

## **Privacy Policy ME-WE Project**

The ME-WE project aims to develop support that works for adolescent young carers by learning more about peoples' experiences as a young carer. This privacy policy covers data collected as part of the project which includes delivering intervention sessions to some young carers and collecting feedback on these through a survey. Carers Trust's full privacy policy of which this forms part can be found [here](#).

Carers Trust are the lead partner for the interventions part of the project taking place in England; it is part of a bigger project happening in different parts of Europe. Carers Trust are registered with the Information Commissioner's Office (ICO) registration number ZA235487. The support for young carers is being delivered by three Carers Trust Network Partners - Sutton Carers Centre, Suffolk Family Carers and Action for Family Carers. The University of Sussex are managing the research data collection in England.

Other organisations throughout Europe are partners in the wider project - Linnaeus University (Sweden), Eurocarers (Belgium), Kalaidos University of Applied Sciences (Switzerland), The Netherlands Institute for Social Research (Netherlands), The National Centre of Expertise for Long-term Care in the Netherlands (Vilans), National Institute of Health and Science on Ageing (INRCA) (Italy), Anziani e non solo societa (Italy) and Univerza v Ljubljani (Slovenia).

More information about the project and partners can be found at [www.me-we.eu](http://www.me-we.eu)  
The project is scheduled to finish on the 31<sup>st</sup> March 2021.

### **Data relating to young carers and their parents or guardians**

We will collect information from young carers who apply to participate in the project. As part of our consent process we will record the young carer's name, address, contact details and school attended. We will also collect the names of parents or guardians of the young carers from them when they provide their consent to the young carer's participation.

A screening assessment will then be completed, which will check that this the right project for the young carer to participate in. As part of this we will collect additional information including age, gender, nationality, whether you speak English and email address.

Young carers participating in the project following the screening will have a unique ID number known only to them which will be used in place of personal information for data collected for the remainder of the project.

The information we collect from young carers and their parents or guardians is necessary for the administration and delivery of the ME-WE project and for its research purposes. We collect and hold this information on the basis of consent. Consent can be withdrawn at any time by contacting Carers Trust.

When sharing data we will always share the minimum amount of information we need to and wherever possible will do so in such a way that young carers are not identifiable. Access to all personal data will be restricted to relevant UK staff working on the project. Partners outside the UK will only be able to view anonymised data. Network partners will only have access to personal data for the young carers to whom they are delivering groups. The names of young carers participating in the project will be provided to their school or college in order to arrange for them to attend intervention groups.

In the event of a safeguarding issue where there is a substantial health or social care risk information may be provided to parents or legal representatives or public formal services and authorities as appropriate.

We store information in a number of ways. Consent forms will be stored in a locked drawer or box until they are scanned. This will take place within 10 working days after which the paper copies will be securely destroyed. These will be stored by Carers Trust using Microsoft SharePoint. Microsoft's privacy policy can be found [here](#).

A list of participants, their contact information and school, an internal ID number to track that consent has been obtained for every young carer participating in the project and a screening assessment has been completed. The name of the Carers Trust network partner delivering the intervention to that participant will also be stored within Microsoft SharePoint with access restricted to relevant members of the project team. All Carers Trust Network Partners will view and input all project administration information including personal data of participants on Carers Trust' Microsoft SharePoint.

Information collected from young carers during screening and evaluation will be and stored on the 1KA system and the privacy policy for 1KA can be found [here](#). The unique ID number will be used for these records and names and contact information will not form part of this data. Each ID number will only be known by the young carer.

If we are unable to collect data from screenings or evaluations directly online then paper copies will be used. These will be sent using a tracked delivery service requiring a signature to the University of Sussex. When not in transit the documents will be stored in a locked drawer or box until they are entered into the 1KA system. This will take place within 10 working days of their receipt following which the paper copies will be securely destroyed.

Survey data will be downloaded from the 1ka site to be stored on the Univerzav v Ljubljani (Slovenia) secure servers. Their privacy policy can be found [here](#).

