

NHS R&D Forum Privacy Policy:

FINAL v0.1 May 25th 2018

This privacy policy is published to provide transparent information about how we use, share and store any personal information that you may provide to us, and also what choices you have about that data, in compliance with the General Data Protection Regulation (GDPR) and UK legislation.

This policy provides information:

- 1. About the NHS R&D Forum and the organisations that act on its behalf**
- 2. About the personal information you may share with the NHS R&D Forum and how it is used.**
- 3. About the lawful basis for processing data**
- 4. About how we keep your data**
- 5. About your rights**
- 6. How to get in contact about your data**

1. About the NHS R&D Forum

The Forum is a professional network and community of practice largely supported by the work of its members. As such the Forum has very few staff or formal business operating systems of its own and instead subcontracts services to a number of organisations that act with and on behalf of the Forum administering company and members of the Forum community.

Health Research & Development Ltd.

A non-profit company called Health Research & Development Ltd administers the Forum as a legal body. The Directors of this company have conducted a data assessment and flow mapping exercise to identify all of the data that passes through the Forum, and they have authorized this privacy notice to explain how it is handled, the lawful basis for doing so and who is accountable for it.

Accountability

In some cases Health Research & Development Ltd will act as the data controller for the personal data that is shared via the NHS R&D Forum. In other cases organisations delivering contracted services, or individual member organisations will act as data controllers, doing so under the terms of their own privacy policies.

Organisations supporting the work of the Forum are as follows. Members of these organisations may access some or all of the personal data identified in this policy for the purposes of delivering the Forum objectives.

- Blueberry Business Support Ltd– <http://www.blueberrybookkeeping.co.uk/#>
- Delegant Ltd - <http://www.delegant.co.uk>
- Kate Greenwood Consulting.
- Forum community members, leadership team & partner organisations
- Training partner organisations that explicitly deliver some of our courses
- Accountancy services
- Printing services

Information shared between Forum members & partners

The Forum Community is made up of members and partner organisations that might share information with each other. In doing this and processing personal information each member does so in their own right and in accordance with their own Organisational data protection and privacy policies.

Some members may not belong to any organisations but may be service users or members of the public.

2. About the personal information that you may share with the NHS R&D Forum and how it is used.

Visitors to Forum websites: www.rdforum.org.uk www.annualrdforum.org.uk

The Forum website is hosted by a third party service. Session cookies are used to enhance user experience, to collect anonymous information about users' activity on the site, for example the number of users viewing pages on the site, to monitor and report on the effectiveness of the site and help us improve it. This service helps to maintain the security and performance of the Forum website. In some cases where you may wish to post a comment online, you will be asked to provide a name and email address. We do not use tracking cookies.

Forum Directory of R&D Department Contacts

The Forum R&D Contacts Directory holds the professional email addresses of NHS R&D departments and, in England, that of the associated Local CRN. The Organisational directory record also contains the professional contact address, phone number and name of the person who has been identified and submitted as the contact for that department.

The information held within the directory is published on the Forum website so that researchers and Sponsors can contact R&D departments and so that R&D offices across the NHS may contact each other. The details are also provided to the Health Research Authority in a monthly excel spreadsheet to support their regulatory systems, the CRN, and the devolved administrations upon request in support of facilitating research set-up, regulation and delivery across the UK. This system of sharing the database records with regulators also now extends to sharing directly with Sponsors such that they can contact R&D departments easily and directly for studies that do not require capacity and capability assessment.

Electronic mailshots: (Forum news, mailshots, courses and conference bulletins)

The Forum uses a third party service called Mailchimp to deliver monthly news and to communicate Forum business and opportunities to the community, which we believe are essential to our providing services as a Professional Network. When you sign up to receive Forum news or register for our conference, you may be added to distribution lists within Mailchimp to allow us to contact you.

Through Mailchimp members of the Forum management team gathers and monitors statistics around email openings and clicks to help us understand and improve our e-communications. This information is identifiable to you and you can manage these settings in Mailchimp here. Mailchimp privacy notice is also available here https://mailchimp.com/legal/privacy/?_ga=2.196510060.1906243466.1527174301-808351267.1472549318

Social Media Platforms

We use twitter and LinkedIn to communicate with and between the Forum members and communities of interest. If you contact us via direct mail in Twitter or LinkedIn this will be stored on those systems. If we re-tweet, post, or connect with you via either of these social media platforms your comments, posts or profile will become visible to our social media followers as well as those who can follow our Twitter feed directly from the Forum website.

