# SPINAL MUSCULAR ATROPHY SCREENING SURVEY (UK)

A survey of the views of families living with SMA in the UK on the possibility of population screening for SMA

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### SMA Screening Survey (UK)

Welcome to the SMA Screening Survey (UK). This survey is part of a research project called 'Imagining Futures: The Social and Ethical Implications of Genetic Screening' (http://www.warwick.ac.uk/imagining\_futures). This survey has been designed to explore the views of people living with SMA (or with SMA in their family) towards the possibility of screening for SMA. 'Screening' refers to the identification of SMA (those with the condition and/or carriers) in the whole UK population, not just within families already known to be affected by the condition. A screening programme would mean that people with no history of SMA in their family would be offered the chance to undergo genetic testing for the condition.

Why is the study being done? In December 2013, after a national consultation, the UK National Screening Committee (the organisation that advises the government on issues related to screening) concluded that screening for SMA should not be offered at this time (http://www.screening.nhs.uk/sma). It was noted in their consultation report that very little is known about how families currently living with SMA would feel about a national screening programme for SMA. This survey is designed to address this gap in understanding, and the outcome of the survey will be submitted to the UK National Screening Committee in their next review of SMA screening policy (around 2016). In order to develop this survey, 36 in-depth interviews with people who either have SMA themselves, or have SMA in their family, were conducted to get a picture of the sorts of views people have on screening. The wide range of views that emerged from these interviews have been incorporated into the survey.

Why am I being asked to take part? You are being invited to complete this survey if you are aged over 18, live in the UK and have any form of SMA in your family (including its variant forms, e.g. SMARD, Kennedy's, Spinal Bulbar Muscular Atrophy etc.) or have the condition yourself. I am interested to hear from a range of family members (e.g. aunts/uncles, cousins, siblings, grand-parents, step- and half-relatives) or anyone who considers themselves a 'family member' of someone with SMA, regardless of whether you are biologically related, and regardless of whether your relative with SMA is still living, or has died.

**How do I participate?** Simply fill in the SMA Screening Survey (UK) and return it in the pre-paid envelope, or to the address found at the back of this survey. The survey takes about 15-20 minutes to complete. Please complete the survey *as an individual*, rather than as a couple or family, as everyone feels differently about screening (even within couples and families) and it is important to get an accurate picture of the range of views on this topic. If you prefer, you may complete this survey online at: http://www.warwick.ac.uk/smascreeningsurvey

What will happen to my information if I participate? The anonymised summary results of this survey (not individual data) will be published in academic journals, written up as a research report for SMA Support UK's (formerly the Jennifer Trust) 'Inspirations' newsletter, as well as the UK SMA Patient Registry newsletter and used for conference presentations (academic, professional and patient). It will also be submitted as research evidence to the UK National Screening Committee in their next review of the policy on screening for SMA in the UK. Upon completion of the Imagining Futures research project, the anonymised data from this survey will be archived with the Economic and Social Data Service (https://www.esds.ac.uk/) so that in the future, other researchers may make use of the data. If you do not want your anonymised survey answers to be archived, please contact us (SMAscreeningsurvey@warwick.ac.uk)BEFORE completing the survey.

What if I change my mind? If you start the survey and decide you do not want to continue, simply do not return it. However, once a completed survey is returned, it will not be possible to withdraw it from the study. This is because the survey is anonymous and therefore it will be impossible to link an individual back to their survey and remove it from the study.

**Will my taking part be kept confidential?** All data collected from this survey will be held anonymously and securely using data encryption software. No data which may identify you (e.g. your name/address) will be asked for, but you will be asked for background information about yourself, as well as the type of SMA affecting your family. This is in order that we can get a clearer understanding of the backgrounds of the people responding. All data will be handled in strict accordance with the Data Protection Act 1998.

**Who is conducting the research?** This research is being conducted by Dr. Felicity Boardman, at Warwick Medical School, and is funded by the Economic and Social Research Council. The research was given a favourable opinion by Warwick's Biomedical and Scientific Research Ethics Committee on 15/7/14 (REF: REGO-2014-903).

