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Using natural language processing to extract structured epilepsy data from unstructured clinic letters: development and validation of the ExECT (extraction of epilepsy clinical text) system

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ABSTRACT

Objective Routinely collected healthcare data are a powerful research resource but often lack detailed disease-specific information that is collected in clinical free text, for example, clinic letters. We aim to use natural language processing techniques to extract detailed clinical information from epilepsy clinic letters to enrich routinely collected data.

Design We used the general architecture for text engineering (GATE) framework to build an information extraction system, ExECT (extraction of epilepsy clinical text), combining rule-based and statistical techniques. We extracted nine categories of epilepsy information in addition to clinic date and date of birth across 200 clinic letters. We compared the results of our algorithm with a manual review of the letters by an epilepsy clinician.

Setting De-identified and pseudonymised epilepsy clinic letters from a Health Board serving half a million residents in Wales, UK.

Results We identified 1925 items of information with overall precision, recall and F1 score of 91.4%, 81.4% and 86.1%, respectively. Precision and recall for epilepsy-specific categories were: epilepsy diagnosis (88.1%, 89.0%), epilepsy type (89.8%, 79.8%), focal seizures (96.2%, 69.7%), generalised seizures (88.8%, 52.3%), seizure frequency (86.3%–53.6%), medication (96.1%, 94.0%), CT (55.6%, 58.8%), MRI (82.4%, 68.8%) and electroencephalogram (81.5%, 75.3%).

Conclusions We have built an automated clinical text extraction system that can accurately extract epilepsy information from free text in clinic letters. This can enhance routinely collected data for research in the UK. The information extracted with ExECT such as epilepsy type, seizure frequency and neurological investigations are often missing from routinely collected data. We propose that our algorithm can bridge this data gap enabling further epilepsy research opportunities. While many of the rules in our pipeline were tailored to extract epilepsy specific information, our methods can be applied to other diseases and also be used in clinical practice to record patient information in a structured manner.

Strengths and limitations of this study

- This study presents a novel method to automatically extract detailed, structured epilepsy information from unstructured clinic letters.
- The method is based on open-source natural language processing technology.
- The performance was validated using 200 previously unseen epilepsy and general neurology clinic letters.
- The generalisability of the algorithm to population-level data and other diseases is limited at present but is possible with further work.

INTRODUCTION

Epilepsy is a common neurological disease with significant co-morbidity. Although advances have been made in understanding the aetiology, treatment and co-morbidity of epilepsy, significant uncertainties still exist. Research using routinely collected data offers an opportunity to explore these uncertainties. Recent studies have shown, for example, an increased onset of psychiatric disorders and suicide before and after epilepsy diagnosis,1 no association between anti-epileptic drug use during pregnancy and stillbirth,2 and an increased risk of premature mortality in people with epilepsy.3

Epilepsy research using routinely collected data currently tends to use sources such as primary care health records or hospital discharge summaries. The main disadvantage of these sources is that they do not contain detailed epilepsy information, for example, epilepsy subtype/syndrome, epilepsy cause, seizure type or investigation results. This limits the quality and type of epilepsy research questions that can be answered successfully.
Almost all patient encounters with hospital specialists in the UK are documented in clinic letters to primary care doctors, other healthcare professionals and patients. Clinic letters have been written electronically for decades and offer a wealth of disease-specific information to enhance routinely collected data for research. Although detailed disease (epilepsy) information is found in clinic letters, they are usually written in an unstructured or semi-structured format, making it difficult to automatically extract useful information.

Natural language processing (NLP) technology can be used to analyse human language and offers a potential solution for automated information extraction from unstructured letters. NLP is increasingly being used for healthcare information extraction applications; for example, to extract symptoms of severe mental illness and adverse drug events from psychiatric health records, to identify patients with non-epileptic seizures and for the early identification of patients with multiple sclerosis.

In this project, our objective was to develop and validate an NLP application to extract detailed epilepsy information from unstructured clinic letters, with the primary aim of using this information to enhance epilepsy research using routinely collected data.

**MATERIALS AND METHODS**

**Study population**

We used manually de-identified and pseudonymised hospital clinic letters to build and test the algorithm. The letters were provided by the paediatric and neurology departments of a local general hospital. Members of the clinical team manually changed patient details, clinician details as well as the names occurring within the text before the letters were available to researchers. We used 40 letters for training purposes to build rule sets, and a validation set of 200 letters to test the accuracy of the algorithm. The training set was randomly selected and included 24 adult (16 epilepsy, 8 general neurology) and 16 paediatric neurology letters. The validation set contained letters from various outpatient clinics (145 adult epilepsy, 37 paediatric epilepsy and 18 general neurology) from new patient and follow-up appointments, written by eight different clinicians.

