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# The experience of taking part in a national survey: A child's perspective – Freja Edwards, aged 10 years

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## Introduction

I took part in a NatCen study. This was a study of health and fitness of children up to 18 years round the whole of the UK. We were picked out by random postcode and they didn't know who lived there. If there was more than one child living in the household, they chose who did it by whose name came first in alphabetical order so it was fair. I had to do it and not my brother because I was first in alphabetical order. It was described as an interview in the letter but one interview led to another. First they just asked questions but that led to keeping a food diary for four days and wearing an ActiGraph (pedometer) for a week.

## Keeping the food diary

With the food diary it was very, and I mean very, detailed. You had to record where you ate, whom you ate with, and whether or not you had the television on. You had to record the exact, or near amount of, what you ate and that included having lots of visits to look at a food atlas (a book of different portions of different foods). With all this being around and on my birthday this was rather hard so the results

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we get back may not be what my usual diet is. I had pizza and chips, for example. This felt a little like work but that was the only way to get £30!

I also had to keep my food wrappers so she could look up the nutritional value of, and the calories, I had eaten.

## **Wearing the ActiGraph**

The ActiGraph is basically a pedometer but the only difference is that it does not calculate how many steps you do but how much exercise you get and how fit you are overall. The annoying thing was that it was not easy to get on and off and it sometimes came unfixed. When it came unfixed on one occasion I was in the middle of my games lesson so it was very annoying! But in doing all this I got an extra £10 to make a total of £40 in shop vouchers! My view on this, though, is that they shouldn't advertise it as an interview and should tell participants what you actually have to do. They also arrange for a nurse to come and take measurements about a month after you took part in the study.

## **Who decided whether to take part?**

The family was sent a letter addressed to the household owner. We were asked to take part in the study and the interviewer asked me whether I wanted to do it or not, and I said yes. If I'd have said no, my brother might have taken part. I read the letter before the interviewer came to ask us so I knew what was happening and I'd already decided that I would say yes. I talked it over with my Mum and Dad but I'd already decided so they didn't really influence my decision. I didn't have to sign anything at all. I didn't have to do it if I didn't want to.

When I said yes, we organized a time for her to come and start the actual study. The study first involved an interview and then she went away and then she came back another day when she checked the diary and went over a food atlas with me, and then she went away again, and came back on my birthday and did the same thing again. The study was in full swing and it was the last day of my food diary, so she had to come and check. I didn't really want to say no, don't come on my birthday. I didn't want to be rude and I wanted to get the study over with. She came back a few days later to collect the finished food diary and the ActiGraph. She did bring me a birthday present, which was a little cookery book to record recipes in. I wouldn't have liked to do it if it were over the period of two weeks, I wouldn't have liked it, but as it was over the period of one week, it was fine. If she'd have come back over two weeks, it would have been difficult to say I don't want to do it anymore. Near the beginning, I could have said no, and I would have said no if she'd described it to me as being over three weeks. I don't know how I'd have got

out of it, if it had been over three weeks. I wouldn't have wanted to do it over three weeks. I could have said I didn't want to answer some questions, though, and the interviewer did say I could say no to her.

### **Why did I take part?**

These results go towards the national health guideline, so you are helping. They gather the information from all the interviews and, at some stage, the guidelines go out to the public to say what food you should eat and how much you should eat, such as smaller portions of crisps and larger portions of salad. Some people do not have an idea about what is healthy to eat and the national guideline gives people an idea of what people should eat. I personally would take part again because you feel like you're helping. I would take part in other studies and not just the food one. I would have taken part without the vouchers but I think people should have the choice whether they do or not. Some people may not want to take part without a reward.

I shared the voucher with my brother, as he could have been chosen and not me. He didn't really want to do it but I gave him half, because if he'd have done it he would have got the money. That's fair.

I didn't mind the interviewer coming to visit but I wouldn't have wanted information about me to go out to the public.

After a few months, the nurse visited the house to ask me whether I would take part in a blood sample test and a urine collection for a whole day. I felt uncomfortable about the urine collection procedure, but with the blood test I decided it would be OK to have a go. A paediatric phlebotomist came to try to get a blood sample but the needle wasn't directly in my vein so it didn't work. As a result of this, I still got another voucher for letting them try to take blood. They also asked me whether I would have let them keep the samples on a long-term basis but I wasn't very keen even though it would have been anonymized. I was also uncomfortable with the tests, in case problems occurred that were not usual and that I might have to have even more tests.

### **A parental perspective, John Edwards, Keele University**

I was keen to support a UK academic study and so when the researcher visited to inform us that we had been randomly selected to take part in the study, I did not hesitate to agree. The process of informing my daughter and me about the study, the anonymized data collection and the capacity to withdraw, was very clear.

Initially, we were led to believe that all we were committed to was an interview. It was only at the first interview that it became clear what the study actually involved. Thus the study morphed into the main interview plus three follow-up visits, a food diary and food label gathering, the ActiGraph, and a follow-up clinical visit by a nurse.

Whilst I understand the desirability of gathering food label data to improve the validity of the study, it did feel rather intrusive – the more so since it was during a period of disruption to the usual domestic routine, as Freja describes.

The follow up clinical visit, to record height, weight, blood pressure, and to request permission to arrange a blood test and 24 hour urine collection, also proved more intrusive than first suspected.

Overall, I consider that the requirements for participation in the study were rather glossed over initially, in order to maximize recruitment, and that there was a presumption that once people had engaged with the process there would be a reluctance to withdraw. This is made all the more likely by dangling a significant financial reward in front of the children as participants. Whereas previously my prior bias was toward participation, were we to be selected again, the researchers would have a big task to persuade me that participation was reasonable. Ways in which the approach might be modified to ameliorate my concerns include:

- being wholly up-front about the demands of participation;
- providing a better breakdown of elements which could be participated in;
- making any incentive known to the responsible adult but not the child.