Original Paper

# Extracting Medical Information From Free-Text and Unstructured Patient-Generated Health Data Using Natural Language Processing Methods: Feasibility Study With Real-world Data

Emre Sezgin[1,2*], PhD; Syed-Amad Hussain[1*], BSc; Steve Rust[1], PhD; Yungui Huang[1], PhD

[1]The Abigail Wexner Research Institute at Nationwide Children's Hospital, Columbus, OH, United States

[2]The Ohio State University College of Medicine, Columbus, OH, United States

[*]these authors contributed equally

**Corresponding Author:**
Emre Sezgin, PhD
The Abigail Wexner Research Institute at Nationwide Children's Hospital
700 Children's Drive
Columbus, OH, 43205
United States
Phone: 1 614 722 3179
Email: emre.sezgin@nationwidechildrens.org

## Abstract

**Background:** Patient-generated health data (PGHD) captured via smart devices or digital health technologies can reflect an individual health journey. PGHD enables tracking and monitoring of personal health conditions, symptoms, and medications out of the clinic, which is crucial for self-care and shared clinical decisions. In addition to self-reported measures and structured PGHD (eg, self-screening, sensor-based biometric data), free-text and unstructured PGHD (eg, patient care note, medical diary) can provide a broader view of a patient’s journey and health condition. Natural language processing (NLP) is used to process and analyze unstructured data to create meaningful summaries and insights, showing promise to improve the utilization of PGHD.

**Objective:** Our aim is to understand and demonstrate the feasibility of an NLP pipeline to extract medication and symptom information from real-world patient and caregiver data.

**Methods:** We report a secondary data analysis, using a data set collected from 24 parents of children with special health care needs (CSHCN) who were recruited via a nonrandom sampling approach. Participants used a voice-interactive app for 2 weeks, generating free-text patient notes (audio transcription or text entry). We built an NLP pipeline using a zero-shot approach (adaptive to low-resource settings). We used named entity recognition (NER) and medical ontologies (RXNorm and SNOMED CT [Systematized Nomenclature of Medicine Clinical Terms]) to identify medication and symptoms. Sentence-level dependency parse trees and part-of-speech tags were used to extract additional entity information using the syntactic properties of a note. We assessed the data; evaluated the pipeline with the patient notes; and reported the precision, recall, and $F_1$ scores.

**Results:** In total, 87 patient notes are included (audio transcriptions n=78 and text entries n=9) from 24 parents who have at least one CSHCN. The participants were between the ages of 26 and 59 years. The majority were White (n=22, 92%), had more than one child (n=16, 67%), lived in Ohio (n=22, 92%), had mid- or upper-mid household income (n=15, 62.5%), and had higher level education (n=24, 58%). Out of 87 notes, 30 were drug and medication related, and 46 were symptom related. We captured medication instances (medication, unit, quantity, and date) and symptoms satisfactorily (precision >0.65, recall >0.77, $F_1$>0.72). These results indicate the potential when using NER and dependency parsing through an NLP pipeline on information extraction from unstructured PGHD.

**Conclusions:** The proposed NLP pipeline was found to be feasible for use with real-world unstructured PGHD to accomplish medication and symptom extraction. Unstructured PGHD can be leveraged to inform clinical decision-making, remote monitoring, and self-care including medical adherence and chronic disease management. With customizable information extraction methods using NER and medical ontologies, NLP models can feasibly extract a broad range of clinical information from unstructured PGHD in low-resource settings (eg, a limited number of patient notes or training data).

***(JMIR Form Res 2023;7:e43014)*** doi: 10.2196/43014

**KEYWORDS**

patient-generated health data; natural language processing; named entity recognition; patient health records; text notes; voice; audio real-world data

## Introduction

Patient-generated health data (PGHD) volume is growing immensely with the increased use of digital devices. The Office of the National Coordinator for Health Information Technology defines PGHD as "health-related data created, recorded, or gathered by or from patients or family members or other caregivers to help address a health concern" [1]. Today, PGHD can be collected out of the clinic using medical and consumer-grade mobile devices as passive or active data, such as blood glucose monitors, wearables (heart rate and SPO), and smartphones (physical activity scores and patient-reported data, such as screening survey responses) [2,3]. PGHD is becoming a necessary component of personal health records as well as remote monitoring and is influencing self-care and clinical decisions [4]. Medical systems have the infrastructure available to integrate digital tools generating PGHD with electronic health record systems to enhance the clinical decision process and eventually improve patients' quality of life and produce better health outcomes [3,5].