**Algorithm construction**

We used the general architecture for text engineering (GATE) framework with its biomedical named entity linking pipeline (Bio-YODIE) (figure 1). We created an automated clinical text extraction system for epilepsy, ExECT (extraction of epilepsy clinical text), which used Bio-YODIE and our own customisations to map clinical terms to Unified Medical Language System (UMLS) concepts. The UMLS is a set of files and software, developed by the US National Library of Medicine, which combines information from over 200 health vocabularies with over 3.6 million concepts and 13.9 million unique concept names. UMLS uses concept unique identifiers (CUIs) to identify senses (or concepts) associated with words and terms. Bio-YODIE applies several strategies to assign the correct UMLS sense to terms in the text, and, where necessary, disambiguates against several possible meanings for the same term. These strategies include term frequency, patterns of co-occurrence with other terms and measures of context similarity.

We supplemented Bio-YODIE’s UMLS lookups with a set of custom gazetteers (native dictionaries used within GATE). We used some custom gazetteers to embed context into extracted UMLS concepts, that is, phrases to determine present, past or future tense, or terms to describe levels of certainty expressed in clinical opinion. For example, in the phrase ‘... could be consistent with simple partial seizures’, simple partial seizures are annotated with a certainty level indicated by the word ‘could’. We used five levels of certainty ranging from 1 (definitely not) to 5 (definitely) (see table 1 for more details). Variables with certainty levels 4 or 5 were considered to be positive findings and those with levels 1–3 to be negative findings. We used other gazetteers for specific vocabulary or colloquial terminology used by patients and clinicians when describing symptoms. Some were necessary to deal with the rigidity of the UMLS terminology, especially

![Figure 1](http://bmjopen.bmj.com/)

**Figure 1** ExECT pipeline to extract clinic date, date of birth and nine categories of epilepsy information from clinic letters. We used GATE architecture, modified versions of the Bio-YODIE, SLAM and ConText plugins with custom dictionaries and JAPE (Java Annotation Patterns Engine) rules. Bio-YODIE, biomedical named entity linking pipeline; POS Tagger, Part-Of-Speech Tagger; D.O.B, date of birth; ExECT, extraction of epilepsy clinical text; GATE, general architecture for text engineering; SLAM, South London and Maudsley.
We deployed the ConText algorithm to annotate ‘spike and wave’ as an abnormal EEG result, assigning it an UMLS CUI for an ‘abnormal EEG outcome.’ We based this information on the UMLS CUI extracted with the epilepsy diagnosis information. We only used explicit mentions of epilepsy types or syndromes within the clinic letters, and did not use other information, such as seizure type or investigation results, to infer the epilepsy type. Only an epilepsy type with a certainty level 4 or 5 was considered to be a true positive.

We based this information on the UMLS CUI extracted with the epilepsy diagnosis information. We only used explicit mentions of epilepsy types or syndromes within the clinic letters, and did not use other information, such as seizure type or investigation results, to infer the epilepsy type. Only an epilepsy type with a certainty level 4 or 5 was considered to be a true positive.

We used and customised the South London and Maudsley (SLaM) GATE application to extract prescription information. We deployed the ConText algorithm to detect negation of extracted terms, that is, ‘this person does not have epilepsy’ and to identify normal test results, such as in ‘The EEG was not abnormal.’ Finally, we used the JAPE scripting language to define rules based on varying combinations of UMLS and custom lookups to extract eight broad categories of information (see table 1 for more information). In total, we created 46 separate gazetteers and over 89 JAPE rule files in order to annotate the variables of interest, establish context and to remove certain annotations from the output.

An illustration of the ExECT GATE pipeline used to extract all items of interest is shown in figure 1. The source code is available at https://github.com/arron-lacey/ExECT. ExECT was built using GATE V.8.4.1.

### Measuring performance

We ran ExECT on a validation set of 200 previously unseen, de-identified, clinic letters. We compared the items of information extracted by ExECT with those extracted by manual review. The review was performed by an epilepsy clinician (WOP) who was blinded to the algorithm results until the review was complete. We used pre-defined criteria for the manual review of information items (see table 1). The core research team (BF-S, ASL and WOP) reviewed every disagreement between the algorithm results and ExECT, and a consensus was obtained from the group on the correct annotation based on our pre-defined guidelines (see table 1). We measured performance on both a per item and a per letter basis.

