

ResearchOne Information Leaflet for Patients

Introduction

ResearchOne is a database of non-identifiable patient information collected from healthcare settings in England. Some of your anonymous health information is included in ResearchOne for the purpose of research and public health surveillance. The researchers given access to ResearchOne are subject to a duty of confidentiality and appropriate ethical approval. Your right to have your anonymous data excluded from ResearchOne will be respected. This leaflet provides information to answer some of the questions you may have. For further information please visit the ResearchOne website (this is given at the end of this leaflet) or contact us directly by visiting the website contacts page.

What is ResearchOne?

ResearchOne is an electronic database of non-identifiable patient data collected from health records across England. At present more than 20 million patients have the opportunity to contribute non-identifiable healthcare data. Researchers with ethical approval use ResearchOne for health and surveillance research. Information about current and previous research projects is available on the website. ResearchOne is an invaluable resource for public health research due to the depth, relevance and quality of the data stored.

How am I Involved?

Your healthcare provider uses the TPP SystemOne clinical system to maintain your electronic patient record. This contains the details of your treatment and medical history in order to help provide you with high quality healthcare. Anonymous data from this electronic patient record is transferred to ResearchOne to facilitate medical research and to benefit public health. No identifiable details, such as name, date of birth, address or NHS number are transferred to ResearchOne. No notes made in your record will be included in ResearchOne.

Each patient who contributes data is helping to create an invaluable research resource, representing an accurate picture of public health across England.

Why does my Health Care Provider Contribute Data?

Your healthcare provider has chosen to contribute to ResearchOne in order to support quality, high-impact medical research, to drive innovation and to deliver the best possible health care for everyone. ResearchOne also helps your provider to improve the quality of their electronic records and to get early access to new risk prediction and decision support tools, for example.



What Type of Data is on ResearchOne?

Selected healthcare information from electronic patient records is included on ResearchOne. This includes current and past medication, diagnostic codes, allergies and sensitivities, laboratory results and vaccinations, for example. A full list of the stored data types is available in the database protocol on the ResearchOne website. No information that could identify you or your healthcare providers is available to researchers. In order to provide an even more comprehensive research environment, the information may be linked with hospital and disease registry data. This is will only be done if the appropriate ethical and governance authorities have approved this data linkage. Patient confidentiality remains the highest priority and is never compromised.

Who Runs ResearchOne?

ResearchOne is run by TPP as a not-for-profit enterprise. TPP manage the patient health records in the SystemOne clinical information system used by your healthcare provider. TPP store all data in fully NHS accredited centrally-hosted secure data centres. This provides the highest possible security level for data storage and access.

Who Monitors ResearchOne?

ResearchOne is developed with the approval of the NHS Research Ethics Committee and subject to their ongoing monitoring. Governance advice is provided by the National Information Governance Board for Health and Social Care and ensures the necessary safeguards for the appropriate use of patient information. The database protocol, including the confidentiality agreement and guidelines for researchers, is available on the ResearchOne website.

There are two committees which govern the management and use of the information. The ResearchOne Database Committee monitors all actions involving ResearchOne and includes patient representatives, GPs, healthcare providers, academic members, researchers and TPP directors. The committee members have years of experience in the medical research sector and the governance and ethical issues which surround it. An additional ResearchOne Project Committee ensures that all research is of high quality, is relevant to current public health initiatives and does not breach patient confidentiality.

Who uses ResearchOne?

ResearchOne is used by medical researchers who have ethical approval from the NHS Research Ethics Committee and any additional appropriate governing bodies. The ResearchOne Project Committee is in place to guarantee that approved projects will be of benefit to public health across the NHS. Researchers will only have access to minimal set of information needed for their research to progress effectively.



How is the Data Collected?

Information is entered into your electronic patient record by your healthcare provider. If your provider has consented to share research data and you have not decided to opt out, then appropriate anonymous information is automatically included in the ResearchOne database at regular intervals. This process all happens electronically; patient information is never physically collected or manually entered into the database in order to maintain the security of patient information.

How is my Information Kept Confidential and Anonymous?

All data stored in ResearchOne is non-patient identifiable. Researchers are subject to a duty of confidentiality and their use of the data is constantly monitored to ensure confidentiality. The information is stored centrally and securely in data centres hosted to full NHS security standards. The policies around anonymisation, use and data storage are available in the database protocol available on the website.

What if I don't want to be Involved?

If you do not want your data to be included in ResearchOne then please discuss this with your healthcare provider. They will record your decision to 'opt out' on your patient record and your data will be automatically removed from ResearchOne within a short period of time.

How can I learn more?

More information will be available after the ResearchOne website launch in February 2013:
www.researchone.org

