

Survey Monkey Questionnaire

Analysis of young people's responses

November 2013

Introduction

A high number of responses were received for the Working Party's Survey Monkey questionnaire aimed at children and young people. Responses came from those who accessed the report independently (46 young people accessed the survey, and 37 completed it) and those who completed the questionnaire as part of a facilitated MCRN group session (71 young people). In total, therefore, 108 responses were received.

Each question is analysed in turn, and key quotes are identified for each.

1. If someone said they wanted you to be involved in clinical research, what do you think that would mean?

A wide range of suggestions were made in response to this question. They can be split into four categories.

i. What the research consists of

- "Research into medicine and ethics"
- "Finding out about hospitals."
- "Clinical research is a branch of medical science that determines the safety and effectiveness of medications, devices, diagnostic products and treatment regimens intended for human use."
- "Researching something medical."
- "Testing new drugs/therapy; understanding the disease/anything unknown."
- Twin studies
- Tests, drugs or therapies
- "Doing many experiments on different people and studying different medicines. Testing drugs on someone. Seeing side effects of new medicines. Testing treatments on people of different ages."
- Surveys and questionnaires
- Data analysis
- Blood samples
- "They would most likely be asking me give consent for myself to become a participant in a clinical trial of a new medicine, drug or medicinal technique which could benefit people in the future, assuming its effectiveness is proven."

ii. What the aims of the research are

- “Research that is conducted to improve clinical approaches to diseases and treatments.”
- “... to get a greater understanding of medicine by experiments, interviews, observations, surveys etc.”
- “Finding answers; learning; controlling; research; trials; observation.”
- “To help doctors get more of an understanding of a condition.”
- “To test new medicines and vaccines.”
- “To see if the benefits outweigh the risks involved and whether they would be cost-effective.”
- “... to take part in a series of trials or experiments that is used to test newly developed drugs and theories e.g. How nutrition affects the development of asthma.”
- “I would think that they would want to know people’s views of clinical research and if people would want to join. Is clinical research meant to be a study or something about research?”

iii. Who does the research

- “I think this would mean that they wanted to help in researching a medicine by either being tested on or a different way – i.e. doctor, researcher, etc.”
- “To take part in research on a medicine to treat an illness that would be carried out by experts and doctors to help yourself and/or other people with the illness in the future.”
- “That I have a medical condition that a nurse or doctors would like to learn about.”
- “To take part in somebody’s (a doctor’s) findings. A doctor that is running a trial in order to find out things about a certain field. This trial will take place in a hospital, and occur weekly.”

iv. What the research means for the young person

- “Being part of an experiment or almost like a guinea pig for a trial run.”
- “I think that it would mean I would have tests conducted on me, for example: seeing how my skin reacts with different substances, having blood samples taken, exercise tolerance tests, drugs would be tested on me, diet questions, X-rays etc.”
- “Maybe they try to test a new drug on me!!”
- “That you would be used as a case study for them.”
- “That I would be monitored and written about.”
- “I think that it would mean having treatment in the process of being developed administered to me, and that it could entail treatment ranging from extra blood tests to surgery. I would also consider that I would be helping the development of a drug, that may then go on to help other people.”
- “To participate in an experiment, given an opinion or help in another way to carry out some form of medical research which may include testing treatments, giving samples, or giving opinions.”
- “Use my data, e.g. medical, in order to come up with predictions – e.g. who is more susceptible to illness.”
- “I think it would mean that we could help.”

- “I would assume that I would be asked to take a medicine/placebo for a study about a medicine and its side effects. I would assume that this research may benefit me if I had an illness. Twin studies. Expect to be paid if I was healthy.”
- “I could be part of a control group in the trial.”
- “I would think that it would involve tests such as blood samples or scans to see how my body responds to certain medication. I would assume that it would require me to make a few trips into hospital in order for the trials to be carried out and might last for a long period of time (e.g. one year).”
- “There was something about me that they would benefit from if I was part of their study.”

Other respondents stated that they were unsure, or did not know, what being ‘involved in clinical research’ meant, or that it meant “nothing”.

2. Who do you think should decide whether you take part in clinical research?

We received 108 completed responses to the Survey Monkey questionnaire aimed at young people. 101 provided their age, and the breakdown below is based on these 101 responses.

Analysis has been subdivided into four age categories: 6-11; 12-15; 16-17; and 18+.

