
Study No: **3938**

Client's Internal PM number: **SG43215**

Study Name: **SMA Patient and Caregiver project**

Date: **March 2021**



[Caregiver] Screenener & QNR

Research Partnership Ltd.

Chester House
81-83 Fulham High Street
London, SW6 3JW
United Kingdom
Tel: + 44 (0) 208 069 5000

SAMPLE AND QUOTAS USED IN CONJUNCTION WITH CAREGIVER (REFERRED AS CG LATER) QNR, NATURAL FALL OUT, BUT THE BELOW QUOTAS TO BE USED AS A GUIDANCE:

	Patients	Caregiver (CG)	Total
Argentina	25-30	25-30	50-60
Brazil	30-40	30-40	60-80
Mexico	25-30	25-30	50-60
Chile	5-10	5-10	10-20
	The below are minimum quotas		
Costa Rica	2-3	2-3	4-6
Dominican Republic	2-3	2-3	4-6
Peru	2-3	2-3	4-6
Panama	2-3	2-3	4-6
Uruguay	2-3	2-3	4-6
Bolivia	2-3	2-3	4-6
Paraguay	2-3	2-3	4-6
Total			230-250

SOFT QUOTAS TO BE APPLIED:

SMA PATIENT TYPE II	SMA PATIENT TYPE III	CG OF SMA PATIENT TYPE I	CG OF SMA PATIENT TYPE II	CG OF SMA PATIENT TYPE III
PATIENT QNR: S4 CODE 2	PATIENT QNR: S4 CODE 3	CG QNR: S4 CODE 1	CG QNR: S4 CODE 2	CG QNR: S4 CODE 3

TREATMENT EXPERIENCED [IN ALL MARKETS EXCEPT URUGUAY] PATIENT/CG QNR: S5 CODE 1-2 [URUGUAY ONLY] PATIENT/CG QNR: S5 CODE 1-3	TREATMENT NAÏVE PATIENT/CG QNR: S5 CODE 4, 99
---	--

PLEASE CREATE QUOTA GROUPS.

QUOTA NAME	Programming instruction
EXPERIENCED SMA PT TYPE II	[IN ALL MARKETS EXCEPT URUGUAY] PATIENT QNR: IF CODE 2 S4 AND CODE 1 OR 2 AT S5 [URUGUAY ONLY] PATIENT QNR: IF CODE 2 S4 AND CODE 1, 2 OR 3 AT S5
NAÏVE SMA PT TYPE II	PATIENT QNR: IF CODE 2 S4 AND CODE 4 OR 99 AT S5

EXPERERENCED SMA PT TYPE III	[IN ALL MARKETS EXCEPT URUGUAY] PATIENT QNR: IF CODE 3 S4 AND CODE 1 OR 2 AT S5 [URUGUAY ONLY] PATIENT QNR: IF CODE 3 S4 AND CODE 1, 2 OR 3 AT S5
NAÏVE SMA PT TYPE III	PATIENT QNR: IF CODE 3 S4 AND CODE 4 OR 99 AT S5
CG OF EXPERERENCED SMA PT TYPE I	[IN ALL MARKETS EXCEPT URUGUAY] CG QNR: IF CODE 1 S4 AND CODE 1 OR 2 AT S5 [URUGUAY ONLY] CG QNR: IF CODE 1 S4 AND CODE 1, 2 OR 3 AT S5
CG OF NAÏVE SMA PT TYPE I	CG QNR: IF CODE 1 S4 AND CODE 4 OR 99 AT S5
CG EXPERERENCED SMA PT TYPE II	[IN ALL MARKETS EXCEPT URUGUAY] CG QNR: IF CODE 2 S4 AND CODE 1 OR 2 AT S5 [URUGUAY ONLY] CG QNR: IF CODE 2 S4 AND CODE 1, 2 OR 3 AT S5
CG NAÏVE SMA PT TYPE II	CG QNR: IF CODE 2 S4 AND CODE 4 OR 99 AT S5
CG EXPERERENCED SMA PT TYPE III	[IN ALL MARKETS EXCEPT URUGUAY] CG QNR: IF CODE 3 S4 AND CODE 1 OR 2 AT S5 [URUGUAY ONLY] CG QNR: IF CODE 3 S4 AND CODE 1, 2 OR 3 AT S5
CG NAÏVE SMA PT TYPE III	CG QNR: IF CODES 3 S4 AND CODE 4 OR 99 AT S5

BLUE = PROGRAMMING NOTES**RED = TERMINATION****GREY BAR = NEW SCREEN****ORANGE = AE NOTES / AE REPORTABLE**

Introduction

You are invited to take part in a market research study as part of a scientific project (hereinafter “research”). To allow you to make an informed decision as to whether or not you want to take part in this research, this document describes the purpose of the research and the data that will be collected in the research. Taking part in this research is your choice.

Please take your time to read the following information carefully. If you have any questions, you may ask the fieldwork agency carrying out the research {Estudio Silva Roca}, for more explanation.

Why are you invited to participate?

You were selected as a possible participant in this research because you have been identified as a person who:

- Is an adult who has a medical diagnosis of spinal muscular atrophy (SMA) type II or III or a caregiver of children with SMA type I, II or III
- We will need all participants to have internet connection in order to complete the survey

What is the purpose of this research?

The purpose of the market research is to understand your views regarding the importance of different aspects of treatments for SMA, and to explore the trade-offs that you as a person with SMA or parent/caregiver of a child with SMA would consider making. Through your participation you can ensure your voice gets heard and help us build an understanding of what type of treatments are preferred and valued by yourself.

Who is financing and conducting this research?

This research is being financed by an international pharmaceutical company. This research is conducted by Estudio Silva Roca on behalf of Research Partnership, a global, independent research consultancy. The research will comply with all data protection policies and adhere to market research and industry codes of conduct (incl. ABPI, BHBIA, EphMRA and MRS).

Who has approved this research?

This research has been reviewed and approved by {Name of IRB/EC}, an organization that is responsible for protecting the rights, safety, and well-being of patients who take part in research activities.

How many people will take part in the research?

Approximately 230-250 patients and caregivers will take part in this research. Consisting of a mix of adult patients with SMA type II and III and caregivers of patients with SMA type I, II and III across 11 markets in Latin America: Argentina, Bolivia, Brazil, Chile, Costa Rica, Dominican Republic, Mexico, Panama, Paraguay, Peru, Uruguay.

What are my obligations if I take part in this research?

If you decide to take part in this research, you will be requested to do the following:

- To complete an online survey of approximately 30 minutes, to the best of your abilities
- You will be able to access the survey by computer (desktop/laptop), tablet and smartphone devices
- Please do not complete the survey more than once

What will happen if I take part in this research?

If you agree to participate in the research, it is necessary that you agree to this Informed Consent Form by ticking the box at the bottom of the screen.

Only then you will be able to access the questionnaire and your answers will be collected and analyzed as part of this research.

Participation is voluntary, and if you wish, you can withdraw at any time. Your participation would remain confidential and only anonymised data would be used for analysis and in reports. The anonymised study results will be used to help healthcare decision-makers understand how adults and caregivers of children with SMA value different aspects of SMA treatments. We also anticipate that the study results will be presented at academic conferences and published in peer-reviewed medical journals.

The following information will be collected during the research:

- Understanding SMA diagnosis, key symptoms and management

- What treatment are you aware of or have experience with
- What treatment aspects would you consider as an ideal treatment and your likelihood to use
- Disease burden and impact of SMA on quality of life (QoL)
- Some demographic information
- **[SHOW TO CAREGIVERS ONLY** Impact of SMA on caregiver's life/health]

Are there benefits to taking part in the research?

There is no direct medical benefit to you from being in this research. The information gained from this research may help researchers and doctors to learn more about SMA in general. You and other patients/caregivers with/for SMA or a similar condition may benefit from results of such research in the future.

Will I be paid for taking part in this research?

You will not be paid for your participation in this research. You will not receive reimbursement for any expenses during your participation in this research.

All research will be conducted in accordance with the UK Data Protection Act 2018 General Data Protection Regulation (GDPR), with the British Healthcare Business Intelligence Association's Legal & Ethical Guidelines and European Pharmaceutical Market Research Association (EphMRA) code of conduct. This is in addition to the codes of conduct as set out by the Market research Society (MRS) and Insights Association and, therefore, all information will be treated confidentially and only used for the research purpose stated above.

Your research data will be labeled with a respondent identification number (ID) that is unique to you and not related to or derived from information that identifies you (such as your name, or any other personally identifying information) will be used in the research. The international pharmaceutical company its affiliates, and its representatives will only have access to research data labeled with a respondent ID number, except as described below.

The international pharmaceutical company, its affiliates, and its collaborators and licensees (people and companies who partner with the international pharmaceutical company) may use research data labeled with your respondent ID number. Your research data may also be shared with independent researchers or government agencies, but only after personal information that can identify you has been removed. Your research data may be combined with other people's data and/or linked to other data collected from you. Your research data may be used to help better understand why people get diseases and how to best prevent, diagnose, and treat diseases, and to develop and provide access to new medicines, medical devices, and healthcare solutions.

The results of from this research will be published in a medical journal/ paper or presented at a scientific meeting.

Information from this research will be retained by Research Partnership for 5 years after the end of the research or for the length of time required by applicable laws, whichever is longer. In addition, the international pharmaceutical company will retain the research data for 10 years after the final research results have been reported or for the length of time required by applicable laws, whichever is longer.

How will my Information be used and shared?

If you agree to this consent form, you give permission to Research Partnership to use and/or share your Information in an anonymized way, which includes research data. Your research

data may be used or shared for the purposes of this research. You do not have to agree to this consent form, but if you do not, you may not take part in this research.

Your research data may be used by and/or shared with the international pharmaceutical company, its affiliates, its representatives, collaborators, and licensees, the Institutional Review Board or Ethics Committee, and regulatory authorities. Your research data may be analyzed in any country worldwide.

You may change your mind and take back your consent at any time without penalty or loss of any benefits to which you are otherwise entitled. If you take back your consent, you will not be able to continue to take part in the research and no new information will be collected about you. However, to comply with regulatory requirements to protect the scientific integrity of the research, the international pharmaceutical company will still be able to use and share any research data about you that have already been collected during this research.

For more information about how we use your information, and what your rights are, please see our privacy notice, which is available at <https://www.researchpartnership.com/who-we-are/ad-hoc-respondent-privacy-notice>

RESEARCH RESULTS

A research report containing the results of this research will generally be made available to anyone who requests a copy. Before this report is provided, additional steps will be taken to protect your information from being linked to you.

If the results of the research are published, your identity will remain confidential

Adverse Events informed consent

We are required to pass on to the sponsoring client any details of side effects or product complaints relating to their products that are mentioned during the interview. This is to help them learn more about the safety of their medicines. If this happens, we will need to collect details and report the side effects or product complaint. You will be asked if you give permission for us to pass your contact details to the company's drug safety department for them to follow up. This will have no impact on the confidentiality and anonymity associated with the interview itself.

Are you willing to participate with this survey on this basis?

	Label	PN
1	Yes	CONTINUE
2	No	CLOSE

If "yes" CODE 1 ABOVE, PLEASE NOTE THE INSTRUCTION.

	Label	PN
1	Willing to be contacted by the client safety team for more information about the AE	CONTINUE
2	Unwilling to be contacted by the client safety team but still willing to participate	CONTINUE

Signature

Please read each point carefully and click at the bottom of the page to proceed

- I have received information about the study and had sufficient time to read through it. I have read it, I understand the information and have had my questions answered.
- I voluntarily give my consent to take part in the study as described. I know I can stop completing the survey at any time.
- I authorise Research Partnership to use and disclose the information as described above in this Informed Consent Form. I agree to the recording of the data I provide in the survey and understand that the researchers will not be able remove data once the survey is completed because no personal identifiable information will be recorded.
- I also agree that my data can be passed on in an anonymous form to authorised specialists to be used for data processing and scientific analysis.
- I also give my consent to the scientific publication of the research results while adhering to data protection legislation such as the UK Data Protection Act 2018. The publication will look at patient and caregiver preferences of SMA treatment features depending on the patient's disease status. The data in the publication will be on an aggregated level only and all responses will remain anonymised.

I understand that a copy of this form will be sent to me in an email after I have agreed to it.

Are you happy to take part in this study?

Please tick the relevant box

	Label	PN
1	I wish to take part in this study	CONTINUE
2	I DO NOT wish to take part in this study	CLOSE

If you wish, you can print or save a copy of this consent text to keep for your records, however we will also email it to you.

SCREENER

HIDDEN AUTOMATED QUESTION, SINGLE CHOICE

S0. Country of residence

	Label	PN
1	Argentina	
2	Brazil	
3	Mexico	
4	Chile	
5	Costa Rica	
6	Dominican Republic	
7	Peru	
8	Panama	
9	Uruguay	
10	Bolivia	
11	Paraguay	

ASK IN ARGENTINA, SINGLE CHOICE

S0B. From the list below, please select the initials of your first and last name.

--	--

SHOW DROPDOWN LIST WITH ALPHABETICAL LETTERS BETWEEN A-Z

ASK ALL, SINGLE CHOICE

We need to ask you some questions to ensure the survey is appropriate for you.

S1. Do you have a child / child you take care of aged under 18 who has been diagnosed with spinal muscular atrophy (SMA)?

	Label	PN
1	Yes, I am the parent or caregiver of a child with spinal muscular atrophy (SMA)	
2	No, I am not the parent or caregiver of a child with spinal muscular atrophy (SMA)	[CLOSE]
99	Prefer not to say	[CLOSE]

ASK ALL, NUMERIC

S2. What is your current age?