Email communications

All emails are stored on the Forum email server @rdforum.org. Some emails are also shared across our management team and held on their third party systems such as gmail, yahoo or livemail. Emails are archived and then deleted according to our data protection and retention times specified below.

Forum surveys

The Forum will distribute surveys to members from time to time. These surveys may use a third party system such as survey monkey, within which your personal data may be held should you choose to provide it. Our surveys are usually anonymous however where personal information is requested or provided by you voluntarily for survey purposes, you may be given the opportunity to opt in and agree to how your information is used.

Working groups

If you become part of a Forum working group, work stream or project group then your email address will be shared by us with other members of that group and circulated in emails to those who are taking part in email communications about a topic.

The content of emails will usually be kept within that group distribution unless otherwise communicated and this practice is promoted to members by the chair of each group. Members of groups may be asked to share their photo for publishing on the Forum website.

Expenses

Service users who are involved in Forum work may claim expenses to cover their costs, in line with our expenses policy. In order to process these claims and to make payments the personal information contained within the claim form is held by our business support and book keeping teams on their electronic systems.

Accountancy & bookkeeping systems

Xero is accountancy software and a compliant system used by Blueberry Business Support Ltd to manage the accounts, invoices and bookkeeping of Health Research & Development Ltd and the Forum. You can more about Xero here: <https://www.xero.com/uk/>

Training & events registration

If you attend one of our training courses or professional events, you will be asked to register some personal information as part of the booking process to include your name, address and dietary requirements. If the event is fee-paying this will include some financial details. Your information will be held in a database by the event and book keeping teams at Blueberry Business and Delegant Ltd and sometimes by an organisation that may be partnering with us to host the event. Names and email addresses and dietary requirements are sometimes held in excel distribution lists for the purposes of managing smaller workshops or group meetings by Forum members. The record of your attendance will be kept for a maximum period of 6 years for quality assurance purposes

Delegate lists and evaluation forms may be shared with course leaders, trainers and other members of the Forum management team. For some of our events a full delegate listing will be published in the event materials along side slides and materials. Sometimes this information is held within a third party system called Drop box. You can read more about Drop box here: https://www.dropbox.com/en_GB/

If we have to create name badges, delegate guides etc then your details (usually name and company/organisation) will be provided in pdf format to a printer for printing

Photographs

We may tweet about or during our training events, meetings, conferences and workshops. In doing so we may also tweet photographs or post them onto one of our websites. We will try to make our intentions clear to all delegates at the time photographs are taken and we will also provide you with the means to contact us if you wish for your photograph not to be taken or posted online. At all times you can register your requests through info@rdforum.org.uk or contact a member of the team by telephone <http://www.rdforum.nhs.uk/content/contact-us/>

The Resources Exchange

The Forum resources exchange <http://www.rdforum.nhs.uk/content/resource-exchange-home-page/> contains links to documents, resources and online tools submitted by the Forum community. They are then displayed on the Forum website and may contain personal information such as authors name and affiliated organisation, if they have been included within that resource. Documents that are submitted that are not already on a public facing website are displayed with the permission of the person making the submission and that person is asked to ensure they have the permission of the resource owner before uploading. Resources can be removed at anytime from the exchange.

3. About the lawful basis for processing your personal data

To be compliant with GDPR we must hold, process and store any personal data that you send to us lawfully and transparently.

We believe that you would expect us to use your personal data as specified above in order to undertake our role as facilitators of a Professional Network and our community of practice. We therefore are using **legitimate interest** as the lawful basis for processing most of the personal data you provide to us during your engagement with the Forum, and we have conducted a legitimate interests test to ensure we are doing so fairly and in a way that you would expect. Within our role as a network we believe you expect to receive up to date information from our partners and us and therefore we do not consider this to be marketing. However in most cases you will also opt-in, electing to receive this information, and you will always be able to opt-out.

Where financial transaction takes place we will use **contracts** as a lawful basis as a contractual relationship is being fulfilled. On occasion we may conduct a survey that includes your identifiable data and when we may need to ask for your explicit consent.

