A big issue in health care and research is access to information, and shared Electronic Health Records (EHRs) offer a fantastic solution to this. To address this need for data TPP, the system supplier responsible for the clinical system, SystmOne, and the University of Leeds have collaborated to create the not-for-profit organisation, ResearchOne. ResearchOne enables 30 million shared patient records to contribute to research that develops clinical understanding and tools, and works to feed these back into clinical practice.

Two years into the collaboration, ResearchOne has already supported many research and public health monitoring projects. These include delivering an electronic system for notifying the Health Protection Agency of infectious diseases, monitoring the impact of vaccinating pregnant women against whooping cough, and providing data to a long term research study in Bradford.

ResearchOne now has national level ethical approval from the NHS Research Ethics Committee (REC) and National Information Governance Board (NIGB) to deliver de-identified data from consenting SystmOne organisations to research projects. This is an incredible leap forward in promoting the accessibility for patients, clinicians and researchers to work together to improve clinical care.
Through clinical research, ResearchOne can directly contribute to the way patient care is delivered. This can range from identifying high risk groups, looking at the effectiveness of certain treatments, or providing insight into how care can be effectively delivered. For example, ResearchOne has been involved in a study looking at whether there is any correlation between the use of calcium supplements and a higher risk of a cardiovascular event, such as a heart attack. This research will be invaluable in making sure patients are given the most appropriate treatments.
Vascular diseases affect both young and old and can cause heart attacks and strokes. In many cases, elements of an unhealthy lifestyle such as smoking, poor diet, lack of exercise, and stress contribute to their development. Making simple changes to lifestyle can significantly reduce the risk of a stroke or heart attack, as well as improving overall health and well-being.

An additional problem is that many people require medical treatment to manage their condition and to reduce risk factors such as high blood pressure. It is often the case that people do not stick to their advised medical regimes and therefore put themselves at higher risk.

The IMproving PRevention Of Vascular diseasE in Primary Care (IMPROVE-PC) project is investigating why people do not follow their clinician’s recommended treatment plan and looks to improve uptake and adherence to their medical regimes. The study also identifies high risk groups for vascular disease and devises ways for people to change their lifestyle before their health is irreversibly compromised. It will consider the barriers to making these changes, such as low income, and how best to support people in leading healthy lives.

IMPROVE-PC gathers both qualitative and quantitative data about vascular disease. ResearchOne has supplied consented, de-identified records information from SystmOne and helped IMPROVE-PC to pseudonymously link this to information from Hospital Episodes Statistics (HES) and the Myocardial Ischemia Audit Program (MINAP). Linking data in this way across primary and secondary care provides opportunities to study care management in Cardio-Vascular Diseases (CVD) and identify optimal patterns of care.

In many cases, CVD patients may have treatments in both primary and secondary care, but often these secondary care episodes are not fed back to GPs. The study will help to quantify this issue and look for areas of high prevalence. By improving this communication, clinicians and patients can have a more holistic view of the patient’s care. The goal will ultimately be to reach a point where this record is accurate and up to date to the extent that patient care can move into more comfortable and cost-effective community settings where patients can be more actively involved in the management of their condition.

Steve Magare, the Data Manager for the project, commented that a centralised system helps clinicians and researchers to access important information recorded in other organisations. “The availability of patient records data has always been seen to be the missing link and the development of ResearchOne will allow research projects such as this to realise the full potential of using linked data to improve healthcare in an efficient and cost effective manner.”
ResearchOne not only provides data that can be used in clinical studies, it is also contributing to the wider NHS goals of increasing efficiency, adhering to clinical guidelines and respecting patient confidentiality. These studies play an important role in making sure that research is always conducted in keeping with best practice, and also in highlighting ways the NHS can improve the services they deliver. Some examples are:

**GP NON-ATTENDANCE**

This project is examining the link between factors such as rurality, appointment time, and appointment booking method with non-attendance at appointments. Did Not Attends (DNAs) are an on-going problem for many care providers, wasting time and valuable resources. There are also wider implications, such as for mental health patients, where missing appointments could indicate a deterioration in the patient’s condition.

De-identified clinical and demographic data from the ResearchOne database is used in data mining explorations to identify any trends with non-attendance. The aim is to develop a clinical decision support system to identify and address risk of non-attendance. This will hopefully reduce the number of DNAs to ensure an efficient service and that patients are receiving appropriate care.
PATIENT PRIVACY IN RESEARCH
E-HEALTH GATEWAY TO THE CLOUDS

ResearchOne has enabled access to health records information in order to develop a tool that will help to maintain privacy, and support best practice in research. The e-health GATEway to the Clouds project is developing a research tool to anonymise free text data from health records. This data is then embedded within a secure cloud-based Virtual Research Environment (VRE). ResearchOne have extracted data from fictional but realistic records, created by medical students on SystmOne, to enable the researchers to pilot the tool securely.

Since 2008, over 3,000 medical and healthcare students at the University of Leeds have received education on the use of clinical systems, through hands-on use of SystmOne, to simulate real patient consultations. Identifiable information such as a patient or clinician’s personal details can be removed so that researcher can work with the valuable health information in health records while respecting patient confidentiality.

MEETING CLINICAL GUIDELINES – ASPIRE

It is essential that research evidence translates into clinical practice. The collaboration between ResearchOne and Action to Support Practices Implementation of Research (ASPIRE) group is working to support general practices in implementing the evidence-based clinical care recommended by the National Institute for Health and Clinical Excellence (NICE) clinical guidelines.

For example, for patients suffering with Chronic Kidney Disease, NICE guidelines set a minimum guide for how many patients should have a blood pressure result and various urine ratios recorded in the last 15 months. They have also stipulated that these patients should be given advice to take exercise, achieve a healthy weight and stop smoking. ResearchOne data would be able to show whether practices were meeting these quotas, and if not, the research groups can look at how to implement solutions to make sure patients are receiving the best level of care.

This five year project is working with 60 practices in West Yorkshire that use SystmOne and is monitoring the impact and adherence to NICE guidelines. These practices contribute de-identified data to the project through ResearchOne. The ASPIRE team is then analysing and interpreting this data. Their findings can be used to develop an intervention package, based on audit and clinical decision support systems, with the aim of supporting guideline adherence. Robbie Foy, Clinical Professor of Primary Care at the University of Leeds said “ResearchOne will help us improve the quality and relevance of research in primary care by providing regulated, approved access to large-scale pseudo-anonymised data. This will enhance our ability, for example, to monitor the uptake of evidence-based practice and evaluate the impact of interventions to improve practice.”

The impact of the interventions will be evaluated using further extracts of de-identified practice data through ResearchOne and interviews with the practices.
In a short time, ResearchOne has made significant contributions to the medical research community. The ability for SystmOne practices to opt-in to sharing data will provide new and exciting opportunities for studies across larger populations and will help to reveal national trends, as well as allowing localised research projects. Through ResearchOne, more people, both clinical staff and patients, are having the opportunity to contribute to medical research that can in turn shape the healthcare landscape across the UK.
For more information please contact
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