### **Data about staff members**

During the project we will collect information about members of Carers Trust and network partner's staff working on the project as required by our funder. This will include name, tasks and hours worked on the project in particular periods These will be stored by Carers Trust using Microsoft SharePoint and used as part of

administering the project. Microsoft's privacy policy can be found [here](#). The basis for this our legitimate interest in running the project in line with our charitable objectives.

As part of the research the names of staff members carrying out evaluations and their organisation will be collected and stored on the 1KA system and the privacy policy can be found [here](#).

Facilitator intervention sessions will be recorded and stored by the University of Sussex. Permission to record the sessions is asked before recording starts and participants are asked to confirm again once the recording has started. These recordings will be kept for 10 years by the University of Sussex. A summary of the key discussion themes will be shared with the ME-WE consortium. The basis for this is consent.

### **All data**

From 2025 other researchers may have access to the anonymised data from the project. Access to the data will be controlled by Linnaeus University (Sweden) and Univerzav v Ljubljani (Slovenia)- who will screen requests in accordance with [FAIR Data Management guidelines](#).

Records where an individual is identifiable such as consent forms and time sheets will be kept for 10 years after the project's end until 31 March 2031. After this date they will be destroyed. Anonymised data may be retained after this date.

### **How can I manage or delete the information you have about me?**

Your rights regarding the data we hold and collect about you are outlined in the data protection policies and legislation of the United Kingdom and, from 25 May 2018, the European Union. These include: the right to access, edit and update, request the deletion of, and restrict the processing of your personal information, the right to object to the collection of your personal data and the right to lodge a complaint with a supervisory authority about your personal information.

If you would like to find out what personal information/data we hold about you, delete any of this data, or update your communication preferences please contact us on 0300 772 9600 (charged at local rates) or email [dpo@carers.org](mailto:dpo@carers.org).

If you have any questions or comments about this Privacy Policy or any of the policies mentioned in this policy, please contact our Data Protection Officer directly at:

Carers Trust  
Unit 101, 164–180 Union Street, London SE1 0LH  
Tel: 0300 772 9600  
Email: [dpo@carers.org](mailto:dpo@carers.org)

If you are not satisfied with our response or believe we are not processing your personal data in accordance with the law you can complain to the Information Commissioner's Office (ICO). You can contact the ICO on 0303 123 1113, at [registration@ico.org.uk](mailto:registration@ico.org.uk) or at Wycliffe House, Water Lane, Wilmslow, Cheshire SK9 5AF.

The full Carers Trust privacy policy can be found [here](#).

The University of Sussex  
Sussex House, Falmer, Brighton, East Sussex BN1 9RH,  
01273 606755

[dpo@sussex.ac.uk](mailto:dpo@sussex.ac.uk)

Their privacy policy can be found [here](#).

Sutton Carers Centre  
Benhill House, 1st Floor, 12-14 Benhill Avenue, Sutton, Surrey SM1 4DA  
Email: [enquiries@suttoncarerscentre.org](mailto:enquiries@suttoncarerscentre.org)

Tel: 020 8296 5611

Their privacy policy can be found [here](#).

Suffolk Family Carers  
Units 6, 8 & 9, Hill View Business Park, Old Ipswich Road, Claydon, Suffolk IP6 0AJ  
Tel 01473 835477

[hello@suffolkfamilycarers.org](mailto:hello@suffolkfamilycarers.org)

Their privacy policy can be found [here](#).

Action for Family Carers, Brickhouse Farm, Poulton Close, Maldon, CM9 6NG.

Tel: 0300 7 70 80 90

Email: [info@affc.org.uk](mailto:info@affc.org.uk)

Their privacy policy can be found [here](#).

Univerza v Ljubljani, Kongresni trg 12, 1000 Ljubljana, Slovenia  
Kongresni trg 12, 1000, Ljubljana, Slovenia  
Professor Valentina Hlebec

Their privacy policy can be found [here](#).