SAGE Research Methods Case Health Submission for Consideration

Case Title

Collecting data among chronically ill adolescents and their parents: How to get their attention?

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Pilot study, Questionnaire, Online survey

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Contributor Biographies

André Berchtold completed a PhD in Econometrics and Statistics at the University of Geneva (Switzerland) in 1996. Then he worked in the field of theoretical and applied statistics with a special interest on applications related to health. He is a specialist in the modeling of categorical variables, with a particular emphasis on Markovian models and time-series analysis. He is currently Associate Professor at the Faculty of social and political sciences of the University of Lausanne (Switzerland) and he is member of the National Center of Competence in Research LIVES.

Christina Akre has a Master's degree in Anthropology and Sociology and is currently a PhD candidate at the University of Lausanne in Life Science on the theme of adolescents with chronic conditions and their families. She accomplished part of her PhD research during a 12 months fellowship at the Harvard School of Public Health/Boston Children's Hospital (MA, USA). She has been conducting research on adolescent health since 2006 at the Institute of Social and Preventive Medicine (Lausanne University Hospital) in the fields of substance use, sexuality, and chronic conditions, with a particular focus on qualitative methods.

Yara Barrense-Dias completed a Master's degree in Criminal Justice, subject area Criminology and Security at the University of Lausanne in 2014. She is currently a Junior Researcher at the Institute of Social and Preventive Medicine (Lausanne University Hospital) in the fields of Internet use, substance use, gambling and sexuality among adolescents and young adults.

Joan-Carles Surís is a pediatrician holding a Master's degree and a PhD in public health and a fellowship in adolescent health. His main research focus of interest are adolescents with chronic conditions, risk behaviors, and the relationship between adolescents and their parents. He is currently Associate Professor in Adolescent Health at the University of Lausanne and director of the Research Group on Adolescent Health at the Institute of Social and Preventive Medicine of the Lausanne University Hospital.

Abstract

We conducted a pilot study for a quantitative survey among chronically ill adolescents and their parents. Our main objectives were to assess the use of an online questionnaire to collect data on the transition process from pediatric to an adult care, and to evaluate the willingness to answer in our target population. A total of 183 adolescents and their parents were contacted by sending them three postal letters (an invitation to participate and two reminders about 3 and 9 weeks after the invitation).

Before the second reminder, we only offered the option to use an online questionnaire, and the response rate stayed very low, only slightly above 10%. With the second reminder, we offered the alternative to answer using a paper-and-pencil questionnaire, and we also gave all participants a gift-card of small value, unconditionally to the completion of the questionnaire. Following the mailing of this second reminder letter, the response rate almost doubled in a few days, and we ended up with more than 35% of answers, both from the adolescents and the parents.

We learned from this pilot study that health data are at least as difficult to collect as any other data, and that chronically ill adolescents are as difficult to survey as healthy adolescents, even when the subject of the study concerns the participants directly. Chronically ill adolescents and their parents can be reluctant to send information regarding their health on the Internet, so the option of answering using a paper-and-pencil questionnaire can be very much appreciated. Moreover, giving a small gift-card to all participants also helps increasing the number of answers.

Learning Outcomes

By the end of this case students should be able to:

1) Understand the difficulties in choosing a mode of data collection (online, paper-and-pencil, etc.).
2) See the fundamental differences between online and paper-and-pencil questionnaires.
3) Understand the importance of incentives for data collection.
4) Realize that even surveys which subject is of direct interest for the respondents will not automatically get high response rates.
5) Understand the importance of investing in the design of quantitative studies.

Case Study

Project Overview and Context

Chronically ill adolescents are a specific subpopulation requiring extensive attention and care. A chronic condition (CC) is defined as a condition lasting more than a year and requiring regular care. Around 10% of youth are concerned. The most common CCs among adolescents are asthma, diabetes, and inflammatory bowel disease (Surís, Viner & Michaud, 2004). Two kinds of financial costs are directly related to chronically ill people: The direct costs linked to the treatment, and the indirect societal cost related to the difficulties of acquiring an education, work and earn an income. Non-financial costs such as emotional costs supported by chronically ill adolescents and their families could also be considered, but are much more difficult to quantify.