1		
---	--	--

 years

CLOSE IF <18 YEARS OF AGE
SHOW DROPDOWN LIST WITH NUMBERS BETWEEN 14-99

ASK ALL, NUMERIC

S2A. In total, how many children under the age of 18 do you care for?

1			Children aged between 0-12 years
2			Children aged between 13-17 years

CLOSE IF '0' IN BOTH CODES 1 AND 2
SHOW DROPDOWN LIST FOR BOTH CODES WITH NUMBERS BETWEEN 0-10

ASK ALL, NUMERIC

S2B. How many **children with SMA** under the age of 18 do you care for in total?

1			Children with SMA aged between 0-12 years
2			Children with SMA aged between 13-17 years

SUM OF CODE 1 + CODE 2 AT S2B MUST BE LESS OR EQUAL TO S2A
SHOW DROPDOWN LIST FOR BOTH CODES WITH NUMBERS BETWEEN 0- THE SUM OF CODE1+CODE2 AT S2A

NEW SCREEN

IF TOTAL OF S2B>2 SHOW ON TOP OF SCREEN:

From now on please focus on only on **one** of your children who is diagnosed with SMA and you take care of and when answering the questions.
 Please think about only that one child throughout the survey.

ASK ALL, NUMERIC

S2C. What is the current age of your child / child you take care of with SMA?

1			months
2			years

SHOW DROPDOWN LIST FOR YEARS WITH NUMBERS BETWEEN 0-17
SHOW DROPDOWN LIST FOR MONTHS WITH NUMBERS BETWEEN 0-11
ERROR MESSAGE IF ENTER ≥18 YEARS: You indicated that the child you take care of is younger than 18 years of age. Please review your answer and click next to confirm.

ASK ALL, SINGLE CHOICE

S3. How old was your child / child you take care of when they **first had symptoms associated with SMA?**

	Label	PN
1	Between 0-6 months of age	
2	Between 7-18 months of age	
3	Between 18 months and 17 years of age	

ASK ALL, SINGLE CHOICE

S4. Please select the type of SMA your child / child you take care of has been diagnosed with.

1	SMA Type 1 (severe, young babies): onset typically between 0-6 months of age; unable to ever sit without support	
2	SMA Type 2 (intermediate, older babies and toddlers): onset typically between 7-18 months of age may be able to sit up without help, but not stand or walk	
3	SMA Type 3 (mild, children and young adults): onset typically between 18 months and 17 years of age; able to stand and walk without help, although may find walking or getting up from a sitting position difficult and may find walking gets gradually harder over time	
4	SMA Type 4 (adults): onset typically at age 18 or later	[CLOSE]
99	I don't know the type of SMA my child / the child I take care of has	

IF CODE 1 OR CODE 4 SELECTED AT S4 AND CODE 2 OR 3 SELECTED AT S3 SHOW THE FOLLOWING ERROR MESSAGE: You have stated earlier that you first had symptoms associated with SMA [INSERT ANSWER FROM S3], but your answer [INSERT BOLDED ANSWER FROM S4] contradicts that. Please review your answer and amend if needed, otherwise click on the 'Next' button!

ASK ALL, SINGLE CHOICE; ROTATE

S5. Has your child / child you take care of ever received or currently receive any of the following treatments (including in clinical trials), specifically for their SMA?

Please select all that apply

	Label	PN
1	Spinraza (nusinersen)	
2	Zolgensma (onasemnogene abeparvovec-xioi)	
3	Evrysdi (risdiplam)	[CLOSE IN ALL MARKETS EXCEPT URUGUAY]
4	Surgery	
99	None of the above	ANCHOR

[IN ALL MARKETS EXCEPT URUGUAY] HVAR1: CODES 1-2 = TREATMENT EXPERIENCED; CODE 4, 99 = TREATMENT NAÏVE
[URUGUAY ONLY] HVAR1: CODES 1-3 = TREATMENT EXPERIENCED; CODE 4, 99 = TREATMENT NAÏVE

ASK ALL, MULTIPLE CHOICE; ROTATE

S6. Are you, or anyone else in your household, primarily employed by any of the following?

Please select all that apply

	Code label
1	Healthcare system (you are a physician, physician assistant, nurse practitioner, etc.)
2	A pharmaceutical, biotechnology or medical device company
3	A market research firm
4	An advertising or public relations company
99	None of the above [ANCHOR; EXCLUSIVE]

[BASE: ALL WHO SCREENED OUT]

Unfortunately, YOUR ANSWERS have shown that you are not eligible to participate in this research at this time and the survey will now close. Thank you for your interest in this research. We will re-contact you if any of the participation requirements change such that you may be eligible.

MAIN SURVEY**[BASE: ALL WHO SCREENED IN]**

You have qualified for this survey, thank you for agreeing to take part.

In the next few minutes we would like to ask you about your views on different SMA (spinal Muscular Atrophy) treatments.

For the purpose of this interview, from now on when you answer the questions please focus on the child with SMA whom you care for.

SECTION 1 –SMA HISTORY**ASK ALL, NUMERIC**

Q1. We understand that you your child / child you take care of was between **[INSERT ANSWER FROM S3]** when they first had symptoms associated with SMA. Exactly how old was your child / child you take care of when they **first had symptoms** associated with SMA?

Please give an estimate if unsure

1		
---	--	--

 years

--	--

 months

SHOW DROPDOWN LIST FOR YEARS WITH NUMBERS BETWEEN 0-17
SHOW DROPDOWN LIST FOR MONTHS WITH NUMBERS BETWEEN 0-11

HVAR2: CALCULATE ANSWER INTO MONTHS
ERROR MESSAGE IF ANSWER ≠ AGE RANGE AT S3

ERROR MESSAGE:
IF AGE AT Q1 > AGE AT S2C SHOW ERROR MESSAGE: 'You have entered an age older than the stated age of the child. Please review your answer'

ASK ALL, NUMERIC

Q2. How old was your child / child you take care of when **first diagnosed** with SMA?

Please give an estimate if unsure

1		
---	--	--

 years

--	--

 months

HVAR3: CALCULATE ANSWER INTO MONTHS
HVAR4: CALCULATION ON TIME SINCE DIAGNOSIS IN MONTHS: HVAR3 MINUS HVAR2

ERROR MESSAGE IF NUMERIC ANSWER LOWER THAN Q1

SHOW DROPDOWN LIST FOR YEARS WITH NUMBERS BETWEEN 0-17
SHOW DROPDOWN LIST FOR MONTHS WITH NUMBERS BETWEEN 0-11

ERROR MESSAGE:

IF AGE AT Q2 > AGE AT S2C SHOW ERROR MESSAGE: 'You have entered a SMA diagnosis age older than the previously stated age of the child. Please review your answer

ASK ALL, SINGLE CHOICE

Q3. Is your child / child you take care of able to sit independently?

	Label
1	Yes
2	No

ASK ALL, SINGLE CHOICE

Q4. Is your child / child you take care of able to walk without using a cane/crutch or other forms of assistance for more than ten steps?

	Label
1	Yes
2	No

ASK ALL, SINGLE CHOICE

Q5. Please think about your child / child you take care of and their current level of **physical (motor) functioning or ability**. Please read the categories below and tick which one best describes them.

You might not find a description that reflects the exact condition of your child / child you take care of, but please mark the one category that best describes the situation of your child / child you take care of.

	Label
1	Cannot sit
2	Can sit with some support (e.g. with back support or arm support)
3	Can sit independently for a few seconds
4	Can sit independently for a longer period of time but cannot stand
5	Can sit independently and stand with assistance , but cannot walk
6	Can sit independently and stand and walk with assistance
7	Can sit, stand and walk independently for a few steps (less than 10 metres)

ASK ALL, SINGLE CHOICE

Q6. Now please think about your child / child you take care of and their **breathing**. Please read the categories below and tick which one best describes your child / child you take care of at present.

You might not find a description that reflects the exact condition of your child / child you take care of, but please mark the one category that best describes the situation of your child / child you take care of.

	Label
1	Need mechanical support to breathe for more than sixteen hours of the day
2	Need mechanical support to breathe for some of the day
3	Can breathe without mechanical support

ASK ALL, MULTIPLE CHOICE

Q7. Not including SMA, **what other conditions or illnesses** if any does your child / child you take care of have which limit their daily activities?

Please select all that apply

	Label
1	Anxiety
2	Cardiovascular disease
3	Chronic pain (e.g. back pain, headaches)
4	Depression
5	Diabetes
6	Digestive pain / discomfort
7	Hypertension (high blood pressure)
8	Sleep problems
9	Stress
98	Other [ANCHOR]
97	My child / the child I take care of does not have other conditions or illnesses [EXCLUSIVE; ANCHOR]
99	Prefer not to answer [EXCLUSIVE; ANCHOR]

ASK NAÏVE PATIENT ONLY CODE 4 OR 99 AT S5, SINGLE CHOICE

Q8. Has does your child / child you take care of been previously assessed for suitability for a pharmaceutical treatment for their SMA by a physician?

	Label	PN
1	Yes, my child / child I take care of has been assessed	
2	No, my child / child I take care of has not been assessed	
3	My child / child I take care of was offered an assessment but have not done so	

ASK IF CODE 1 AT Q8 MULTIPLE CHOICE, ROTATE

Q9A. You stated that your child / child you take care of has been assessed for suitability for a pharmaceutical treatment for their SMA. What are the reasons that your child/ child you take care of has not yet received any pharmaceutical treatment for their SMA?

Please select all that apply

	Label
1	High cost of the pharmaceutical treatment
2	Healthcare Coverage Plan does not reimburse the pharmaceutical treatment
3	Pharmaceutical treatment is not yet available
4	Pharmaceutical treatment is not accesible at my hospital
5	The doctor of my child/ the child I take of doctor has not mentioned any specific pharmaceutical treatment
6	The doctor is not trained to provide pharmaceutical treatment
7	My child/ the child I take care of is due to receive it in the next few weeks
8	Assessment occured before COVID-19 and standard care has not yet returned in my area
9	I need more information on the pharmaceutical treatment to make up my mind
10	I am concerned about side effects for my child/ the child I take care of on top of the already debilitating disease
11	I am unable to take my child / the child I take care of to the hospital
98	Other [ANCHOR]
99	Prefer not to answer [EXCLUSIVE; ANCHOR]

ASK IF CODE 3 AT Q8 MULTIPLE CHOICE, ROTATE

Q9B. You stated that your child / child you take care of was offered an assessment for suitability for a pharmaceutical treatment for their SMA, but have not yet done so. What are the reasons for not yet being assessed for an SMA treatment?

Please select all that apply

	Label
1	High cost of the pharmaceutical treatment
2	Healthcare Coverage Plan does not reimburse the pharmaceutical treatment
3	Pharmaceutical treatment is not yet available
4	Pharmaceutical treatment is not accesible at my hospital
5	I have not had time yet to take my child/ child I take of to an assessment
6	No genetic testing available in my hospital/ area
7	I have scheduled an appointment / My child/ child I take care of is due to receive an assessment in the next few weeks
8	My child/ child I take care of is waiting - standard care has not yet returned in my area due to Covid-19
9	I need more information on the pharmaceutical treatment to make up my mind
10	I am concerned about side effects for my child/ the child I take care of on top of the already debilitating disease
11	I am unable to take my child / the child I take care of to the hospital
98	Other [ANCHOR]
99	Prefer not to answer [EXCLUSIVE; ANCHOR]

ASK ALL, SINGLE CHOICE TREATMENT; ROTATE TREATMENT

Q10. How would you rate **your level of knowledge** on the different types of treatments currently available for SMA for your child / child you take care of, on a 1 to 5 scale where 1 means 'No knowledge at all about this treatment' and 5 means 'I know a great deal about this treatment'?

	Label	1 = No knowledge at all about this treatment				5 = I know a great deal about this treatment	Don't know [EXCLUSIVE CODE AND IF CODE SELECTED AT S5 CANNOT BE A DON'T KNOW HERE]
		1	2	3	4	5	
1	Spinraza (nusinersen)						
2	Zolgensma (onasemnogene abeparvovec)						
3	Evrysdi (risdiplam)						

ASK ALL, MULTIPLE CHOICE; ROTATE

Q11. Which of the following tools/equipment does your child / child you take care of currently use to support/help them with their SMA?

Please select all that apply

	Label	PN
1	Breathing machine/mechanical ventilation	
2	Feeding tube	
3	Suction machine to help clear their throat	
4	Walking frame	
5	Wheelchair	
98	Other	[ANCHOR]
99	None	[EXCLUSIVE; ANCHOR]

SECTION 2 – TREATMENT CHOICES – DISCRETE CHOICE EXERCISE (DCE)

We want to understand how important different aspects of treatment are for parents and caregivers who have children with SMA or take care of children with SMA. To do this, we will present you with pairs of hypothetical treatments and we will ask you to choose which treatment you believe is best.

These treatments will be described in terms of their effectiveness in improving motor function (or preventing decline), how the treatment is taken (e.g. an injection or oral liquid), as well as possible side effects of the treatments.

The treatments are similar to current treatments but not exactly the same.

These hypothetical treatments do not reflect the treatments available from your child's physician, nor should you ask your child's doctor to make treatment decisions based on the hypothetical treatments as described in this survey.