Age	You	Your parents/ guardians	Your doctor	Your parents/ guardians and doctor	You and your parents/ guardians	You and your parents/ guardians and your doctor	You and your doctor	Total
6 to 11	2	1	0	1	7	2	0	13
12 to 15	12	2	0	0	10	14	0	38
16 to 17	10	0	1	0	8	15	1	35
18 plus	3	0	0	0	0	9	3	15
Total	27	3	1	1	25	40	4	101

Very few additional comments were received to supplement the tick box responses for this question, and only where respondents indicated that decisions should be taken by themselves, their parents/guardians, *and* their doctor:

- Assent/child consent form for child, but means nothing
- BUT, a *joint* decision
- If under the necessary age
- But primarily you, with input and advice for parents and doctors

3. What do you think should happen if you want to take part in research but your parents or guardians disagree?

Responses to this question were split broadly into three categories: those from young people who felt that it was their decision; those who felt that further discussion would be necessary; and those who would take their parents' advice absolutely. Responses in the second category were by far the most frequent, with the third category obtaining the fewest subscribers.

i. Young person's own decision

Several respondents took the view that the decision to participate was their own to make.

Other respondents felt that this question depended on the age of the young person; for example, "if [the young person is] over 16, ultimately the decision lays with the individual, and make that clear." Others felt that the threshold should be set at a younger age: "...if the child is over the age of 11 or they have a long-term condition, they should be able to voice that they wish to be a part of the research regardless of what their parents or guardians may say."

Another view taken by respondents was that if the child or young person's doctor felt that the research was acceptable, then this might override the view of the individual's parents or guardians.

Risk also featured in responses, for example: "it should be my decision as long as my health and well being wasn't in danger."

Other substantive quotes:

- "Well it's up to the person they are asking. So, if the person they are using says yes then I think the parents should agree."
- "Listen carefully to their opinions, but in the end it's up to me."
- "I think it's up to the person asked because it's them who is being used."

ii. Further discussion necessary

Several respondents stated that facilitated discussion could be helpful in situations where disagreements arose, such as the involvement of other independent doctors or nurses who are "unaffiliated to the family or research".

Other respondents took a different approach to the neutrality of doctors, commenting that "your doctor [should] be consulted to give the overriding vote."

The role of young people themselves in 'persuading' their parents was also mooted, with one respondent suggesting that young people might "tell them of the benefits and try to convince them" or "manage to encourage them to agree to take part by stating optimistic statements."

Again, age also featured in this group of responses such as "We should talk about it and decide, but because I am 13 I should have a lot of say."

Other substantive quotes:

- “I think that you should have a discussion with them about why you want to take part, listen to why they don’t want you to take part and try and come to an agreement. If they still don’t want you to take part then I think that I should be able to make the decision for myself as I am the one who will undergo the research.”
- “We should be given a chance to explain why we want to.”
- “Discuss reasons why and try to understand parents while trying to convince them, but don’t push it. Maybe go to the doctor for a second opinion. If the final answer is ‘no’, don’t take part.”
- “That you should discuss it until you reach a decision that you all agree on.”
- “Discuss – if parents still disagree, go with their decision.”
- “You should be given time and the opportunity to appeal to your parents about this, as long as your doctor also agrees you should take part. If your parents still disagree, then the research shouldn’t happen until you are 16 years old or older.”
- “You should talk about it at home as they might have a good reason why you shouldn’t take part in the research.”
- “I think that you should use your own opinion, however you should think and listen to what your parents have to say and talk through it with them.”

iii. Listen to parents’ or guardians’ advice absolutely

A response which summarises the stance taken by respondents who fitted into this category is: “If mummy and daddy say no I shouldn’t do it.” Similarly, another respondent stated unequivocally that “I wouldn’t do it”, and others that “You should not participate”, “I won’t be part of it then”, and “I wouldn’t be allowed to go.”

Other substantive quotes:

- “It should not take place because it could affect the parent if the person got ill.”
- “You should still be able to do it, but if your parents had a decent reason why not to then you probably shouldn’t.”

4. What do you think should happen if you don’t want to take part in research, but your parents or guardians think you should?

The vast majority of responses to this question responded by stating that the young person should not take part in the research if they did not want to, regardless of the opinions of their parents or guardians. Responses included:

- “Obviously you don’t do it.”
- “They shouldn’t be able to force you.”