Are there any disadvantages to taking part? Some people may find the topic of screening for SMA distressing. Should the completion of this survey raise any issues for you which you would like support with, or further information on, please contact SMA Support UK (formerly the Jennifer Trust for Spinal Muscular Atrophy) www.smasupportuk.org.uk/ (01789 267520).

What if there's a problem? Any complaint about the way you have been dealt with during this study, or any harm you may have suffered, will be properly addressed. Please address your complaint to: Jo Horsburgh, Deputy Registrar, Deputy Registrar's Office, University of Warwick, Coventry, CV4 8UW. J.Horsburgh@warwick.ac.uk

If you have any comments or queries about the survey, or to request further paper copies, please contact us at SMAscreeningsurvey@warwick.ac.uk or complete the comments box at the end of the survey. You may want to tear off and keep the cover page of this survey before returning it in order to retain the project details. Alternatively, email the SMA Screening Resource and ask for a copy of this information to be posted or emailed to you.

Thank you!

### SMA Screening Survey (UK)

### Section 1: About You

In this section you will be asked for basic background information about yourself. These questions are being asked in order that the researcher can gain a better understanding of the social backgrounds of people living with SMA in their family.

2. What is your age?  O 18-25 years O 26-34 years O 35-45 years O 46-55 years O 66-5 years O 66+ years 3. What is your highest qualification level? O No qualifications O GCSE or O Level O GCE, A level or similar O vocational (BTEC/NVQ/Diploma) O Degree level or above O Other (please specify):  4. What is your ethnic group? (Continued over the page) O White- British O White- Irish O White- Gypsy or Traveller O White- European O Mixed- White and Black Caribbean O Mixed- White and Black African O Mixed- White and Black African O Mixed- White and Asian O Asian- Pakistani O Asian- Pakistani O Asian- Bangladeshi O Asian- Bangladeshi O Asian- Bangladeshi O Asian- Chinese O Black- African O Black- Caribbean	1. What is your sex?	
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O White- British O White- Irish O White- Gypsy or Traveller O White- European O Mixed- White and Black Caribbean O Mixed- White and Black African O Mixed- White and Asian O Asian- Indian O Asian- Pakistani O Asian- Bangladeshi O Asian- Chinese O Black- African	4. What is your ethnic group? (Continued over the pag	e)
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O Mixed- White and Black African O Mixed- White and Asian O Asian- Indian O Asian- Pakistani O Asian- Bangladeshi O Asian- Chinese O Black- African	O White- European	
O Mixed- White and Asian O Asian- Indian O Asian- Pakistani O Asian- Bangladeshi O Asian- Chinese O Black- African	O Mixed- White and Black Caribbean	
O Asian- Indian O Asian- Pakistani O Asian- Bangladeshi O Asian- Chinese O Black- African	O Mixed- White and Black African	
O Asian- Pakistani O Asian- Bangladeshi O Asian- Chinese O Black- African	O Mixed- White and Asian	
O Asian- Bangladeshi O Asian- Chinese O Black- African	O Asian- Indian	
O Asian- Chinese O Black- African	O Asian- Pakistani	
O Black- African	O Asian- Bangladeshi	
	O Asian- Chinese	
O Black- Caribbean		
O Arab		
O Prefer not to say		
O Other (please specify):	O Other (please specify):	