The per item test compared every mention of an information item in each letter. Frequently, there were several items in a particular category. For example, a letter could contain the following phrases, all of which confirm an epilepsy diagnosis: ‘diagnosis: temporal lobe epilepsy’
... frequent complex partial seizures consistent with a
diagnosis of temporal lobe epilepsy...’ and ‘Given that X
has temporal lobe epilepsy, the best treatment is...’

The main purpose of ExECT is to enrich routinely
collected data sets with epilepsy information and for
this purpose a per letter score is potentially a more useful
measure of its performance. For example, a letter may
confirm temporal lobe epilepsy three times but only one
mention of temporal lobe epilepsy is required to correctly
classify that person’s epilepsy. In this context, extracting
only one mention of temporal lobe epilepsy is as useful
as extracting all three. In the per letter test, we, therefore,
aggregated multiple mentions within a category in each
letter to a binary decision based on ExECT’s ability to
extract at least one true positive mention. In the above
example, if ExECT had only correctly identified one of
the three mentions of temporal lobe epilepsy, we would
have scored it as having a recall of 100% on a per letter
basis but only 33% (1/3) on a per item basis. We used a
similar approach with seizure frequency, clinic date and
date of birth; multiple mentions were counted in a per
item, but only one true mention (in the absence of contra-
dictory information) was considered to give a true posi-
tive result in the per letter method. For the medication
annotation, in the per letter approach, only a full list of
the drugs prescribed with the respective doses was considered
to be a positive outcome.

Patient and public involvement
This research was carried out without specific patient
or public involvement in the design or interpretation
of results. Patients and members of the public did not
contribute to the writing or editing of this manuscript.

Analysis and statistical tests
We used precision, recall and F1 score to measure the accu-

racy of ExECT. Precision is defined as the proportion of
the instances extracted by the algorithm which are true,
recall is the proportion of true instances extracted by
the algorithm and F1 score is the unweighted harmonic
mean of precision and recall: (2×precision×recall)/(precision+recall).

RESULTS
We identified 1925 items in 11 categories across 200
letters. See Table 2 for a summary of the performance
of ExECT in identifying these items of information and
table 3 for the evaluation of the results.

DISCUSSION
We developed an application capable of extracting a
range of detailed epilepsy information from unstructured
epilepsy and general neurology clinic letters, in order
to enrich routinely collected data for research. ExECT
reliably extracted epilepsy information from 200 clinic
letters, written by different clinicians, with an overall
precision, recall and F1 score of 91%, 81% and 86%,
respectively, on a per item basis. ExECT performed best in
extracting clinic date and date of birth (F1 scores of 98%
and 99%) given that these fields consist of fixed format
dates which are easier to extract. In terms of epilepsy-spe-
cific information, ExECT performed best for medication
(F1=95%), epilepsy diagnosis (89%), epilepsy type (85%)
and focal seizure types (81%). These items are frequently
mentioned and presented in a relatively standard format.

<table>
<thead>
<tr>
<th>Variable</th>
<th>All items extracted</th>
<th>Number of letters with items extracted</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Clinician Algorithm</td>
<td></td>
</tr>
<tr>
<td></td>
<td>TP</td>
<td>FP</td>
</tr>
<tr>
<td>Clinic date</td>
<td>191</td>
<td>188</td>
</tr>
<tr>
<td>Date of birth</td>
<td>201</td>
<td>197</td>
</tr>
<tr>
<td>Epilepsy diagnosis</td>
<td>383</td>
<td>387</td>
</tr>
<tr>
<td>Epilepsy type</td>
<td>89</td>
<td>79</td>
</tr>
<tr>
<td>Focal seizures</td>
<td>145</td>
<td>105</td>
</tr>
<tr>
<td>Generalised seizures</td>
<td>151</td>
<td>89</td>
</tr>
<tr>
<td>Seizure frequency</td>
<td>153</td>
<td>95</td>
</tr>
<tr>
<td>Medication</td>
<td>316</td>
<td>309</td>
</tr>
<tr>
<td>CT scan</td>
<td>17</td>
<td>18</td>
</tr>
<tr>
<td>MRI scan</td>
<td>109</td>
<td>91</td>
</tr>
<tr>
<td>EEG</td>
<td>170</td>
<td>157</td>
</tr>
<tr>
<td>All</td>
<td>1925</td>
<td>1715</td>
</tr>
</tbody>
</table>

EEG, electroencephalogram; ExECT, extraction of epilepsy clinical text; FN, false negative (an item annotated by the clinician but not annotated by ExECT); FP, false positive (an item annotated by ExECT but not annotated by the clinician); TP, true positive (an item annotated by the clinician and ExECT).
for example, medication is usually stated as drug name-strength-unit-frequency, and diagnosis appears at the top of letters in structured lists or in text with clear references to the patient.