First of all, we want to describe the different features of the treatments. Please take a look at each screen:

NEW SCREEN. FORCE AT LEAST 10 SECONDS ON THIS SCREEN

Treatment effectiveness

Motor function

Treatments can vary in terms of their average effectiveness in improving motor function of people with SMA. A simplified scale of motor function is shown below:

	Label
1	Cannot sit
2	Can sit with some support (e.g. with back support or arm support)
3	Can sit independently for a few seconds
4	Can sit independently for a longer period of time but cannot stand
5	Can sit independently and stand with assistance , but cannot walk
6	Can sit independently and stand and walk with assistance
7	Can sit, stand and walk independently for a few steps (less than 10 metres)
8	Can sit, stand and walk independently over longer distances (more than 10 metres)

We will describe the effectiveness of the hypothetical treatment – on average – in terms of worse, stable, or better motor function.

1	Worse	After 12 months, motor function will have deteriorated by one level on the motor function scale
2	Stable	After 12 months, motor function will remain on the current level of function
3	Better	After 12 months, motor function will have improved by one level on the motor function scale

Breathing

Treatments can vary in terms of their average effectiveness in improving breathing ability among SMA patients.

We will describe the effectiveness of the hypothetical treatment – on average – in terms of worse, stable, or better breathing function.

1	Worse	After 12 months, breathing function will get worse
2	Stable	After 12 months, breathing function will stay the same

3	Better	After 12 months, breathing function will get better
----------	---------------	---

NEW SCREEN. FORCE AT LEAST 10 SECONDS ON THIS SCREEN

Administering the Treatment

Treatments can vary in terms of whether they are administered by injection or orally. The different hypothetical treatments you will see will be administered using the following methods:

1	Intrathecal (IT) <i>Injection into the spine at the lower back</i>	Injection into the spine at the lower back - Administered by injection in the lower back using a needle inserted into the space around the spinal cord, also known as a lumbar puncture. When your child / child you take care of first starts the treatment they will receive it every two weeks, then a month apart. After your child / child you take care of would need to return to hospital every four months for an injection
2	Oral	An oral liquid to be taken once daily at home. It can also be administered via a gastric tube at home after you have received some training
3	Intravenous (IV)	Treatment will be taken intravenously (IV): a one-time only 60 minute long infusion in the vein and taking oral corticosteroids starting 1 day before the IV and continuing for a minimum of 1 month up until liver functions are unremarkable

NEW SCREEN. FORCE AT LEAST 10 SECONDS ON THIS SCREEN

Reactions to the treatment

People can experience a reaction to their treatment immediately after taking it or can develop side effects at a later stage. These reactions may vary in severity (mild, moderate, severe).

Treatments could also cause reactions, lasting between less than 24 hours and 3-4 days:

1	No fever, headache, vomiting and/or body pain due to treatment
2	Fever, headache, vomiting and/or body pain for 1-2 days every four months
3	Fever, headache, vomiting and/or body pain for 3-4 days every four months

NEW SCREEN. FORCE AT LEAST 10 SECONDS ON THIS SCREEN

Activities of daily living

SMA can affect daily activities in a number of ways. Treatments can vary in terms of their average effectiveness in improving simple activities such as eating, reaching for an object or using the bathroom.

We will describe the effectiveness of the hypothetical treatment – on average – in terms of more difficult, stable or easier management of daily activities.

1	After 12 months, carrying out daily activities will become more difficult.
2	After 12 months, carrying out daily activities will remain the same.
3	After 12 months, carrying out daily activities will become easier.

NEW SCREEN

CHOOSING A TREATMENT

On the following series of screens you will be presented with a series of **hypothetical** treatment choices with two options, Treatment 'A' or Treatment 'B'. We would like you to read each scenario carefully and think about which treatment you would prefer for your child / child you take care of: A or B. (None of these match actual treatments). There are a whole series of choice questions to complete. There are no right or wrong answers; it is up to you to decide which you would prefer for your child / child you take care of.

Please take a moment to have another look at the motor function scale before continuing with the choice questions:

MOTOR FUNCTION SCALE

	Label
1	Cannot sit
2	Can sit with some support (e.g. with back support or arm support)
3	Can sit independently for a few seconds
4	Can sit independently for a longer period of time but cannot stand
5	Can sit independently and stand with assistance , but cannot walk
6	Can sit independently and stand and walk with assistance
7	Can sit, stand and walk independently for a few steps (less than 10 metres)
8	Can sit, stand and walk independently over longer distances (more than 10 metres)

NEW SCREEN, ASK ALL, SINGLE CHOICE PER SCREEN

Sample Choice Set (14 choice sets to be presented per participant)

You will now be shown multiple screens, each screen will include two different hypothetical SMA treatments.

The two **treatments will be different each time you see them**, so please take your time in reviewing the information and in making your selections.

These descriptions shown, contain assumptions and should be treated as hypothetical for market research purposes only; it is not intended to be promotional.

The information is for market research purposes only and these products may or may not become available in the future.

Please imagine that you are asked to choose a treatment for your child / child you take care of.

Q12. For each choice below please indicate whether you prefer treatment A or B for your child / child you take care of.

SEE DISCRETE CHOICE EXERCISE GRID IN APPENDIX

NEW SCREEN, ASK ALL; SINGLE CHOICE PER SCREEN. ASK AS MANY TIMES AS Q12 APPEARS

Q13. Would you use this treatment to treat SMA for your child / child you take care of?

	Label
1	Yes
2	No

SECTION 3 – SMA IMPACT ON QUALITY OF LIFE (EQ-5D-5L PROXY VERSION)

KEEP ON TOP OF SCREEN FOR QE1 AND QE2

For the following questions please focus on the health status of your child/ child you care for with SMA as of today.

We would now like to understand a bit more about the overall health of your child/ child you care for with SMA.

The caregiver (the proxy) is asked to rate the patient's health-related quality of life in their (the proxy's) opinion

THIS SECTION NOT TO BE TRANSLATED. WE ARE USING OFFICIAL TRANSLATIONS PLEASE USE PROVIDED LAYOUT FOR PROGRAMMING

ASK ALL, SINGLE CHOICE PER GROUP

QE1.

Under each heading, please tick the ONE box that you think best describes the person's health TODAY.

	Label	
A1	Mobility	No problems walking
A2		Slight problems walking
A3		Moderate problems walking
A4		Severe problems walking
A5		Unable to walk

B1	Self-Care	No problems washing or dressing him/herself
B2		Slight problems washing or dressing him/herself
B3		Moderate problems washing or dressing him/herself
B4		Severe problems washing or dressing him/herself
B5		Unable to wash or dress him/herself
C1	Usual Activities (e.g. work, study, housework, family or leisure activities)	No problems doing his/her usual activities
C2		Slight problems doing his/her usual activities
C3		Moderate problems doing his/her usual activities
C4		Severe problems doing his/her usual activities
C5		Unable to do his/her usual activities
D1	Pain / Discomfort	No pain or discomfort
D2		Slight pain or discomfort
D3		Moderate pain or discomfort
D4		Severe pain or discomfort
D5		Extreme pain or discomfort
E1	Anxiety / Depression	Not anxious or depressed
E2		Slightly anxious or depressed
E3		Moderately anxious or depressed
E4		Severely anxious or depressed
E5		Extremely anxious or depressed

ASK ALL, SLIDING SCALE

For the following questions please focus on the health status of your child/ child you care for with SMA as of today.

We would now like to understand a bit more about the overall health of your child/ child you care for with SMA.

QE2.

We would like to know how good or bad you think the person's health is TODAY.

- This scale is numbered from 0 to 100.
- **100** means the **best health you can imagine**.
- **0** means the **worst health you can imagine**.
 - Please mark an X on the scale to indicate how you think the person's health is TODAY.
- Now, please write the number you marked on the scale in the box below.

0 = worst health you can imagine										100 = best health you can imagine
----------------------------------	--	--	--	--	--	--	--	--	--	-----------------------------------

0	10	20	30	40	50	60	70	80	90	100
---	----	----	----	----	----	----	----	----	----	-----

1 THE PERSON'S HEALTH TODAY

SECTION 4– COVID IMPACT

ASK ALL, MULTIPLE CHOICE; ROTATE

QC1. During the time of the COVID-19 pandemic, what aspects of SMA and its management of your child / child you take care of have been impacted?

	Label
1	The treatment plan of my child / child I take care of has changed
2	Due to restrictions I am unable to visit physicians of my child / child I take care of
3	Due to restrictions I am unable to visit my pharmacy
4	The surgery of my child / child I take care of has been postponed
5	The treatment (not surgery) of my child / child I take care of has been postponed
6	It affected the mental health of my child / child I take care of
7	Caretaker not being able to provide regular support
98	Other [ANCHOR]
99	None [ANCHOR; EXCLUSIVE]

ASK ALL, SINGLE CHOICE

QC2. On a 1 to 5 scale where 1 means 'Has not impacted at all' and 5 means 'Impacted a great deal', to what extent has the COVID-19 pandemic impacted access to healthcare in relation to SMA of your child / child you take care of?

1 = Has not impacted at all				5= Impacted a great deal
1	2	3	4	5

ASK ALL, SINGLE CHOICE

QC3. On a 1 to 5 scale where 1 means 'Not at all' and 5 means 'Extremely', to what extent has the COVID-19 pandemic made you more concerned / worried about attending the hospital for any type of appointments?

1 = Not at all				5 = Extremely
1	2	3	4	5

ASK ALL, SINGLE CHOICE; ROTATE 1-3

QC4. Thinking about a time when there would not be any restrictions in place due to the pandemic, if your child / child you take care of was given an **oral** SMA treatment, how would you prefer this treatment to be delivered to you?

	Label
--	-------

1	Home delivery
2	Collect from local pharmacy
3	Collect from hospital

ASK ALL, SCALE; ROTATE 1-3; SINGLE CHOICE PER ROW

QC5. Now, considering restrictions in place due to the COVID-19 pandemic, please tell us your preference for each delivery method for an **oral** SMA treatment on a 1 to 5 scale where 1 means 'I don't prefer this delivery method at all for my child / child I take care' and 5 means 'I highly prefer this delivery method for my child / child I take care'

		1 = I don't prefer this delivery method at all for my child / child I take care'				5 = I highly prefer this delivery method for my child / child I take care'
		1	2	3	4	5
1	Home delivery					
2	Collect from local pharmacy					
3	Collect from hospital					

SECTION 5 – DEMOGRAPHICS

Finally we would like to ask a few demographic questions about your child / child you take care of and yourself.

ASK ALL, SINGLE CHOICE

QD1. Is your child / child you take care of with SMA...

	Label
1	Male
2	Female
98	Other
99	Prefer not to say

ASK ALL, SINGLE CHOICE

QD2. How would you best describe the current healthcare coverage / insurance plan for your child/ child you take care?

	Label
1	Publically insured [DO NOT SHOW IN BRAZIL]
2	Social security
3	Privately insured

4	Mix of public and private insurance
99	Prefer not to answer

ASK ALL, SINGLE CHOICE

QD3. What is your current living situation?

	Label
1	Living with partner / spouse
2	Living together with my child / child you take care of with SMA, but not with a partner or spouse
3	Living with relatives(s)
4	Other

ASK ALL, SINGLE CHOICE

QD5. Are you...

	Label
1	Male
2	Female
98	Other
99	Prefer not to say

ASK ALL, SINGLE CHOICE

QD6. We would like to get a general picture of your own health.

Please select the most appropriate answer

	Label
1	I am normally fit and well and do not take any prescription medication
2	I have a chronic illness that means I need to take prescription medicine

ASK ALL, MULTIPLE CHOICE; ROTATE

QD7. Do you think or has a doctor told you that you may have any of the following chronic health conditions?

Please select all that apply

	Label
1	Anxiety
2	Cardiovascular disease
3	Chronic pain (e.g. back pain, headaches)
4	Depression
5	Diabetes
6	Digestive pain / discomfort

7	Hypertension (high blood pressure)
8	Sleep problems
9	Stress
98	Other [ANCHOR]
97	None of the above [EXCLUSIVE; ANCHOR]
99	Prefer not to answer [EXCLUSIVE; ANCHOR]

ASK ALL, SINGLE CHOICE

QD8. How would you describe your main daily activity?

	Label
1	Paid employment – full time
2	Paid employment – part time
3	Looking after family and/or home and not in paid employment
3	Retired
4	Seeking work, unemployed
5	Not working because of health problems
6	In education or training
98	Other
99	Prefer not to answer

ASK ALL, SINGLE CHOICE

QD9. Which of the following statements would best describe your current financial circumstances?

	Label
1	The family income is sufficient to cover our daily living expenses and we <u>can</u> also save some extra money every month
2	The family income is sufficient to cover our daily living expenses, but we <u>cannot</u> save extra money every month
3	The family income is <u>not</u> sufficient to cover our daily living expenses
99	Prefer not to answer

ASK ALL, SINGLE CHOICE

QD10. Have you changed your employment or employment status as a result of your role as a caregiver of (a) child(ren) with SMA?

	Label
1	No
2	Yes – stopped working
3	Yes – reduced working hours
4	Yes – changed jobs to be more flexible
98	Yes - Other

ASK ALL, SINGLE CHOICE**QD11.** What is the highest level of education you have completed?

	Label
1	Incomplete elementary school
2	Completed elementary school
3	Incomplete high school
4	Completed high school
5	Incomplete college or graduate education
6	Completed college or graduate education
98	Other
99	Prefer not to answer

ASK ALL, SINGLE CHOICE**QD13.** What region do you live in?**SEE LIST OF REGIONS IN APPENDIX****ASK ALL, SINGLE CHOICE****QD14.** How would you best describe the area you live in?

	Label
1	Urban (city)
2	Semi-urban (town)
3	Rural
99	Prefer not to answer

[BASE; ALL SELECTING CODE 2 OR 3 AT QD14]**QD15.** Approximately how far away is the nearest city from you?