In a patient's journey (especially patients with chronic conditions or special health care needs), physical medical diaries and patient notes have been the primary source of free-text patient information ("unstructured PGHD"), facilitating the collection of health information. With the adoption of smart devices, there is an increased use of personal devices for digital medical diaries and note-taking [6]. In addition, automatic speech recognition, conversational agents, and voice-interactive technologies ease the process of note-taking via natural conversations [7-9]. However, the patient experience, health events, medications, and symptoms captured in personal notebooks or devices are expected to be communicated verbally or written periodically, such as, during clinical visits. Given the limited time and ability to read and communicate patient notes, this information could be underused and create an additional burden [10]. Integrating PGHD into electronic health record systems is an acknowledged contribution, as it can create a more comprehensive view of health conditions and eventually inform shared decision-making [11]. Yet, free-text patient notes or unstructured PGHD integration requires further considerations on clinical workflow and clinical burden [3].

Therefore, a pipeline for processing unstructured PGHD to inform self-care and clinical decision processes is needed and preferable [12]. In the literature, there are a number of studies reporting natural language processing (NLP) applications on clinical notes to identify symptoms and conditions [13,14]. A subset is focusing on electronic patient-authored texts, which are the patient-reported symptoms and conditions that are shared on the web but mostly out of medical records. The studies report that the NLP applications accompanying large public data sets of electronic patient-authored texts (eg, web-based forums or social media posts) are based on rules, machine learning, or a hybrid combination [15]. Rule-based methods are preferable with the use of clinical domain knowledge (eg, ontologies) for increasing accuracy in entity extraction at the expense of generalizability [14]. Machine learning solutions have been effective in extracting word or sentence meaning by using probabilistic models and being structure-agnostic with variations in spelling and grammar [16]. Yet, machine learning models could be resource intensive. Hybrid models leverage the strength of both approaches in terms of combinatorial patterns among words and semantic relationships [17,18] and are adaptive to low-resource settings.

In this paper, we evaluate a hybrid (machine learning + rule-based) NLP pipeline [19] with low-resource unstructured PHGD (ie, not depending on a large data set for training) and report its feasibility. We focus on extracting medication and symptom information, which must be tracked and communicated to patients with chronic conditions. We complete an empirical evaluation of automatic component extraction where we measure the model's ability to conduct automatic entity extraction using ontologies (medication dose: RxNORM, symptoms: SNOMED CT [Systematized Nomenclature of Medicine Clinical Terms]) [14,20] from the patient note data set. Namely, this NLP pipeline constitutes a rule-based system that leverages the dependency parsing, named entity recognition (NER), and ontology-linking capabilities of pretrained machine learning models (specifically, deep learning and pretrained language models [PLMs]), allowing for increased interpretability, ease of deployment, and generalization.

## Methods

### Overview

Our study reports a secondary data analysis using the data set collected on a prior research project [21].

