



A sensitive topic: the ethics of social surveys (A)

In August 2004, Dr David Darwin, chair of the Human Research Ethics Committee for the Canzalian Department of Family and Workforce Planning, received a letter marked for his urgent attention. It was written by a clearly outraged Cecily Melbourne, recounting events a week earlier when her partner John Sydney was questioned for over 30 minutes during a phone survey sponsored by the Department. Cecily described how her partner was asked very intimate questions about herself. She was concerned about a number of aspects including the questions themselves, the conduct of the survey, and the privacy and storage of the data gathered. She expected a prompt and decisive response, she told Dr Darwin.

The Lifestyle Study

In 2002, the Canzalian Department of Family and Workforce Planning secured \$2 million funding from the Canzalia 2020 Bright Futures Fund for its largest-ever research project. This was an ambitious long-term study into the changing nature of family groups, including the attitudes and behaviours that impacted on parenting and on readiness for the workforce.

Researchers had found that a lack of good data in these areas was hindering a variety of important projects on societal change, at a time when there was increasing demand from government for current information on which to base policy decisions. Topics to be covered by what would be called The Canzalian Longitudinal Family Lifestyle Study included violence within the family, and the sexual health and habits of family members. The findings would be used to inform public policy for programmes such as parent education, modification of violent behaviour, and HIV/AIDS prevention.

This case was written by Janet Tyson, Australia and New Zealand School of Government, for Dr George Argyrous, University of New South Wales. It has been developed from a real-life situation, to enable class discussion; however names and other identifying details have been changed. ANZSOG acknowledges the generous assistance of the Australian Broadcasting Corporation's Health Report in the preparation of this case.

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Submitting the proposal to the Department's Human Research Ethics Committee for approval, the research team acknowledged the ground-breaking nature of the study, and the wealth of behavioural data, some never gathered before, that would be an ongoing resource for the public good. The Department would develop the survey in association with the internationally-respected Centre for the Study of Healthy Populations at the University of Rotorua at Rainbow Springs.

The Department contracted the work to the University, which subsequently sub-contracted the field work to the well-regarded Paradigm Research Company. Paradigm's website noted its skill in achieving high levels of response to telephone interviews. Interviewees would be chosen at random; the scope of questions put to the selected interviewee would include some asking for information about his or her partner and children.

Paradigm's practice was to "de-identify" all the personal information gathered in the survey, holding it in separate databases to protect it. Each interview would be coded, and the code-breaker kept in a secure place.

The Department's Human Research Ethics Committee provided its own framework of protection for the subjects of research studies. In line with national guidelines its primary purpose was "to protect the welfare and rights of participants in research, and the primary responsibility of each member is to decide independently whether in his or her opinion the conduct of each research proposal submitted to the Human Research Ethics Committee will so protect participants."

The Family Lifestyle project was examined by an expert subcommittee, which recommended it for approval by the Department's ethics committee at its quarterly meeting. Considered along with a batch of other applications, the project was endorsed by the full committee.

Personal questions

By mid-2004, the study was in full swing and several hundred survey interviews had been conducted.

When the phone rang at 6 pm one winter evening, John Sydney knew it was probably the woman who had already called him on two earlier occasions, asking him to take part in a survey on family health and lifestyle. As he understood it, the survey was being conducted by the University of Rotorua's Centre for the Study of Healthy Populations. Because the university had a good reputation for social science research, he felt he should support it.

Each previous time the woman had rung, he had had to ask her to call back, as he was too busy or preoccupied to take part. Now, with his partner Cecily Melbourne still on her way home, he felt it was time to "get it out of the way, and get it done."

"Having been married, and having another partner, having had a number of children between us, I thought that I could contribute," he recalled.

The interviewer began by repeating the name and purpose of the study, and saying that anonymity and confidentiality were guaranteed. The interviewer also told John he was free to stop the interview at any time, then started the survey.

Half an hour and over a hundred rapid-fire questions later, John put down the phone, and turned to Cecily, who had arrived during the call.

“Gosh, that was explicit,” he said.

“What do you mean?” she asked.

“It was a study on health and relationships run by Centre for the Study of Healthy Populations, and they even asked about you...[questions like] have you ever been pregnant?”

The survey had asked John to answer many questions about his partner, almost all of them intimate details of her health and sexual behaviour and experience:

“Now, some questions about your partner’s health...Has she used cannabis?... Has your partner ever been pregnant? ... Is she currently taking an oral contraceptive like the pill...The next few questions are about your last sexual experience with her...The last time you had sex with her did you kiss, cuddle or hug, stroke her body, perform oral sex on her?... Did she stimulate your penis with her hand?...Did she stimulate herself with her hand? The last time you had any sex with a female was it with her?...What is your approximate family income before tax and other deductions?”

John told Cecily he had felt increasingly uncomfortable as the survey progressed, trying to get through it as quickly as possible and doing it as well as he could, “but getting to a point where I’m thinking I’m not so sure that I really want to be answering some of these questions...It seems to me that I really shouldn’t be answering for somebody else.” If the questions had not come from “a university or a hospital”, he thought he might have queried it more.

