

UK SECURE eRESEARCH PLATFORM

UKSeRP



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DATA SHARING: WHY SHOULD WE SHARE DATA?

It is common practice for organisations to routinely collect and hold data on their clients, patients, research subjects or other individuals, and many make good use of their own data to conduct research. But increasingly, and particularly in light of an increasing demand for access to data from the research community along with current and impending statutory obligations to do so, there is greater emphasis on organisations sharing their data safely and anonymously for research purposes to improve the lives of the wider population.

There is no doubt that by leveraging the power of shared data and opening up access to masses of data that would not otherwise be accessible for research, the enormous potential to drive insight is unlocked for the benefit of society. Data sharing stimulates new ideas and areas for research and increases the potential for collaboration, particularly on larger national scale research projects.

Organisations that were previously limited to using only their own data can benefit from collaborating and sharing data with approved partners, both from within their own organisations or more broadly across industry sectors, giving access to a much wider pool of vital information. In doing so data owners will realise the full potential of their own data to benefit the wider research community and society.



DATA LINKAGE - HARNESS THE POWER OF RELATIONAL DISCOVERIES

The ability to link multiple sources of data together that relate to e.g. a particular individual, a geographical location or an event, brings a new dimension to answering research questions. Data linkage allows researchers to use existing collections of extensive data that has been routinely collected and stored to identify patterns across entire populations to give a much broader picture. Previously unnoticed relationships can be identified giving greater depth of clarity and understanding that wouldn't otherwise be possible from analysis using a single source of data alone. Using existing data is far more cost effective than having to collect the equivalent data through other methods such as surveys, and is overall far less intrusive.

UKSeRP - SHARE AND LINK DATA SAFELY AND SECURELY

UKSeRP is a high powered, safe and secure e-research platform. It allows data owners and researchers to store, access, share, analyse and link data at scale in a governed environment whilst maintaining full control of the data at all times.

UKSeRP is the perfect solution for any organisation that has accumulated a large amount of data, that intends to share that data for the purposes of research and long term benefit to society, and that wants to do so in the most secure and safe way possible to reduce associated risks.

WHO SHOULD USE UKSeRP?

Organisations such as the NHS and Health Boards, Government Departments and Academic Centres in particular would all benefit from using UKSeRP.



HEALTHCARE

Hospitals and health care systems routinely collect and hold large amounts of data on their patients through health records and there is strong emphasis on the need to share data in order to continually improve upon the services provided to patients and accelerate the research process to deliver improvements in healthcare.

Research using shared and linked data can provide insight into areas that can be developed to provide more efficient services, offer improved care and treatments to patients, enhance the patient experience, enhance existing services and develop new ones, and ensure a more considered distribution of provisions and co-ordination of services.

Key to successful data sharing and data linkage for the healthcare sector is the trustworthy use of patient data and patient privacy. UKSeRP provides the mechanism to exchange data between healthcare organisations (or other relevant external organisations) whilst providing a safe, secure and governed environment to ensure that patient data is safeguarded with confidence.

Access to the data is strictly controlled by the data custodians to respect data protection rights and ensure anonymity. UKSeRP uses international best practice to de-identify your data with a variety of different approaches e.g. using trusted third parties that protects data owners and individuals alike.



LOCAL AND CENTRAL GOVERNMENT

Government departments are keen to harness the potential of using administrative data for research to identify opportunities where resources can be re-directed for the greater welfare of society. Public agencies that already hold large amounts of data and wish to share it would benefit from proportional use of appropriately shared data to improve the welfare of individuals, enhance administrative processes and procedures for users, identify and recover cases of fraud and other financial losses that can be redirected back into public services, and to produce more accurate official statistics. The benefits to society could be further enhanced if data were not only shared between public agencies, but also between public agencies and other sectors such as health and social care to give greater depth of understanding to research questions.

Governments recognise the compelling arguments for the benefits of sharing and using administrative data for research and statistics to develop policies and services that will benefit society in a more targeted way. To progress proposals for improving the availability of administrative data in safe settings for valuable research it is essential to establish a code of practice for collecting and storing data, creating suitable controls for sharing data and, arguably most importantly, ensuring safe guards to protect the identity of individuals and organisations through effective de-identification. UKSeRP is an all-encompassing solution that effectively addresses all of these important factors to make data sharing and data linkage possible.



ACADEMIC RESEARCH

It is widely agreed that access to shared research data not only improves the quality and frequency of new research but also the fact that reusing 'old' data for new research questions facilitates innovation, as far less time and effort is expended on collecting data leaving more time for answering research questions. Add to this the fact that networking and collaboration opportunities increase when data is shared through increased visibility among peers in the academic community. However, sharing data between academic institutions, although widely supported and acknowledged as a great enabler to scientific progress, is not yet widely practiced.

The issues hindering data sharing amongst the Academic community are numerous and complex ranging from data owners retaining control of the data, secondary users ability to understand and interpret others' data sets, concerns surrounding the security of storing data, ensuring de-identification of sensitive data, the quality of data if it is to be shared, and having access to a data sharing process that is simple to use.

