

## Child consent

OPEN Health are conducting a research project that has been sponsored by a pharmaceutical company. The purpose is to better understand the psychological experiences of patients diagnosed with Neurofibromatosis Type I (NF-1), their caregivers and healthcare professionals involved in their care, across the UK. We would like to hear about your personal experiences, and your child's experiences in relation to their diagnostic journey and beyond. We would like to explore the psychological impact of living with the condition and hear about the emotional and clinical experiences and pathways from diagnosis to symptom management and disease progression.

The interview will be conducted by an independent interviewer from OPEN Health. The interview will be conducted remotely via an online screen sharing platform (or via the telephone) and will last for around 60 minutes. The interviews will be audio and video recorded with your consent. These recordings will only be used by OPEN Health and the commissioning pharmaceutical company in accordance with the consents that you provide.

You are free to be with your child while they complete the interview and can assist them with the questions, but the responses should be from your child's perspective only.

### Consent for processing personal data:

A	I confirm that I have read and understood all of information about this project and that I have been able to consider the information and ask any questions which have been answered satisfactorily	<input type="checkbox"/> Yes	<input type="checkbox"/> No
B	I consent to OPEN Health collecting and using the information that my child or I voluntarily provide including my child's personal data for the purposes of market research.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
C	I consent to my interview being <b>audio recorded</b> for analysis by OPEN Health. This recording will be stored for 12 months to allow OPEN Health to review if needed.	<input type="checkbox"/> Yes	<input type="checkbox"/> No
D	I consent to people from the sponsoring pharmaceutical company (from marketing, market research and medical roles) to <b>listen</b> to my child's <b>audio recording</b> (after the interview) to help them <b>understand the market research better</b> . The recording will be stored for 12 months to allow the client to review it if needed. <b>[This question is optional and you can continue with this study whether you opt into this or not].</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
E		<input type="checkbox"/> Yes	<input type="checkbox"/> No

	I consent to <b>audio recording</b> (after the interview) being used for training with internal pharmaceutical company staff within the UK and globally. The recording will be stored for 12 months to allow the client to review it if needed. <b>[This question is optional and you can continue with this study whether you opt into this or not].</b>		
F	I consent to <b>anonymous</b> quotes from my child's interview to be provided in the final report from this market research, that will be given to the sponsoring pharmaceutical company (please note: identifiable information will be removed from the quotes, and they will not be tied to my child as an individual) <b>[This question is optional and you can continue with this study whether you opt into this or not].</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
G	I consent to <b>anonymous</b> quotes from my child's interview to be provided in the final report from this market research, that will be given to the sponsoring pharmaceutical company to be used externally for diseases awareness activities (please note: identifiable information will be removed from the quotes, and they will not be tied to my child as an individual) <b>[This question is optional and you can continue with this study whether you opt into this or not].</b>	<input type="checkbox"/> Yes	<input type="checkbox"/> No
H	I consent to OPEN Health storing my child's personal data for 12 months in case they need to re-contact them to ask any follow up questions about the market research to clarify any points	<input type="checkbox"/> Yes	<input type="checkbox"/> No
I	I consent to OPEN Health storing my child's personal data for 12 months in case they need to re-contact them to ask about a change in use or audience for the information they have provided.	<input type="checkbox"/> Yes	<input type="checkbox"/> No

**Informed consent:** Please can you confirm that you are happy for your child to participate in a research interview as per the details and rights outlined above (recruiter to clarify any points as required):

- I agree
- I do not agree

Parent's Name:

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

**Child/ Young person assent:** Your parent/ guardian has agreed for you to participate in an interview for a project that will help us understand the experiences of children and young people diagnosed with Neurofibromatosis Type I (NF-1). Are you happy to take part in an interview?

- Yes, I agree to take part
- No, I do not want to take part

## OPEN Health Privacy Notice

This privacy policy governs the collection, storage, use of personal information collected by us, OPEN Health Communications LLP (“OPEN Health”). It provides details about the personal information that we collect from you, how we use your personal information, and your rights regarding the personal information that we hold about you. Please read this privacy policy carefully - by using our services, you confirm that you have read, understood, and agree to this privacy policy in its entirety.

### Who is OPEN Health?

OPEN Health Communications LLP (whose registered address is at C/O Corporation Service Company (UK) Limited, 25 Canada Square, 37th Floor, Canary Wharf, London E14 5LQ, United Kingdom and registered number OC360224) together with its subsidiary entities ([details available here](#)) operate in the healthcare and digital sector providing communications, market access, consultancy, public relations, meetings and events, medical education, data analytics, and health economic modelling services.

### Data Controller

OPEN Health is made up of [different legal entities](#). This privacy policy is issued on behalf of the OPEN Health Group, so when we mention “OPEN Health” “we,” “us,” or “our” in this privacy policy, we are referring to the relevant company in the OPEN Health Group responsible for processing your data. OPEN Health Communications LLP is the controller and responsible for this website.

