

**Patient-Initiated Follow-Up (PIFU) Study
UK General Data Protection Regulation (GDPR) Statement**

How will we use information about you?

Patients: We will need to use information from you and from your medical records for this research project. This information will include your:

- NHS number (information held by NHS Grampian)
- Name (information held by NHS Grampian, unless you provide this as part of the survey)
- Contact details (information held by NHS Grampian, unless you provide this as part of the survey)

Carers: We will need to use information from you this research project. This information will include your:

- Name (information to be held by University of Aberdeen, when you provide this)
- Contact details (information to be held by University of Aberdeen, when you provide this)

Health professionals: We will need to use information from you this research project. This information will include your:

- Name (information to be held by University of Aberdeen, when you provide this)
- Contact details (information to be held by University of Aberdeen, when you provide this)

People will use this information to do the research or to check your records to make sure that the research is being done properly. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

The University of Aberdeen is the sponsor of this research. The University of Aberdeen is responsible for looking after your information. We will share your information related to this research project with the following types of organisations:

- If you agree for data linkage: Grampian Data Safe Haven (DaSH): a secure, virtual data analysis and storage centre, established by the University of Aberdeen and NHS Grampian (patients only)
- If you participate in the focus groups: A professional transcription company approved by the University of Aberdeen.

We will keep all information about you safe and secure by:

- Storing data you provide for the study separately from personal details like your name and email address.
- Using study ID instead of your name (where possible)
- Storing electronic data on secure drives and physical copies in locked cabinets at the University of Aberdeen that have access restricted to only a few members of the study team who require this to do the research.

International transfers: Your data will not be shared outside the UK.

How will we use information about you after the study ends?

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study. We will keep your study data for a maximum of six of years. The study data will then be fully anonymised and securely archived or destroyed.

What are your choices about how your information is used?

- you can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have
- you have the right to ask us to access, remove, change or delete data we hold about you for the purposes of the study. You can also object to our processing of your data. We might not always be able to do this if it means we cannot use your data to do the research. If so, we will tell you why we cannot do this
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

Where can you find out more about how your information is used?

You can find out more about how we use your information:

- by asking one of the research team
- by sending an email or phoning the University's Data Protection team:
dpa@abdn.ac.uk; 01224272596
- by visiting www.abdn.ac.uk/about/privacy/