled from amongst the older twin cohort (born before 1958) first assessed by questionnaire in 1975. Data on lifetime tobacco use, nicotine dependence, and associated factors were obtained by a detailed diagnostic telephone interview (average duration 120 minutes) and subsequent questionnaire. The interview yields diagnoses of nicotine dependence defined using Diagnostic and Statistical Manual of Mental Disorders (4th ed.; DSM-IV; American Psychiatric Association, 1994) and the Fagerström Test for Nicotine Dependence, and the questionnaire yields a quantitative measure of nicotine dependence from the Nicotine Dependence Syndrome Scale (Shiffman et al., 2004). In addition, multiple other measures of smoking history including details on initiation, cessation and withdrawal symptoms are assessed as well as alcohol use, psychiatric comorbidity and demographics. DNA samples are collected by blood sampling at local health centers. A total of 2265 individuals from 762 families participated; 59% of invited families participated. Participants were somewhat older than nonparticipants, more often women than men, but participants and nonparticipants did not differ in amount smoked based on earlier questionnaire information.

Datasets

The Finnish Twin Cohorts (Kaprio et al., 1978; Kaprio, 1994) form a national resource for genetic epidemiological studies. Twins and their families have been ascertained in three stages from the Central Population Register for studies of the genetic and environmental determinants of common, chronic diseases. In this paper we will focus on recent and in-progress research based on the older twin cohort. A comprehensive list of publications and a review of studies completed by the early 1990s was published in 1994 (Kaprio, 1994).

Cohort of Older Like-sexed Twins (Born Before 1958)

The older part of the Finnish Twin Cohort consists of all Finnish twin pairs of the same gender born before 1958 with both co-twins alive in 1975. These twin pairs were selected from the Central Population Registry of Finland in 1974. Three surveys of the entire cohort have been carried out. The first questionnaire was mailed to all pairs in August-October 1975. Two follow-up questionnaire studies have been carried out in 1981 and 1990. Twin zygosity was determined by a validated questionnaire methods initially in the entire cohort (Sarna et al., 1978). In studies of selected twin pairs, genetic markers have been used for validation. The total number of MZ and DZ twin pairs was 13,888 in the beginning of prospective follow-up in August 1975.

File	Modified 
PDF File Q75_FIN.pdf 1975 questionnaire in Finnish	2010-09-24 by Jaakko Kaprio
PDF File Q81_FIN.pdf 1981 questionnaire in Finnish	2010-09-24 by Jaakko Kaprio
PDF File Q90_FIN.pdf 1990 questionnaire in Finnish	2010-09-24 by Jaakko Kaprio
PDF File Twin questionnaire 1981 English.pdf 1981 questionnaire in English	2011-01-04 by Jaakko Kaprio
PDF File Opposite-sex pair questionnaire 1996_97.pdf Opposite sex questionnaire from 1996-97 (in Finnish)	2011-01-04 by Jaakko Kaprio
PDF File Q2011_FIN.pdf 2011-12 questionnaire in Finnish	2019-10-28 by Jaakko Kaprio
PDF File Twin Questionnaire 2011 for twins born 1945-57 English.pdf 2011 questionnaire in English	2019-10-28 by Jaakko Kaprio
PDF File Twin Questionnaire 1975 English.pdf 1975 questionnaire in English	2019-10-28 by Jaakko Kaprio

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Expansion of Older Cohort in 1996 to Include Opposite-sex Pairs

In 1996, opposite-sex (OS) twins born 1938--1949 have been identified from the Central Population Registry. So far, questionnaire data and DNA samples from over 1500 pairs have been collected in 1997. These are pairs in which one or both of the twins reported that they have been diagnosed with one of selected chronic diseases. This new material represents a substantial new population of sibpairs, while permitting the expansion of the twin design to assess sex by gene, sex by environment as well as sex by gene by environment interactions. Questionnaire data have been used to study sex-limitation models such as for height (Silventoinen et al., 2001), but also as phenotypic information to identify affected sibpairs for molecular genetic studies as described below.

Table 1. The Components of the Finnish Twin Cohort

Birth years	Like-sexed pairs	Opposite-sex (OS) pairs	Notes
Before 1938	13,888 pairs of known zygosity (compiled 1974)	Not identified	
1938-1949		5017 candidate pairs, estimated c. 85% twins	New cohort compiled in 1996 from CPR
1950-1957		3047 twin pairs	
1958-87	21,958 pairs of which 7922 OS-pairs (compiled 1987) born 1958-1986		FinnTwin16: twins born 1975-79 FinnTwin12: twins born 1983-1986 & 1987 (added later)

Follow-up in 2011-2012

A fourth wave was initiated in 2011 with a pilot study to test the questionnaire. Since the 1990 questionnaire, many twins have been asked to participate in selected substudies which have focused on specific study questions and traits, but no unselected questionnaire survey had been conducted after that. While many follow-up outcomes can be assessed by medical register linkage-studies in Finland, many health-related factors need to be assessed by interview or questionnaires given to the participants. To test the acceptability of what turned out to be an extensive questionnaire, we sent 254 pairs with both members alive and 299 twins from pairs where only one twin was available (due to death, migration or lack of address of the other twin) a questionnaire in February-March 2011. The response rate was 70% for full pairs, but only 55% for 'single' twins. With approval from the ethical committee, we revised the invitation cover letter to the 'single' twins to better motivate their participation in the 35 year follow-up.

From October 2011 to June 2012, we approached all available twins in the same-sexed twin cohort irrespective of their zygosity or earlier response status. Overall we sent the questionnaire, either in Finnish or Swedish (Finland being a bilingual country) to 11738 twins born 1945 -1957, and obtained 8501 responses, a response rate of 72%. Data entry and cleaning are in progress, so the numbers may still change somewhat. The questionnaire was mailed rather than administered by internet given the age of the subjects and the fact that the three prior questionnaires had been paper ones. So, a change of mode of administration was not wanted in order to retain comparability across waves. We expect to have the data set ready for analysis by summer of 2013.

The content of the questionnaires was a balance between retention of items used in the earlier questionnaires in order to get 2,3 or 4 measures over time and a need to assess age-specific outcomes of interest, such as intentions to retire. Despite the development of better measures for some topics, we retained the original questions (such as used in 1975 and 1981) wherever possible. A total of 241 items were included in the questionnaires, covering domains such as twin pair relationships, general health and risk factor measurements (blood pressure, diabetes, cholesterol), standard symptoms (chronic bronchitis, dyspnea), musculoskeletal pain, bruxism, history of common diseases and use of various medications including hormone replacement therapy for women. We asked six questions on sleep and seven items on work and retirement. A detailed smoking history was taken again supplemented by nicotine dependence scales (FTND, WISDM) and exposure to second-hand smoke over their lifetime. Quantity, frequency and problem measures of alcohol use and abuse were asked, including a modified MmMAST. Coffee and tea use were queried. Physical activity and sedentariness were asked using 10 questions. Life events and traumatic experiences in childhood and adulthood were assessed. Close social relationships and social support were asked using seven items. Depression was assessed using the CES-D scale and the short extraversion and neuroticism scales from 1975 & 1981 were repeated. Finally a history of weight, weight changes and dieting were included. The invitation letter included a tape measure, and the respondents were asked to record their waist circumference; preliminary data indicates that 98% of subjects reported their waist circumference.