ExECT was less accurate in identifying CT (F1=57%), MRI (75%) and EEG results (78%), seizure frequency (66%) and generalised seizure terms (66%). These terms occasionally did not map completely to UMLS terms and had a more varied format in the clinic letters. For example, UMLS contains terms such as ‘EEG with irregular generalised spike and wave complexes’; however, there were often a variety of words between EEG and the associated result, for example, ‘EEG was found to show generalised spike and wave complexes’. Consequently, we created custom gazetteers that map to specific terms such as ‘spike and wave’ or ‘EEG’ and wrote JAPE rules to associate these terms with the EEG term to improve the performance of our algorithm. While this approach allows for variations seen in our training set, previously unseen variations in the validation set could not be captured. Similarly, the reporting of seizure frequency is highly varied, for example, ‘she had five seizures since March last year’ or ‘one or two focal seizures every evening’.

We achieved higher scores for precision, recall and F1 score (95%, 87% and 91%, respectively) on a per letter basis. A lower recall rate for medication on a per letter basis was due to the scoring method, where only a complete list of all medications was considered a true positive result. For example, if one medication was missing out of a list of four, this would be a negative result on a per letter basis. This lead to an increase in the false negative scores as compared with a per item approach. We propose that a per letter measure for categories containing multiple mentions, such as confirmation of epilepsy, provides a practical way to summarise information from clinic letters. Additionally, a per person measure (results summarised over several letters) could be used to determine epilepsy status as there will normally be several letters per person over a period of time.

**Strengths**

We used a gold standard data set of de-identified clinic letters to build and test ExECT, from which we accurately extracted novel epilepsy information for research. We can now iteratively develop ExECT over larger sets of clinic letters and use it to extract detailed epilepsy information for research. We can also develop our algorithm for other diseases and potential clinical applications, for example, efficiently extracting relevant clinical information from historical letters to aid clinicians. Our system uses UMLS terminologies including the ability to map findings to CUI codes. This can be powerful in curating structured data sets that can be easily linked with high agreement to other coding systems, for example, SNOMED-CT.15

We used the open source GATE framework to develop our algorithm which provides useful built-in applications and user-developed plugins for NLP such as Bio-YODIE and the SLaM medication application. This undoubtedly made the process easier and quicker than other potential

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**Table 3** The *per item* and *per letter* accuracy of ExECT when extracting epilepsy information from a validation set of 200 clinic letters, where an information item is defined as a single item in any category identified by the human annotator (see the Materials and methods section for more details).

<table>
<thead>
<tr>
<th>Variable</th>
<th>200 letters—results <em>per item</em></th>
<th>200 letters—results <em>per letter</em></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of information items identified by clinician</td>
<td>Precision</td>
</tr>
<tr>
<td>Clinic date</td>
<td>191</td>
<td>98.9</td>
</tr>
<tr>
<td>Date of birth</td>
<td>201</td>
<td>100.0</td>
</tr>
<tr>
<td>Epilepsy diagnosis</td>
<td>383</td>
<td>88.1</td>
</tr>
<tr>
<td>Epilepsy type</td>
<td>89</td>
<td>89.9</td>
</tr>
<tr>
<td>Focal seizures</td>
<td>145</td>
<td>96.2</td>
</tr>
<tr>
<td>Generalised seizures</td>
<td>151</td>
<td>88.8</td>
</tr>
<tr>
<td>Seizure frequency</td>
<td>153</td>
<td>86.3</td>
</tr>
<tr>
<td>Medication</td>
<td>316</td>
<td>96.1</td>
</tr>
<tr>
<td>CT scan</td>
<td>17</td>
<td>55.6</td>
</tr>
<tr>
<td>MRI scan</td>
<td>109</td>
<td>82.4</td>
</tr>
<tr>
<td>EEG</td>
<td>170</td>
<td>81.5</td>
</tr>
<tr>
<td>All</td>
<td>1925</td>
<td>91.4</td>
</tr>
</tbody>
</table>

EEG, electroencephalogram; ExECT, extraction of epilepsy clinical text.
methods and provided a useful model for future similar information extraction applications.

Weaknesses

We used a relatively small number of letters sourced from one health board. Abertawe Bro Morgan University Health Board is responsible for planning and providing healthcare services to approximately half a million people in southwest Wales. This limited the number of writing styles and letter structures available to validate our algorithm, given that manually de-identifying letters was resource intensive. The generalisability of our algorithm may, therefore, be limited. However, we have made efforts to extract information from the main body of text within clinical letters rather than relying on the letter structure alone.

