



Introduction

First of all, thank you for agreeing to complete this survey. Most of the information explaining the background, rationale and aims of this study were made available to you in the invitation sheet. If you have any further questions, please feel free to e-mail me. If you are reading this introduction, I am assuming that you are happy to proceed and I thank you for this. As I said in the invitation, I believe this research can help make a difference and, as such, I appreciate any time you spend towards this.

Eligibility criteria: who should be taking part?

Just to recap, you should be completing this survey if:

1. You are an adult who has SM; or
2. You are an adult who still had, or whose SM started, beyond 18 but consider yourself to be recovered

NB: You are still very much invited to take part if your SM is part of another diagnosis you have been given, such as Asperger's or an Autism Spectrum Disorder (ASD). You will be asked if this is the case as part of the survey. NB: you do not have to complete this particular question if you do not want to.

If none of the above categories apply, thank you for taking the time to look at this survey, but unfortunately you are not "eligible" to take part in this particular study.

You should NOT take part if ...

1. You do not fulfil the eligibility criteria.
 2. You believe that doing so will detrimentally affect your personal and/or emotional wellbeing.
 3. Doing so will cause harm to another or cause another to be at risk.
 4. Even though your identity will be protected, you think that you may feel uncomfortable about any information you provide being disseminated in a public accessible research study (e.g. in a research journal.)
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Intended outcomes of this research

Just to remind you, the intended outcomes of the research are:

1. To assert the existence of SM in adulthood, in order to challenge the perception that SM is solely a childhood "disorder";
2. To investigate the varied ways that SM affects adults with SM, individually;
3. To investigate the varied "reasons" that SM occurs;
4. To investigate how adult sufferers of SM conceptualize SM; and
5. To investigate why SM did not dissipate in childhood for adults who have SM.

As such, this survey is designed to ask you questions about these specific areas.

Please note: following submission of this survey, in accordance with British Psychological Society guidelines, you can withdraw your data from this study at any point up until 3rd May 2013. To do this, please e-mail me at carl@s-m.org.uk.

You do not need to give any reason for withdrawing your data and, upon such a request, your data will be destroyed.

How will my information be used?

As referred to previously, this research is being carried out within strict accordance with [British Psychological Society](#) (BPS) Guidelines; these [can be viewed here](#). In addition, the content of this survey, and associated data storage and analysis procedure have been reviewed and authorized by the University of Chester, Department of Psychology Ethics Committee, UK.

Your data will be used in two ways:

1. To enable statistical comparisons, such as age of onset and maximum age of severity, with other people who have/had SM; and
2. Because this study is particularly interested in individual, personal experiences of SM, some of the information you provide may be used in an exploratory way. In this latter instance, any information you provide will be reported using a "pseudo-name" of your own choosing. Please, therefore, only provide information (albeit anonymised) which you feel comfortable with sharing publicly.

What do I do if participating upsets me?

If you feel upset by any of the issues raised by the survey, either during completion of this survey, or after you have completed it, please note that the following organisations are available to help you:

If you are in the UK or the ROI, please contact [Samaritans](#)
Telephone 08457 909090 (UK) or 1850 609090 (ROI)

If you are outside the UK and the ROI, please contact [Befrienders Worldwide](#)
Telephone numbers available worldwide (please visit their web-site to find a local telephone number)

Please note: even if you cannot use the phone, both of these organisations accept e-mails and provide online support.

How do I submit my responses?

When you have completed as much of the survey as you feel comfortable doing, please press the SUBMIT button on the final page; this will anonymously submit your responses. Alternatively you can save this file (if you are working with the PDF version of the survey, rather than completing the online version) and e-mail it to carl@s-m.org.uk.

If you prefer, you could also print this survey off (hand-written answers are acceptable too) and post it to me via the following postal address:

C. Sutton (Selective Mutism survey)
Department of Psychology
University of Chester
Parkgate Road
Chester
CH1 4BJ

You are now ready to start the survey, beginning with informed consent. As you will see, some of the questions have a space for you to write your answers, and others have options for you to select. Please, also, remember that your participation in this study is voluntary and you do not have to complete any questions that you do not wish to answer.

Section 1: Consent

1.1. My first name (or pseudonym, if you prefer) is

1.2. My e-mail address is (optional)

1.3. Can you be contacted on the e-mail address above in relation to any of the information provided?

Yes, I am happy to be contacted

No, please do not contact me

1.4. I live in the following country

1.5. Consent

I duly consent for any information provided for this survey (apart from my e-mail address) to be used in academic research and for any data I supply to be, potentially, publicly disseminated (e.g. as a research publication.) I am aware that any or all of the data I provide here can be removed from this study up until 3rd May 2013 by contacting the researcher directly.

1.6. Participation

I am aware that participation in this study is voluntary and that I do not have to answer any question I don't wish to answer.

Section 2: Basic details

2.1. I am

Female

Male

Don't wish to say

2.2. My age on 3rd May 2013 shall be

2.3. At what age did your SM start? If you were very young, you may have been told this by a parent for instance. (Put the number "0" if you believe you were born with SM. Leave this blank if you just don't know.)