	Label
1	Within 20km
2	21-50km
3	51-99km
4	More than 100km

[SHOW ALL]

For your information the international pharmaceutical company sponsoring this market research study is Roche.

Upon knowing the sponsoring company, are you happy to submit your data?

A research report containing the results of this research will generally be made available to anyone who requests a copy. Before this report is provided, additional steps will be taken to

protect your information from being linked to you and if the results of the research are published, your identity will remain confidential.

	Label	PN
1	Yes, I am happy to submit my data to this research	USUAL PROCEDURE, PLEASE STORE THE DATA
2	No, I would like to withdraw my participation from this research	MAKE SURE DATA FOR THIS RESPONDENT IS REMOVED

[SHOW ALL]

Thank you for your time. It is very much appreciated. We look forward to welcoming you again to one of our studies.

This is the end of the survey.

APPENDIX

DISCRETE CHOICE EXERCISE GRID

ATTRIBUTES	LEVEL1	LEVEL2	LEVEL3
Motor Function	Worse - After 12 months, motor function will have deteriorated by one level on the motor function scale	Stable - After 12 months, motor function will remain on the current level of function	Better - After 12 months, motor function will have improved by one level on the motor function scale
Breathing	Worse - After 12 months, breathing function will get worse	Stable - After 12 months, breathing function will stay the same	Better - After 12 months, breathing function will get better
Administering the treatment	Intrathecal - Injection into the spine at the lower back - Administered by injection in the lower back using a needle inserted into the space around the spinal cord, also known as a lumbar puncture. When your child / child you take care of will first start the treatment they will receive it every two weeks, then a month apart. After they would need to return to hospital every four months for an injection	Oral - An oral liquid to be taken once daily at home. It can also be administered via a gastric tube at home after you have received some training.	Intravenous - Treatment will be taken intravenously (IV): a one-time only 60 minute long infusion in the vein and taking oral corticosteroids starting 1 day before the IV and continuing for a minimum of 1 month up until liver functions are unremarkable
Reactions caused by treatment	Fever, headache, vomiting and/or body pain for 3-4 days every four months	Fever, headache, vomiting and/or body pain for 1-2 days every four months	No fever, headache, vomiting and/or body pain due to treatment
Activities of daily living	After 12 months, carrying out daily activities will become more difficult	After 12 months, carrying out daily activities will remain the same	After 12 months, carrying out daily activities will become easier

APPENDIX FOR QD13: REGIONS

Code label	BRAZIL REGIONS	ARGENTINE REGIONS
1	Região Norte: Acre, Amapá, Amazonas, Pará, Rondônia, Roraima, Tocantins	Region Noroeste [Jujuy, Salta, Tucuman, etc.]
2	Região Nordeste: Alagoas, Ceará, Bahia, Maranhão, Paraíba, Pernambuco, Piauí, Rio Grande do Norte, Sergipe	Region Nordeste [Formosa, Chacho, Corrientes, etc]
3	Região Centro-Oeste: Goiás, Brasília - Distrito Federal, Mato Grosso, Mato Grosso do Sul	Region Pampeana [Santa Fe, Buenos Aires, Cordoba, etc]
4	Região Sudeste: Rio de Janeiro, Espírito Santo, São Paulo, Minas Gerais	Region de Cuyo [La Rioja, San Luis, Mendoza, etc.]
5	Região Sul: Rio Grande do Sul, Paraná, Santa Catarina	Region Patagonica [Rio Negro, Chubut, Santa Cruz, etc.]

Code label	CHILE REGIONS	MEXICO REGIONS	COSTA RICA REGIONS
1	Arica y Parinacota-Antofagasta	Center: Mexico City, State of Mexico, Morelos, Hidalgo, Tlaxcala	San José
2	Atacama-Coquimbo	West: Jalisco, Michoacán, Colima, Nayarit	Heredia
3	Valparaiso-Maule	South: Puebla, Oaxaca, Guerrero, Veracruz	Alajuela
4	Biobio-Los Lagos	South-West: Chiapas, Tabasco, Yucatán, Quintana Roo, Campeche	Cartago
5	Aysen-Magallanes	North: Nuevo León, Coahuila, Tamaulipas	
6		North-East: Baja California (north and south), Sonora, Chihuahua, Sinaloa, Durango	
7		Bajío Area: Guanajuato, Aguascalientes, Querétaro, San Luis Potosí, Zacatecas	

Code label	DOMINICAN REPUBLIC REGIONS	PERU REGIONS	PANAMA REGIONS
1	Santo Domingo	Greater Lima	Panamá City
2	Santiago	Arequipa	San Miguelito
3		Chiclayo	Arraiján
4		Trujillo	Colon

Code label	URUGUAY REGIONS	BOLIVIA REGIONS	PARAGUAY REGIONS
1	Montevideo	La Paz-El Alto	Asunción
2	Other	Cochabamba	Other
3		Santa Cruz	

APPENDIX FOR PRIVACY

This Privacy Notice ("Privacy Notice") for The Research Partnership Limited and its affiliates, The Research Partnership Inc and The Research Partnership Healthcare Asia Pte Ltd, ("The Research Partnership", "we", "our" or "us"), explains how information that may be collected from you ("you" or "your") may be used. This information may be collected in connection with your participation in healthcare market research studies with Research Partnership.

Research Partnership takes your privacy seriously. We may update this Notice from time to time and shall indicate on our website (www.researchpartnership.com) when changes have been made.

We collect data on behalf of our research sponsors (our clients). The types of research engagements we conduct include face to face, telephone and online market research.

All the data we collect is presented to the sponsors in aggregate form. We do not share any of your Personal Data with our sponsors. The only exception may be in the reporting of any Adverse Events you may mention during the course of the market research engagement; however, your Personal Data would only be shared with your consent. In case of a refusal, your Personal Data will not be released as part of the reporting process.

Research Partnership is registered with the Information Commissioner's Office in the United Kingdom as a Data Controller in accordance with the provisions of the Data Protection Act 2018. Further details of the registration are available at www.ico.org.uk/

Research Partnership is proud to be members of the pharmaceutical market research governing bodies and the main market research associations listed below and we follow their guidance on all matters relating to market research codes of conduct, data protection and adverse event reporting.

- BHBIA (British Healthcare Business Intelligence Association)
- EphMRA (European Pharmaceutical Market Research Association)
- ESOMAR (European Society for Opinion and Market Research)
- Intellus Worldwide
- MRS (Market Research Society)
- Market Research Society, Singapore

Topics:

- What Personal Data do we collect?
- How will we use your Personal Data?
- For how long will we retain your Personal Data?
- To whom will we disclose your Personal Data?
- How do we protect your Personal Data?
- How can you access and update your Personal Data?
- Changes to this Notice
- How to contact us

What Personal Data do we collect?

Personal Data may be collected from you when you participate our market research studies. If we collect Personal Data as part of the research engagement, we will obtain your consent for the processing of this Personal Data at the time that the research engagement takes place. These consents are aligned with our industry association Codes of Conduct and Legal/Ethical Guidelines for Market Research.

Some of the Personal Data we may collect could include your medical specialty and sub-specialty, associated hospital and practice name, or relevant medical conditions,). On rare occasions we may need to collect additional elements of Personal Data which would be specific to the research engagement and for which we would obtain your specific consent to allow for such collection.

We will not sell, share, transfer, or rent any Personal data to any third-parties in ways different from what is disclosed in this Privacy Notice and our Terms and Conditions. We shall not process Personal Data in a way that is incompatible with the purposes for which it has been collected or subsequently authorized by you. To that end, we will take reasonable steps to ensure that Personal Data is reliable for its intended use, accurate, complete, and current. We use reasonable efforts to maintain the accuracy and integrity of Personal Data and to update it as appropriate.

How will we use your Personal Data?

We use Personal Data that we collect directly from our research participants for the following business purposes, without limitation:

- (1) maintaining and supporting our services, delivering and providing the requested services including payment of honoraria to our research participants, and complying with our contractual obligations related thereto;
- (2) satisfying governmental reporting, tax, and other requirements;
- (3) storing and processing data, including Personal Data, in computer databases and servers located in the United Kingdom and Ireland;
- (4) verifying identity of our research participants;
- (5) as requested by our research participants;
- (6) for other business-related purposes permitted or required under applicable local law and regulation; and
- (7) as otherwise required by law.

Our legal basis for the processing of your Personal Data is consent.

For how long will we retain your Personal Data?

The Research Partnership has a responsibility to maintain records relating to our research activities, in accordance with legal obligations, client contractual terms and suggested

industry guidelines, and will retain your Personal Data according to the following retention guidelines:

Research (Survey) Data and associated research materials

This applies to all research (survey) data and associated research materials (screeners, questionnaires, audio-video files, adverse event reports, etc.). We will retain this data for a period of ten (10) years or per the guidelines dictated by our client contractual terms if different from our internal retention guidelines, after which time disposal will be completed in a secure manner. The retention period for the specific research engagement in which you participate will be shared as part of the consent process.

To whom will we disclose your Personal Data?

We do not share your Personal Data with third-parties other than transcription providers and the research sponsor's pharmacovigilance department or in the rare occasions mentioned earlier for which we would obtain your specific consent.

We may provide Personal Data to such third-parties for the following purposes, without limitation: translation and transcription of market research interviews and Adverse Event reporting.

We may also disclose Personal Data under the following circumstances:

1. Responding to witness summons, court orders, or legal process, or to establish or exercise our legal rights or defend against legal claims;
2. When we believe it is necessary to share information to investigate or prevent fraud, or to take action regarding illegal activities, situations involving potential threats to the physical safety of any person, or as otherwise required by law;
3. In rare situations, it may be necessary to disclose Personal Data in response to lawful requests by public authorities, including to meet national security or law enforcement requirements.

We are potentially liable in cases of onward transfers of Personal Data to third-parties, such as when third-parties that act as agents on our behalf process Personal Data in a manner inconsistent with the data protection principles. We will ensure that any third-party to which we disclose personal information provides the same level of privacy protection as is required by the applicable data protection principles and agrees in writing to provide an adequate level of privacy protection. Except as otherwise provided herein, we disclose Personal Data only to third-parties who reasonably need to know such data. Such recipients must agree to abide by confidentiality obligations that adequately comply with our compliance requirements.

We recognize that you have the right to limit the use and disclosure of your Personal Data, and we are committed to respecting those rights. We offer individuals the opportunity to opt out of disclosures of Personal Data to a third-party or the use of Personal Data for a purpose that is materially different from the purpose(s) for which it was originally collected or subsequently authorized by you. We will comply with the applicable data protection principles with respect to disclosures of Sensitive Data including, when applicable, obtaining the explicit consent (i.e., opt in consent) of an individual prior to disclosing Sensitive Data to

a third-party or using Sensitive Data for purposes other than those for which it was originally collected or subsequently authorized by the individual.

How do we protect your Personal Data?

We have implemented physical and technical safeguards to protect Personal Data from loss, misuse, and unauthorized access, disclosure, alternation, or destruction.

For example, electronically stored Personal Data is stored on a secure network with firewall protection, and access to our electronic information systems requires user authentication via password or similar means. We also employ access restrictions, limiting the scope of staff members who have access to your Personal Data. Further, we use secure encryption technology such as SSL or a comparable standard to protect certain categories of Personal Data.

To the extent that we keep physical records containing your Personal Data, we limit access to such Personal Data to staff members whom we reasonably believe need that information to provide our services to you.

Despite these precautions, no data security safeguards guarantee 100% security all the time.

We have designated the Compliance Department to oversee our information security programme. The Compliance Department shall review and approve any material changes to this programme as necessary. Any questions, concerns, or comments regarding this Notice also may be directed to privacy@researchpartnership.com. We will maintain, monitor, test, and upgrade information security policies, practices, and systems to assist in protecting the Personal Data that we collect.

Our personnel will receive training, as applicable, to effectively implement this Privacy Notice.

How can you access and update your Personal Data?

Access:

You have the right to obtain confirmation about whether Personal Data is included about you in our databases. Upon request, we will provide an individual access to your Personal Data within thirty (30) days of receipt of such request. We will permit an individual to know what Personal Data about him/her is included in our databases and to ensure that such Personal Data is accurate and relevant for the purposes for which we collected the Personal Data.

You may review your Personal Data stored in the databases and correct, update, modify, or delete any data that is incorrect or incomplete.

Your right to access your Personal Data may be restricted in exceptional circumstances, including, but not limited to:

- when the burden or expense of providing this access would be disproportionate to the risks to your privacy in the case in question; or

- where the rights of persons other than you would be violated by the provision of such access.

If we determine that your access should be restricted in a particular instance, we will provide you with an explanation of our determination and respond to any enquiries you may have.

We will track each of the following and will provide notice to the appropriate parties under law and contract when either of the following circumstances arise:

(a) legally binding request for disclosure of the Personal Data by a law enforcement authority unless prohibited by law or regulation; or

(b) requests received from you.

Rectification and Erasure

You may request that we rectify or delete any of your Personal Data that is incomplete, incorrect, unnecessary or outdated. In making modifications to your Personal Data, you must provide only truthful, complete, and accurate information.

Objection

You may object, at any time, to your Personal Data being processed for a specific purpose.

Restriction of Processing

You may restrict processing of your Personal Data for certain reasons, such as, for example if you consider your Personal Data collected by us to be inaccurate or you have objected to the processing and the existence of legitimate grounds for processing is still under consideration.

Data Portability

You may request the Personal Data you provided to us in a commonly used and machine-readable form.

Right to Withdraw Consent

You have the right to withdraw your consent at any time, without affecting the lawfulness of our processing based on such consent before it was withdrawn, including processing related to existing contracts for our Services.