### Data Processor

OPEN Health also conducts data processing activities on behalf of its clients who will be the data controller for such activities. Where OPEN Health is a data processor, we may only process personal data in accordance with the controller’s documented instructions as set out in a data processing agreement or contractual arrangements. We may only transfer personal data out of the EEA and appoint sub-processors as permitted by the data processing agreement. OPEN Health is also given data sets for the purposes of research in a pseudonymised format which means the data subject will not be identifiable to OPEN Health because we have no access to the code that will re-identify the data.

### Contact us

If you have any questions about this privacy policy, including any requests to exercise your legal rights, please email us at [dataprivacy@openhealthgroup.com](mailto:dataprivacy@openhealthgroup.com). Please note that this email address is not intended or designed for any other communications.

### You have the right to make a complaint at any time

You have the right to make a complaint at any time to the Information Commissioner's Office (ICO; the UK regulator for data protection issues; [www.ico.org.uk](http://www.ico.org.uk)) if you are based in the UK. If you are based in Europe, you have the right to make a complaint at any time to the Dutch DPA, who we have nominated as our lead data-protection authority (<https://autoriteitpersoonsgegevens.nl>). We would, however, appreciate the chance to deal with your concerns before you approach the ICO or the Dutch DPA, so please contact us directly at [dataprivacy@openhealthgroup.com](mailto:dataprivacy@openhealthgroup.com) in the first instance.

### External links

This website may include links to external websites, plug-ins, and applications. Clicking on those links or enabling those connections may allow other parties to collect or share data about you. We do not control these external websites and are not responsible for their privacy statements. When you leave our website, we encourage you to read the privacy policy of every website you visit.

## Changes to this Privacy Notice

We keep our privacy notice under regular review. This version was last updated on 22.03.2021.

It is important that the personal data we hold about you is accurate and current. Please keep us informed if your personal data changes during your relationship with us.

### How is your personal data collected?

We use different methods to collect data from and about you, which may not always be collected directly from you, including through:

**Direct interactions.** You may give us your identity data, contact data, and financial data by filling in forms or by corresponding with us by post, telephone, email, or otherwise. This includes personal data you provide when you do any of the following:

- Meet us at an event
- Take part in research either online, through video conferencing, by phone, or face to face
- Subscribe to publications and/or other marketing material
- Take part in a campaign where you share your personal data and experiences
- Approach and/or contract with us to perform services
- Share your knowledge and expertise with us
- Give us feedback
- Contact us online in a networking or social media forum
- Make an enquiry to our website
- Send us your CV or biography
- Contact us to request our services

**Automated technologies or interactions.** As you interact with our website, we may automatically collect technical data about your equipment, browsing actions, and patterns. This may also include your internet protocol (IP) address. We collect such personal data by using cookies, server logs, and other similar technologies. Please see our [Cookie Policy](#) for further details.

**Third parties or publicly available sources.** We may receive personal data about you indirectly, from various third parties and publicly available sources including those below:

- Analytics providers
- Registers of information - e.g. Specialist Information, Getty Images, Shutterstock, Stock
- Search information providers such as Google, Chrome
- Social media sites
- Identity and contact data from publicly available sources such as Companies House and the Electoral Register, British Medical Association, Association of the British Pharmaceutical Industry, Health Research Authority, National Institute for Health Research, and similar international organisations, if applicable
- Medical journals and conference organisers

- Partner institutions and our clients
- Healthcare provider organisations
- Agents and recruitment consultants
- Suppliers
- Third-party data collection specialists - e.g. BrandWatch
- Contego Solutions Limited (trading as “Northrow”), a third party that provides us with compliance services
- Technical data from the following:
  - Our website hosting provider may collect your IP address; however, this information is anonymised so OPEN Health does not receive such data in a way that it can be personally identifiable and is therefore *not personal data*
  - We generate log files about browsing patterns; this is statistical data which does not identify you as an individual
  - This website uses Google Analytics, a web analytics service provided by Google, Inc. (“Google”); Google Analytics uses cookies to analyse how visitors use the website

**Major Incidents and Health Emergencies** As part of research studies conducted by OPEN Health on behalf of clients we collect from or are given pseudonymised patient data by a Healthcare Provider Organisations. In these cases the data is not collected directly from the patient (Data Subject). OPEN Health does not hold the re-identification criteria or “key” to this personal data. Therefore OPEN Health is unable to confirm to any data subject whether they hold their personal data or from which Healthcare Provider Organisation from which it came.

**Healthcare Provider Organisations.** As part of research studies conducted by OPEN Health on behalf of clients we collect from or are given pseudonymised patient data by a Healthcare Provider Organisations. In these cases the data is not collected directly from the patient (Data Subject). OPEN Health does not hold the re-identification criteria or “key” to this personal data. Therefore OPEN Health is unable to confirm to any data subject whether they hold their personal data or from which Healthcare Provider Organisation from which it came.

Therefore, without the ability to re-identify the data subject OPEN Health is unable to provide a data protection notice directly to any of the data subjects held in these pseudonymised patient records and, as required by GDPR Article 14 OPEN Health shall take appropriate measures to protect the data subject’s rights and freedoms in respect to the data it holds. In these cases the original data protection notice issued to the data subject by the data controller will apply.