2.4. Roughly at what age did you know you had SM, even if you didn't know there was a name for it at the time. If you have "always" known, put the number "0" here.

2.5. What made you realise that you were different to other people in terms of speaking?

2.6. Roughly at what age did you come to know that SM was a named condition?

2.7. Roughly at what age did you discover that other people had SM?

2.10. Please answer the following by ticking all explanations that have EVER applied to you.

When I have been mute I couldn't speak because...

- There is no way to explain it - I just couldn't speak
- I was worried about what people thought about me
- I was sometimes afraid of the people I couldn't speak to
- I was quiet
- There were things I didn't want people to know about me
- I didn't like showing how I was feeling
- My voice sounded strange to me
- People made fun of me
- I found other people overwhelming
- I couldn't speak because nobody expected me to speak
- I felt I didn't have much in common with other people
- There was too much hustle and bustle - I shut down
- I was experiencing loss
- People could sense how I felt and I didn't like it
- I was different to other children
- I was afraid of the repercussions if I spoke
- What I had to say was less important or worthwhile than what others had to say
- I was more sensitive than average to my environment
- I was afraid of speaking
- I didn't like the sound of my voice
- I was bullied
- People made fun of my voice
- It was something to do with my mouth or my teeth
- I was shy
- I didn't need to speak - someone else often spoke for me
- I didn't have anything to say
- Other people's anxiety rubbed off on me
- I wasn't allowed to speak sometimes - someone else always took over
- I couldn't speak because I had never spoken to ...
- I didn't like hearing my voice
- I was punished for not speaking
- Other people's emotions were more important than mine
- I felt responsible for another person's emotional welfare
- Other

2.11. Which of these best explains your SM? (Tick all that apply)

- | | |
|---|--|
| A genetic difference | A learned behaviour |
| A way of dealing with anxiety | A response to life experience |
| An anxiety disorder | A form of social phobia |
| Due to a sensory integration difficulty | An individual difference |
| An "autistic trait" | The outcome of being a highly sensitive person |
| A specific phobia | A mental health problem |
| An illness | A disability |
| An avoidant behaviour | A response to my childhood family environment |
| An emotional problem | |
| Other | |

2.12. This may be a difficult question to answer, but how do *you* personally define SM?

2.13. Please rate how much you agree / disagree with each of the following questions:

As an adult ...

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree	Don't know
SM has affected my life opportunities						
I succeeded in life, despite having SM						
Without SM, I would have been very different						
SM has caused me a lot of emotional distress						
I have been ashamed of having SM, which made it even worse						
Having SM gets easier as you get older						
It is easier to have SM now as a child compared to when I was a child						
I blame other people for my SM						
SM is something I was born with						
SM is something I value						
I enjoy silence						
I am afraid of silence						
I wish I did not have / had not had SM						
People with SM are my kind of people						

Section 3: Childhood & adolescent experience of SM

If you did not develop SM until adulthood, you can skip to Section 4.

3.1. Was there a trigger, or any environmental factors, which started, or contributed, to your SM?

Yes

No - Skip to 3.3

Not sure

3.2. If you did experience a trigger or there were environmental factors involved in the forming of or maintaining of your SM, what would you say it was / these were?

3.3. **At around age 10 years**, who, consistently, could you NOT talk to

Other children at school

In social settings

Teachers

Father

Mother

Sibling(s)

Step-father

Step-mother

Step-brother(s) / sister(s)

Grandmother

Grandfather

Aunties

Uncles

Cousins

Other relatives

Strangers

Doctors

Other professionals

The opposite sex

Other children outside school

Other

3.4. By the time you were **about 15 years old**, had this pattern changed?

Yes

No - if you answer No, please go to 3.6.

3.5. In what way had the pattern changed?

3.6. How did significant life events in your childhood contribute to or make your SM worse? If you don't feel there were any significant life events involved, please put **NOT APPLICABLE** or **N/A** here.

3.7. How did you communicate when you couldn't speak during childhood?

I didn't communicate

I wrote things down

I used rudimentary signing (hand gestures etc.)

I used an electronic speech aid

I smiled

I nodded and shook my head

I got other people to communicate for me

I used a toy/puppet to speak for me

Other

3.8. In childhood did you have other issues that you were aware of, such as anxiety or depression?

Yes

No - Skip to 3.10

3.9. You **DO NOT** have to answer this question, but what kind of issues did you suffer from?

Depression

Anxiety

Eating disorder

Panic disorder

Social phobia / social anxiety

Agoraphobia

Separation anxiety

OCD

Post-traumatic stress disorder

Other

3.10. What was your childhood and adolescence like, having SM?

Section 4: Adult experience of selective mutism

Please note that you need to answer this question even if you are an adult who had SM as an adult and now consider yourself to be recovered.

4.1. Has the severity of your SM reduced since you first developed SM?

Yes, I have now overcome SM completely and consider myself recovered

Yes, the severity has reduced but I still suffer from SM

No, it has not reduced

4.2. If you have overcome SM, at what age did you do that? Please put **NOT APPLICABLE** or **N/A** if you have not fully overcome SM.