To exercise any of the abovementioned rights, please contact us by phone, postal mail or email at the How to contact us section of this Privacy Notice.

We recommend that you include documents that prove your identity and a clear and precise description of your request. Please note that in some cases, especially if you wish us to delete or cease the processing of your Personal Data, we may no longer be able to provide our Services to you.

The Research Partnership is committed to ensuring privacy in all markets we work in and would therefore like to add the new California Consumer Privacy Act (CCPA) effective January 1st 2020 to our Privacy Notice to provide our users who reside in the state of California how we collect, store and use their data.

The CCPA grants the respondents' rights as listed below which are not dissimilar to those of the EU GDPR covered already in the Research Partnership's Privacy notice such as the ability to

- Request information
- Have personal information deleted
- Opt out of the sale of their personal information
- Be informed that personal data is being disclosed or sold

While our Privacy notice already cover the first two (requesting information or having data erased), as a market research agency we do not participate in selling personal data and will seek consent in the cases where your personal data is disclosed to the end client usually in the form of reporting adverse events.

Changes to this Notice

This Privacy Notice may be amended from time to time, consistent with applicable data protection and privacy laws and principles. We will notify you if we make changes that materially affect the way we handle Personal Data previously collected, and we will allow you to choose whether your Personal Data may be used in any materially different manner.

How to contact us

If you have any questions or complaints about this Privacy Notice or our data collection practices, please contact us at the details listed below and specify your country of residence and the nature of your question.

Compliance Manager
The Research Partnership Ltd
Chester House
81-83 Fulham High Street
London SW6 3JW
United Kingdom
Email: privacy@researchpartnership.com
Phone: +44 (0)20 8069 5000


If you consider our processing activities of your Personal Data to be inconsistent with the applicable data protection laws, you may lodge a complaint with your local supervisory authority responsible for data protection matters.

Study No: **3938**

Client's Internal PM number: **SG43215**

Study Name: **SMA Patient and Caregiver project**

Date: **March 2021**



[Patient] Screenener & QNR

Research Partnership Ltd.

Chester House
81-83 Fulham High Street
London, SW6 3JW
United Kingdom
Tel: + 44 (0) 208 069 5000

SAMPLE AND QUOTAS USED IN CONJUNCTION WITH CAREGIVER (REFERRED AS CG LATER) QNR, NATURAL FALL OUT, BUT THE BELOW QUOTAS TO BE USED AS A GUIDANCE:

	Patients	Caregiver (CG)	Total
Argentina	25-30	25-30	50-60
Brazil	30-40	30-40	60-80
Mexico	25-30	25-30	50-60
Chile	5-10	5-10	10-20
	The below are minimum quotas		
Costa Rica	2-3	2-3	4-6
Dominican Republic	2-3	2-3	4-6
Peru	2-3	2-3	4-6
Panama	2-3	2-3	4-6
Uruguay	2-3	2-3	4-6
Bolivia	2-3	2-3	4-6
Paraguay	2-3	2-3	4-6
Total			230-250

SOFT QUOTAS TO BE APPLIED:

SMA PATIENT TYPE II	SMA PATIENT TYPE III	CG OF SMA PATIENT TYPE I	CG OF SMA PATIENT TYPE II	CG OF SMA PATIENT TYPE III
PATIENT QNR: S4 CODE 2	PATIENT QNR: S4 CODE 3	CG QNR: S4 CODE 1	CG QNR: S4 CODE 2	CG QNR: S4 CODE 3

TREATMENT EXPERIENCED [IN ALL MARKETS EXCEPT URUGUAY] PATIENT/CG QNR: S5 CODE 1-2 [URUGUAY ONLY] PATIENT/CG QNR: S5 CODE 1-3	TREATMENT NAÏVE PATIENT/CG QNR: S5 CODE 4 OR 99
---	--

PLEASE CREATE QUOTA GROUPS.

QUOTA NAME	Programming instruction
EXPERIENCED SMA PT TYPE II	[IN ALL MARKETS EXCEPT URUGUAY] PATIENT QNR: IF CODE 2 S4 AND CODE 1 OR 2 AT S5 [URUGUAY ONLY] PATIENT QNR: IF CODE 2 S4 AND CODE 1, 2 OR 3 AT S5
NAÏVE SMA PT TYPE II	PATIENT QNR: IF CODE 2 S4 AND CODE 4 OR 99 AT S5
EXPERIENCED SMA PT TYPE III	[IN ALL MARKETS EXCEPT URUGUAY] PATIENT QNR: IF CODE 3 S4 AND CODE 1 OR 2 AT S5 [URUGUAY ONLY] PATIENT QNR: IF CODE 3 S4 AND CODE 1, 2 OR 3 AT S5

NAÏVE SMA PT TYPE III	PATIENT QNR: IF CODE 3 S4 AND CODE 4 OR 99 AT S5
CG OF EXPERIENCED SMA PT TYPE I	[IN ALL MARKETS EXCEPT URUGUAY] CG QNR: IF CODE 1 S4 AND CODE 1 OR 2 AT S5 [URUGUAY ONLY] CG QNR: IF CODE 1 S4 AND CODE 1, 2 OR 3 AT S5
CG OF NAÏVE SMA PT TYPE I	CG QNR: IF CODE 1 S4 AND CODE 4 OR 99 AT S5
CG EXPERIENCED SMA PT TYPE II	[IN ALL MARKETS EXCEPT URUGUAY] CG QNR: IF CODE 2 S4 AND CODE 1 OR 2 AT S5 [URUGUAY ONLY] CG QNR: IF CODE 2 S4 AND CODE 1, 2 OR 3 AT S5
CG NAÏVE SMA PT TYPE II	CG QNR: IF CODE 2 S4 AND CODE 4 OR 99 AT S5
CG EXPERIENCED SMA PT TYPE III	[IN ALL MARKETS EXCEPT URUGUAY] CG QNR: IF CODE 3 S4 AND CODE 1 OR 2 AT S5 [URUGUAY ONLY] CG QNR: IF CODE 3 S4 AND CODE 1, 2 OR 3 AT S5
CG NAÏVE SMA PT TYPE III	CG QNR: IF CODES 3 S4 AND CODE 4 OR 99 AT S5

BLUE = PROGRAMMING NOTES

RED = TERMINATION

GREY BAR = NEW SCREEN

ORANGE = AE NOTES / AE REPORTABLE

Introduction

You are invited to take part in a market research study as part of a scientific project (hereinafter “research”). To allow you to make an informed decision as to whether or not you want to take part in this research, this document describes the purpose of the research and the data that will be collected in the research. Taking part in this research is your choice.

Please take your time to read the following information carefully. If you have any questions, you may ask the fieldwork agency carrying out the research {Estudio Silva Roca}, for more explanation.

Why are you invited to participate?

You were selected as a possible participant in this research because you have been identified as a person who:

- Is an adult who has a medical diagnosis of spinal muscular atrophy (SMA) type II or III or a caregiver of children with SMA type I, II or III
- We will need all participants to have internet connection in order to complete the survey

What is the purpose of this research?

The purpose of the market research is to understand your views regarding the importance of different aspects of treatments for SMA, and to explore the trade-offs that you as a person with SMA or parent/caregiver of a child with SMA would consider making. Through your participation

you can ensure your voice gets heard and help us build an understanding of what type of treatments are preferred and valued by yourself.

Who is financing and conducting this research?

This research is being financed by an international pharmaceutical company. This research is conducted by Estudio Silva Roca on behalf of Research Partnership, a global, independent research consultancy. The research will comply with all data protection policies and adhere to market research and industry codes of conduct (incl. ABPI, BHBIA, EphMRA and MRS).

Who has approved this research?

This research has been reviewed and approved by {Name of IRB/EC}, an organization that is responsible for protecting the rights, safety, and well-being of patients who take part in research activities.

How many people will take part in the research?

Approximately 230-250 patients and caregivers will take part in this research. Consisting of a mix of adult patients with SMA type II and III and caregivers of patients with SMA type I, II and III across 11 markets in Latin America: Argentina, Bolivia, Brazil, Chile, Costa Rica, Dominican Republic, Mexico, Panama, Paraguay, Peru, Uruguay.

What are my obligations if I take part in this research?

If you decide to take part in this research, you will be requested to do the following:

- To complete an online survey of approximately 30 minutes, to the best of your abilities
- You will be able to access the survey by computer (desktop/laptop), tablet and smartphone devices
- Please do not complete the survey more than once

What will happen if I take part in this research?

If you agree to participate in the research, it is necessary that you agree to this Informed Consent Form by ticking the box at the bottom of the screen.

Only then you will be able to access the questionnaire and your answers will be collected and analyzed as part of this research.

Participation is voluntary, and if you wish, you can withdraw at any time. Your participation would remain confidential and only anonymised data would be used for analysis and in reports. The anonymised study results will be used to help healthcare decision-makers understand how adults and caregivers of children with SMA value different aspects of SMA treatments. We also anticipate that the study results will be presented at academic conferences and published in peer-reviewed medical journals.

The following information will be collected during the research:

- Understanding SMA diagnosis, key symptoms and management
- What treatment are you aware of or have experience with
- What treatment aspects would you consider as an ideal treatment and your likelihood to use
- Disease burden and impact of SMA on quality of life (QoL)
- Some demographic information

- [SHOW TO CAREGIVERS ONLY Impact of SMA on caregiver's life/health]

Are there benefits to taking part in the research?

There is no direct medical benefit to you from being in this research. The information gained from this research may help researchers and doctors to learn more about SMA in general. You and other patients/caregivers with/for SMA or a similar condition may benefit from results of such research in the future.

Will I be paid for taking part in this research?

You will not be paid for your participation in this research. You will not receive reimbursement for any expenses during your participation in this research. All research will be conducted in accordance with the UK Data Protection Act 2018 General Data Protection Regulation (GDPR), with the British Healthcare Business Intelligence Association's Legal & Ethical Guidelines and European Pharmaceutical Market Research Association (EphMRA) code of conduct. This is in addition to the codes of conduct as set out by the Market research Society (MRS) and Insights Association and, therefore, all information will be treated confidentially and only used for the research purpose stated above.

Your research data will be labeled with a respondent identification number (ID) that is unique to you and not related to or derived from Information that identifies you (such as your name, or any other personally identifying information) will be used in the research. The international pharmaceutical company its affiliates, and its representatives will only have access to research data labeled with a respondent ID number, except as described below.

The international pharmaceutical company, its affiliates, and its collaborators and licensees (people and companies who partner with the international pharmaceutical company) may use research data labeled with your respondent ID number. Your research data may also be shared with independent researchers or government agencies, but only after personal information that can identify you has been removed. Your research data may be combined with other people's data and/or linked to other data collected from you. Your research data may be used to help better understand why people get diseases and how to best prevent, diagnose, and treat diseases, and to develop and provide access to new medicines, medical devices, and healthcare solutions.

The results of from this research will be published in a medical journal/ paper or presented at a scientific meeting,

Information from this research will be retained by Research Partnership for 5 years after the end of the research or for the length of time required by applicable laws, whichever is longer. In addition, the international pharmaceutical company will retain the research data for 10 years after the final research results have been reported or for the length of time required by applicable laws, whichever is longer.

How will my Information be used and shared?

If you agree to this consent form, you give permission to Research Partnership to use and/or share your Information in an anonymized way, which includes research data. Your research data may be used or shared for the purposes of this research. You do not have to agree to this consent form, but if you do not, you may not take part in this research.

Your research data may be used by and/or shared with the international pharmaceutical company, its affiliates, its representatives, collaborators, and licensees, the Institutional Review

Board or Ethics Committee, and regulatory authorities. Your research data may be analyzed in any country worldwide.

You may change your mind and take back your consent at any time without penalty or loss of any benefits to which you are otherwise entitled. If you take back your consent, you will not be able to continue to take part in the research and no new information will be collected about you. However, to comply with regulatory requirements to protect the scientific integrity of the research, the international pharmaceutical company will still be able to use and share any research data about you that have already been collected during this research.

For more information about how we use your information, and what your rights are, please see our privacy notice, which is available at <https://www.researchpartnership.com/who-we-are/ad-hoc-respondent-privacy-notice>

RESEARCH RESULTS

A research report containing the results of this research will generally be made available to anyone who requests a copy. Before this report is provided, additional steps will be taken to protect your information from being linked to you.

If the results of the research are published, your identity will remain confidential.

Adverse Events informed consent

We are required to pass on to the sponsoring client any details of side effects or product complaints relating to their products that are mentioned during the interview. This is to help them learn more about the safety of their medicines. If this happens, we will need to collect details and report the side effects or product complaint. You will be asked if you give permission for us to pass your contact details to the company's drug safety department for them to follow up. This will have no impact on the confidentiality and anonymity associated with the interview itself.

Are you willing to participate with this survey on this basis?

	Label	PN
1	Yes	CONTINUE
2	No	CLOSE

If "yes" CODE 1 ABOVE, PLEASE NOTE THE INSTRUCTION.

	Label	PN
1	Willing to be contacted by the client safety team for more information about the AE	CONTINUE
2	Unwilling to be contacted by the client safety team but still willing to participate	CONTINUE

Signature

Please read each point carefully and click at the bottom of the page to proceed

- I have received information about the study and had sufficient time to read through it. I have read it, I understand the information and have had my questions answered.
- I voluntarily give my consent to take part in the study as described. I know I can stop completing the survey at any time.
- I authorise Research Partnership to use and disclose the information as described above in this Informed Consent Form. I agree to the recording of the data I provide in the survey and understand that the researchers will not be able remove data once the survey is completed because no personal identifiable information will be recorded.
- I also agree that my data can be passed on in an anonymous form to authorised specialists to be used for data processing and scientific analysis.
- I also give my consent to the scientific publication of the research results while adhering to data protection legislation such as the UK Data Protection Act 2018. The publication will look at patient and caregiver preferences of SMA treatment features depending on the patient's disease status. The data in the publication will be on an aggregated level only and all responses will remain anonymised.

