

Privacy Notice

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NHS England and Adelphi Real World Data Processing Privacy Notice

This Privacy Notice was last updated on 19th September 2023

Our commitment to your privacy

Adelphi Real World is committed to protecting and respecting individuals privacy and protecting anonymised and pseudonymised data. We take our responsibilities regarding the security of information that we have collected seriously. This privacy notice sets out how we use and protect the information that NHS England provides to us. Please read this notice carefully. If you have any questions, please contact compliance.team@adelphigroup.com

About this Privacy Notice

This Privacy Notice applies to Adelphi Real World who are processing personal data under the UK General Data Protection Regulation, UK Data Protection Act 2018 (UK GDPR).

This Privacy Notice supplements the other Privacy notices applicable to the Adelphi Group of Companies and is not intended to override them. The Adelphi Real World website contains the core business Privacy Notice.

This Privacy Notice provides information on:

- how we use your personal data;
- why we use your personal data;
- types of personal data we collect;
- sources of your personal data;
- legal grounds for processing your personal data;
- sharing your personal data;
- retention of personal data;
- our policy on correcting and updating personal data;
- making a complaint about our handling of your personal data.

This Privacy Notice also includes specific information for exercising your rights under data protection legislation (UK GDPR).

How we use your information?

Who are we

Adelphi Real World and the commissioning client jointly determine the purpose and the means of processing the personal data (joint data controllers) and will ensure that the personal data is processed according to data protection legislation including assurance that the personal data can be legitimately used for the intended research purpose.

NHS England are an independent data controller for the personal data prior to transfer of the Data insofar as the Data constitutes Personal Data.

We have appointed a data protection officer (DPO) who is registered with the UK Information Commissioner's Office and can assist with questions in relation to this privacy notice. If there are any questions about this privacy notice, including information on exercising individual rights, please contact the DPO using the details set out on page 8.

How we use your personal data

Adelphi Real World use your personal data for conducting research analysis for improvements in healthcare, service delivery and treatment, health outcomes or observational research projects on behalf of our commissioning client.

Adelphi Real World may also be required to use your personal data for adherence and compliance with legal and regulatory obligations, requirements, and guidance.

All personal data received by NHS England, is assigned a unique identifier (pseudonymised), so we will not know your identity.

Why we use your personal data

We use your personal data for the following purposes:

- Performance of research and analysis in order to achieve specific primary research objectives, either as Adelphi Real World or on behalf of our commissioning client;
- To contribute to the improvement of health and social care planning for the areas of interest;
- To describe the pharmacological and other interventional (i.e., surgery, radiotherapy) treatment patterns for patients diagnosed with specific areas of interest;
- To describe healthcare resource utilisation and direct medical costs for patients;
- The evaluation of real-world effectiveness outcomes for patients diagnosed with a specific area of interest.

We will only use data for the purposes for which we collected it, unless we reasonably consider that we need to use it for another reason and that reason is compatible with the original purpose. If data subjects wish to get an explanation as to how the processing for the new purpose is compatible with the original purpose, please contact Adelphi Real World or NHS England using the contact details in the Contact details section on page 8.

Types of personal data we collect

We process pseudonymised data provided to us, by NHS England.

Types of personal data that may be collected include:

- Individual identifier assigned by NHS England;
- Information concerning sociodemographics (such as age, gender, and ethnicity);

- Health Data: Clinical characteristics, diagnosis, and treatment details (e.g., surgeries, systemic anti-cancer therapies and radiotherapy);
- Secondary Care administrative data e.g., hospitalisation records, A&E admissions, referral details;
- Website Cookies (For further information on our use of website cookies, please see the 'If you use our website' section).

Sources of your personal information

Adelphi Real World receives personal data directly from NHS England. Any personal data provided to Adelphi Real World, is done so under specific agreements in place. Personal data is received directly from NHS England in a pseudonymised format, meaning that we will not be able to directly identify any individuals from the personal data.

Legal grounds for processing your personal data

Under data protection legislation, there are various grounds on which we can rely when processing your personal data. In some contexts, more than one ground applies. Our legal grounds for processing the personal data provided to us by NHS England is legitimate interest.

Adelphi Real World may also be required to use your personal data to comply with a legal obligation or for the purpose of fulfilling a contract. In some instances, we rely on consent e.g., website cookies (for further information on our use of website cookies, please see the 'If you use our website' section.)