It is difficult to account for the variability of the language used to express patient information in clinic letters. Some items of information such as seizure frequency and investigations require many complex rules where patterns are hard to predict. Further work could be focused on employing machine learning methods to complement a rule-based approach; however, this would require a significant amount of time to annotate the large amount of documents required for such a task. All disagreements between ExECT and manual annotation were reviewed by the research team as a whole but we only used one clinician to review the letters, which might have added bias to how the validation set was annotated.

Comparison with other studies

NLP is being increasingly used for clinical information extraction purposes. The i2b2 project used Apache clinical Text Analysis and Knowledge Extraction System and Health Information Text Extraction to extract the following phenotypes with positive predictive value (precision) and sensitivity (recall): Crohn’s disease (98%, 64%), ulcerative colitis (97%, 68%), multiple sclerosis (MS) (94%, 68%) and rheumatoid arthritis (89%, 56%). A recent study on patients with MS, identified from electronic healthcare records, used NLP techniques to extract MS-specific attributes with high positive predictive value and sensitivity, namely, Expanded Disability Status Scale (97%, 89%), Timed 25 Foot Walk (93%, 87%), MS subtype (92%, 74%) and age of onset (77%, 64%).

A study used clinic letters (available at www.mntsamples.com) to determine whether sentences containing disease and procedure information were attributable to a family member using the BioMedICUS NLP system. This achieved an overall precision, recall and F1 score of 91%, 94% and 92%, respectively.

To our knowledge, there are only a few published studies on clinical epilepsy information extraction systems. Cui et al developed the rule-based epilepsy data extraction and annotation (EpiDEA) system, which extracts epilepsy information from epilepsy monitoring unit discharge summaries. EpiDEA achieved an overall precision, recall and F1 score of 94%, 84% and 89%, respectively, when extracting EEG pattern, past medications and current medication from 104 discharge summaries from Cleveland, Ohio, USA. Cui et al also developed the rule-based phenotype extraction in epilepsy (PEEP) pipeline. PEEP extracted the epilepto-genic zone, seizure semiology, lateralising sign, interictal and ictal EEG pattern with an overall precision, recall and F1 score of 93%, 93% and 92%, respectively, in a validation set of 262 epilepsy monitoring unit discharge summaries from Cleveland, Ohio, USA. Sullivan et al used a machine-based learning NLP pipeline to identify a rare epilepsy syndrome from discharge summaries and EEG reports in Phoenix, Arizona, USA and achieved a precision, recall and F1 score of 77%, 67% and 71%, respectively. The majority of these studies used discharge letters that are generally more structured than the clinic letters used in our study, which presents a greater challenge for NLP application.

CONCLUSION

Using the GATE framework and the existing applications, we have developed an automated clinical-text extraction system, ExECT, which can accurately extract epilepsy information from free text in clinic letters. This can enhance routinely collected data for epilepsy research in the UK. The types of information extracted using our algorithm such as epilepsy type, seizure frequency and neurological investigation results are often missing from routinely collected data. We propose that our algorithm can be used to fill this data gap, enabling further epilepsy research opportunities. While many of the rules in our pipeline were tailored to extracting epilepsy specific information, the methods employed could be generalised to other disease areas and used in clinical practice to record patient information in a structured manner.

Future work

We are developing ExECT to extract other epilepsy variables including age of seizure onset and co-morbidities. In addition, we aim to deploy ExECT in hospital information systems to enhance the availability of structured clinical data for clinicians.

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Contributors WOP, ASL and BF-S were responsible for study design. ASL and BF-S developed the platform with assistance from AR and WOP. WOP, ASL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S developed the platform with assistance from AR and WOP. WOP, ASL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript. AA, ST, DVF, RAL and BF-S validated the algorithm and drafted the initial manuscript.
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Competing interests WOP has received clinical research fellow salary support in the form of an unrestricted grant from UCB Pharma and has undertaken work commissioned by the biopharmaceutical company. We confirm that we have read the Journal’s position on issues involving ethical publication and affirm that this report is consistent with those guidelines.

Patient consent for publication Not required.

Ethics approval This research was conducted with anonymised and de-identified routinely collected clinic letters and therefore specific ethical approval was not required.

Provenance and peer review Not commissioned; externally peer reviewed.

Data sharing statement We do not have a data sharing agreement for the data, however we are exploring ways of obtaining patient consent and endeavour to produce a minimum dataset for cross-platform testing.

Author note MIR and WOP were equal senior authors

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