- “The decision of the patient, no matter how old, should always be the first to be considered. If I, as a young person, do not want to take part in the research then that should be my right to veto.”
- “I think if you are old enough to speak for yourself then your parents have no say.”
- “If the young person is able to give informed consent then they should not be forced to take part in research against their will. If it is a young child who is saying no because they are scared of the treatment or similar then their parents should decide for them.”
- “It’s your body and you shouldn’t be forced to agree to doing something you don’t want to or aren’t comfortable with.”
- “The child should always be a willing participant, parents could explain to the child why it is advisable for them to take part but should not be able to force it upon the child.”
- “You’re your own person and you don’t have to do something if you don’t want to.”

However, a small number of respondents favoured discussion as a way through disagreements about participation.

- “The same as if you want to go take part and your parents don’t. A talk that is supported by healthcare professionals discussing opposing ideas.”
- “I think you should tell them why you don’t want to take part and hear why they want you to. If you still don’t want to take part then you should explain that it is your decision to make as you would be the one taking part.”
- “Discussions with parents and doctors, ultimately you have no choice.”
- “Try it out, go to an open day, see why they want you do to it.”
- “It depends how I would be affected, it’s my decision, but if my parents thought it was a good thing I would want to know why.”
- “I think the same applies with the age barriers. A young child should be given all the information in an easy way to understand.”
- “You shouldn’t be pressured into taking part for whatever reason, e.g. financial? Surprised about ‘assent’. Child should be interviewed separate from parents by trial people to make sure they want to take part.”

Other respondents felt that the age of the child or young person was an important factor, for example: “Under 12 – parents decide. 12-16 – need both to approve. 16+ - your decision.”

5. Using the scale below, please state how you feel about taking part in these types of research¹

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	Don't know/doesn't apply
Answering questions about my health	48	48	6	2	0	1
Having regular blood tests	18	43	19	17	5	1
Having tests such as MRI scans (which produce pictures of the inside of your body)	28	49	10	11	2	4
Trying out new medicines or medical techniques to see if they work (for example, where a medicine has been used in adults before but not in children)	12	42	29	10	6	4
Talking to someone about my feelings, for example if I feel sad or worried	37	40	14	7	4	1

6. What would be your concerns or worries about taking part in research?

A wide range of concerns and worries were raised by respondents, including:

- Taking part in early stage research: “the further through the better...”
- Confidentiality
- Anonymity
- Invasive procedures
- Being unable to give an answer to the question the researcher asks.
- Side effects
 - Severe

¹ Please note that not all respondents addressed each option.

- Long-term effects, especially if radiation used
- If it would affect future survival or quality of life
- Physical or mental
- Harm to the body
- Dying
- “Big talks about emotions. I think it’s important to talk about feelings and emotions, but it doesn’t mean that ill like it.”
- If it didn’t work; if it didn’t actually help others.
- “Depends on the research and who was doing it. I have met some good nice medical people and some bad horrible ones.”
- Time commitment/effect on social life/how long the study will last
- Effect the research has on normal treatment received
- Size of pills that need to be taken
- Travel commitments
- If it abides by research regulations.
- Discomfort
- If the researchers “take too much blood”
- “I’m not really a fan of having blood taken.”
- “Not wanting to complete the research”
- “being asked personal questions”

In particular, the issue of side effects was mentioned frequently. For example:

“I would be worried if something went wrong and may cause me harm – blood tests/injections; side effects – be aware – if something would be a risk; time commitment – if you have to fast for a long time; if the trial abides to all standards and regulations for research.”

No concerns

Other respondents stated that they had no concerns or worries. For example:

- “Nothing. I would like to help.”

7. What could be done to make you feel more comfortable about taking part in clinical research, and less worried?

Respondents offered a range of suggestions:

- Assurance of compensation if things go wrong
- Signing an agreement with the research team
- Good communication from the research team (to young people themselves, rather than just their parents) at every stage of the process
- Reassurance about the safety of the research
- Having distractions – e.g. play room/therapist
- “The research being conducted somewhere I feel comfortable.”
- “Knowing who the research will be shared with.”
- Ongoing care and support

- “Having an unconnected 3rd party to talk about it- before, during and after!”
- “Knowing how many other people are taking part in the trial – getting to know them.”; “Getting to know everyone taking part.”
- “[Having] a booklet of information (that’s easy to read).”
- Rewards
- “Doctors and nurses being friendly.”; friendly nurses
- A comfortable research environment
- Less jargon
- “Reassurance that nothing will go wrong.”
- “Forums and regular meetings with peers/others taking part in the study to see how others are coping and to talk to others.”
- “Parents being with be throughout it all.”; “Parents are involved all the time in the research.
- Seeing evidence from previous tests and trials
- No needles or blood tests.
- “Being told exactly what could happen to me (even the worst case scenario) and what could be done fix any damage.”
- “Making it fun.”