5. Do you have a religious faith?

O Yes	O No O Prefer not to say	
1	If yes, how would you describe your religious faith?	
C	O Christian (any denomination)	
C	O Jewish	
C	O Muslim	
C	O Sikh	
C	O Hindu	
C	O Buddhist	
C	O Other (please specify):	
Section	on 2: SMA and Your Family	
n this sectio pe of SMA ell-being	on you will be asked questions about the number of people affected by SMA in your fa in your family as well as your perceptions of your own, and your family members' hea	mily, the alth and
	you have any children? (This might include step-children, foster children, ed children or any child for whom you consider yourself to be the parent or le ian)	gal
O Yes	O No	
If yes,	how many children do you have?	
	nat is your relationship to SMA? se tick all that apply)	
O I have	ve SMA myself O Someone in my family has, or has died from, SMA	
8. Wh	nat type of SMA do you have yourself, or do you have in your family? se tick all that apply)	
O Don't	t Know	
ОТуре	0 (in utero onset)	
ОТуре	I (also known as Werdnig-Hoffman Disease)	
ОТуре		
ОТуре	III (also known as Kugelberg-Welander Disease)	
О Туре	IV	
O Distal	l Spinal Muscular Atrophy	
O Spina	al Muscular Atrophy and Respiratory Distress (SMARD)	
O Other	r (please specify):	
Ottner	r (please specify):	

9. Please list your relationships to family members (to a maximum of 10) affected by SMA and their type of SMA (if known). This may include extended family members. If your family member(s) have died, please state their approximate year of death and age at death (if known). If no one else in your family has SMA, please go on to question 11.

	Relationship to family member	Type of SMA	Year of death (if applicable)	Age at death (if applica ble)
<b>a.</b> Family member 1				
<b>b.</b> Family member 2				
<b>c.</b> Family member 3				
<b>d.</b> Family member 4				
e. Family member 5				
<b>f.</b> Family member 6				
<b>g.</b> Family member 7				
h. Family member 8				
i. Family member 9				
j. Family member 10				

10. Do you currently, or have you at any point in the past, lived in the same household as your family member(s) listed in question 9 (please answer for each family member as listed in the order above)? 'Living in the same household' would include living together on a temporary basis with your family member(s) affected by SMA, e.g. regular holidays or stays of more than two weeks in the same household.

Yes	No
0	
	0
0	0
0	0
0	0
0	0
0	0
0	0
0	0
0	0
0	0
	0 0 0 0 0

### 11. How would you rate your current health and well-being?

O Very good

O Good

O Fair

O Bad

O Very Bad

### 12. How would you rate the current health and well-being of your family members affected by SMA listed in question 9? Please rate in the order you listed them in above. If you have no family members affected by SMA, please go on to Section 3.

	Current Health and Well-being of Family Members with SMA								
	Very good	Good	Fair	Bad	Very Bad	Don't know	Not applicable (family member died)		
a. Family member 1	0	0	0	0	0	0	0		
<b>b.</b> Family member 2	0	0	0	0	0	0	0		
c. Family member 3	0	0	0	0	0	0	0		
d. Family member 4	0	0	0	0	0	0	0		
e. Family member 5	0	0	0	0	0	0	0		
f. Family member 6	0	0	0	0	0	0	0		
g. Family member 7	0	0	0	0	0	0	0		
h. Family member 8	0	0	0	0	0	0	0		
i. Family member 9	0	0	0	0	0	0	0		
j. Family member 10	0	0	0	0	0	0	0		

#### Section 3: Your Use of Genetic and Screening Technologies

In this section, you will be asked about your previous use of genetic and screening technologies for SMA and other conditions.

The Hall	and the same and t		Management of the control of the con	
A SEC. U	Aug Mail			r trying to get pregnant?
(H 10/16-19	. Are vou.	or vour partner.	Currentiv breamant o	or trying to det pregnant?

O Yes

O No

O Prefer not to say

14. In your current, or previous pregnancies, have you, or your partner, ever used any of the following technologies? Please tick all that apply. Please see 'Glossary' at the end of the survey for further explanation of these technologies. (Please go on to Section 4 if you, or your partner, have never been pregnant before)

- O CVS or Amniocentesis (diagnostic testing in pregnancy) for SMA
- O CVS or Amniocentesis (diagnostic testing in pregnancy) for a condition other than SMA
- O Pre-Implantation Genetic Diagnosis (PGD) (creation of embryos using IVF prior to testing) for SMA
- O Pre-Implantation Genetic Diagnosis (PGD) (creation of embryos using IVF prior to testing) for a condition other than SMA
- O Screening for Down's Syndrome (usually offered as a scan and/or blood test at around 12 weeks of pregnancy)
- O Carrier Testing for SMA (a test to see if you, or your partner, are a carrier of SMA)
- O None of the above