### Recruitment and Study Setting

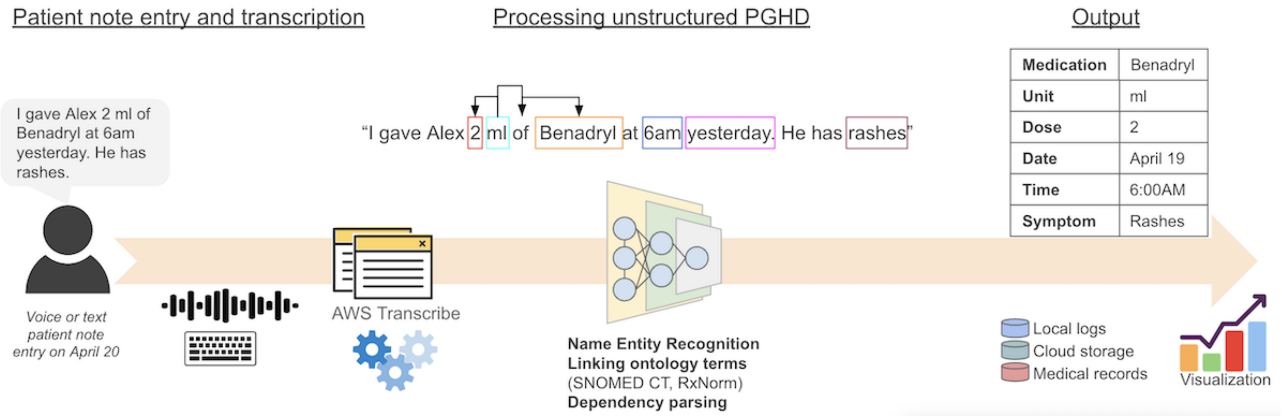
A convenience (nonrandom) sampling method was used to invite participants (parents and caregivers) to participate in the study within the network of the complex care clinic at a large pediatric hospital in the midwest. We sent email invitations and announced the research participation opportunity over social media and digital boards at the hospital. The recruitment occurred between October-December 2020. Inclusion criteria for the study were being a parent of a child with one or more complex medical conditions and having an iPhone with iOS 13 or above (or an iPhone 8 or above) during the study period. A total of 41 participants met these criteria and consented to participate. Of these, 24 participants completed the full study, which included a 2-week period of app use.

### Data Collection

Data were collected from 24 parents of children with special health care needs (CSHCN) between October 2020 and January 2021. Participants were onboarded to the study via a web-based screening and survey tool. The eligible participants were guided through a web-based tutorial to install and use the research app. The app has functions to record, transcribe, and store notes [21].

Participants were instructed to use the app for a 2-week period for medical note-taking. During the study period, participants received periodic (every 2-3 days) reminders and tips about how to use the app features. They had the option to create medical note entries through voice or text while at home. Voice entries were transcribed by using Amazon Web Services Transcribe services [22], and the transcriptions were used as patient notes for analysis (Figure 1).

**Figure 1.** Data collection, processing, and output flow. AWS: Amazon Web Services; PGHD: patient-generated health data; SNOMED CT: Systematized Nomenclature of Medicine Clinical Terms.



## Data Analysis

Building upon an earlier NLP pipeline proposal with simulated notes [19], we created a pipeline that leverages NER to identify and map terms to existing ontologies, particularly the RXNorm and SNOMED CT ontologies for medication and symptoms, respectively. After that, our algorithm searches over the sentence-level dependency parse trees alongside part-of-speech tags to extract further entity information based on the syntactic properties of the note [19]. Additionally, the relative date of the note (the date reported in the notes), if different from the authorship date, is derived with the assistance of the dateparser python library [23]. The NER and dependency parsing tools are retrieved from the open-source SciSpaCy Python package, which consists of PLM and ML models [24]. More specifically, our pipeline uses the SpaCy en_core_sci_lg model, which is a pipeline for biomedical data leveraging word embedding with more than 780,000 vocabulary terms and 600,000 word vectors [24], and a set of tools that use deep learning models to process biomedical and clinical text [25,26]. Researchers (SAH, ES) compared the model output against the original sentence and assessed it. They marked the information that the model incorrectly extracted (false positive), incorrectly left behind (false negative), and correctly extracted (true positive and true negative) for the categories of medication instance and symptom. We then calculated precision, recall, and combined $F_1$ score. This pipeline uniquely seeks to extract information about medication and symptoms using a zero-shot approach, which requires no training data and is adaptive to low-resource settings [27]. Likewise, our study does not have standardized tasks; therefore, no other baseline pipelines are available to compare against it. For this reason, evaluation metrics are presented solitarily to enable the evaluation and feasibility of the approach.