4.3. If your SM has reduced, at what age, roughly, did the severity of your SM reduce? Please put **NOT APPLICABLE** or **N/A** if this does not apply to you.

4.4. If appropriate, how did you overcome SM, or how did your SM reduce? Please put **NOT APPLICABLE** or **N/A** if this does not apply to you.

4.5. **Around age 18-20 years**, who, consistently, could you not talk to

Other students / colleagues

In social settings

Teachers / lecturers / bosses

Father

Mother

Siblings(s)

Step-father

Step-mother

Step-brother(s) / sister(s)

Grandmother

Grandfather

Aunties

Uncles

Cousins

Other relatives

Strangers

Doctors

Other professionals

The opposite sex

Other students / colleagues (outside work)

Other

4.6. Why do you think your SM continued into adulthood?

4.7. What could have helped you to avoid SM in adulthood? (Tick all that apply)

- | | |
|--|---|
| Nothing | Better understanding of SM in the school system |
| Better professional understanding of SM | Medication in childhood |
| Tough love / being forced to speak by my parents | Speech therapy |
| Counselling or CBT in childhood | |
| Other | |

4.8. **If you still have SM**, who, consistently, can't you talk to

- | | | |
|------------------|----------------------------|-----------------------------|
| Colleagues etc. | Anyone in a social setting | Bosses etc. |
| Father | Mother | Sibling(s) |
| Step-father | Step-mother | Step-brother(s) / sister(s) |
| Grandmother | Grandfather | Aunties |
| Uncles | Cousins | Other relatives |
| Strangers | Doctors | Other professionals |
| The opposite sex | | |
| Other | | |

4.9. What kind of difficulties have you encountered being an adult with SM?

Please select the option which most applies to you:

4.10. Other issues

- I now have other psychological or emotional issues, which directly stemmed from my SM
- I now have other psychological or emotional issues, which did not directly stem from my SM
- I have no other issues

4.11. **As a result of your SM**, do you have any other issues in adulthood? **Please remember you can leave this blank if you don't feel comfortable answering this question.**

- | | | |
|--------------------|--------------------------------|--------------------------------|
| Depression | Anxiety | Eating disorder |
| Panic disorder | Social phobia / social anxiety | Agoraphobia |
| Separation anxiety | OCD | Post-traumatic stress disorder |
| Other | | |

4.12. Do you feel you could have avoided these issues with professional support?

- Yes
- No
- Partly
- Other

4.13. **Not related to your SM**, do you have any other issues in adulthood? **Please remember you can leave this blank if you don't feel comfortable answering this question.**

- | | | |
|--------------------|--------------------------------|--------------------------------|
| Depression | Anxiety | Eating disorder |
| Panic disorder | Social phobia / social anxiety | Agoraphobia |
| Separation anxiety | OCD | Post-traumatic stress disorder |
| Other | | |
-

Section 5: Who has helped you or tried to help you with SM?

Please complete this section whether you still have SM or don't.

The emphasis is on who helped or tried to help you, less so about outcome.

5.1. Who has helped or tried to help you with SM (in childhood or adulthood)? (Tick all that apply)

- I received effective professional support, which helped me [at least a little bit]
- I received professional support which was ineffective
- I received professional "support" which was detrimental
- My parents / relatives did help me
- My parents / relatives tried to help me but didn't know how to, or they weren't able to
- My parents made the problem worse
- My other relatives made the problem worse
- My friends helped me
- My friends tried to help me but they didn't know how to, or they weren't able to
- Teachers etc. helped me
- Teachers etc. tried to help me but they didn't know how to, or they weren't able to
- Teachers etc. made the problem worse
- Nobody helped me
- Others helped me:

5.2. In childhood ...

- My parents did not know or seem to notice that I had SM
- My parents knew I had SM and tried to get effective help for me
- My parents knew I had "a problem" and tried to get effective help for me
- My parents knew I had SM but did not try to get help for me
- My parents knew I had "a problem" but did not try to get help for me
- My parents were part of the problem
- I don't wish to say
- Other

5.3. In adulthood ...

- I have not sought professional help for myself AND it has not been sought for me
- I have found effective professional help for myself OR it has been sought for me
- I have found the professionals I have come into contact with ineffective OR their treatment inappropriate
- I don't wish to say
- Other

5.4. If you would like to include anything about the professional support you have encountered - good or bad - as an adult or as a child, please state it below:

Section 6: Life story / other information

If you have a life story or other information you would like to share, for the purposes of Selective Mutism research, please e-mail it to carl@s-m.org.uk or post it to the address given at the start of this survey.

Section 7: Submit your responses

Thank you for taking the time to complete this survey. Your responses are greatly appreciated.

7.1. If you have any further comments about this research, including ideas for further research that you would like to suggest, please state them below.

To submit your responses please either click the SUBMIT button below or (if you are completing this survey via a downloaded PDF file) e-mail the completed survey to carl@s-m.org.uk. In either case, you will receive an e-mail acknowledgement to say that your responses have been received.

Alternatively, you can print this survey and post your answers to the address given towards the start of this survey.