### How we use your personal data

We will only use your personal data when the law allows us to. Most commonly, we will use your personal data in the following circumstances:

- Where we need to perform a contract we are about to enter into or have entered into with you
- Where it is necessary for our legitimate interests (or those of a third party) and your interests and fundamental rights do not override those interests
- Where we need to comply with a legal or regulatory obligation
- Where it is in the public interest to do so
- With your explicit consent (which you may withdraw at any time)

## The personal data we may collect about you

Personal data means data which relate to a living individual who can be identified from those data, or from those data and other information which is in our possession, or is likely to come into our possession, and includes any expression of opinion about an individual and any indication of our intentions or the intentions of any other person in respect of the individual.

We may collect, use, store, and transfer different kinds of personal data about you, which we have grouped examples of these together as follows:

- **Identity data** include first name, maiden name, last name, username or similar identifier, marital status, emergency contacts, title, date of birth, profession, audio/visual recordings and gender
- **Contact data** include billing address, delivery address, email address, and telephone numbers
- **Educational and biographical data** include information about your work history, specialisms, qualifications, professional licence numbers for accredited bodies, progression, achievements, and extra-curricular activities
- **Financial data** include bank account and payment card details
- **Transaction data** include details about payments to and from you
- **Technical data** include IP address, login data, browser type and version, time zone setting and location, browser plug-in types and versions, operating system and platform, and other technology on the devices you use to access our websites
- **Profile data** include your interests, preferences, feedback, and any survey responses
- **Marketing and communications data** include your preferences in receiving marketing and or newsletters from us and any communication preferences collected
- **Market research data** include any personal and or special categories of personal data including health data, genetic or biometric data, and data that relate to your sexual orientation or sex life that you have shared with us as a participant in a research study or survey or as part of our agreement with you; such data may exist in a pseudonymised form with a code and we may not know which individual the code relates to
- **Pseudonymised Data** such as patient records not collected directly from a patient via a Healthcare Provider Organisation such as a hospital or doctor's general practice. There is no way for OPEN Health to re-identify this data as the re-identification criteria or "key" always remains with the Healthcare Provider Organisation in these circumstances.
- **Aggregated data** are statistical or demographic data for any purpose and may be derived from your personal data but are not considered personal data by law, as these data do not directly or indirectly reveal your identity
- **Subscription data** include data collected from data agencies to whom you subscribe (e.g. Specialist Information)
- **Special categories of personal data** include details about your race or ethnicity, religious or philosophical beliefs, sex life, sexual orientation, political opinions, trade union membership, health, and genetic and biometric data
- **Usage data** include information about how you use our website

### **If you fail to provide personal data**

Where we need to collect personal data by law, or under the terms of a contract we have with you, and you fail to provide that data when requested, we may not be able to perform the contract we have or are trying to enter into with you (e.g. to provide you with goods or services). In this case, we may have to cancel a product or service you have with us but we will notify you if this is the case at the time.

### **Purpose for which we will use your personal data**

We have set out below a description of all the ways we plan to use your personal data, and which of the legal bases we rely on to do so. We have also identified what our legitimate interests are, where appropriate.

Note that we may process your Personal Data for more than one lawful ground, depending on the specific purpose for which we are using your data. Please contact us if you need details about the specific legal ground we are relying on to process your personal data where more than one ground has been set out in the details below.

**Legitimate interest** means the interest of our business in conducting and managing our business to enable us to give you the best service/product and the best and most secure experience. We make sure we consider and balance any potential impact on you (both positive and negative) and your rights before we process your personal data for our legitimate interests. We do not use your personal data for activities where our interests are overridden by the impact on you (unless we have your consent or are otherwise required or permitted to by law).

**Performance of contract** means processing your data where it is necessary for the performance of a contract to which you are a party or to take steps at your request before entering into such a contract.

**Comply with a legal or regulatory obligation** means processing your personal data where it is necessary for compliance with a legal or regulatory obligation that we are subject to.

## **Research Participants (Survey or formal research project)**

### **RELATIONSHIP TO OPEN HEALTH**

You are taking part in a survey or formal research project as a research participant.

### **PURPOSE/ACTIVITY**

To facilitate your participation in the survey or formal research project.

### **TYPE OF DATA**

- Identity
- Contact
- Educational and biographical
- Special categories of personal data (e.g. health data you have agreed for us to hold)

### **LAWFUL BASIS FOR PROCESSING INCLUDING BASIS OF LEGITIMATE INTEREST**

- Performance of a contract with you
- Necessary for our legitimate interests to perform research in an area
- Necessary for a task carried out in the public interest



- Necessary for archiving in the public interest, scientific or historical research purposes, or statistical purposes (Article 89 GDPR) necessary for complying with a legal obligation

#### **WHO DO WE SHARE IT WITH?**

As set out in our agreement with you but may include:

- Specified healthcare research organisations and identified healthcare providers, e.g. NHS
- The applicable regulators, e.g. in the UK, HRA, REC, IRB, ABPI, MHRA, BHBIA, and EFPIA

#### **HOW LONG WILL WE KEEP IT?**

For a minimum period of 3 years unless otherwise specified in our agreement with you or specified by law.