UKSeRP is a complete solution created to solve such issues and opens the way to safe, secure data sharing and data linkage in an uncomplicated manner requiring minimum time and effort.

Naturally, control and ownership of the data in terms of who exactly will be using it are important concerns, and UKSeRP ensures that any access to the data is strictly controlled by the data owner to ensure appropriate and agreed use for further research. Best practice approaches to de-identification deal with any legal uncertainty surrounding data sharing, especially when

researchers are working with sensitive data.

The data management facilities include automatic analysis of the data for quality assessment, and a comprehensive metadata cataloguing system that enables interoperability and removes any effort on the part of the data owner to have to explain the content of the data. It allows permitted users to make sense of data sets and prevents misinterpretation without any additional assistance being required from the data owner.

Previous problems that are typically associated with the physical act of sharing data, such as how and where will researchers using the owner's data store and protect it, are no longer a concern as data stored in a UKSeRP provides complete reassurance of being contained within a robust, accredited and highly regulated environment.

UKSeRP simplifies the data sharing and linkage processes in a safe yet accessible environment making it easy for academics to embrace and engage with the practice of sharing data without the need for technical skills.

UKSeRP: A COMPLETE SOLUTION FOR DATA SHARING AND DATA LINKAGE IN A SAFE, SECURE AND CONTROLLED ENVIRONMENT

A COMPLETE PRE-INSTALLED SOFTWARE SUITE An All-In-One Solution

Designed to be very user friendly, UKSeRP is really quick to set-up and operate without the need for any specialist technical skills or training. Having a complete solution takes away the need to acquire separate pieces of software to do different jobs making this a convenient and low cost alternative.

Each organisation's particular security considerations that require specialist solutions to meet specific needs will benefit from the bespoke design and implementation service to create a tailored product specifically to meet those requirements.

To get started we will work closely with you to gain a full understanding of your requirements so that we can set up your very own UKSeRP.

Once established, data owners can begin to upload and prepare their data, create projects, set up user accounts and make the necessary preparations to start sharing the data.

Researchers or analysts can then request an online account and, if you approve, you can easily create a secure desktop for them to access a range of statistical research software and start to use the data you have agreed to make available.

ACCESS CONTROLS AND PERMISSIONS Data Owners Retain Full Control

With UKSeRP the data custodians retain complete ownership and remain in full control of their data at all times with the ability to define roles and to set preferred access controls and project permissions to ensure that particular datasets are accessed only by pre-approved individuals as defined by you. Not only does this give complete confidence in the knowledge that your data remains private and protected, but it also significantly reduces reputational risk in an increasingly transparent 'business' environment.

Further to this, storing and using data in a governed environment is also very reassuring for stakeholders, so by demonstrating high levels of security around your data and data usage, you will certainly increase your credibility.

SECURE REMOTE ACCESS Continuous Access from Anywhere in the World

All organisations holding sensitive data want to ensure that it is protected at all times and it is imperative that such data is not physically moved from one place to another due to the high level of risk. At the same time, it is important that the right people can access the data they need to without hindrance in order to conduct research quickly and effectively. UKSeRP's solution to this conundrum is its secure remote access facility.

Approved users can access data from any desktop from anywhere in the world at any time, or from an established 'safe zone' if preferred, so that research activity isn't restricted. This highly secure yet agile approach means that not only can collaborative teams constantly capitalise on new opportunities with ease, but equally importantly, sensitive data is never sent to anyone ever again offering organisations complete protection from associated risks. Secure remote access is particularly attractive to dispersed research teams as it reduces costs, and having such flexibility enhances the work life balance for employees leading to long term staff retention.

UKSeRP simplifies the process of sharing data in the most secure, low risk way eliminating geographical limitations of access to data and the need to compromise security previously associated with moving data around.

UKSeRP offers a coherent environment that is specifically designed to support and simplify the process of not only sharing data but also linking data easily and effectively.

GOVERNED ENVIRONMENT Protection For You and Your Data

Already pre-approved as an accredited platform for HSCIC (Health and Social Care Information Centre) data sharing framework agreements, the ISO27001 'kite mark' and regular audits and inspections gives your programme increased credibility with enhanced security. Additionally, full audit trails of use are available upon request at any time.

So not only does UKSeRP protect your organisation from reputational risk of potential data compromises by storing data in an accredited and highly regulated environment, it also facilitates the re-use of person based data to satisfy increased public awareness, reduces the time it takes to gain necessary approvals, and enhances cooperation, agreement and data sharing.

STATE-OF-THE-ART DATA LINKAGE Gain New Insights from the Data

UKSeRP has a world class data linkage mechanism at the push of a button. The fully automated probabilistic data linkage system eliminates all of the technical challenges typically associated with linking data (with optional manual inspection and tuning if required). This will effectively reduce time spent on projects by performing fast and accurate data linkage on demand.

This advanced technology brings with it the ability to create new complex datasets more easily than ever before to increase research insight. UKSeRP makes easy work of using and linking your own data which not only increases the value of your existing data, but will also save you the time and expense of collecting primary data. By linking your data the process has the added advantage of highlighting any irregularities and improving the quality and consistency of your data for research.

GETTING STARTED

SET UP A UKSeRP



Tell us exactly what you need and we will create a UKSeRP to the required size and scale

DATA OWNER UPLOADS AND PREPARES DATA



Upload, analyse, catalogue and de-identify your data and set access controls ready for use

RESEARCHERS ACCESS THE DATA



Allow researchers access to the data through their secure remote desktop

ALL THE ESSENTIAL FEATURES FOR YOUR PROJECTS

SIMPLE USER INTERFACE Upload Data Easily

UKSeRP gives users a straightforward way to migrate large amounts of data into a highly regulated secure environment for peace of mind. An easy to use system, it requires no specialist technical skills or training thereby reducing technical problems and allowing the focus to remain on the research question. By eliminating the need for manual processing you can avoid lengthy delays to your projects and enjoy reduced associated costs.

DATA QUALITY ANALYSIS Cleaning the Data

Once data has been uploaded into UKSeRP, it can be automatically analysed in order to highlight any anomalies in the data such as missing fields or whether any fields are corrupted etc. giving you the opportunity to improve the quality of your data before use. This ensures that you produce precision data to reduce errors and mistakes that would otherwise affect the research results.

METADATA CATALOGUING Making Sense of the Data

Once data has been uploaded into UKSeRP and cleaned for irregularities, how can you make sense of such a massive amounts of data and source the right data sets for your research questions?

The answer lies in the semi-automated metadata cataloguing system that has been built with the user in mind to eliminate the need for training and associated costs. No-one knows more about the content of the data being uploaded than the owners who are best positioned to augment the data sets with descriptors of what each dataset contains. Approved users can then quickly identify data sources that can be linked for specific research questions with ease and increase productivity.

Being able to catalogue the contents of your data is a great way to increase potential collaborations by sharing the descriptors of your data in an uncomplicated format. The metadata catalogue allows you to attach supporting documentation to your datasets giving researchers additional intelligence to quickly select the most appropriate data sets for their projects when they need them and to stimulate new research activities.* Access to view metadata catalogues when sourcing the right data reduces the time it takes to source data and helps to prevent costly delays associated with acquiring new data.

DATA DE-IDENTIFICATION Anonymising the Data

When sharing person based data with pre-approved research partners, the data can be rendered de-identified by removing personal details such as names, addresses etc. in order to keep each individual anonymous. This ensures complete privacy and protection of individuals' data whilst still allowing it to be shared and used for research.

UKSeRP uses international best practice to de-identify your data, whilst allowing others safe and secure access for research. This is a very efficient process with a variety of different approaches to de-identification e.g. using trusted third parties that protects data owners and individuals alike.

WIDE RANGE OF ANALYTICAL TOOLS Analysing the Data

UKSeRP comes with a wide ranging suite of analysis tools so that users have access to tools they are already familiar with without the need to learn anything new whilst taking full advantage of using new powerful software. UKSeRP ensures you are using the tools best suited for each job with the added advantage of a lower cost of ownership.

WIDE RANGE OF DATA STORAGE TECHNOLOGIES Manage, Store and Process the Data

It is important to have the right type of data storage for your specific requirements and budget and UKSeRP offers the flexibility to choose the most appropriate option from DB2, SQL Server, PostgreSQL, Hadoop or NoSQL. Having instant access to various storage options that are fully managed and maintained requires no involvement on your part saving both time and money, and allows you to concentrate your efforts entirely on your project knowing that your data is safe and secure.

DIVERSE FORMS OF DATA Store and Analyse with Ease

UKSeRP is a robust, large scale high performance data storage and analysis platform for large complex data sets. There is infinite scalable capacity for data to be stored in a safe neutral shared environment that has the capability to integrate diverse forms of data from multiple record systems for analysis with ease.

LARGE SCALE HPC CAPABILITY Solve Larger Problems with the Data

HPC, or High Performance Computing, is essential for large scale data-intensive analysis requiring fast, reliable and efficient processing power. Whatever the size of your project or programme, UKSeRP is completely scalable and customisable to your specific requirements to empower innovation and advance discoveries faster. UKSeRP's highly scalable HPC also gives the added advantage that you only pay for what you need to process large complex datasets giving you real value for money.

CUSTOMISABLE OPTIONS Only Use What Your Project Requires

If you are still unsure whether a complete off-the-shelf solution is right for your projects, organisation and budget, then you'll be pleased to know that UKSeRP has a wide variety of customisation options available to suit your project including a variety of multi-modal add-ons for different data types (e.g. genetics, imaging etc.)

It is possible to incorporate your own software or systems within UKSeRP negating the need to spend time and money on training, and it is an expandable, flexible and reconfigurable solution that grows with your project as it develops over time.

Whilst you remain in full control of your own data, you can also enjoy the convenience of ownership whilst only paying for what you actually need keeping your costs as low as possible.

HOW TO GET STARTED

If you would like to know more about UKSeRP and how to get started please contact us for more information.

Contact the UKSeRP Service Centre:
info@UKSeRP.ac.uk

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We are extremely grateful for the MRC's support in developing this vital piece of infrastructure, that will enable more large-scale data linkage research to be carried out securely, quickly and cost effectively.