Legitimate interests

We will process your personal information where there is a legitimate interest in us doing so if it is reasonably necessary to achieve our or others' legitimate interests (as long as that processing is fair, balanced and does not unduly impact your rights). We ensure we consider and balance any potential impact on the data subject (both positive and negative) and your rights before we process your personal data for our legitimate interests.

Contract

We may process your personal data if it is necessary for the execution of a contract in which we or you are a party.

Legal Obligation

We may process your personal data where it is necessary for compliance with a legal or regulatory obligation to which we are subject.

How long do we keep your personal data for?

Your personal data is stored securely. We will only retain information for as long as necessary to fulfil the purposes we collected it and for only to the extent we are required to do so by legal and regulatory obligations.

Data is maintained in line with the NHS England Data sharing Agreement which determines that the length of time records should be kept, should not exceed the length of the agreement (no longer than 3 years).

We keep a backup of our data to restore the original data after a data loss event. When we delete your personal data, it will be deleted from the live storage immediately but there will be a delay before it is removed from the backup data.

Who do we share your information with?

We do not share any of your personal data, provided to us by NHS England, with any other third party and not without the prior written consent of NHS England.

We use selected software providers to host our website. Such third parties will be authorised to process and use your information but only to fulfil their contractual obligations to us and will not be permitted to use it for any other purpose. We retain full responsibility for how your personal information, collected via our website, may be used by such agents.

We may be required to share your personal information so that we can comply with a legal obligation to which we are subject. For example: where we are obliged to share your personal information with regulatory bodies which govern our work and services; government departments such as law enforcement and HMRC; court orders etc. We may also share with our legal, professional, and financial advisors.

For example, if you are requesting information about a company or a service from Adelphi Real World, we may pass your personal data onto another member of the Adelphi Group of Companies to enable them to appropriately respond to your request. Again, unless you consent to the contrary, that member shall only use your personal data to provide the information you have requested.

Adelphi Real World does not sell, trade, or rent your personal information.

If you use our website

When you visit the Adelphi Real World website, we automatically use some cookies that are strictly necessary to provide our services to you and allow the website to operate; for all other cookies we need your consent. This is why when you first logged onto our website you were asked for your permission to append these nonessential cookies such as Google Analytics/Click Dimensions.

Our web servers capture IP Addresses that are stored in log files by default for troubleshooting connections. We purge all web server log files every 30 days.

We do not make any attempt to find out the identities of those visiting our websites. We will not associate any data gathered from these sites with any personally identifying information from any source. If we do want to collect personally identifiable information through our websites, we will ask your permission and explain what we intend to do with it. Appropriate security measures are in place, in our physical facilities to protect against the loss, misuse or alteration of information that we have collected from our websites.

Reason for using Cookies

Like most websites we use 'cookies' to collect statistics about how people use the site, and to help us keep it relevant for the user. Cookies 'remember' bits of information from your visit to the site to tell us how many people have visited each web page, how they got there, and where they navigate from there. We only collect IP addresses; this is for the purpose of security and to help prevent malicious activity occurring on our websites. The IP addresses are only stored and retained for 24 hours and then deleted. A cookie is a simple text file that's stored on your computer or mobile device by a website's server. Only that server can retrieve or read the contents of that cookie. Each cookie is unique to your web browser. So, if we put a cookie on your computer, it can't be read by any other website

Opting out of Cookies

If you don't want your web visits to be tracked for statistical purposes like this, you can disable the cookies from the cookie banner that is displayed when you first log onto our website or by clicking the cookie tab. You can also set your computer to block cookies at any time. The way in which you do this depends upon the web browser which you use. Go to <http://www.allaboutcookies.org/> to find out more, contact Adelphi Real World by using the contact details in the contact details section on page 8.

Transfers of personal data outside the EEA

We do not transfer any personal data received by NHS England, outside the European Economic Area (EEA) and have applicable technical and organisational measures in place to ensure your personal data remains in the UK.

How we protect your information?

We have put in place appropriate security measures to prevent your personal data from being accidentally lost, used, or accessed in an unauthorised way, altered, or disclosed. In addition, we limit access to your personal data to those who have a business need to know. They will only process your personal data on our instructions, and they are subject to a duty of confidentiality.

We have put in place procedures to deal with any suspected personal data breach and will notify NHS England and any applicable regulator of a breach where we are legally required to do so.

