

What will we do next?

We still have some more analysis to do. We are then going to tell the European Parliament and Governments in each country what we have found out; and we hope they will do something about it. After all they gave us the money for the research so we could advise them.

We would like to visit you again when you are 5 years older. Nearly all of you said it would be all right to contact you again; you can then decide if you want to join the next part of the study.

We think it will be very interesting because you will all be teenagers by then and have new ideas about life and what you want to do.

Before we can arrange this we have got to get money to pay for a researcher to visit you again. So we hope we can get this money and then hope we will be able to visit you again.

If you would like to know more, please visit the project website or phone Allan.

So once again, many thanks for your help with SPARCLE. It only worked because of all your efforts.

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THE SPARCLE STUDY



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Summary of results, written for children in the study

Do you remember the SPARCLE study? We visited children between 8 and 12 years old across Europe – and you were one of them. About two years ago you kindly talked to the researcher, Kerry Anderson.

We want to say thank you; and tell you the results of the research.

We have had to do a lot of work and that is why it has taken two years to write to you again – although we did tell your parents about a year ago how it was going.

There were 116 of you in the study from Northern England and 818 of you all together. The number of questions answered by you or your parents was about 400. Therefore $400 \times 818 = 327,200$ answers which we had to analyse! Computers helped a lot but we had to type in your answers; this was done by Emma Hutchinson in Newcastle, so we are grateful to her.

How do you feel about you life?

The first thing we found was that you and the other children with cerebral palsy we visited are just like other children in how you feel about life, happy or sad, get on well or not so well with your parents etc.

This will not be a surprise to you but it was to some people who thought a person with cerebral palsy would be unhappy or find it more difficult to get on with people or would not feel good about themselves.

Of course you are not all happy all the time or always have as many friends as you want; but that is the same for children who do not have cerebral palsy.

Aches and pains

We found that children with cerebral palsy had more pains than we had expected. We did not ask you which part of your body the pain came from, so we will do that in the next stage of the research.

Do children and their parents agree?

The next thing we found was that parents and children do not always agree. Again perhaps not a surprise when it comes to whether you think you have enough pocket money! But also you, the children, usually felt more positive about your life and your future and your friends than your parents thought you did. That was true for most children but not all; you might be one of the families where children and parents agree.

What do you do in your life?

When we looked at what you did, rather than how you felt about life, then there were differences between you and children without cerebral palsy. As a group you found it more difficult to do things and not surprisingly many of you needed assistance at times.

There were some things you did as often or more than other children such as eating out, using a computer, riding a bicycle or wheelchair for fun. However most things you did less often such as playing sports, watching sports events, tourist activities, doing housework.

Children in some countries did more things than children in other countries. We had thought this might be the case but now we have proved it. Why is this? The children are the same and their parents love them just as much; but some countries are better at making sure you can do as much as other children. We will say this to the European Parliament.

End of the visit

Do you remember that at the end we asked you what you thought of the visit? You put your answers into a special box and we did not take them out until the study was finished. Here is what the children from Northern England said:

Most of you enjoyed answering the questions; three of you did not like it.

You nearly all liked the researcher who visited you but two of you did not.