I understand that a copy of this form will be sent to me in an email after I have agreed to it.

Are you happy to take part in this study?

Please tick the relevant box

	Label	PN
1	I wish to take part in this study	CONTINUE
2	I DO NOT wish to take part in this study	CLOSE

If you wish, you can print or save a copy of this consent text to keep for your records, however we will also email it to you.

SCREENER

HIDDEN AUTOMATED QUESTION, SINGLE CHOICE

S0. Country of residence

	Label	PN
1	Argentina	
2	Brazil	
3	Mexico	
4	Chile	
5	Costa Rica	
6	Dominican Republic	
7	Peru	
8	Panama	
9	Uruguay	
10	Bolivia	
11	Paraguay	

ASK IN ARGENTINA, SINGLE CHOICE

S0B. From the list below, please select the initials of your first and last name.

--	--

SHOW DROPDOWN LIST WITH ALPHABETICAL LETTERS BETWEEN A-Z

ASK ALL, SINGLE CHOICE

We need to ask you some questions to ensure the survey is appropriate for you.

S1. Have you been diagnosed with spinal muscular atrophy (SMA)?

	Label	PN
1	Yes, I have been diagnosed with spinal muscular atrophy (SMA)	
2	No, I have not been diagnosed with spinal muscular atrophy (SMA)	[CLOSE]
99	Prefer not to say	[CLOSE]

ASK ALL, NUMERIC

S2. What is your current age?

1			years
---	--	--	-------

CLOSE IF <18 YEARS OF AGE
SHOW DROPDOWN LIST WITH NUMBERS BETWEEN 10-99

ASK ALL, SINGLE CHOICE

S3. How old were you when you **first had symptoms** associated with SMA?

	Label	PN
1	Between 0-6 months of age	
2	Between 7-18 months of age	
3	Between 18 months and 17 years of age	
4	At age 18 or later	

ASK ALL, SINGLE CHOICE

S4. Please **select the type of SMA** you have been diagnosed with.

1	SMA Type 1 (severe, young babies): onset typically between 0-6 months of age; unable to ever sit without support	[CLOSE]
2	SMA Type 2 (intermediate, older babies and toddlers): onset typically between 7-18 months of age may be able to sit up without help, but not stand or walk	
3	SMA Type 3 (mild, children and young adults): onset typically between 18 months and 17 years of age; able to stand and walk without help, although may find walking or getting up from a sitting position difficult and may find walking gets gradually harder over time	
4	SMA Type 4 (adults): onset typically at age 18 or later	[CLOSE]
99	I don't know the type of SMA I have	

IF CODE 1 OR CODE 4 SELECTED AT S4 AND CODE 2 OR 3 SELECTED AT S3 SHOW THE FOLLOWING ERROR MESSAGE: You have stated earlier that you first had symptoms associated with SMA [INSERT ANSWER FROM S3], but your answer [INSERT BOLDDED ANSWER FROM S4] contradicts that. Please review your answer and amend if needed, otherwise click on the 'Next' button!

ASK ALL, MULTIPLE CHOICE; ROTATE

S5. Have you ever received or currently receive any of the following treatments (including in clinical trials), specifically for your SMA?

Please select all that apply

	Label	PN
1	Spinraza (nusinersen)	
2	Zolgensma (onasemnogene abeparvovec-xioi)	
3	Evrysdi (risdiplam)	[CLOSE IN ALL MARKETS]

		EXCEPT URUGUAY]
4	Surgery	
99	None of the above	ANCHOR

[IN ALL MARKETS EXCEPT URUGUAY] HVAR1: CODES 1-2 = TREATMENT EXPERIENCED; CODE 4, 99 = TREATMENT NAÏVE
[URUGUAY ONLY] HVAR1: CODES 1-3 = TREATMENT EXPERIENCED; CODE 4, 99 = TREATMENT NAÏVE

ASK ALL, MULTIPLE CHOICE, ROTATE

S6. Are you, or anyone else in your household, primarily employed by any of the following?

Please select all that apply

Code number	Code label
1	Healthcare system (you are a physician, physician assistant, nurse practitioner, etc.)
2	A pharmaceutical, biotechnology or medical device company
3	A market research firm
4	An advertising or public relations company
99	None of the above [ANCHOR; EXCLUSIVE]

[BASE: ALL WHO SCREENED OUT]

Unfortunately, YOUR ANSWERS have shown that you are not eligible to participate in this research at this time and the survey will now close. Thank you for your interest in this research. We will re-contact you if any of the participation requirements change such that you may be eligible.

MAIN SURVEY

[BASE: ALL WHO SCREENED IN]

You have qualified for this survey, thank you for agreeing to take part.
In the next few minutes we would like to ask you about your views on different SMA (spinal Muscular Atrophy) treatments.

SECTION 1 –SMA HISTORY

ASK ALL, NUMERIC

Q1. We understand that you were [INSERT ANSWER FROM S3] when you first had symptoms associated with SMA. Exactly how old were you when you **first had symptoms** associated with SMA?

Please give an estimate if unsure

years months

SHOW DROPDOWN LIST FOR YEARS WITH NUMBERS BETWEEN 0-35
SHOW DROPDOWN LIST FOR MONTHS WITH NUMBERS BETWEEN 0-11

HVAR2: CALCULATE ANSWER INTO MONTHS
ERROR MESSAGE IF ANSWER ≠ AGE RANGE AT S3

ASK ALL, NUMERIC

Q2. How old were you when **first diagnosed** with SMA?

Please give an estimate if unsure

years months

HVAR3: CALCULATE ANSWER INTO MONTHS

ADD IN ERROR MESSAGE IF HVAR3<7 You stated earlier that you have [PULL ANSWER FROM S4] with an onset typically after 6 months of age, please review your answer and amend if needed, otherwise click the 'Next' button.

ADD IN ERROR MESSAGE IF HVAR3>18 AND S3 IS CODE 2 You stated earlier that you have [PULL ANSWER FROM S4] with an onset typically before 18 months of age, please review your answer and amend if needed, otherwise click the 'Next' button.

ADD IN ERROR MESSAGE IF HVAR3 IS BETWEEN 7-216 (18YEARS) AND S4 IS CODE 3
You stated earlier that you have [PULL ANSWER FROM S4] with an onset typically between 7-18 months of age, please review your answer and amend if needed, otherwise click the 'Next' button.

HVAR4: CALCULATION ON TIME SINCE DIAGNOSIS IN MONTHS: Q2-HVAR3 MINUS Q1-HVAR2

ERROR MESSAGE IF NUMERIC ANSWER LOWER THAN Q1

SHOW DROPDOWN LIST FOR YEARS WITH NUMBERS BETWEEN 0-35
SHOW DROPDOWN LIST FOR MONTHS WITH NUMBERS BETWEEN 0-11

ASK ALL, SINGLE CHOICE

Q14. Are you able to walk without using a cane/crutch or other forms of assistance for more than ten steps?

	Label
1	Yes
2	No

ASK ALL, SINGLE CHOICE

Q3. Please think about your current level of **physical (motor) functioning or ability**. Please read the categories below and tick which one best describes you.

You might not find a description that reflects your condition exactly, but please mark the one category that describes your situation the closest.

	Label
1	Cannot sit
2	Can sit with some support (e.g. with back support or arm support)
3	Can sit independently for a few seconds
4	Can sit independently for a longer period of time but cannot stand
5	Can sit independently and stand with assistance , but cannot walk
6	Can sit independently and stand and walk with assistance
7	Can sit, stand and walk independently for a few steps (less than 10 metres)

ASK ALL, SINGLE CHOICE

Q4. Now please think about your **breathing**. Please read the categories below and tick which one best describes you at present.

You might not find a description that reflects your condition exactly, but please mark the one category that describes your situation the closest.

	Label
1	Need mechanical support to breathe for more than sixteen hours of the day
2	Need mechanical support to breathe for some of the day
3	Can breathe without mechanical support

ASK ALL, MULTIPLE CHOICE, ROTATE

Q5A. Not including SMA, **what other conditions or illnesses**, if any, do you have which limit your daily activities?

Please select all that apply

	Label
--	-------

1	Anxiety
2	Cardiovascular disease
3	Chronic pain (e.g. back pain, headaches)
4	Depression
5	Diabetes
6	Digestive pain / discomfort
7	Hypertension (high blood pressure)
8	Sleep problems
9	Stress
98	Other [ANCHOR]
97	I do not have other conditions or illnesses [EXCLUSIVE; ANCHOR]
99	Prefer not to answer [EXCLUSIVE; ANCHOR]

ASK ALL, SCALE

Q5B.

People with SMA can experience fatigue, meaning it could interfere with your physical functioning, your level of energy or your motivation, or it can impact your work, family and social life.

On a 1 to 5 scale where 1 means 'I don't experience fatigue at all in my daily life' and 5 means 'I experience fatigue to a high level in my daily life', to what extent would you say you experience fatigue in your daily life?

1 = I don't experience fatigue at all in my daily life				5 = I experience fatigue to a high level in my daily life
1	2	3	4	5

ASK NAÏVE PATIENT ONLY CODE 4 OR 99 AT S5, SINGLE CHOICE

Q6. Have you been previously assessed for suitability for a pharmaceutical treatment for your SMA by a physician?

	Label	PN
1	Yes, I have been assessed	
2	No, I have not been assessed	
3	I was offered an assessment but have not done so	

ASK IF CODE 1 AT Q6, MULTIPLE CHOICE, ROTATE

Q7A. You stated that you have been assessed for suitability for a pharmaceutical treatment for your SMA. What are the reasons that you have not yet received any pharmaceutical treatment for your SMA?

Please select all that apply

	Label
1	High cost of the pharmaceutical treatment
2	Healthcare Coverage Plan does not reimburse the pharmaceutical treatment
3	Pharmaceutical treatment is not yet available
4	Pharmaceutical treatment is not accesible at my hospital
5	My doctor has not mentioned any specific pharmaceutical treatment
6	The doctor is not trained to provide pharmaceutical treatment
7	I am due to receive it in the next few weeks
8	Assessment occured before COVID-19 and standard care has not yet returned in my area
9	I need more information on the pharmaceutical treatment to make up my mind
10	I am concerned about side effects on top of the already debilitating disease
11	I am unable to go to the hospital
98	Other [ANCHOR]
99	Prefer not to answer [EXCLUSIVE; ANCHOR]

ASK IF CODE 3 AT Q6, MULTIPLE CHOICE, ROTATE

Q7B. You stated that you were offered an assessment for suitability for a pharmaceutical treatment for your SMA for your SMA, but have not yet done so. What are the reasons for not yet being assessed for an SMA treatment?

Please select all that apply

	Label
1	High cost of the pharmaceutical treatment
2	Healthcare Coverage Plan does not reimburse the pharmaceutical treatment
3	Pharmaceutical treatment is not yet available
4	Pharmaceutical treatment is not accesible at my hospital
5	I have not had time yet
6	No genetic testing available in my hospital/ area
7	I have scheduled an appointment / I am due to receive an assessment in the next few weeks
8	I am waiting - standard care has not yet returned in my area due to Covid-19
9	I need more information on the pharmaceutical treatment to make up my mind
10	I am concerned about side effects on top of the already debilitating disease
11	I am unable to go to the hospital
98	Other [ANCHOR]
99	Prefer not to answer [EXCLUSIVE; ANCHOR]

ASK ALL, SINGLE CHOICE PER TREATMENT; ROTATE TREATMENT

Q8. How would you rate **your level of knowledge** on the different types of treatments currently available for SMA on a 1 to 5 scale where 1 means 'No knowledge at all about this treatment' and 5 means 'I know a great deal about this treatment'?

	Label	1 = No knowledge at all about this treatment	2	3	4	5 = I know a great deal about this treatment	Don't know [EXCLUSIVE CODE AND IF CODE SELECTED AT S5 CANNOT BE A DON'T KNOW HERE]
1	Spinraza (nusinersen)						
2	Zolgensma (onasemnogene abeparvovec)						
3	Evrysdi (risdiplam)						

ASK ALL, MULTIPLE CHOICE; ROTATE

Q9. Which of the following tools/equipment do you currently use to support with your SMA?

Please select all that apply

	Label	PN
1	Breathing machine/mechanical ventilation	
2	Feeding tube	
3	Suction machine to help clear the throat	
4	Walking frame	
5	Wheelchair	
98	Other	[ANCHOR]
99	None	[EXCLUSIVE; ANCHOR]

SECTION 2 – TREATMENT CHOICE – DISCRETE CHOICE EXERCISE (DCE)

We want to understand how important different aspects of treatment are for people with SMA. To do this, we will present you with pairs of hypothetical treatments and we will ask you to choose which treatment you believe is best.

These treatments will be described in terms of their effectiveness in improving motor function (or preventing decline), how the treatment is taken (e.g. an injection or oral liquid), as well as possible side effects of the treatments.

The treatments are similar to current treatments but not exactly the same.

These hypothetical treatments do not reflect the treatments available from your physician, nor should you ask your doctor to make treatment decisions based on the hypothetical treatments as described in this survey.

