

UKIDS Privacy Notice

This Privacy Notice is being provided for the participants taking part in the UK Imaging Diabetes Study Seeing Diabetes Clearly (“UKIDS”) trial. It provides information about how data is collected about you as part of the trial, and how we handle and process it.

1. Who is responsible for your data?

The Data Controller and the Sponsoring organisation for UKIDS is Perspectum Ltd (“us”, “we”). This means that we, as well as our study partners, are responsible for looking after your information and using it properly in accordance with the UK General Data Protection Regulation (UK GDPR).

Our study partners include:

- Moorfields Eye Hospital NHS Foundation Trust
- Oxford Community Diagnostic Centre
- Eynsham Medical Group
- Windrush Medical Practice
- The House Partnership
- St Bartholomew & Hollow Way Medical Practice
- Hedena Health
- Woodlands Medical Centre
- The Manor Surgery
- Whitehorse Medical Centre
- NHS University Hospitals of Liverpool Group.
- Swansea Bay Local University Health Board

2. Personal data we collect about you

Personal information about people taking part in UKIDS comes mainly from the questionnaires that we our study partners share with you and the information collected at the two visits (described in the UKIDS Patient Information Leaflet shared with you, available here [<https://perspectum.com/ukids/>]).

We may receive information about your health status at 1, 3, and 5 years after you joined the study from NHS health registries. The information may concern diabetes and diseases of the eye, heart, kidney and liver, as well as deaths (mortality data), healthcare appointments (primary care data) and hospital admissions (hospital episode statistics). We provide relevant details about you to the NHS health registries in order to receive this information.

3. Why we collect and process your data

We are using your data for the long-term follow-up phase of the UKIDS study to assess the health of multiple organs, including the liver, kidneys, pancreas, heart, lungs and spleen, in people who have been diagnosed with type 2 diabetes.

We will only process your personal data for the purposes for which we collected it, unless we reasonably consider that we need to use it for another related reason that is compatible with the original purpose.

We do not use your personal data for any form of automated decision-making or public profiling, and we will not use your data for any unrelated purposes

4. How we use your personal data

The legal basis for the processing and storage of your personal data for UKIDS is our legitimate interests (Article 6(1)(a) UK General Data Protection Regulation (UK GDPR)). In addition, a required condition under the UK GDPR to process your special category (sensitive) personal data is met as it is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes (Article 9(2)(j) UK GDPR).

5. How long we keep your data

We will retain information about you for up to 25 years after the end of the study (when the last piece of health data is collected about study participants), in line with Good Clinical Practice (GCP) and relevant legislation. The study is expected to end on 30 June, 2026. Your direct identifiers will be stored until [2037], unless you consent to a longer period in your Informed Consent Form. At the end of the retention period, your personal data will either be deleted. The need to retain your data will be reviewed regularly.

We may need to retain your personal data for longer if, and only to the extent, required by law. We may also information about you, excluding any information from which you can be identified, for further research for which a legal basis exists, but this will always be done in accordance with data protection laws. Article 5(1)(e) allows us to store personal data for a longer period than necessary for the purposes for which it is procured, where the processing is solely for research purposes.

6. How we protect your data

We protect your personal data against unauthorised access, unlawful use, accidental loss, corruption, and destruction.

We use technical measures such as encryption and password protection to protect your data and the systems in which they are held, and the information that we receive is stored securely in a study database. Access to the study database is by unique combinations of usernames and passwords and only authorised study personnel can access information about participants.

We also use operational measures to protect the data, for example by limiting the number of people who have access to the databases in which your data is held. And whenever possible, your personal identifiers (such as name) will be removed and replaced by a unique trial ID number. Your data is treated in the strictest confidence and is used solely for academic research purposes. Importantly, no individuals will be identified in any publications arising from this work.

We keep these security measures under review to ensure we address new or emerging risks.

7. Sharing your data

Any personal data that identifies you are collected and managed by the site you attended for your visits and will not be shared with anyone else, except as permitted by law (for example, if required in response to an adverse event).

At the end of the trial (when we have stopped collecting new data and reported our results), information may be used in accordance with the Informed Consent Form. This information will not identify you, unless you agreed to and will not be combined with other information in a way that could identify you.

8. Transfer of your data outside of the European Economic Area (EEA)

Your data is securely stored. We, and our study partner, use industry leading hosting providers based in the UK, EU, and USA when processing information about you.

9. Your rights

Under the UK General Data Protection Regulation (UK GDPR), you have the following rights in relation to the information that we hold about you (your 'personal data'):

- **The right to request access to your data (commonly known as a "subject access request").** This enables you to receive a copy of your data and to check that we are lawfully processing it.
- **The right to request correction of your data.** This enables you to ask us to correct any incomplete or inaccurate information we hold about you.
- **The right to request erasure of your data.** This enables you to ask us to delete or remove your data in certain circumstances for example, if you consider that there is no good reason for us continuing to process it. You also have the right to ask us to delete or remove your data where you have exercised your right to object to processing (see below).
- **The right to object to the processing of your data.** This enables you to oppose our using your data where we are processing it to meet our public tasks or legitimate interests (or the legitimate interests of a third party) and there is something about your particular situation which makes you want to object to processing on this ground. You also have the right to object where we are processing your data for direct marketing purposes.
- **The right to request that the processing of your data is restricted.** This enables you to ask us to suspend the processing of your data, for example, if you want us to establish its accuracy or the reason for processing it.
- **The right to access, change or move your data.** Depending on the circumstances, we may have grounds for not complying with your request, for example, where we consider that deleting your information would seriously harm the research or where we need to process your data for the performance of a task in the public interest.

If you wish to exercise any of these rights, please contact [Clinicalresearch@Perspectum.com].

If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

10. Changes to this privacy notice

We reserve the right to update this privacy notice at any time. Updated versions will be provided on the UKIDS website. This version is dated 30 April, 2026.

11. Complaints

If you wish to raise a complaint about how we have handled your personal data, you can contact our Data Protection Officer (Legal@Perspectum.com), who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO) by visiting their website at <https://ico.org.uk/make-a-complaint/>.