Figure 1 illustrates the data collection, processing, and output flow. In summary, a patient or caregiver creates the notes through voice interaction or text entries. Amazon Web Services transcribes voice entries and stores. The entries, unstructured PGHD, are processed using the proposed NLP model in this study to identify medication amount, dose, medication name (dependency parsing is shown with arrows), time and date, and symptoms. The extracted information can be integrated into a chart that can be used to inform a patient, caregiver, and provider through local logs on a device, cloud services, or medical records assisted by data visualization tools [19]. The integration component is not in the scope of this study.

## Ethics Approval

The study involves human participants and was reviewed and approved by the institutional review board at Nationwide Children's Hospital (#00000231). The participants signed written informed consent to participate in this study, allowing the use of the data set for the data analyses described here. All data reported in this study are deidentified. Participants were compensated for their time with a gift card (US $30).

# Results

## Participant Demographics

The participants were aged between 26 and 59 years (mean 39, median 38), mostly White (n=22, 92%), had more than one child (n=16, 67%), lived in Ohio (n=22, 92%), had mid or upper-mid household income (n=15, 62.5%), and received higher-level education (n=24, 58%). Participants had CSHCN with multiple chronic conditions. Frequently reported conditions included developmental delay; speech, vision, and physical problems; and genetic and neurological disorders. The majority of parents were "always" or "often" tracking their child's symptoms, medications, or conditions (n=17, 71%) using an app (n=13, 54%) or patient portal (n=16, 67%).

## Notes Characteristics

In total, 87 patient notes were included (voice entry transcriptions n=78 and text entries n=9). Thirty of the notes are drug and medication-related, and 46 of the notes are symptom-related, but there are overlapping notes having both or none of the symptom and medication information. More specifically, 24 notes have no symptom or medication information; 33 notes have only symptom information but no medication information; 17 notes have only medication information and no symptom information; 13 notes have both medication and symptom information. Each note is structured as 1 to 3 sentences, briefly recording the state of the patient, medication given, and symptoms (see Textbox 1, [21]). Content-wise, a patient note entry may have multiple components (symptom and medication detail), such as a summary of the day instead of multiple notes created throughout a day. Please see Multimedia Appendix 1 for the medication and symptoms captured through the pipeline and their frequencies.

**Textbox 1.** Sample patient notes [21].

**Symptoms or health condition**

- “Spot on lip is gone. Overall doing well. Has a runny nose it no fever or any other symptoms.”
- “[patient name] oxygen was still hanging out around 80 today...blood sugar is 127.”

**Medication with dose, unit, and time**

- “Gave [patient name] 2 Benadryl at 6:00 am…[patient name] does not take his medicine after lunch.”
- “Yesterday we started…gabapentin at a rate of 2.6 ml that will continue for one week, then we will switch rate to 2 ml over the course of another week, then 1.6 ml for another week with final rate at 0.6 ml...”

## Evaluation Results

Table 1 presents precision, recall, and $F_1$ scores. In the table, notes refer to the number of individual notes considered for each data component (eg, medication or symptom-related term). Instances refer to the number of times a data component is considered with allowance for multiple instances per note. A medication instance refers to all subcomponents (medication name, unit of measurement, quantity, and date information) of the medication when present. An instance is correct if all subcomponents are correctly extracted when present and is wrong if any one of the presented subcomponents is wrong. Precision-recall scores of medication information subcomponents provide a granular breakdown per extracted instance. Some of the extracted symptoms could be ambiguous to be classified as a symptom, such as emotional states (eg, “happiness”). We categorized them as symptoms in our research, as mood can affect health conditions.