First of all, we want to describe the different features of the treatments. Please take a look at each screen:

NEW SCREEN. FORCE AT LEAST 10 SECONDS ON THIS SCREEN

Treatment effectiveness

Motor function

Treatments can vary in terms of their average effectiveness in improving motor function of people with SMA. A simplified scale of motor function is shown below:

	Label
1	Cannot sit
2	Can sit with some support (e.g. with back support or arm support)
3	Can sit independently for a few seconds
4	Can sit independently for a longer period of time but cannot stand
5	Can sit independently and stand with assistance , but cannot walk
6	Can sit independently and stand and walk with assistance
7	Can sit, stand and walk independently for a few steps (less than 10 metres)
8	Can sit, stand and walk independently over longer distances (more than 10 metres)

We will describe the effectiveness of the hypothetical treatment – on average – in terms of worse, stable, or better motor function.

1	Worse	After 12 months, motor function will have deteriorated by one level on the motor function scale
2	Stable	After 12 months, motor function will remain on the current level of function
3	Better	After 12 months, motor function will have improved by one level on the motor function scale

Breathing

Treatments can vary in terms of their average effectiveness in improving breathing ability among SMA patients.

We will describe the effectiveness of the hypothetical treatment – on average – in terms of worse, stable, or better breathing function.

1	Worse	After 12 months, breathing function will get worse
2	Stable	After 12 months, breathing function will stay the same
3	Better	After 12 months, breathing function will get better

NEW SCREEN. FORCE AT LEAST 10 SECONDS ON THIS SCREEN

Administering the Treatment

Treatments can vary in terms of whether they are administered by injection or orally. The different hypothetical treatments you will see will be administered using the following methods:

1	Intrathecal (IT) <i>Injection into the spine at the lower back</i>	Injection into the spine at the lower back - Administered by injection in the lower back using a needle inserted into the space around the spinal cord, also known as a lumbar puncture. When you first start the treatment you will receive it every two weeks, then a month apart. After that you would need to return to hospital every four months for an injection
2	Oral	An oral liquid to be taken once daily at home. It can also be administered via a gastric tube at home after you have received some training
3	Intravenous (IV)	Treatment will be taken intravenously (IV): a one-time only 60 minute long infusion in the vein and taking oral corticosteroids starting 1 day before the IV and continuing for a minimum of 1 month up until liver functions are unremarkable

NEW SCREEN. FORCE AT LEAST 10 SECONDS ON THIS SCREEN

Reactions to the treatment

People can experience a reaction to their treatment immediately after taking it or can develop side effects at a later stage. These reactions may vary in severity (mild, moderate, severe). Treatments could also cause reactions, lasting between less than 24 hours and 3-4 days:

1	No fever, headache, vomiting and/or body pain due to treatment
2	Fever, headache, vomiting and/or body pain for 1-2 days every four months
3	Fever, headache, vomiting and/or body pain for 3-4 days every four months

NEW SCREEN. FORCE AT LEAST 10 SECONDS ON THIS SCREEN

Activities of daily living

SMA can affect daily activities in a number of ways. Treatments can vary in terms of their average effectiveness in improving simple activities such as eating, reaching for an object or using the bathroom. We will describe the effectiveness of the hypothetical treatment – on average – in terms of more difficult, stable or easier management of daily activities.

1	After 12 months, carrying out daily activities will become more difficult.
2	After 12 months, carrying out daily activities will remain the same.
3	After 12 months, carrying out daily activities will become easier.

NEW SCREEN. FORCE AT LEAST 10 SECONDS ON THIS SCREEN

Fatigue

People with SMA can experience fatigue meaning it could interfere with physical functioning, level of energy or motivation, or impact work, family and social life. Treatments can vary in terms of their average effectiveness in improving fatigue. We will describe the effectiveness of the hypothetical treatment – on average – in terms of worse, stable or reduced fatigue.

1	After 12 months, fatigue will get worse.
2	After 12 months, fatigue will stay the same.
3	After 12 months, fatigue will reduce/ improve.

NEW SCREEN

CHOOSING A TREATMENT

On the following series of screens you will be presented with a series of **hypothetical** treatment choices with two options, Treatment 'A' or Treatment 'B'. We would like you to read each scenario carefully and think about which treatment you would prefer: A or B. (None of these match actual treatments). There are a whole series of choice questions to complete. There are no right or wrong answers; it is up to you to decide which you would prefer.

Please take a moment to have another look at the motor function scale before continuing with the choice questions:

MOTOR FUNCTION SCALE

	Label
1	Cannot sit
2	Can sit with some support (e.g. with back support or arm support)
3	Can sit independently for a few seconds
4	Can sit independently for a longer period of time but cannot stand
5	Can sit independently and stand with assistance , but cannot walk
6	Can sit independently and stand and walk with assistance
7	Can sit, stand and walk independently for a few steps (less than 10 metres)
8	Can sit, stand and walk independently over longer distances (more than 10 metres)

NEW SCREEN, ASK ALL, SINGLE CHOICE PER SCREEN

Sample Choice Set (14 choice sets to be presented per participant)

You will now be shown multiple screens, each screen will include two different hypothetical SMA treatments.

The two **treatments will be different each time you see them**, so please take your time in reviewing the information and in making your selections.

These descriptions shown, contain assumptions and should be treated as hypothetical for market research purposes only; it is not intended to be promotional.

The information is for market research purposes only and these products may or may not become available in the future.

Please imagine that you are asked to choose a treatment for yourself.

Q10. For each choice below please indicate whether you prefer treatment A or B.

SEE DISCRETE CHOICE EXERCISE GRID IN APPENDIX

NEW SCREEN, SINGLE CHOICE PER SCREEN. ASK FOR EACH CHOICE SET AT Q10

Q11. Would you use this treatment to treat your SMA?

	Label
1	Yes
2	No

NEW SCREEN, TO BE SHOWN ONCE AFTER THE Q10-Q11 LOOP FOR DCE IS COMPLETED, ASK ALL, SINGLE CHOICE

SECTION 3 – SMA IMPACT ON QUALITY OF LIFE (EQ-5D-5L)

We would now like to understand a bit more about your overall health.

THIS SECTION NOT TO BE TRANSLATED. WE ARE USING OFFICIAL TRANSLATIONS. PLEASE USE PROVIDED LAYOUT FOR PROGRAMMING

ASK ALL, SINGLE CHOICE PER GROUP

QE1. Under each heading, please tick the ONE box that best describes your health TODAY.

	Label	
A1	Mobility	I have no problems walking
A2		I have slight problems walking
A3		I have moderate problems walking
A4		I have severe problems walking
A5		I am unable to walk
B1	Self-Care	I have no problems washing or dressing myself
B2		I have slight problems washing or dressing myself
B3		I have moderate problems washing or dressing myself
B4		I have severe problems washing or dressing myself
B5		I am unable to wash or dress myself

C1	Usual Activities (e.g. work, study, housework, family or leisure activities)	I have no problems doing my usual activities
C2		I have slight problems doing my usual activities
C3		I have moderate problems doing my usual activities
C4		I have severe problems doing my usual activities
C5		I am unable to do my usual activities
D1	Pain / Discomfort	I have no pain or discomfort
D2		I have slight pain or discomfort
D3		I have moderate pain or discomfort
D4		I have severe pain or discomfort
D5		I have extreme pain or discomfort
E1	Anxiety / Depression	I am not anxious or depressed
E2		I am slightly anxious or depressed
E3		I am moderately anxious or depressed
E4		I am severely anxious or depressed
E5		I am extremely anxious or depressed

ASK ALL, SLIDING SCALE

QE2. We would like to know how good or bad your health is TODAY.

- This scale is numbered from 0 to 100.
- **100** means the **best health you can imagine**.
- **0** means the **worst health you can imagine**.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

0 = worst health you can imagine											100 = best health you can imagine
0	10	20	30	40	50	60	70	80	90	100	

1	YOUR HEALTH TODAY		
----------	-------------------	--	--

SECTION 4 – COVID IMPACT

ASK ALL, MULTIPLE CHOICE; ROTATE

QC1. During the time of the COVID-19 pandemic, what aspects of your SMA and its management have been / are impacted?

	Label
1	My treatment plan has changed
2	Due to restrictions I am unable to visit my physicians
3	Due to restrictions I am unable to visit my pharmacy

4	My surgery has been postponed
5	My treatment (not surgery) has been postponed
6	It affected my mental health
7	Caretaker not being able to provide regular support
98	Other [ANCHOR]
99	None [ANCHOR; EXCLUSIVE]

ASK ALL, SINGLE CHOICE

QC2. On a 1 to 5 scale where 1 means 'Has not impacted at all' and 5 means 'Impacted a great deal', to what extent has the COVID-19 pandemic impacted your access to healthcare in relation to your SMA?

1 = Has not impacted at all				5 = Impacted a great deal
1	2	3	4	5

ASK ALL, SINGLE CHOICE

QC3. On a 1 to 5 scale where 1 means 'Not at all' and 5 means 'Extremely', to what extent has the COVID-19 pandemic made you more concerned / worried about attending hospital for any type of appointments?

1 = Not at all				5 = Extremely
1	2	3	4	5

ASK ALL, SINGLE CHOICE; ROTATE 1-3

Q12. Thinking about a time when there would not be any restrictions in place due to the pandemic, if you were given an **oral** SMA treatment, how would you prefer this treatment to be delivered to you?

	Label
1	Home delivery
2	Collect from local pharmacy
3	Collect from hospital

ASK ALL, SCALE; ROTATE 1-3; SINGLE CHOICE PER ROW

Q13. Now, considering restrictions are in place due to the COVID-19 pandemic, please tell us your preference for each delivery method for an **oral** SMA treatment on a 1 to 5 scale where 1 means 'I don't prefer this delivery method at all' and 5 means 'I highly prefer this delivery method'

		1 = I don't prefer this delivery method at all				5 = I highly prefer this delivery method
		1	2	3	4	5
1	Home delivery					

2	Collect from local pharmacy					
3	Collect from hospital					

SECTION 5 – DEMOGRAPHICS

Finally we would like to ask a few questions about yourself.

ASK ALL, SINGLE CHOICE

QD1. Are you...

	Label
1	Male
2	Female
98	Other
99	Prefer not to say

ASK ALL, SINGLE CHOICE

QD2. How would you best describe your current healthcare coverage / insurance plan?

	Label
1	Publically insured [DO NOT SHOW IN BRAZIL]
2	Social security
3	Privately insured
4	Mix of public and private insurance
99	Prefer not to answer

ASK ALL, SINGLE CHOICE

QD8. How would you describe your main daily activity?

	Label
1	Paid employment – full time
2	Paid employment – part time
3	Looking after family and/or home and not in paid employment
3	Retired
4	Seeking work, unemployed
5	Not working because of health problems
6	In education or training
98	Other
99	Prefer not to answer

ASK ALL, SINGLE CHOICE

QD9. Which of the following statements would best describe your current financial circumstances?

	Label
1	The family income is sufficient to cover our daily living expenses and we <u>can</u> also save some extra money every month
2	The family income is sufficient to cover our daily living expenses, but we <u>cannot</u> save extra money every month
3	The family income is <u>not</u> sufficient to cover our daily living expenses
99	Prefer not to answer

ASK ALL, SINGLE CHOICE

QD11. What is the highest level of education you have completed?

	Label
1	Incomplete elementary school
2	Completed elementary school
3	Incomplete high school
4	Completed high school
5	Incomplete college or graduate education
6	Completed college or graduate education
98	Other
99	Prefer not to answer

ASK ALL, SINGLE CHOICE

QD13. What region do you live in?

SEE LIST OF REGIONS IN APPENDIX

ASK ALL, SINGLE CHOICE

QD14 How would you best describe the area you live in?

	Label
1	Urban (city)
2	Semi-urban (town)
3	Rural
99	Prefer not to answer

[BASE; ALL SELECTING CODE 2 OR 3 AT QD15]

QD15. Approximately how far away is the nearest city from you?

	Label
1	Within 20km
2	21-50km

3	51-99km
4	More than 100km

[\[SHOW ALL\]](#)

For your information the international pharmaceutical company sponsoring this market research study is Roche.

Upon knowing the sponsoring company, are you happy to submit your data?

A research report containing the results of this research will generally be made available to anyone who requests a copy. Before this report is provided, additional steps will be taken to protect your information from being linked to you and if the results of the research are published, your identity will remain confidential.

	Label	PN
1	Yes, I am happy to submit my data to this research	USUAL PROCEDURE, PLEASE STORE THE DATA
2	No, I would like to withdraw my participation from this research	MAKE SURE DATA FOR THIS RESPONDENT IS REMOVED

[\[SHOW ALL\]](#)

Thank you for your time. It is very much appreciated. We look forward to welcoming you again to one of our studies.

This is the end of the survey.

