

## Lawful Processing

**GDPR states that personal data can only be stored and used (processed) under a lawful basis. The lawful basis' we use are either Consent or Legitimate interest. The following states how this is obtained or decided and how it is recorded**

### 1. First contact via our website

The majority of our first contacts come via our website forms. These require the person to tick the box to say that they consent to our processing their information before the form can be submitted. They are advised they can read more detail in the Privacy Notices – which are linked:

I consent to SMA UK safely storing and using this contact information so that you can respond to my request. SMA UK will not share my information with any third party unless I give permission, or they are required to do so by law. I know I can read more about this in the [Privacy Policy](#)

### 2. First contact by phone

When people first contact our service, they are often in a state of emotional distress and shock at having been given difficult news about a diagnosis. They may be very tentative about making contact. The strength of our service is that it is open to anyone and responds at the pace the individual wishes. It is not unusual for first calls to be anonymous or for a person to only use their first name. Feedback from families suggests that the great strength of our service is that it is unbureaucratic, doesn't involve lots of paperwork, and that staff are understanding and available as a listening ear and guide.

We need to balance maintaining this 'friendly' service with ensuring people are aware of our data protection and confidentiality practices

It's not always easy or appropriate to interrupt a person and ask them for their consent to hold and process their information, but if it will not be detrimental to the 'flow' of the call, staff may be able to say, for example,

*"I just wanted to mention that I have taken some notes of our discussion, in case you want to come back to us. Are you happy for me to store them confidentially on our computer database for now?... **reply...** If you want to know more about how we look after your information there is a Privacy Notice link on the front page of our website."*  
(or offer to send them the website link to our Privacy Notices.)

In such cases, we use the General Data Protection Regulation (GDPR) test of whether we have a 'legitimate interest' which allows us to do this. This test is 'are we using the person's personal data in a way that they would reasonably expect, and which will have a minimal impact on their privacy?'

### 3. First contact via email / social media

#### Staff email signatures all say:

##### Data Protection Act

If this email is in response to an information or support enquiry, please note that your contact information and brief details of your request have been stored and processed using our computerised database. We will use this information to assist you. Your information will not be used for any other purposes. For further information please see our privacy notice: [www.smauk.org.uk/your-privacy](http://www.smauk.org.uk/your-privacy)

This directs people to full details, including this Appendix re: Lawful processing.

Arrangements for Home Visits are made via email and information is also sent in this way. Service users therefore see this notice. They also see the link to our privacy policy on our leaflets about our outreach service.

### 4. Contact with children

We only have contact with children and young people under the age of 18 if we have the written consent of their parent/guardian.

### 5. Recording Lawful processing status

All new individual database records should have the attribute '**Lawful Process**'. Based on the above, this should be dated and either read:

- Given
- Legitimate Interest

Members of the household will also have a '**Lawful Process**' attribute. If it is 'given' the comment box will state who by which member of the household.

Records set up prior to these new regulations have only ever been set up to: provide an information / support service; respond to an offer of help; process a donation / shop purchase. In our view, they pass the GDPR test that we are using the person's personal data only in a way that they would reasonably expect, and which will have a minimal impact on their privacy. They are therefore all marked under the 'lawful process' attribute as **legitimate interest**.

### 6. Follow up review of lawful processing status

The Support Services Manager reviews all new support services contacts – usually after some 3 months plus. If it is possible (GDPR) / appropriate to write to the person and their record indicates their status is 'legitimate interest', the letter states:

I would also like to make sure you are aware that your contact information and brief details of our contact with you have been stored and processed using our secure computerised database. We have used, and only would use this information to assist you. It will not be used for any other purposes.

If you have time, it's helpful for our records if you can confirm by email to [office@smauk.org.uk](mailto:office@smauk.org.uk) that you '**consent to SMA UK holding my information as outlined in their privacy policy**'. We completely understand you may well not have time so, if we don't hear otherwise from you, we will assume you have no objections to this.

For further information please see our privacy notice: [www.smauk.org.uk/your-privacy](http://www.smauk.org.uk/your-privacy)

## **7. Children's Data and Health Data**

We are aware that Children's data and anyone's Health data are specifically mentioned in the GDPR. They merit specific protection with regard to their processing. With that in mind:

Children's data is only collected for the purposes of accessing appropriate support and information and for ensuring we follow our child safeguarding policy. It is only recorded when given directly by a parent, legal guardian or health or other professional where we have the parent / guardian's consent for contact. We never share this data with any third party without consent – unless we are required to do so by law (child safeguarding)

To record and use health data we follow the guidelines set out by article 9 of the GDPR and in accordance with the [House of Lords Bill March 2018 Amendment 83](#) which supports the processing of data if it is "carried out by a not-for-profit body which provides support for an individual with a particular disability or medical condition." We never share this data with any third party without consent – unless we are required to do so by law (child safeguarding).

## **7. Consent to share information outside the organisation**

Staff should always obtain verbal agreement if they are going to contact anyone on behalf of the individual / family or if any other issues regarding consent to sharing of personal information arise. This verbal agreement should be recorded in the database actions.

**Last reviewed Feb 2021**