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Data Collection: Challenges, Achievements and New Directions

Data Collection for the Health Component (2008-2009) of the Longitudinal Study of Child Development in Quebec (ÉLDEQ)

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Data Collection for the Health Component (2008-2009) of the Longitudinal Study of Child Development in Quebec (ÉLDEQ)

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Abstract

The ÉLDEQ initiated a special data gathering project in March 2008 with the collection of biological materials from 1,973 families. During a typical visit, a nurse collects a blood or saliva sample from the selected child, makes a series of measurements (anthropometry, pulse rate and blood pressure) and administers questionnaires. Planned and supervised by the Institut de la Statistique du Québec (ISQ) and the Université de Montréal, the study is being conducted in cooperation with two private firms and a number of hospitals. This article examines the choice of collection methods, the division of effort among the various players, the sequence of communications and contacts with respondents, the tracing of families who are not contacted, and follow-up on the biological samples. Preliminary field results are also presented.

Key Words: Data collection, Longitudinal study, Birth cohort, Biological samples.

1. Introduction

1.1 Description of the ÉLDEQ and the research objectives

Each year since 1996, the Institut de la Statistique du Québec (ISQ) has been surveying a cohort made up of some 2,000 children in Quebec to advance scientific knowledge about child development. The Longitudinal Study of Child Development in Quebec (ÉLDEQ) is funded by the Ministère de la Santé et des Services sociaux, the Ministère de la Famille et des Aînés, the Fondation Lucie et André Chagnon and the ISQ. Its main objective is to identify the early-childhood factors that affect Quebec children's social adjustment and academic performance. Its secondary objectives are to gain a clearer understanding of the role of certain public programs (childcare, parental leave, health promotion, etc.) and to guide the development of future programs.

The ÉLDEQ is a multidisciplinary study based on a bio-psychosocial approach. While most of the data are collected from individuals, information about families and the environments in which the children live is also recorded. The information is collected from parents, teachers and the children themselves. The various respondents are surveyed with paper or telephone questionnaires, and the children are given cognitive tests on a regular basis.

1.2 Samples

A sample of 572 families was selected in 1996 for the ÉLDEQ's pre-tests. Part of the sample (449 families) was chosen for data collection by the Université de Montréal, and the remaining 123 families formed the sample for the actual pre-test of the core survey, administered by the ISQ. The core survey itself started with 2,120 families that agreed to take part in 1998, when the children were five months old. The sample is representative of children (single births) born in Quebec in 1997-1998. In the most recent survey, conducted in 2008, 1,974 families were approached for collection, and 1,396 took part.

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1.3 Collection program

Between 1998 and 2006, "regular" data collection was carried out annually so that detailed trajectories could be produced for various facets of development. Subsequently, there were to be two more collection operations, in 2008 and 2010, to conclude the program that covers the period of elementary school attendance. Special surveys on nutrition, child care and psychomotility were added to regular data collection in 2000. Ad hoc funding for those surveys came from various sources. The health component described at this symposium is a special survey conducted as part of the regular collection process in 2008.

2. Description of the ÉLDEQ's health data collection process

2.1 Overview of health data collection

The idea of collecting health data was initiated by two Université de Montréal research groups funded by the Canadian Institutes of Health Research (CIHR) and the Fonds de recherche en santé du Québec (FRSQ). Researchers Louise Séguin, Gilles Paradis and Marie Lambert, of the Groupe de Recherche Interdisciplinaire en Santé (GRIS), are investigating indicators of the risks of cardiovascular diseases in relation to poverty and stress. Meanwhile, Richard E. Tremblay and Michel Boivin, of the Groupe de Recherche sur l'Inadaptation Psychosociale chez l'enfant (GRIP), are investigating genetic influences on various behavioural disorders. Both groups are also interested in a third direction of research, namely environmental health (lead and omega levels in blood samples). Two private firms took part in the collection operations: a survey firm was responsible for recruiting participants, and a nursing firm hired and trained the nurses who conducted the home visits.

Since the blood samples had to be taken while the respondents were fasting, most visits took place on weekend mornings. About 20% refused to give blood samples. Those families still contributed by providing saliva samples, which at least made it possible to carry out the planned genetic tests. Some families also chose to take part in the survey without a home visit. The questionnaires and saliva collection tubes were mailed to them. During the summer, collection was carried out every weekday and on weekends. Although the collection period was originally scheduled to begin March 1, 2008 and end in October 2008, the pace of health data collection was slower than planned due to a shortage of nurses, and the collection period was thus extended to March 15, 2009. There was a slight overlap between collection for the core survey and the special health survey.

The project was complicated somewhat by time constraints. Specifically, the children had to be surveyed within a specified period so that their data would be collected when they were 10 years old. Due to financial constraints, the expensive equipment needed for the visits was in limited supply and had to be shared among the nurses.

2.2 Measurements and collection instruments

The collection activities for health data collection participants are listed in Text Box 2.2-1 below.

Text Box 2.2-1
Heath component measurements and collection instruments

- Self-administered parent questionnaire (20 minutes)
- Child questionnaire administered by the nurse (20 minutes)
- Self-assessment of sexual maturity (Tanner) (5 minutes)
- Measurement of heart rhythm variability (Holter) (continuous)
- Anthropometric measurements on the child (20 minutes)
- Blood collection from fasting child (10 minutes)
- Blood pressure measurement on child in sitting position (10 minutes)
- Saliva collection for DNA preparation, if necessary (5 minutes)
- Saliva collection for cortisol measurement (4 x 2 minutes)

3. Steps in the collection process

3.1 Recruiting participants

The ISQ was responsible for making the initial contacts with participating families. The first contact, made by mailing out an introductory letter about the regular component, helped identify households whose contact information was out of date. The team was able to trace families that had moved using administrative data from the Ministère de l'Éducation, des Loisirs et du Sport (MELS). Next, the survey firm contacted respondents by telephone to confirm their consent to take part in the regular collection process and to make an appointment. At the same time, the families were offered the opportunity to receive information in the mail about a new "health" component in which they were invited to take part. With their permission, the reference materials were sent to them, and they were called two weeks later to obtain their oral consent to participate in the special survey. Written consent was obtained at the time of the nurse's visit.

3.2 Scheduling an appointment with the family

Initially, the survey firm made the appointments and informed the nursing firm, which then assigned them to available nurses. However, because of the shortage of nurses and the limited availability of the nurses hired for the project, it proved more efficient to provide the nurses with lists of families and let them make their own appointments. The nurse then called the participating family two days in advance to confirm the appointment and to remind the parents that the child had to be fasting at the time of the visit. With fewer intermediaries, there were fewer communications between the private firms, which made the project easier to manage.

3.3 Visiting the family

The visit with the participating family took about 2.5 hours. The flow of collection activities is listed in Text Box 3.3-1 below.

Text Box 3.3-1
Health data collection flow

- Obtain written consent (20 min)
- Collection activities
  - Apply anaesthetic cream to child
  - Attach Holter monitor to child (10 min)
  - Take child's anthropometric measurements (20 min)
  - Collect blood sample from fasting child (10 min)
  - Child eats breakfast (30 min)
  - Nurse prepares the blood samples (30 min)
  - Nurse administers the child questionnaire (20 min)
  - Self-assessment of sexual maturity (5 min)
  - Mother completes self-administered parent questionnaire (20 min)
  - Nurse takes blood pressure of child in sitting position (10 min)
  - Nurse collects saliva for DNA preparation, if necessary (5 min)
- Post-collection activities
  - Rewards and results given to family
  - A week after the home visit, child and mother take saliva samples

3.4 Submitting the specimens and the data

After completing the family collection activities, the nurse took care of getting the specimens and the data to the appropriate laboratories. The first step was to drive the blood samples to one of the 26 participating regional laboratories so that they could be frozen and placed in storage. They were then shipped to the central laboratory, where they were tested on a bi-weekly basis for cholesterol levels and blood lead concentration. The cholesterol results were provided to the ISQ, which forwarded them to the respondents in confidence. If abnormal lead levels were found, the affected families and the public health offices were notified, since lead poisoning is subject to mandatory reporting.

The nurse was required to send the blood samples taken for genetic and epigenetic testing by registered mail to two separate laboratories as soon as possible. The completed questionnaires and the heart rhythm data were shipped monthly to two other centres for data capture. As for the saliva samples taken a week after the nurse's visit, the family had to send them by registered mail to a different laboratory for cortisol testing to detect the mother's and child's stress levels. Each centre responsible for receiving specimens or data prepared a monthly report for the project managers at the Université de Montréal. The latter made sure that all collected materials had been shipped to the right places in the agreed time frames.

4. Results and discussion

4.1 Preliminary results

By January 31, 2009, after 11 months of collection, 877 of an expected total of 1,000 families had taken part in the survey. On average, about 80% of the participants agreed to blood collection at the time the appointment was made. Blood collection was successful in 80% of those cases. The main reasons for the failure to collect blood samples from 20% of participants were as follows: child refused, child afraid, and inability to find a vein. The final number of expected participants was therefore lowered to about 950, including 700 blood sample donors.

4.2 Participation and attrition

From a broader perspective, it is important to identify the factors that helped motivate respondents to take part and the factors that led to refusals. Future health surveys may be able to maximize participation by taking those factors into account. First, a home visit by a nurse is a special event for families that know how busy nurses are today. The fact that she has a centrifuge with her and turns the house into a "laboratory" for a few hours also makes the collection process interesting. Health is certainly a hot topic at present, and parents and their child are undoubtedly willing to donate some of their time to research. The parents may also receive personalized results concerning their child – a cholesterol profile – following the blood test. The $40 compensation also probably played a role in encouraging some families to participate.

The following were identified as negative factors that may account for refusals to participate: the length of the visit (2.5 hours); the invasive nature of the measurements (blood sample, heart monitor, blood pressure); the partial overlap with regular collection; and the fact that this is the tenth time that families have been asked to participate since 1998. This last issue arises in every longitudinal study: one day, respondents may simply decide that they have had enough.

4.3 Conclusion

In summary, the collection of health data has been positive overall, but the problems encountered along the way should be used as a benchmark for future province-wide surveys. The lessons learned concern various aspects of collection management. Limiting the number of players in the process would have provided greater control over the various activities. Specifically, it would have been more efficient to have the nurses managed by the Université de Montréal from the outset, rather than by a private firm that also had to communicate with another firm. Having the

nurses make the appointments themselves was also more efficient and limited the number of cancellations, which was high at the beginning of field operations. Finally, one feature that should be retained in future collection operations is the fact that each family was provided with its own test results as this was highly appreciated by the families.