In addition to the usual changes appearing during adolescence, chronically ill adolescents face the additional challenge of *transition*: They have to move from their pediatric specialist to an adult specialist. This transition has to be well prepared, since data indicate that many young people see their health and level of care decrease soon after, implying more societal costs. For instance, Okumura et al. (2013) found a 3.6 fold after transition increase in the proportion of those who delayed or forgone necessary health care. The whole transition process is divided into three parts: a preparation phase when the adolescent is still in pediatric care, a transfer phase to adult services, and an engagement phase in adult services. In the entire transition process, which can last for years, the specific moment of the effective *transfer* from pediatric to adult care needs to be carefully planned out with all involved parties (adolescent, family, health professionals).

Main study

Our project was to study the process of transition among chronically ill adolescents in Switzerland, the main idea being to demonstrate that a successful transition is beneficial for the adolescent, but also for his/her family and for society in general, since it implies lower medium- and long-term costs. A first project was submitted for funding on October 1st 2014 to the Swiss National Science Foundation. We wanted to conduct a survey at two time points fifteen months apart among a group of chronically ill adolescents between 16 and 29 years old, their parents, and healthy matched friends. The age range was chosen to obtain answers from different groups: pre-transition adolescents still in pediatric care, adolescents engaged in the process of transfer to adult care, and young adults who had already been transferred to adult care. Our main objectives were

1) To establish the prevalence rate of successful transitions in Switzerland.
2) To assess the impact of a successful transfer versus a poor one in terms of continuity of care and health costs.
3) To define guidelines and recommendations for improving the quality of transfer in Switzerland.

Among the existing ways of collecting information about transition, we chose to use questionnaires as our first objective was to establish the prevalence of successful transition in Switzerland, and because no secondary data were available on this subject to be reanalyzed. In other countries, the prevalence rate of successful transitions was found to vary between 22% and 47%. Using a Type I error of 5%, the required sample size for an estimation within a ±3% error margin was then of about n=1063 (see e.g. Ryan, 2013, for technical information about sample size computation). Taking into account a possible attrition up to 50% between the two time points, a minimum of 2130 youths were required at baseline to obtain accurate data and to fulfill the main objectives. Considering only five specific conditions (diabetes mellitus, cystic fibrosis, epilepsy, arthritis, and inflammatory bowel disease), the number of concerned young adolescents in Switzerland was estimated to be of about 9500, what we considered a sufficient population regarding our required sample size.

On March 25, 2015, our funding request was rejected by the Swiss National Science Foundation. Even though our project was judged original and important in view of the very limited data available yet on this topic, several criticisms were raised, the main being the lack of demonstration of the feasibility of the project.

Pilot study

Before resubmitting the project, we decided then to run a pilot study. Our objective was not to obtain preliminary results regarding our population of interest, but to verify some key aspects of our methodology (Kistin & Silverstein, 2015). We wanted to

1) Assess the use of online questionnaires.
2) Evaluate the willingness to answer among the target populations (adolescents and parents).

We chose to collect data on one occasion only in the pilot study. Indeed, attrition between waves was not part of our focus of interest, since we already had experience from past longitudinal studies (Piguet et al., 2015).

Questionnaires

We built two questionnaires, one for adolescents and one for their parents, to be answered by one of the parents. Answers were anonymous, but to be able to match answers from adolescents and their parents, all respondents (adolescents and parents) were asked at the beginning of the questionnaire to create a code consisting in six elements:

- The first and last letters of the first name of the adolescent
- The first and last letters of the last name of the adolescent
- The birth day of the adolescent (between 1 and 31)
- The birth month of the adolescent (between 1 and 12)

We provided the following example: *Someone called Claire-Sophie Duval who was born on the 12th of March should answer as follows: C E D L 12 3.* It was made very clear that this code was only asked for matching purposes and that it would be deleted from the database before performing analyses.

Adolescents were also offered the possibility to refuse to participate in the study. In that case, adolescents were asked to provide at least some basic health and socio-demographic information: age, gender, chronic condition, and reason for refusal to participate. Parents were offered the same possibility, in which case they were asked about their family relation with the adolescent (mother, father, and so on), gender, the chronic condition of their child and the reason they refused to participate. These data were not mandatory.

The questionnaire for adolescents was relatively short. In addition to the 6 questions required for creating the code, the questionnaire comprised 51 questions for a total of 68 items. Seven of these questions appeared only according to the answer given to a previous question. Almost all questions were multiple choices. The following questions are examples taken from the questionnaire:

1. Did you feel ready for the transfer to adult specialist?
    - ☐ Very
    - ☐ Enough
    - ☐ A little
    - ☐ Not too much
    - ☐ Not at all
2. When have you seen a doctor for the last time? …………………….. (date)
3. Since you transferred to adult care, have you missed scheduled appointments without warning?
    - ☐ No, never
    - ☐ Yes, once
    - ☐ Yes, several times but not consecutively
    - ☐ Yes, several times consecutively

The questionnaire for parents comprised 47 questions (59 items), with seven of these questions appearing only according to the previous answer. Even if questionnaires were short, we did not have a precise estimate of the time required to fill them out, so the pilot test should also provide information on that point.

At the end of each questionnaire, we asked for authorization to contact the respondent again later for a next wave of the survey. If they agreed, they had then to provide an email address.

Even if this pilot study was not intended as longitudinal, we wanted to check the willingness of respondents to be included in a long term data collection.

Research design

For this pilot study, we chose to consider only two diseases and our inclusion criteria were:

1) To be aged 17 or more;
2) To suffer from diabetes or rheumatism;
3) To have already been transferred to adult care.

We relied on pediatrician colleagues of the Lausanne University Hospital to obtain the names and postal addresses of eligible adolescents they followed. A total of 183 adolescents aged 17 and more were then contacted to take part in the pilot study, 134 suffering from diabetes and 49 from rheumatism. Three letters were sent to the adolescents by post, and similar letters were also sent to their parents:

L0: Invitation to participate in the study, June 10th (diabetics) – June 22nd (rheumatics), 2015.

L1: First reminder, July 3rd (diabetics) – July 6th (rheumatics), 2015.

L2: Second reminder, August 13th (diabetics) – August 17th (rheumatics), 2015.

All letters were signed both by the head of the research team conducting the study and by the pediatrician who followed the adolescents before their transfer to the adult service.

Data collection was closed on October 27th, 2015.

L0: Invitation to participate

The first letter sent mid-June 2015 to the adolescents indicated the goal of the study and provided the link to the online questionnaire. Due to technical constraints related to the use of *Sphynx*, the standard online survey tool used at the Lausanne University Hospital, and to having to send the invitation by post (emails of the included adolescents were not available), respondents had to copy by hand in their Internet browser a quite lengthy Internet address (54 characters) to reach the questionnaire. No information was provided concerning the number of questions and the time required to fill out the questionnaire, neither in the letter, nor at the beginning of the questionnaire itself, since it was one of the aspects to be examined through the pilot survey. A progress bar indicating the percentage of completion of the questionnaire was displayed at the bottom of each page, but this bar was not fully informative, since it reflected mainly the number of pages in the questionnaire rather than the number of questions or the required time.

The letter indicated the following: *"This survey is anonymous (do not put your name on it) and voluntary (you do not have to answer if you do not want)."* It was also said that knowing their opinions and wishes, as well as those of their parents, would make the transition process easier from pediatric to adult care, but no direct benefits were offered to the participants. By direct benefit, we mean a gift, the participation to a prize-draw, or specific advices for their own transition.

A similar letter containing the link to the parents' questionnaire was sent at the same time to the parents of each adolescent.

L1: First reminder

A first reminder letter was sent at the beginning of July 2015 to all adolescents. The questionnaire being anonymous, it was not possible to automatically filter those having already answered, so we asked them to ignore the letter if they had already answered. We also indicated more clearly than in the first letter that they had the possibility to indicate if they did not want to participate by going to the online questionnaire.

At the beginning of the letter, we wrote *"We have already received lots of responses, but we have not yet reached the minimum number required for the study to be valid."* To motivate the respondents and to improve the response rate, we wrote, that this study would allow improving the quality of life of chronically ill youths entering adult life. We also wrote *"You are the true expert in this domain and your opinion is extremely important!"* Besides these written encouragements, again we did not provide any direct benefit to the participants.

A similar reminder letter was also sent to the parents of each adolescent.

L2: Second reminder

A second and last reminder was sent to the adolescents mid-August 2015. There were four main differences with the first reminder letter:

1) Before sending this reminder, we checked the database and manually matched the codes defined by respondents with the names of the whole database of 183 adolescents from the Lausanne University Hospital. By doing that, we identified adolescents having already answered the questionnaire to avoid sending them a useless additional reminder.
2) A ten Swiss-franc voucher (about ten US dollars) for a very popular general store was inserted in the letter, unconditionally to the completion of the questionnaire. This small amount was selected so that the respondents did not have the impression of being paid to answer, which could have resulted in a negative effect (Ernst Stähli and Joye, 2016).
3) Before sending this reminder, we opened an Internet web site and we put the link to the questionnaire directly on it. From then on, the respondents only had to type an easy-to-remember web address of 14 characters (www.lesados.ch) and to click on the link leading to the questionnaire instead of typing in a 54 character link.

4) We also inserted in the reminder letter a paper version of the questionnaire and a stamped envelope to return the questionnaire. By doing this we wanted both to offer a more traditional way of answering for people not willing to answer online, and to show them that the questionnaire was quite short.

A similar reminder letter was also sent to the parents of each adolescent with the same 10 Swiss-franc voucher.

Number of answers

Figure 1 shows the evolution of the number of questionnaires answered from the first mailing (L0) to October 27th 2015. It is important to note that for questionnaires returned by post, we do not know the exact date of completion. In that case, we considered the date of reception of the envelope containing the questionnaire. We could also have used the date of the postal stamp, but in some cases it was not readable.

At first, the parents' response rate was higher than the adolescents' one, but adolescents caught up with parents on August 23rd after which the difference remained small. Until sending the first reminder (L1), we had only 3 answers from adolescents and 12 from parents. After that, the numbers grew up to respectively 20 and 23 answers, but it was only after the second reminder (L2) that the number of answers began to really increase, doubling in a few days.

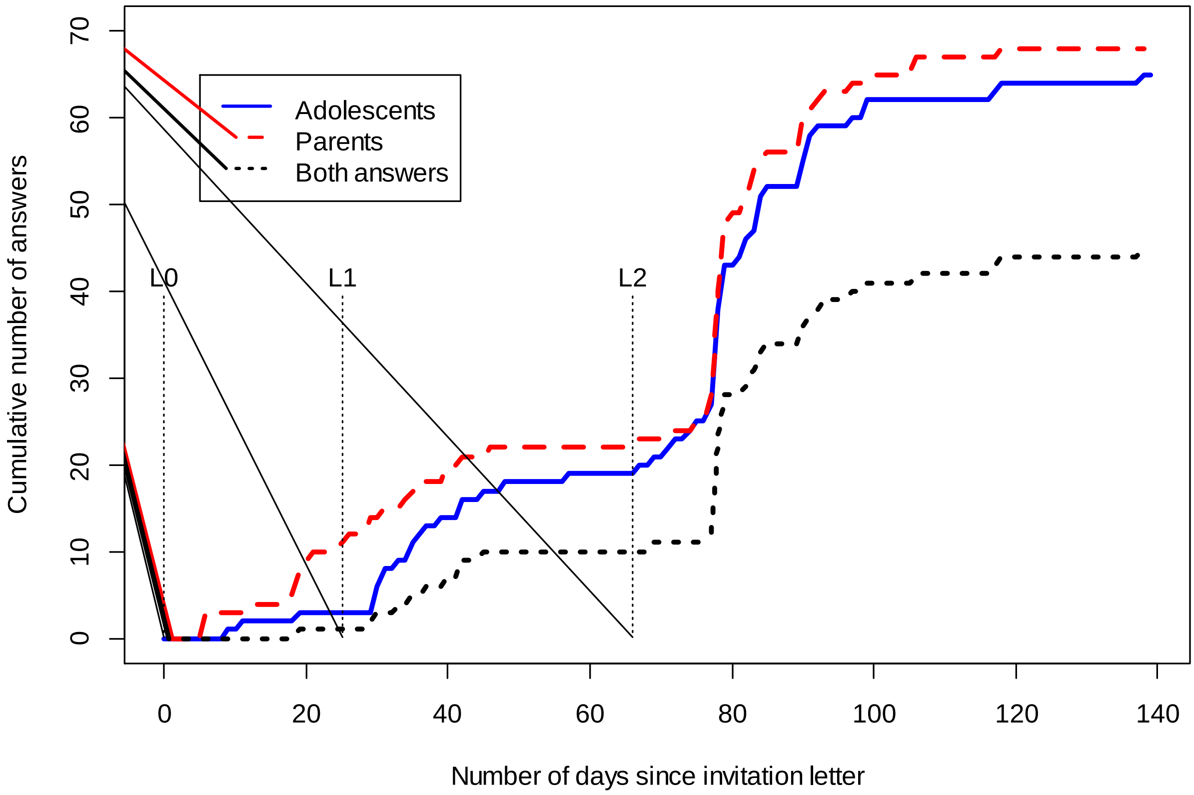

Figure 1. Cumulative number of answers from the adolescents, the parents and both an adolescent and his/her parent. L0, L1 and L2 indicate the time of sending of the three letters.

No statistically significant difference appeared between answers provided by diabetic and rheumatic adolescents, nor by their parents, even if the final percentage of answers from diabetic adolescents is somewhat higher than the corresponding percentage among the rheumatic ones (Table 1). The number of participants having indicated through the questionnaire that they did not want to participate in the study was very low (3 adolescents and 2 parents).

Regarding the third phase of data collection, when respondents had the choice between a paper-and-pencil and an online version of the questionnaire, the vast majority of them chose the paper-and-pencil option (38 adolescents out of 45 having answered during this phase, and 42 parents out of 45).

If the total percentage of adolescents and parents having answered are similar (35.5% and 37.2%, respectively), the percentage of families where both the adolescent and the parents answered is much lower (24.6%), the difference with the response rates of adolescents-only and parents-only being both statistically significant at the 1% level.

Table 1: Number of answers, response rate, and cumulative response rate for the three periods of data collection. Data are provided separately for adolescents, their parents, and having answered both (adolescent and parent). A total of 183 invitations to participate were sent (134 diabetics and 49 rheumatics). RR: Response rate of the period. CRR: Cumulative response rate since the beginning of data collection.

		Period 1 (between L0 and L1)			**Period 2 (between L1 and L2)**			**Period 3 (after L2)**			**Refusals**
		n	**RR %**	**CRR %**	**n**	**RR %**	**CRR %**	**n (paper version)**	**RR %**	**CRR %**	**n**
Adolescents	**All**	3	1.6	**1.6**	17	9.3	**10.9**	45 (38)	24.6	**35.5**	3
	Diabetic	3	2.2	**2.2**	8	6.0	**8.2**	34 (28)	25.4	**33.6**	1
	Rheumatic	0	0	**0**	9	18.4	**18.4**	11 (10)	22.4	**40.8**	2
Parents	**All**	12	6.6	**6.6**	11	5.8	**12.2**	45 (42)	24.6	**37.2**	2
	Diabetic	8	6.0	**6.0**	6	4.5	**10.4**	34 (32)	25.4	**35.8**	1
	Rheumatic	4	8.2	**8.2**	5	10.2	**18.4**	11 (10)	22.4	**40.8**	1
Adolescents & Parents	**All**	1	0.5	**0.5**	4	2.2	**2.7**	40	21.9	**24.6**	-
	Diabetic	1	0.7	**0.7**	2	1.5	**2.2**	31	23.1	**25.4**	-
	Rheumatic	0	0	**0**	2	4.1	**4.1**	9	18.4	**22.4**	-

Finally, 35 adolescents (53.8% of the respondents) and 35 parents (51.5%) agreed to be contacted again later for a next wave of the survey.

Discussion

Considering both the subject of this study and the amount of time invested in the project, we cannot be satisfied with response rates only slightly above one third. Relying only on the idea that people care a lot about their health is clearly not sufficient to collect data. Even letters signed by physicians they know personally are not sufficient for inciting them to answer, and surveys among adolescents with special health care needs and their parents who could be thought to have even more interest in filling in this type of survey to improve their health care do not have much weight either. Surveys about health should therefore be considered exactly like any other survey.

Online questionnaire

Some mistakes during the data collection process can explain in part the low response rate, but very valuable information can be deducted from our results. The kind of questionnaire, online vs paper, was much more important than we thought at first. In all of our recent data collections on Internet use and gambling, we had used online questionnaires only, so the option of offering the choice between online and paper-and-pencil was not really discussed when we decided to run this study. Moreover, different studies have shown that online questionnaires provide better results than paper-and-pencil ones when applied to adolescent health (Wu and Newfield, 2007). However, our previous surveys mostly took place in schools, during classes, where respondents (students) have very few reasons not to answer. For instance, in a study on gambling conducted in the Swiss canton of Bern, we reached a 97% response rate. Assuming that our population would answer as if they were students was clearly a mistake.

During the first two phases of the study, only the online option was offered and with the specific cost of having to type in a lengthy web address. That could have discouraged some people to answer. Since we did not have access to email addresses or cellular phone numbers of our population, sending them an email or a text message with a simple link to click on was not feasible. In the 2nd reminder letter, we simplified access to the online questionnaire by providing the address of a web site giving a much more direct access to the questionnaire. However, since this measure was put into action simultaneously with the mailing of the paper version of the questionnaire, we were unable to analyze properly its efficiency.

After designing the pilot study with the 183 adolescents from the Lausanne University Hospital, another colleague gave us the email address of 9 other rheumatic adolescents who agreed to answer the questionnaire. These adolescents and their parents were contacted by email during the period covered by our pilot study, with 5 adolescents and 5 parents providing answers through the online questionnaire. In 3 cases, both the adolescent and the parent answered. This additional sample is of course too small to allow for sound conclusions, but the fact of reaching globally a 50% response rate can be put in relation with the fact that a simple click on a link in the email was sufficient to access the online questionnaire and that they were asked directly by their physician in consultation. On the other hand, since these adolescents and their parents had previously agreed to participate in the study, a 50% response rate is disappointing.

Paper-and-pencil questionnaire

The second measure introduced with the 2nd reminder letter was the option to answer through a traditional paper-and-pencil questionnaire as an alternative to the online one. Even if, as will be discussed later, the timing of this 2nd reminder was better than the previous one, it does not explain why a large majority of respondents chose the paper-and-pencil option. We see five advantages to the paper-and-pencil option:

1) The questionnaire is available to be answered immediately, without any delay.
2) The length of the questionnaire is clearly visible.