### 15. Have you, or your partner, ever undergone a pregnancy termination (abortion) due to a prenatal diagnosis of SMA?

O Yes

O No

O Prefer not to say

## 16. Have you, or your partner, ever undergone a pregnancy termination (abortion) due to a prenatal diagnosis of a condition other than SMA?

O Yes

O No

O Prefer not to say

16 a. If yes, please state for which condition(s)

### **Section 4: Your Views About SMA**

In this section, you will be asked about your views about SMA as a condition. You will be asked about how far you agree, or disagree, with, a list of statements. These statements were derived from interviews conducted with families living with SMA and represent a wide range of views on the condition. This survey will measure how widespread these views are and how strongly they are held by the wider population of families living with SMA. Please note, there are no right and wrong answers to these questions and everyone feels differently.

### 17. Please state how far you agree, or disagree with, the following statements about SMA.

	Views About SMA							
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know		
<b>a.</b> People with SMA can have a good quality of life	0	0	0	0	0	0		
<b>b.</b> Having SMA causes people to suffer	0	0	0	0	0	0		
c. People with SMA have heightened intelligence	0	0	0	0	0	0		
<b>d.</b> People with SMA and their families are well supported by society	0	0	0	0	0	0		
<b>e.</b> Quality of life varies greatly across the types of SMA	0	0	0	0	0	0		

### Section 5: Your Views on Screening for SMA

In this section, you will be asked your views on screening for SMA. You will be asked how far you agree, or disagree with a list of statements about SMA, derived from interviews with families living with SMA. These statements represent a wide range of views. This survey will measure how widespread these views are, and how strongly they are held by the wider population of families living with SMA.

Screening for SMA would involve the identification of SMA in the whole UK population, not just within families already known to be affected by the condition. However, screening in the general population could not accurately diagnose the type of SMA in that family.

Screening for SMA could be done in different ways:

1) **Pre-conception genetic screening** would identify 'carriers' of SMA (people who carry the faulty gene associated with SMA but do not have symptoms of SMA themselves) before they have children, or whilst

they are planning a pregnancy, in order that they could be made aware of their chances of having a child with SMA before the baby is conceived.

- 2) **Prenatal genetic screening,** through the use of a routine blood test, would identify carriers of SMA amongst all pregnant women in the UK (and where appropriate, also their partners). This would be done to determine the couple's overall chance of their foetus (unborn baby)having SMA. If both partners are found to be carriers of SMA, a diagnostic test (a test that could confirm for certain if the foetus had SMA, although not which type of SMA) would be offered, and depending on the results, the couple might be offered a termination of their pregnancy (abortion).
- 3) **Newborn genetic screening** would identify babies affected by SMA shortly after their birth through a blood test, although, like the other forms of screening described above, it may not be clear from the results of the screen what type of SMA the baby had. Newborn genetic screening could also identify some carriers of SMA. This information would be passed on to the child when they were old enough to understand the meaning of their carrier status and may be used in their future reproductive decisions.

You will be asked a general question about screening for SMA, before being asked to agree, or disagree with statements relating to the three different types of screening outlined above.

Please be reminded that some people may find the topic of screening for SMA distressing. Should the completion of this survey raise any issues for you which you would like support with, or further information on, please contact SMA Support UK (formerly the Jennifer Trust for Spinal Muscular Atrophy) www.smasupportuk.org.uk/ (01789 267520).

18. I think t	hat screening the po	pulation for SMA is a good idea.	
O Agree	O Disagree	O Don't know	

19. These statements relate to pre-conception genetic screening for SMA. Please state how far you agree or disagree with them by ticking in the appropriate box. Pre-conception genetic screening would allow people the option to know of their carrier status for SMA before conceiving a pregnancy, so that they could be made aware from the outset of any future child's chance of having SMA.