**Table 1.** Evaluation of extracting medication and symptom information through precision, recall, and $F_1$ scores.

| Data component | Precision | Recall | $F_1$ | Notes, n | Instances, n |
|---|---|---|---|---|---|
| **Medication instance** | 0.83 | 0.77 | 0.80 | 30 | 62 |
| Medication | 0.97 | 0.84 | 0.90 | 30 | 62 |
| Unit | 0.86 | 0.53 | 0.66 | 14 | 27 |
| Quantity | 0.50 | 0.19 | 0.27 | 9 | 16 |
| Date | 0.93 | 0.76 | 0.84 | 13 | 33 |
| Symptom | 0.65 | 0.82 | 0.72 | 46 | 71 |

At an instance level, which is considered correct if all relevant subcomponents are correctly extracted, the medication-instance extraction pipeline has moderately good performance, with a precision and recall both near 0.8. At the subcomponent level, medication name recognition has the highest performance with high precision, while unit and quantity extraction have low recalls. In medication-related false-positive cases, patient names, or common terms (eg, water) overlap with medication names or ingredients (eg, water irrigation solution) within the RXNorm ontology. Unit and quantity extraction errors are often caused by irregular sentence structures or information split between multiple sentences. Date extraction performs well in both precision and recall (except in cases with phrasal referents, such as “A few days ago”). Both brand names and generic names are identified with errors caused by overlap between patient names and RXNORM. For symptoms, we find recall scores higher than precision, implying that often entities were extracted when they were not proper symptoms (eg, “sitting” and “sign”).

# Discussion

## Principal Findings

We present findings of our proposed NLP pipeline with real-world PGHD to demonstrate the feasibility of its implementation. The results demonstrate that the NLP pipeline performance matches contemporary works with a zero-shot approach for information extraction [28], specifically for most of our targeted information categories of medications and symptoms (with an $F_1$ score above 0.6). These results cannot be compared directly since the other studies in the literature do not focus on PGHD or the same combination of medication, dosage, and symptom extraction. However, the results indicate acceptable performance when using NER and dependency parsing through open-source and hybrid NLP models. The performance of the pipeline may increase over time with improvements in automatic speech recognition and text prediction and suggestion methods (methods that also use NLP models that are not covered within the scope of this study) [29-31]. However, in this study, the pipeline performance was potentially affected by the transcription errors or typing errors existing in the data set (n=16, 18% of 87 notes had at least one error; errors have not been corrected to contain real-world data features).

This study extends the existing literature [15], presenting the capability of current models to extract key information from patient notes. This approach can inform patients and caregivers out of the clinic toward enabling self-care (eg, improving medical adherence, symptom tracking) and remote monitoring (eg, detection, intervention, and communication) [11]. In clinical practice, the use of such artificial intelligence and machine learning approaches potentially facilitates the inclusion of personal health records into medical records, which can allow the identification of health condition changes and build early detection mechanisms [3,32]. Integrating unstructured PGHD via an NLP pipeline within electronic medical records can also contribute to improving patient-reported outcomes and shared decision-making at the clinic, allowing health care providers to remotely observe health conditions and intervene in a timely manner [33,34].

### Extending Digital Health Technologies for Special Health Care Needs

Considering the patient population with special health care needs and their caregivers that receive care from multiple providers and clinics, there is a continuous need for documentation, medication, and symptom tracking during home care. Timely communication of patient conditions with multiple health care providers is needed but creates additional burden and stress for patients and caregivers given their daily life and workload [35,36]. The literature shows that currently available digital health technologies including mobile apps, SMS text messages, and web portals have been used for patient care management [37-41] and communication of patient medical conditions remotely [41-44]. As digital health technology eases the process of documentation and the tracking of symptoms and medications, NLP approaches can improve the process by enabling the use of natural and preferred language. Furthermore, an NLP pipeline integrated with preferred technologies (text-based and voice-interactive apps, patient portals) can reduce the burden and complexity of accessing personal notes, summarizing and searching patient notes, and reducing the need to learn a technology to complete tasks or take notes, and reduce required attention on a device or modality and time spent on documentation [12,21,45]. In addition, the use of the zero-shot approach demonstrates the ability to use artificial intelligence and machine learning in data-scarce environments (eg, data on rare diseases, data from rural hospitals), which increases the equitable and accessible use of artificial intelligence and machine learning in health care.