3) The simple existence of the questionnaire on a “real” form can give more importance to it. If the people conducting the survey did invest money in a paper version, this is because they consider it as really important.
4) A pre-stamped envelope with the address of a renowned institution can even increase this psychological effect: Respondents have then a concrete proof that the survey is really conducted by this institution, what is more difficult to ensure with an online survey.
5) Respondents may be reluctant to send data online and prefer the traditional paper option, especially regarding sensitive data such as questions about their health.

In line with the last point, the paradata (that is information such as time for answering the questionnaire or time when the questionnaire was finished) available from our online survey system indicated that 35 more questionnaires were partially answered by the adolescents and 40 by the parents, but since the corresponding answers were not recorded, it was not possible to determine whether the persons who cancelled the completion of the questionnaire completed a questionnaire later on or not, either online or paper-and-pencil.

It could have been hypothesized that older parents, who were born before the invention of Internet, could have been more prone to answer on paper, but a Student t-test showed that the mean age of parents answering on paper was not significantly different from the mean age of parents using the online form (p=0.183).

Mixed modes of data collection

In addition to the use of both paper and online questionnaires, other options are possible to increase the means to answer, hence the response rate:

1) Most online surveys are designed to be answered on a personal computer, but in today’s world, smartphones and tablets become the main tools used to surf the Internet. As a consequence of their reduced screen size, it is necessary to develop specific versions of the questionnaires (Mavletova & Couper, 2014). These additional developments imply also additional costs. This can be viewed as a downside of the technological evolution which could sometimes incite us to go back to paper-and-pencil questionnaires as a way to be certain that all people answer to a strictly identical questionnaire.

2) When contact data are available for the surveyed population, these persons can be contacted through different channels: postal letter, email, phone, text message, instant messaging services, but also social networks. Even if further research is necessary on that point, it can be hypothesized that there is not an overall best contact mean, and that contact means have to be selected according to the respondent’s profile (such as age, gender or activity).

3) In addition to online and paper questionnaires, which are self-reported tools, some people might be more accustomed or can feel more comfortable answering in an

interview setting, either in face-to-face or by phone. Allowing these answering modes too can help improve the response rate, but data collected through very different means can be less comparable (Jäckle et al., 2010).

Benefits for the respondent

A third very important measure was finally taken for the 2nd reminder: A voucher of small value (10 Swiss francs) was given unconditionally in all L2 letters. There are proofs in the survey literature (Martinson et al., 2000) that

1) Any direct benefit given to the respondents improves the response rate.
2) A benefit of small value is sufficient to help improve the response rate.
3) Benefits given unconditionally to the completion of the questionnaire are more effective than conditional ones.

Again, the influence of this voucher cannot be distinguished from the availability of the paper questionnaire, but the combination of both measures implied in our case a dramatic boost in the response rate. In previous studies, we relied several times on lotteries to improve the response rate, but this strategy was never effective. Even prizes worth more than 500 Swiss francs (about 500 US dollars) have not helped, so a small unconditional benefit given to all participants seems a better choice.

We chose to offer only a monetary benefit, but other forms of benefits are possible. First of all, we offered an indirect benefit to all participants by writing that this study – hence their answers – would help improve the transition process from pediatric to adult services of all chronically ill adolescents. Another option that we did not consider would have been to offer them a more direct benefit by providing general advices for a good transition, such as a fact sheet written by pediatric and adult specialists, or even individual counsels according to their answers, provided that they agreed to let us contact them again.

One adolescent returned the voucher with the questionnaire, indicating that s/he did not want to participate in the study. We do not know whether other people not answering the questionnaire used their voucher.

Survey period

The time for this pilot study was not optimal, since it covered the summer holiday break, but we did not have many other options, since we had to obtain results before being able to resubmit our main project for funding on October 1st 2015. However, even if the timing was not perfect, it cannot really explain our results. If people were willing to answer, they had the opportunity to do so during the second half of June, before summer holidays. Moreover, the number of answers increased slightly but consistently during the first three weeks of July, after the 1st reminder letter. Finally, data collection spanned over 3 months when summer vacations in Switzerland are usually no longer than 3 weeks.