The R&D contacts directory hosted by the R&D Forum website is part of a UK-wide research management system that supports the regulatory landscape. We encourage all information in this database to be professional and include a generic office email address only, as we regularly share downloads of these addresses with research Sponsors and regulators in order for them to contact your office about research studies. As such we do not believe that true consent can be fairly obtained and that legitimate interest is the appropriate lawful basis for processing this information.

4. How we keep your data

Retention & destruction:

- We will keep financial records and records of your course attendance for quality assurance and audit purposes for a 6 year retention period or there is an overriding legitimate interest for holding it further.
- We will keep all other records (emails and any other records of activity) for a maximum of 6 years, unless you tell us otherwise or there is an overriding legitimate interest for holding it further.

Security

Health Research & Development Ltd on behalf of the NHS R&D Forum takes the care of your personal data very seriously and together with our partners we use a combination of measures to protect it, including secure servers, passwords and virus and malware protection.

We do not process or store any special category data and all members who have access to your data will have received training to make sure they understand the importance of keeping it safe. We always encourage the sharing of professional personal data only wherever possible.

Servers used to store your personal information are all located within the EU and we do not use your information for automated decision making

Whilst we take all of the measures that we've outlined above, unfortunately the transmission of information using the Internet is not completely secure. Although we will do our best to protect your personal data sent to us this way, we cannot guarantee the security of data transmitted to our site.

In the extremely unlikely event that we experience a data breach, our data protection function will work immediately to close the breach, analyze the cause of the breach and put in place preventive measures to avoid a similar breach recurring.

5. About your rights

Your right to rectification

You have the right to ask us to rectify information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete. This right always applies.

Your right to erasure

You have the right to ask us to erase your personal information **in certain circumstances**. This right is not absolute You can read more about this right on the Information Commissioners Office Website here: <https://ico.org.uk/your-data-matters/your-right-to-get-your-data-deleted/>

Your right to restriction of processing

You have the right to ask us to restrict the processing of your information **in certain circumstances**. You can read more about this right on the Information Commissioners Office Website here <https://ico.org.uk/your-data-matters/your-right-to-limit-how-organisations-use-your-data/>

Your right to object to processing

You have the right to object to processing if we are able to process your information because the process is in our legitimate interests. You can read more about this right on the Information Commissioners Office: here: <https://ico.org.uk/your-data-matters/the-right-to-object-to-the-use-of-your-data/>

The NHS R&D Forum, which includes all contracted organisations working as part of the management team, values your contribution to the Forum and will never sell or lease your personal information. We will only share your information:

- **With third party service providers and agents** to process information on our behalf to undertaken Forum business and to support the health and care research endeavour across the UK.
- **To comply with the law:** To comply with legal or regulatory requirements and to respond to lawful requests, court orders and legal process.
- **To enforce our rights, prevent fraud and for safety purposes:** To protect and defend the rights, property, or safety of us or third parties, including enforcing contracts or policies, or in connection with investigating and preventing fraud.

You have full control of your personal mailing list account details and you can opt out of receiving Forum news at any time should you wish to do so. You can also request to be removed from the Forum Directory, to be replaced with a generic contact address or another member of your team, at anytime. If your details are contained within a resource on the resources exchange that you wish to be removed we can do this on your request.

If you would prefer us to:

- Stop contacting you
- Amend your information
- Delete your information
- Change your preferences (for instance if you would prefer us to only contact you about certain things or restrict what information we have about you)
- Any other change

Please tell us. You can do so by emailing anyone from NHS R&D Forum management team via info@rdforum.org.uk. We will make any changes requested within 1 month, or sooner where we can. If you wish to see the information that we hold about you, you can make a subject access request via info@rdforum.org.uk

Right of portability

You are able to request a copy of the information we hold about you or ask for us to send the information to another data controller with your permission if you provided this information to us. The right of data portability only applies if we are processing your information based on your consent or we are in talks about entering into a contract or the process is automated. We can send personal data in structured, commonly used and machine-readable formats, using secure methods.

6. How to get in contact about your data

We value your contribution to the NHS R&D Forum and hope that you continue to support our good work. If you have any questions at all about the processing of your personal data please get in touch with a member of the team via the details below:

Email: info@rdforum.org.uk

Post: Health Research & Development Limited, Boston House, Grove Business Park, Wantage