8. What might encourage you to take part in clinical research? (Tick as many as you like.)

The results of this question are set out below, alongside relevant quotes for each option, where available.

Knowing about local research opportunities: n=58

- “Being informed about new opportunities in clinical research.”

Feeling appreciated: n=64

Finding out what happened after the research (e.g. whether it led to any changes in children’s medical treatment in the future): n=93

Making it easy to take part (e.g. close to home or through school/college): n=72

Money or vouchers as a reward for taking part: n=61

- Toys would be good.
- Incentive maybe not money, but an incentive is needed for most things, especially [for] people not necessarily interested in the topic.
- enough information

Other ideas:

- A condition you are suffering from is being researched – e.g. if you had diabetes and the research concentrated on diabetes; paid for travel; finding out results (even if they’re bad).
- knowing you will receive full support.

9. If you were told that the research probably wouldn't help you but might help other children in the future, would you still take part? (Please explain.)

The majority of respondents who chose to answer this question answered 'yes'. Various reasons were offered for taking this view, including that to do otherwise would be selfish, and that there is a desire to help other children.

Others were less certain: one respondent, for example, stated, "no – I don't know", whereas others felt that their answer would depend on the type of research in question.

Key quotes

Respondents who stated they would still take part:

- "Of course I assumed we were talking about volunteers for medical research anyway. Not necessarily people reaping the benefits."
- "... if it can help others then it is worth taking part in."
- "I would know that I had helped somebody else."
- "...if no one will care for the children in the future, what will happen to them?"
- "There have been a lot of times where my experiences have helped others and I think that's always the 2nd priority after yourself."
- "Research is to help prevent temporary and permanent illness within our society not in ourselves. Being selfish would cause more harm to us than it would to help a fellow human."
- "...you do need to make sacrifices for the greater good. From one result, you could possible change most children's future."
- "Yes, to quote Spock, the needs of the many outweigh the needs of the few."
- "Yes, because I know that other children/adults have done this for my generation."
- "Yes, to help find a cure."

Many respondents who stated that they would still take part referred to the need to help others through their contributions.

Respondents who would not/may not still take part:

- "It would also depend on what the research involved exactly."
- "If it was invasive and time commitment was high, possibly not."
- "Probably, it would depend on the risks and effects on my life."
- "It depends how it would help them because if they had cancer, I would. If they had chicken pox I wouldn't, and it depends on how big it was, e.g. operations."
- "Probably not; the research would still be done with other children, and I wouldn't be at risk. Selfish, but that's would be what I would do."
- "I wouldn't because it doesn't help *me* in general."

10. About me

35% of respondents who were not part of MCRN group responses (and chose to respond to this question) stated that they had taken part – or been invited to take part – in clinical research at least once. 65% stated that they had never been invited to take part in clinical research.

67 MCRN group members responded to this question, and four declined to do so. Of those who responded, 86% had never been invited to take part in clinical research; 14% had been invited to take part in clinical research at least once.

Some respondents chose to give further details about the research they had participated in, including:

- I have taken part in a drug trial at GOSH, alongside my younger brother
- I was invited to take part in the SCOT trial (I think that's what it was called) to receive four cycles of chemo instead of the usual eight. I declined as I had been told I had a high risk of recurrence so I felt I should do everything possible to prevent that. My team agreed that this was the best choice for me.
- I was a healthy control in a study when I was three I took part in research on the impact of Mozart on seizures, but had to leave the study as I had to not listen to Mozart for two weeks and I started having about 70 seizures a day as I usually do listen to Mozart. I have taken part in several multi-choice questionnaires.
- They just took some blood while I was under anaesthetic anyway. Can't remember what it was for.

A small number of comments were also received from those who had never taken part in clinical research:

- Public awareness is not good, I have never heard of clinical testing opportunities before.
- I have only learn about them but I have a rough idea of what goes on.

11. Age of respondents

The age of respondents ranged from 6 to 25.