	Pre-Conception Genetic Screening for SMA						
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	
<b>a.</b> Identifying carriers of SMA before a pregnancy is conceived will affect people's choice of reproductive partner (the person you choose to have a baby with)	0	0	0	0	0	0	
<b>b.</b> Identifying carriers of SMA in the general population will lead to carriers feeling stigmatised or different	0	0	0	0	0	0	
c. Identifying carriers of SMA before a pregnancy is established is a good thing, as it will reduce the number of terminations due to SMA as parents will be aware of the chances beforehand	0	0	0	0	0	0	
<b>d.</b> Identifying carriers of SMA in the general population will increase awareness of SMA as a condition	0	0	0	0	0	0	
e. People from the general population won't be interested in finding out their SMA carrier status as they won't think it's relevant to them	0	0	0	0	0	0	
<b>f.</b> Pre-conception genetic screening is a form of 'social engineering' (a way of controlling the genetic make-up of the population)	0	0	0	0	0	0	
<b>g.</b> I would support a pre-conception genetic screening programme for SMA	0	0	0	0	0	0	

20. These statements relate to prenatal genetic screening for SMA. Please state how far you agree or disagree with them.

Prenatal genetic screening would identify the carrier status of all pregnant women (and sometimes also their partners) to assess the overall chances of their foetus (unborn baby) having SMA. This form of screening may lead to the recommendation of a diagnostic test of the foetus, if the chances of it having SMA are deemed high.

	Prenatal Genetic Screening for SMA						
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	
a. Identifying SMA in pregnancy will inevitably lead to less people with SMA coming into the world who could have lived fulfilling lives	0	0	0	0	0	0	
<b>b.</b> Screening for SMA in pregnancy will enable everyone to make informed decisions about whether or not to bring a child with SMA into the world	0	0	0	0	0	0	
c. Screening for SMA in pregnancy will prevent unnecessary suffering	0	0	0	0	0	0	
<b>d.</b> Screening for SMA in pregnancy will raise awareness of the condition in the general population	0	0	0	0	0	0	
e. It would be a loss to society to have less people with SMA coming into the world	0	0	0	0	0	0	
<b>f.</b> It would be hard for pregnant women and their partners to refuse screening for SMA in pregnancy	0	0	0	0	0	0	
g. Screening for SMA in pregnancy is still useful even if they can't tell you which type of SMA the foetus (unborn baby) has	0	0	0	0	0	0	
h. Termination of pregnancies affected by milder forms of SMA is unfortunately necessary if we are to make sure that children with severe forms of SMA are not born	0	0	0	0	0	0	
i. I would support a prenatal screening programme for SMA	0	0	0	0	0	0	

21. These statements relate to newborn screening for SMA. Please state how far you agree or disagree with them.

Newborn genetic screening for SMA would identify babies affected by SMA shortly after birth through a blood test. It might also identify some carriers of SMA.

	Newborn Genetic Screening for SMA						
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know	
a. Identifying SMA at birth would lead to better support and health care for the child with SMA and their family	0	0	0	0	0	0	
<b>b.</b> Identifying SMA at birth would extend the life expectancy of a child with SMA	0	0	0	0	0	0	
c. Identifying SMA at birth (and not in pregnancy) takes away the parents' right to make an informed decision about whether or not to have a child with SMA in the first place	0	0	0	0	0	0	
<b>d.</b> Identifying SMA before a child develops any symptoms prevents the child and their family from enjoying life whilst they are still symptom-free	0	0	0	0	0	0	