The 2nd reminder was sent mid-August, meaning after the majority of people are back, which can have also boosted the number of answers observed during the second half of August, but again it is not possible to really distinguish this effect from the different improvements associated with this last reminder (voucher, paper version of the questionnaire, …).

In a very active world, where we all have many activities and duties, it is important to identify and use the most favorable time period to perform a survey. For instance, when surveying students for other projects, we always made sure that the chosen days or weeks were not at the beginning or end of a crucial term, or that they did not conflict with important exams.

Answers from the adolescent and the parent

A particularity of this study is that we would like to compare the answers of the adolescents with those of their parents on an individual basis. To do so, we not only have to be able to match both answers (what we can do with the code provided for at the beginning of the questionnaire), but more basically, we need to have both the adolescent and one of the parents answer. A good idea would have been to mention this fact explicitly in the three letters. It would have also been possible to give an additional voucher upon completion of the questionnaire both to the adolescents and the parents, but that would have required having a way of contacting them, which would have implied less anonymity.

Anonymity

Even if this theme was not prominent in our pilot study, anonymity must be guaranteed at least to ensure a better quality of answers. If you know for sure that no one will be able to link your answers with your identity, then you have much fewer reasons to alter the truth. This is especially true in the context of a health survey, when many questions are sensitive. Here, respondents did not have to give their name, so their anonymity was preserved, but on the other hand, the code created at the beginning of the questionnaire, provided the answers were honest, could have been used to link some respondents with their answers, which might have created doubts for some regarding the level of anonymity of this study.

The traditional solution in such cases is to store the codes created by the respondents in a different database than the one used for the real questions. A person different from the research team is then asked to perform the matching between the codes created by the adolescents and the parents. The research team analyzing the data has then no way to link respondents’ identity and content of answers.

Practical Lessons Learned

We summarize here the main lessons we retain from this pilot study:

- If people do not have to answer on a mandatory basis, it is sound to assume that they will not answer. Based on this premise, we can imagine strategies to catch their attention concerning the subject of the study, hence to incite them to answer.
- It is possible that some of the contacted youths or their parents did not answer because the relationship with the pediatric specialist did not end well. By contacting them

through other networks, such as patients' associations, it could be possible to overcome this barrier and have a better response rate.

- When using an online questionnaire, the access to the questionnaire must be as straightforward as possible. The best solution is to have invitations sent by email or other electronic messaging services such as text messaging with a simple link on which to click to access the questionnaire. When such an option is not feasible, the link leading to the questionnaire must be as short as possible.
- To be taken seriously by respondents, a survey or a questionnaire has to look trustworthy. For instance, providing a complete version of the questionnaire on paper can be viewed as more serious than a simple web address. A pre-stamped envelope to return the questionnaire to the address of a recognized institution is another proof of credibility.
- An unconditional voucher of small value given to all contacted persons is a very effective way both for thanking participants and giving the message that we consider them as important for the study.
- The timing of a survey is very important. There is already a sufficient share of the population not willing to answer without adding people not able to answer because they are absent at the time of the study.
- Pilot studies have to be very well designed. Here, giving a voucher at the same time as offering the paper-and-pencil option did not allow us to separately analyze the respective effect of each measure.

Exercises and Discussion Questions

1) What are the specificities of collecting data on health in contrast with data on less sensible subjects, such as music for instance?
2) How can a paper-and-pencil questionnaire help improve the response rate of a study?
3) Exercise: Write a letter of invitation to participate in a survey among chronically ill adolescents. What points should be highlighted?
4) Subject for in-class group discussion: How would this pilot study have been run in 1990 as compared to what was done in 2015?
5) Subject for in-class group discussion: If you were surveyed about your health, which benefits would incite you the most to answer?

Further Readings

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Web Resources

None.

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