APPENDIX

DISCRETE CHOICE EXERCISE GRID

ATTRIBUTES	LEVEL1	LEVEL2	LEVEL3
Motor Function	Worse - After 12 months, motor function will have deteriorated by one level on the motor function scale	Stable - After 12 months, motor function will remain on the current level of function	Better - After 12 months, motor function will have improved by one level on the motor function scale
Breathing	Worse - After 12 months, breathing function will get worse	Stable - After 12 months, breathing function will stay the same	Better - After 12 months, breathing function will get better
Administering the treatment	Intrathecal - Injection into the spine at the lower back - Administered by injection in the lower back using a needle inserted into the space around the spinal cord, also known as a lumbar puncture. When you will first start the treatment you will receive it every two weeks, then a month apart. After you would need to return to hospital every four months for an injection	Oral - An oral liquid to be taken once daily at home. It can also be administered via a gastric tube at home after you have received some training.	Intravenous – Treatment will be taken intravenously (IV): a one-time only 60 minute long infusion in the vein and taking oral corticosteroids starting 1 day before the IV and continuing for a minimum of 1 month up until liver functions are unremarkable
Reactions caused by treatment	No fever, headache, vomiting and/or body pain due to treatment	Fever, headache, vomiting and/or body pain for 1-2 days every four months	Fever, headache, vomiting and/or body pain for 3-4 days every four months
Activities of daily living	After 12 months, carrying out daily activities will become more difficult	After 12 months, carrying out daily activities will remain the same	After 12 months, carrying out daily activities will become easier
Fatigue	After 12 months, fatigue will get worse	After 12 months, fatigue will stay the same	After 12 months, fatigue will reduce/ improve

APPENDIX FOR QD13: REGIONS

Code label	BRAZIL REGIONS	ARGENTINE REGIONS
1	Região Norte: Acre, Amapá, Amazonas, Pará, Rondônia, Roraima, Tocantins	Region Noroeste [Jujuy, Salta, Tucuman, etc.]
2	Região Nordeste: Alagoas, Ceará, Bahia, Maranhão, Paraíba, Pernambuco, Piauí, Rio Grande do Norte, Sergipe	Region Nordeste [Formosa, Chacho, Corrientes, etc]
3	Região Centro-Oeste: Goiás, Brasília - Distrito Federal, Mato Grosso, Mato Grosso do Sul	Region Pampeana [Santa Fe, Buenos Aires, Cordoba, etc]
4	Região Sudeste: Rio de Janeiro, Espírito Santo, São Paulo, Minas Gerais	Region de Cuyo [La Rioja, San Luis, Mendoza, etc.]
5	Região Sul: Rio Grande do Sul, Paraná, Santa Catarina	Region Patagonica [Rio Negro, Chubut, Santa Cruz, etc.]

Code label	CHILE REGIONS	MEXICO REGIONS	COSTA RICA REGIONS
1	Arica y Parinacota-Antofagasta	Center: Mexico City, State of Mexico, Morelos, Hidalgo, Tlaxcala	San José
2	Atacama-Coquimbo	West: Jalisco, Michoacán, Colima, Nayarit	Heredia
3	Valparaiso-Maule	South: Puebla, Oaxaca, Guerrero, Veracruz	Alajuela
4	Biobio-Los Lagos	South-West: Chiapas, Tabasco, Yucatán, Quintana Roo, Campeche	Cartago
5	Aysen-Magallanes	North: Nuevo León, Coahuila, Tamaulipas	
6		North-East: Baja California (north and south), Sonora, Chihuahua, Sinaloa, Durango	
7		Bajío Area: Guanajuato, Aguascalientes, Querétaro, San Luis Potosí, Zacatecas	

Code label	DOMINICAN REPUBLIC REGIONS	PERU REGIONS	PANAMA REGIONS
1	Santo Domingo	Greater Lima	Panamá City
2	Santiago	Arequipa	San Miguelito
3		Chiclayo	Arraiján
4		Trujillo	Colon

Code label	URUGUAY REGIONS	BOLIVIA REGIONS	PARAGUAY REGIONS
1	Montevideo	La Paz-El Alto	Asunción
2	Other	Cochabamba	Other
3		Santa Cruz	

APPENDIX: PRIVACY

This Privacy Notice ("Privacy Notice") for The Research Partnership Limited and its affiliates, The Research Partnership Inc and The Research Partnership Healthcare Asia Pte Ltd, ("The Research Partnership", "we", "our" or "us"), explains how information that may be collected from you ("you" or "your") may be used. This information may be collected in connection with your participation in healthcare market research studies with Research Partnership.

Research Partnership takes your privacy seriously. We may update this Notice from time to time and shall indicate on our website (www.researchpartnership.com) when changes have been made.

We collect data on behalf of our research sponsors (our clients). The types of research engagements we conduct include face to face, telephone and online market research.

All the data we collect is presented to the sponsors in aggregate form. We do not share any of your Personal Data with our sponsors. The only exception may be in the reporting of any Adverse Events you may mention during the course of the market research engagement; however, your Personal Data would only be shared with your consent. In case of a refusal, your Personal Data will not be released as part of the reporting process.

Research Partnership is registered with the Information Commissioner's Office in the United Kingdom as a Data Controller in accordance with the provisions of the Data Protection Act 2018. Further details of the registration are available at www.ico.org.uk/

Research Partnership is proud to be members of the pharmaceutical market research governing bodies and the main market research associations listed below and we follow their guidance on all matters relating to market research codes of conduct, data protection and adverse event reporting.

- BHBIA (British Healthcare Business Intelligence Association)
- EphMRA (European Pharmaceutical Market Research Association)
- ESOMAR (European Society for Opinion and Market Research)
- Intellus Worldwide
- MRS (Market Research Society)
- Market Research Society, Singapore

Topics:

- What Personal Data do we collect?
- How will we use your Personal Data?
- For how long will we retain your Personal Data?
- To whom will we disclose your Personal Data?
- How do we protect your Personal Data?
- How can you access and update your Personal Data?
- Changes to this Notice
- How to contact us

What Personal Data do we collect?

Personal Data may be collected from you when you participate our market research studies. If we collect Personal Data as part of the research engagement, we will obtain your consent for the processing of this Personal Data at the time that the research engagement takes place. These consents are aligned with our industry association Codes of Conduct and Legal/Ethical Guidelines for Market Research.

Some of the Personal Data we may collect could include your medical specialty and sub-specialty, associated hospital and practice name, or relevant medical conditions,). On rare occasions we may need to collect additional elements of Personal Data which would be specific to the research engagement and for which we would obtain your specific consent to allow for such collection.

We will not sell, share, transfer, or rent any Personal data to any third-parties in ways different from what is disclosed in this Privacy Notice and our Terms and Conditions. We shall not process Personal Data in a way that is incompatible with the purposes for which it has been collected or subsequently authorized by you. To that end, we will take reasonable steps to ensure that Personal Data is reliable for its intended use, accurate, complete, and current. We use reasonable efforts to maintain the accuracy and integrity of Personal Data and to update it as appropriate.

How will we use your Personal Data?

We use Personal Data that we collect directly from our research participants for the following business purposes, without limitation:

- (1) maintaining and supporting our services, delivering and providing the requested services including payment of honoraria to our research participants, and complying with our contractual obligations related thereto;
- (2) satisfying governmental reporting, tax, and other requirements;
- (3) storing and processing data, including Personal Data, in computer databases and servers located in the United Kingdom and Ireland;
- (4) verifying identity of our research participants;
- (5) as requested by our research participants;
- (6) for other business-related purposes permitted or required under applicable local law and regulation; and
- (7) as otherwise required by law.

Our legal basis for the processing of your Personal Data is consent.

For how long will we retain your Personal Data?

The Research Partnership has a responsibility to maintain records relating to our research activities, in accordance with legal obligations, client contractual terms and suggested industry guidelines, and will retain your Personal Data according to the following retention guidelines:

Research (Survey) Data and associated research materials

This applies to all research (survey) data and associated research materials (screeners, questionnaires, audio-video files, adverse event reports, etc.). We will retain this data for a period of ten (10) years or per the guidelines dictated by our client contractual terms if different from our internal retention guidelines, after which time disposal will be completed in a secure manner. The retention period for the specific research engagement in which you participate will be shared as part of the consent process.

To whom will we disclose your Personal Data?

We do not share your Personal Data with third-parties other than transcription providers and the research sponsor's pharmacovigilance department or in the rare occasions mentioned earlier for which we would obtain your specific consent.

We may provide Personal Data to such third-parties for the following purposes, without limitation: translation and transcription of market research interviews and Adverse Event reporting.

We may also disclose Personal Data under the following circumstances:

1. Responding to witness summons, court orders, or legal process, or to establish or exercise our legal rights or defend against legal claims;
2. When we believe it is necessary to share information to investigate or prevent fraud, or to take action regarding illegal activities, situations involving potential threats to the physical safety of any person, or as otherwise required by law;
3. In rare situations, it may be necessary to disclose Personal Data in response to lawful requests by public authorities, including to meet national security or law enforcement requirements.

We are potentially liable in cases of onward transfers of Personal Data to third-parties, such as when third-parties that act as agents on our behalf process Personal Data in a manner inconsistent with the data protection principles. We will ensure that any third-party to which we disclose personal information provides the same level of privacy protection as is required by the applicable data protection principles and agrees in writing to provide an adequate level of privacy protection. Except as otherwise provided herein, we disclose Personal Data only to third-parties who reasonably need to know such data. Such recipients must agree to abide by confidentiality obligations that adequately comply with our compliance requirements.

We recognize that you have the right to limit the use and disclosure of your Personal Data, and we are committed to respecting those rights. We offer individuals the opportunity to opt out of disclosures of Personal Data to a third-party or the use of Personal Data for a purpose that is materially different from the purpose(s) for which it was originally collected or subsequently authorized by you. We will comply with the applicable data protection principles with respect to disclosures of Sensitive Data including, when applicable, obtaining the explicit consent (i.e., opt in consent) of an individual prior to disclosing Sensitive Data to a third-party or using Sensitive Data for purposes other than those for which it was originally collected or subsequently authorized by the individual.

How do we protect your Personal Data?

We have implemented physical and technical safeguards to protect Personal Data from loss, misuse, and unauthorized access, disclosure, alternation, or destruction.

For example, electronically stored Personal Data is stored on a secure network with firewall protection, and access to our electronic information systems requires user authentication via password or similar means. We also employ access restrictions, limiting the scope of staff members who have access to your Personal Data. Further, we use secure encryption technology such as SSL or a comparable standard to protect certain categories of Personal Data.

To the extent that we keep physical records containing your Personal Data, we limit access to such Personal Data to staff members whom we reasonably believe need that information to provide our services to you.

Despite these precautions, no data security safeguards guarantee 100% security all the time.

We have designated the Compliance Department to oversee our information security programme. The Compliance Department shall review and approve any material changes to this programme as necessary. Any questions, concerns, or comments regarding this Notice also may be directed to privacy@researchpartnership.com. We will maintain, monitor, test, and upgrade information security policies, practices, and systems to assist in protecting the Personal Data that we collect.

Our personnel will receive training, as applicable, to effectively implement this Privacy Notice.

How can you access and update your Personal Data?

Access:

You have the right to obtain confirmation about whether Personal Data is included about you in our databases. Upon request, we will provide an individual access to your Personal Data within thirty (30) days of receipt of such request. We will permit an individual to know what Personal Data about him/her is included in our databases and to ensure that such Personal Data is accurate and relevant for the purposes for which we collected the Personal Data.

You may review your Personal Data stored in the databases and correct, update, modify, or delete any data that is incorrect or incomplete.

Your right to access your Personal Data may be restricted in exceptional circumstances, including, but not limited to:

- when the burden or expense of providing this access would be disproportionate to the risks to your privacy in the case in question; or
- where the rights of persons other than you would be violated by the provision of such access.

If we determine that your access should be restricted in a particular instance, we will provide you with an explanation of our determination and respond to any enquiries you may have.

We will track each of the following and will provide notice to the appropriate parties under law and contract when either of the following circumstances arise:

(a) legally binding request for disclosure of the Personal Data by a law enforcement authority unless prohibited by law or regulation; or

(b) requests received from you.

Rectification and Erasure

You may request that we rectify or delete any of your Personal Data that is incomplete, incorrect, unnecessary or outdated. In making modifications to your Personal Data, you must provide only truthful, complete, and accurate information.

Objection

You may object, at any time, to your Personal Data being processed for a specific purpose.

Restriction of Processing

You may restrict processing of your Personal Data for certain reasons, such as, for example if you consider your Personal Data collected by us to be inaccurate or you have objected to the processing and the existence of legitimate grounds for processing is still under consideration.

Data Portability

You may request the Personal Data you provided to us in a commonly used and machine-readable form.

Right to Withdraw Consent

You have the right to withdraw your consent at any time, without affecting the lawfulness of our processing based on such consent before it was withdrawn, including processing related to existing contracts for our Services.

To exercise any of the abovementioned rights, please contact us by phone, postal mail or email at the How to contact us section of this Privacy Notice.

We recommend that you include documents that prove your identity and a clear and precise description of your request. Please note that in some cases, especially if you wish us to delete or cease the processing of your Personal Data, we may no longer be able to provide our Services to you.

The Research Partnership is committed to ensuring privacy in all markets we work in and would therefore like to add the new California Consumer Privacy Act (CCPA) effective January 1st 2020 to our Privacy Notice to provide our users who reside in the state of California how we collect, store and use their data.

The CCPA grants the respondents' rights as listed below which are not dissimilar to those of the EU GDPR covered already in the Research Partnership's Privacy notice such as the ability to

- Request information
- Have personal information deleted
- Opt out of the sale of their personal information
- Be informed that personal data is being disclosed or sold

While our Privacy notice already cover the first two (requesting information or having data erased), as a market research agency we do not participate in selling personal data and will seek consent in the cases where your personal data is disclosed to the end client usually in the form of reporting adverse events.

Changes to this Notice

This Privacy Notice may be amended from time to time, consistent with applicable data protection and privacy laws and principles. We will notify you if we make changes that materially affect the way we handle Personal Data previously collected, and we will allow you to choose whether your Personal Data may be used in any materially different manner.

How to contact us

If you have any questions or complaints about this Privacy Notice or our data collection practices, please contact us at the details listed below and specify your country of residence and the nature of your question.

Compliance Manager
The Research Partnership Ltd
Chester House
81-83 Fulham High Street
London SW6 3JW
United Kingdom
Email: privacy@researchpartnership.com
Phone: +44 (0)20 8069 5000

If you consider our processing activities of your Personal Data to be inconsistent with the applicable data protection laws, you may lodge a complaint with your local supervisory authority responsible for data protection matters.