		Newbor	n Genetic	Screening	for SMA	X TUBILL
the result to your little result	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
e. Identifying SMA at birth would help research into treatments by enabling more children to be enrolled into clinical trials early on	0	0	0	0	0	0
<b>f.</b> Identifying SMA at birth would interfere with the early bonding process between parent and child	0	0	0	0	0	0
<b>g.</b> Identifying SMA at birth would make the diagnosis easier for parents to accept	0	0	0	0	0	0
<b>h.</b> Identifying SMA at birth would spare parents the difficulties associated with finding a diagnosis for their child later on	0	0	0	0	0	0
i. Even though parents would not know for sure the type of SMA affecting their newborn baby, it's still better that they know about the SMA straight away	0	0	0	0	0	0
j. Identifying SMA at birth is important as it would enable parents to make informed decisions about future pregnancies as they would be aware of their own potential carrier status straight away	0	0	0	0	0	0
<b>k.</b> It is unethical to screen newborn babies for conditions which have no effective treatments	0	0	0	0	0	0
I. I would support a newborn genetic screening programme for SMA	0	0	0	0	0	0

### Section 6: Your Wider Views on Termination of Pregnancy (Abortion)

In this section, you will be asked about your wider views on pregnancy termination (abortion). The question in this section is replicated from a 2003 survey, 'Views and Decisions about Prenatal Screening', which was given to pregnant women undergoing screening for Down's Syndrome. This question is being asked to explore whether families living with SMA view termination of pregnancy (abortion) differently to women from the general population in the circumstances listed below.

### 22. These statements relate to attitudes towards termination of pregnancy (abortion).

Please state whether you personally agree with a woman having a termination if...

	Wider Views on Termination of Pregnancy					
	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Don't know
a. The family has a low income and cannot afford any more children	0	0	0	0	0	0
<b>b.</b> The woman decides she does not wish to have a child	0	0	0	0	0	0
c. The child is certain to have a serious mental disability and will never live independently	0	0	0	0	0	0
<b>d.</b> The child is certain to have a serious physical disability and will never live independently	0	0	0	0	0	0
e. The child would live in good health, but would be certain to die in his/her twenties or thirties	0	0	0	0	0	0
f. The child would be healthy but would never grow taller than an eight year old (between 124cm and 132cm on average)	0	0	0	0	0	0

### Thank you!

Thank you for completing the SMA Screening Survey (UK). Please return your survey in the pre-paid envelope, or to the following address:

SMA Screening Survey (UK) C/O Dr. Felicity Boardman, Division of Health Sciences, Warwick Medical School Gibbet Hill Road Coventry CV4 7AL

Some people may find the topic of screening distressing. Should the completion of this survey raise any issues for you which you would like to discuss further, please contact SMA Support UK (formerly the Jennifer Trust for SMA) www.smasupportuk.org.uk/ (01789 267520).

Please feel free to pass this survey on to your relatives, and any friends/acquaintances you know with SMA in their family, however please be aware that screening can be a sensitive topic, and the views of others may not be the same as yours. You can contact us for extra paper copies (SMAscreeningsurvey@warwick.ac.uk) or use the link to the online version: http://www.warwick.ac.uk/smascreeningsurvey

You can find out more about the Imagining Futures research project by visiting: www.warwick.ac.uk/imagining\_futures

#### **Glossary of Terms**

CVS/Amniocentesis- CVS and amniocentesis are diagnostic procedures used in pregnancy which usually involve the insertion of a needle through the abdomen to remove samples to be genetically tested.

Pre-Implantation Genetic Diagnosis- refers to the creation of embryos using IVF procedures. The embryos can then be tested for genetic conditions, such as SMA, before being transferred back to the mother's uterus.

Screening for Down's Syndrome- Down's Syndrome is a chromosomal disorder caused by an extra copy of chromosome 21 which leads to varying degrees of learning difficulty. It is also known to be associated with particular health problems, including heart problems, reduced vision and hearing, as well as early-onset Alzheimer's Disease (a form of senile Dementia). Screening for Down's Syndrome is offered to all pregnant women in the UK and usually involves a blood test and/or a scan (to measure the foetus' nuchal fold- the back of the neck) at around 12 weeks of pregnancy.

If you have any comments about the SMA Screening Survey (UK) please write them in the box below: