Privacy Notice – Research

We are a research active organisation committed to bringing the best care to you through new treatments and therapies by active involvement in innovative research and developing and harnessing new ideas. Our portfolio covers a range of specialities within the mental health arena, offering patients, carers, staff and members of the public, the opportunity to take part in a wide choice of research studies.

This privacy notice tells you what to expect us to do with your personal data in respect of research studies.

Our contact details

Name:	North Staffordshire Combined Healthcare NHS Trust
Address:	Lawton House, Bellringer Road, Trentham Stoke-on-Trent ST4 8HH
General phone number:	0300 123 1535

Website: www.combined.nhs.uk

Data Protection Officer contact details

Our Data Protection Officer is Sahra Smith who is responsible for monitoring our compliance with data protection requirements. You can contact her with queries or concerns relating to the use of your personal data at DPO@combined.nhs.uk.

Data Controllers in health and care research

- The research Sponsor acts as the data controller in relation to the research data
- If you are a service user, the same data may be provided to your care team. In this case, the organisation is also the controller
- If the purpose of collecting the data was the delivery of your healthcare and you are not participating in a research study, then the Trust is the controller
- If the data is then transferred to a research Sponsor, the Sponsor has obtained it indirectly and becomes the controller for the processing of the data for research purposes

Further information regarding the controller of your research data can be obtained from our research and development (R&D) team at research@combined.nhs.uk.

Patient data and health and care research

All NHS organisations (including Health & Social Care in Northern Ireland) are expected to participate in and support health and care research. The Health Research Authority (HRA) and government departments in Northern Ireland, Scotland and Wales set standards for NHS organisations to make sure they protect your privacy and comply with the law when they are involved in research. Research ethics committees review research studies to make sure that the research uses of data about you are in the public interest and meet ethical standards. The HRA reviews research studies to ensure good governance and legal compliance.

Health and care research may be exploring prevention, diagnosis or treatment of disease, which includes health and social factors in any disease area. Research may be sponsored by companies developing new medicines or medical devices, NHS organisations, universities or medical research charities. The research Sponsor decides what information will be collected for the study and how it will be used.

Health and care research should serve the public interest, which means that research Sponsors have to demonstrate that their research serves the interests of society as a whole.

They do this by following the UK Policy Framework for Health and Social Care Research. They also have to have a legal basis for any use of personally identifiable information.

Anonymised information about your participation in research will be held on EDGE, a secure electronic national research management system. This is accessible by our R&D team, local research teams and the Local Clinical Research Network (LCRN) for reporting purposes only.

Lawful basis for processing personal identifiable data for research purposes

- Article 6 (1) (e): Necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller
- Article 9 (2) (j): Necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89 (1) 'subject to appropriate safeguards that ensure technical and organisation measures are in place in particular in order to ensure respect for the principle of data minimisation. Those measures may include pseudonymisation provided that those purposes can be fulfilled in that manner. Where those purposes can be fulfilled by further processing which does not permit or no longer permits the identification of data subjects, those purposes shall be fulfilled in that manner'

Your choices about health and care research

We will inform you about opportunities to take part in relevant research unless you ask us not to. We want to ensure that everyone who has used our services hears about research opportunities and we may contact you about research that you may be eligible to take part in.

We will contact you directly to ask whether you would like to participate in research, rather than asking your clinician on your behalf. You do not have to take part. It is up to you to decide whether to find out more about the research we contact you about. We do not share patient data outside of NSCHT as part of this process, without your explicit consent.

If you do not want to hear about research opportunities, you can tell us:

By email: research@combined.nhs.uk

If you have previously told us that you do not wish to hear about research, this preference will continue to be recorded.

It's important for you to be aware that if you are taking part in research, or information about you is used for research, your rights to access, change or move information about you are limited. This is because researchers need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from a study, the Sponsor will keep the information about you that it has already obtained. They may also keep information from research indefinitely.

If you would like to find out more about why and how patient data is used in research, please visit the Understanding Patient Data website or read the Patient Data and Research leaflet - Health Research Authority (hra.nhs.uk)

Consent

Section 251 of the NHS Act 2006 allows the common law duty of confidentiality with regard to patient data to be set aside in specific circumstances, where anonymised data is not sufficient and where patient consent is not practical. This legislation provides for the use of confidential patient data for medical research purposes under strict guidelines.

We still need your consent to actually take part in research projects unless approval is in place under Section 251 of the NHS Act 2006.

For the processing of health and care personal data for research purposes to be legal, the following criteria must be satisfied:

- The UK GDPR lawful basis must be identified
- The common law duty of confidentiality must be met through consent unless section 251 support is in place

Consent is not our legal basis for processing your personal data for research purposes.

Common Law – Confidentiality

Information is considered confidential in law if:

- It is not in the public domain
- It can be related to an identifiable individual (both living and deceased)
- It has a degree of sensitivity associated with it
- It is given with the expectation that it will be kept confidential (the common law of confidentiality does allow us to share confidential information in relation to crime and safeguarding, when in the overwhelming public interest)

Reasonable Expectations

When confidential information is given to a clinical team and/or a research team, it will be handled in line with 'reasonable expectations'. Collaboration between clinical teams and research is commonplace and we will tell you what our intentions are in relation to your information to ensure you understand what is proposed and what it means for you.

Data will be anonymised where possible.

Disclosure of information outside reasonable expectations to support research

We are able to disclose your data outside of reasonable expectations if we have 'Section 251' approval to do so and such disclosure is approved by the Health Research Authority (www.hra.nhs.uk/). This does not affect our obligation to abide by the UKGDPR.

If we disclose personal data under 'section 251' both recipient and disclosing organisations will:

- Have a legal basis to hold and use the data (both personal and special categories)
- Be fair and transparent about holding and using the data – patient notification will be issued

National opt-out programme and the common law duty of confidentiality

This opt-out only applies to the common law of confidentiality and not the UKGDPR and should not be confused with the UKGDPR Right to Object.

Further information regarding the national opt-out can be found at www.digital.nhs.uk/

Safeguards

- Processing personal data for research purposes will not cause distress or damage to someone and will only be processed in the public interest
- Only the absolute minimum amount of personal data required for research will be used
- Data will be pseudonymised where compatible with the achievement of the research purpose
- Where the research purpose can be satisfied by processing anonymised data, identifiable data will not be used
- A suite of Information Governance Policies are in place together with the use of the common law duty of confidentiality to ensure your data is adequately protected and processed in accordance with the law

How patient data may be used for research

When you agree to take part in a research study, the Sponsor will collect the minimum personally identifiable information needed for the purposes of the research .

Information about you will be used in the ways needed to conduct and analyse the research study.

NHS organisations may keep a copy of the information collected about you. Depending on the needs of the study, the data that is passed to the research sponsor may include personal data that could identify you.

You can find out more about the use of patient data for the study you are taking part in from the research team or the study Sponsor. You can find out who the study Sponsor is from the information you are given when you agree to take part in a study.

For some research studies, you may be asked to provide information about your health to the research team, for example in a questionnaire.

Sometimes information about you will be collected for research at the same time as for your clinical care, for example when a blood test is taken.

In other cases, data may be copied from your health records. Data from your health records may be linked to information from other places such as central NHS records, or data about you collected by other organisations.

You will be told about this when you agree to take part in a study.

Keeping information for future research

Information about you that is collected during a research study may be kept securely to be used in future research in any disease area, including research looking at social and economic factors affecting health. This may include combining it with information about you held by other health or government organisations such as NHS Digital.

Usually, the information is combined together by matching information that has the same NHS number. Doing this makes maximum use of the information you have provided and allows researchers to discover more.

Researchers may not be able to specify all the possible future uses of the information they keep. It could include providing the information to other researchers from NHS organisations, universities or companies developing new treatments or care. Wherever this happens it will be done under strict legal agreements. The data about you will be depersonalised wherever possible so that you cannot be identified. Where there is a risk that you can be identified your data will only be used in research that has all relevant regulatory approvals in place.

On rare occasions NHS organisations may provide researchers with confidential patient data from your health records when we are not able to seek your agreement to take part in a study, for example because the number of patients involved is too large or the NHS organisation no longer has your contact details.

Researchers must have special approval before they can do this.

What to do if there is a problem

If you wish to raise a complaint on how any research organisation has handled your personal data, you can contact the relevant Data Protection Officer who will investigate the matter. If you are not satisfied with their response or believe they are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Trust Contacts

Dr Ravindra Belgamwar, Director of Medical Education and Research

Email: research@combined.nhs.uk

Sahra Smith, Data Protection Officer

Email: DPO@combined.nhs.uk