To protect your personal data Adelphi Real World employ:

- We strive to capture a minimal amount of personal data and only share it with other organisations where the law permits us to do so.
- Technical measures, including but not limited to, robust network security, firewalls, anti-virus protection, regular internal and external oversight, and inspection, including penetration testing, access controls, audit trails, encryption of devices and data both whilst at rest and during any transmission in order to keep your personal data secure.
- Organisational measures including, but not limited to, training of all individuals who process personal data in data protection and information governance, the creation of and adherence to appropriate policies and procedures.
- Techniques such as **anonymisation** (individuals are not identifiable and cannot be re-identified by any means) or **pseudonymisation** (individuals are given a unique identifier by NHS England and are therefore not directly identifiable from the data).
- Privacy by Design principles including data privacy impact and risk assessments which clearly document the privacy risks and the measures taken to mitigate those risks.
- Retention and Archiving measures so data that is no longer actively used is either deleted securely or moved to a separate storage location, with additional access controls, for retention.

Your data protection rights

You have specific rights in connection to your personal data processed by Adelphi Real World, although in some cases these rights are subject to certain conditions and limitations.

Any personal data provided to us from NHS England, will be pseudonymised, meaning that we will not know or be aware of your identity. To exercise any of these rights please contact NHS England, using the contact details in the contact details section on page 8.

Right to be informed

You have the right to be told how your personal information is/will be used. This Privacy Notice is intended to provide a clear and transparent description of how your personal data, received from NHS England, may be used.

Right of access to your information

You can request a copy of the information held relating to you from NHS England directly, using the contact details in the contact details section on page 8.

Right of erasure (right to be forgotten)

You have the right to have your personal data deleted but only where there is no lawful reason for it to be retained.

Right of rectification

If you believe your records are inaccurate or incomplete, you have the right to ask for these to be updated.

Right to object

You have the right to object to the processing of your personal data based on consent, legitimate interests, or the performance of a task in the public interest or exercise of official authority including profiling activity, direct marketing including profiling activity; and processing for purposes of scientific and or historical research and statistics.

Right to data portability

You have the right to data portability which allows individuals to obtain and or reuse their personal data for their own purposes across different services. It allows you to move, copy or transfer personal data easily from one IT environment to another in a safe and secure way, without hindrance to usability.

Right to be aware of automated decision-making

You have right to be made aware of any automated decision-making, that is made without any human involvement, and/or profiling of your personal information.

Adelphi Real World currently do not conduct any automated decision-making.

Right to 'block' or suppress

You have the right to 'block' or suppress the processing of your personal data. Processing of your personal data may be restricted in the event it is no longer essential to support the use of services provided to you and is no longer needed for any contractual, legal, or financial reasons.

Opting out

You can withdraw consent, (if the processing of your personal data is based on consent) or opt out of having your data processed at any time. However, this will not affect the lawfulness of any processing carried out before consent is withdrawn.

You can opt out by contacting the NHS England directly, using the contact details in the contact details section on page 8.

Complaints

If you have complaints relating to our processing of your personal data, you should raise these with the Adelphi Real World compliance department; see section Contact details on page 8, or you can raise directly with the relevant supervisory authority.

In the UK: Information Commissioner's Office (ICO). They can be contacted via their website <https://ico.org.uk/>

Contact details

Adelphi Data Protection Officer

The Adelphi Data Protection Officer (DPO) is registered with the UK Information Commissioner's Office and can be contacted via the Adelphi Real World contact details.

Adelphi Real World (UK office), ATTN: Compliance Department

Adelphi Mill, Bollington

Cheshire SK10 5JB, UK

Email: compliance.team@adelphigroup.com

Phone: +441625 577 829

NHS England

If you wish to exercise your rights or find information for the National Opt Outs here: [National data opt-out - NHS Digital](#) or email directly on: NDRSoptout@nhs.net

For information about the NDRS opt outs which is where the data for these studies will derive, this can be found here: [Opting out of disease registration - NDRS \(digital.nhs.uk\)](#)

If you wish to contact NHS England directly, exercise your rights, or find out further information then you can email their Data Protection Officer directly at: ndrsenquiries@nhs.net

Changes to this Privacy Notice

We keep our Privacy Notice under regular review and reserve the right to revise it at any time. There is a date at the beginning of this Privacy Notice which indicates the date it was updated. Historical Versions can be obtained by contacting us on the details above.