Without consent

Cecily, astounded to learn the content of the questions, became increasingly distressed.

“[When] he said [they asked] about what we did when having sex I was so upset, because that was the most intimate of questions. Then as I got into more of the other questions I was even more distressed because apart from anything else, that phone is in my name, I was the identifiable party...I couldn’t believe that somebody could come into my home via telephone or any other way and convinced somebody else to give that sort of information about me without my consent... I just couldn’t believe it.”

Initially, she was angry with John, who at first thought her reaction was “over the top”. Subsequent events convinced him that her outrage was justified, and he came to share her view that he had been “manipulated” by a skilful interviewer who asked a lot of innocuous questions before leading in to the more explicit ones. “I think he was probably lulled into a false sense of security and then just got trapped in it and it was too hard to disengage,” Cecily reflected.

That night, she went to the website the researcher had given to John. There she learnt that the main player was not in fact the Centre for the Study of Healthy Populations, but the Department of Family and Workforce Planning; she was also to discover that the Centre had subcontracted the interviews to Paradigm Research.

The next day, Cecily rang the Department of Family and Workforce Planning to complain, following up with an email to the research team. In turn the team forwarded her email to the Department's Human Research Ethics Committee, whose secretary suggested to Cecily that she should write directly to the chairman, Dr David Darwin.

The Ethics Committee responds

Dr David Darwin, chair of the Human Research Ethics Committee for the Department of Family and Workforce Planning, wrote back to Cecily explaining that, as far as the Department was concerned, the study had been set up within the normal guidelines and with the usual protections for the privacy of participants. This was not what Cecily had expected.

“When I wrote to the chair of the Ethics Committee initially, I was convinced he would say this is terrible, we'll stop this straight away. But he didn't.”

Dr Darwin told Cecily that, if the Department was to investigate further, John himself would have to make a complaint.

John promptly lodged a written complaint as requested. Apart from a brief acknowledgement, this was all he would hear from the Ethics Committee for the next four months. Eventually, his complaint was tabled for discussion.

By then, Cecily, frustrated at the lack of progress, and convinced that something should be done, had contacted Privacy Canzalia, the Canzalia 2020 Bright Futures Fund that had funded the study, and the Canzalian National Ethics Committee. She said

“...thousands of people have been affected by this and many of them wouldn't even know that their partners have given this information about them. I wanted consent, like I wanted consent from the partners of those concerned, and I also wanted true consent from the person who actually gave the information to the interviewer because I don't believe they gave true consent either.”

Another early step she took was to ask the Department to have the data gathered about John during the interview deleted from Paradigm Research's databases. Two days later she was told it would be, and eventually she was informed that the deletion had happened five or six days after the interview. She later found out that the research company hadn't got round to “de-identifying” the data during that period. As they were using a so-called reverse telephone directory to choose their interviewees, it would during that period have been easy for someone to reverse from a listed phone number to a person's name. With the phone in Cecily's name, it would have been easy to identify her.

Concerns and changes

When it finally investigated John's complaint, members of the Department's Human Research Ethics committee raised their concerns about the way things had been done and

asked for changes, including the renaming of the study as The Longitudinal Study of Family Dynamics and Sexual Relationships, to more clearly reflect what it was about.

This prompted spirited debate, during which members of the research and policy teams reiterated the increasing difficulties caused by gaps in the fundamental data needed for government decision-making. Material gathered by the project was already providing the stimulus for further essential research. The team also pointed out that a large number of research projects involve gathering information about third parties.

“Like any citizen with any phone call, John had the right to put the phone down and end the interview at any point,” one team member said. After a lengthy discussion, the meeting agreed that the study should be given the new, more explicit name.

At a later meeting, this decision was reversed and the study continued under its old name, the researchers having argued successfully that the change of title would lower their response rates and cause a problem if a child answered the phone.

By now the Canzalian Public Service Commission, the overall arbiter of ethical behaviour in the public service, was also aware of the situation. However it was beyond its scope either to force the Department to reconsider its changes, or to overturn the ban the Department had placed on any of its staff speaking to the media. Until Cecily made a Freedom of Information request, the Public Service Commission was also reluctant to release details of the study’s original (and taxpayer-funded) research grant proposal.

Fifteen months after the phone call that so distressed her, Cecily’s complaint to the Privacy Commissioner was scheduled to be heard before the Canzalian Civil and Administrative Tribunal, CCAT.

In preparation for the hearing the Department and Paradigm Research provided the CCAT, and Cecily, with copies of two of the interviews that they had coded for privacy.

To Cecily’s alarm, the secure code proved to be anything but. She found it would be very easy to identify the two men interviewed but refrained because she knew the material would contain intimate details. She also learned that the same courtesy had not been extended to John. From a witness statement it was clear that at least one person at Paradigm Research had read John’s interview before deleting it as requested.

Dr Darwin now faced the prospect of appearing before the Tribunal, where he would be questioned at length. Now was the time for him to consider whether anything had gone wrong with the Department’s research project, and if so, what it was and how it could be prevented from being repeated in future.