The Challenge:
Multiple Sclerosis (MS) is a chronic, inflammatory, autoimmune disease. The cause of MS is unknown and currently there is no known cure. The overall burden of the disease is considerable on the individual, their family, social care and the NHS.

There is a serious lack of data and information about MS in the UK. This extends from not knowing how many people have the disease to what form of the disease that they have - Relapsing Remitting, Primary Progressive or Secondary Progressive.

The MS Register is the world’s first register, for any condition, to combine information directly from people with MS (PwMS), with clinical and NHS data; it is helping to form a picture that is already revolutionising our understanding of MS in the UK.

However, the data provided by the NHS can be limited and lacks richness. There is an enormous amount of unused unstructured data buried in outpatient and doctor’s notes that contains important information about a patient’s condition, treatment plan and care circumstances. This information could be used to form a better understanding of a PwMS unique clinical story.

The Research:
The UK MS Register is working in partnership with, Bridgend based company, Clinithink to address this challenge. Clinithink have developed the CLiX platform, which uses Natural Language Processing (NLP) technology. NLP is a technology which makes sense of unstructured data in clinical notes and transform it into the SNOMED terminology, which can then be easily utilised by researchers.

CLiX will extract information from clinical notes (including doctors Dictaphone notes) from 21 hospitals, including: discharge summaries, clinical notes and other clinical documents. These notes can contain details on: the patients housing situation; related health conditions, symptoms and medication; partners or carers details; and gaps in care records, i.e. did the patient not have symptoms or was the data just not entered?

This rich information extracted by CLiX is then linked with the existing MS Register data held in the Secure Anonymised Information Linkage (SAIL) Databank. This clinical data from patient letters enhances the information already held by the Register - giving the team of Farr researchers based at the UK MS Register a rich source of data to study.

The Results:
As with any innovative technology, the project has experienced a few challenges along the way, for example the way medical terminology has evolved meant it can have difficulties in distinguishing between words that are the same but have different meanings, for example in a clinician’s notes, the word “Parkinson,” for instance, could refer to the medical condition— but it could also refer to a patient’s surname. The researchers have been working with Clinithink to overcome these issues in order for the project to progress onto the next stage - which is the routine capture of the clinical notes.

The Impact:
CLiX is a cost effective way to automatically collect data held in clinical notes. These notes contain a wealth of medically useful data: hidden links between symptoms, treatments and outcomes.

By unlocking this unstructured clinical data and making it usable researchers can gather new evidence on MS to help drive improvements in workflow, performance and outcomes. This collaboration between the UK MS Register and industry, offers up new and exciting insights that can benefit people with MS, clinicians and researchers.

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