### Implementing NLP Pipeline

Our study presents the feasibility of PLM use within zero-shot biomedical settings. Whereas other works require specialized pretraining of NLP models [28,46] or are limited to handling the formalized writing style of the biomedical literature, our approach makes use of more task-general biomedical PLMs to better generalize over the various syntactic forms found in PGHD. Namely, we gather our PLMs from the SciSpacy model suite, which shows high performance in its various capabilities when evaluated on PubMed and clinical notes [25]. We use SciSpacy's entity extraction capabilities before linking to various ontologies. It is followed by the extraction of additional information related to these entities, such as medication dosage information by leveraging sentence-level dependency parse trees, providing insight into the capabilities and using automatic dependency parsing. This is a novel approach to our study, which has not previously been implemented in biomedical research [47-49]. Furthermore, the performance of our pipeline can be improved through the use of cohort- or patient-specific vocabularies to augment the NER subcomponent, allowing for a human-in-the-loop component to our hybrid model where domain experts can define model parameters and integrate human knowledge [50]. Human-in-the-loop methods span a variety of directions with the general consensus being that such methods allow for compensation of model weaknesses with domain expertise and vice versa, alongside a high ratio of model performance against model creation cost, causing it to be an increasingly important component of applied machine learning [18,50]. Using publicly available models and ontologies improve the dissemination of the model as well as access and customization specific to conditions and patient populations. Since our NLP models are pretrained on clinical data and use publicly available ontologies, replication and scalability of a pipeline have low costs in terms of the requirement for training data, computational power requirements, and expertise.

### Limitations

Our study has several limitations. We did not use fine-tuned models or custom vocabularies, which might improve the performance (eg, missing condition-specific treatments and therapies). In addition, we do not implement and evaluate negation. We are unable to compare the feasibility of our pipeline against other NLP models. This is, in part, due to the lack of comparable and available pipelines and tasks to those presented in this study. However, future work is suggested to compare our pipeline against other PLMs as well as performance comparison against a model fine-tuned on general PGHD and clinical notes. These additional approaches may inform how our pipeline can be improved in the future to improve task completion or generalizability.

Our evaluation process was toward feasibility, rather than only performance assessment. In that regard, we used a nonstandard evaluation process as we annotated the examples coming after we ran the pipeline over these examples. As it was necessary to capture the false positives that the pipeline extracted, certain extracted values were considered partially valid only after the model was seen to have captured them, such as moods being considered symptoms. In these cases, the capture of such entities was not considered a false positive, while omittance was not necessarily considered a false negative. Additionally, for medication and dosage entities, it was unlikely for bias to be introduced due to the definite nature of these values (eg, if “Tylenol” is referenced, it is clearly a medication that should be captured).

Due to the limited text-based entries against voice entries, we were not able to measure the discrepancy of the model performance of extracting entities from written notes versus voice transcriptions.

## Technical Contribution

The first key contribution is the use of pretrained language and deep learning models and the extraction of information using syntax parsing and entity-to-ontology linking in the proposed methodology. To our knowledge, these individual components have yet to be combined into a clinical information extraction pipeline. Second, we focus on PGHD for chronic conditions which has been understudied, and, to our knowledge, no examples exist in the literature regarding the use of a text-processing pipeline with the real-world PGHD from this specific population (CSHCN). While previous studies explore similar NLP pipelines with NER, only a few studies use the automatic dependency parser for further relation and entity extraction [47], layer multiple rounds of dependency parsing to extract general relationships from within scientific literature [49], and use dependency parsing to identify SNOMED CT expressions form clinical notes and [48]. These studies show the promise of using syntactic dependency trees to improve generalizability but do not fit the unstructured format of PGHD and are not focused on extracting values related to chronic care, such as medications and dosages.

To accomplish the task of extracting key care-related information from PGHD (medications and symptoms), we created a pipeline that applies dependency parsing to key terms and relationships for chronic care management. Instead of expanding generalizability through training of a deep learning model, which can often be costly in time and labor, the pipeline can be improved and expanded with a system to allow for user input to inform NER and dependency-based relation extraction systems. This inclusivity of users (eg, clinician, patient, or caregiver) allows for flexibility of modification of our system depending on patient condition or clinical needs [19]. Furthermore, by using publicly available ontologies and models, the proposed pipeline can be replicated, customized, and improved for different cohorts with chronic conditions.

## Future Work

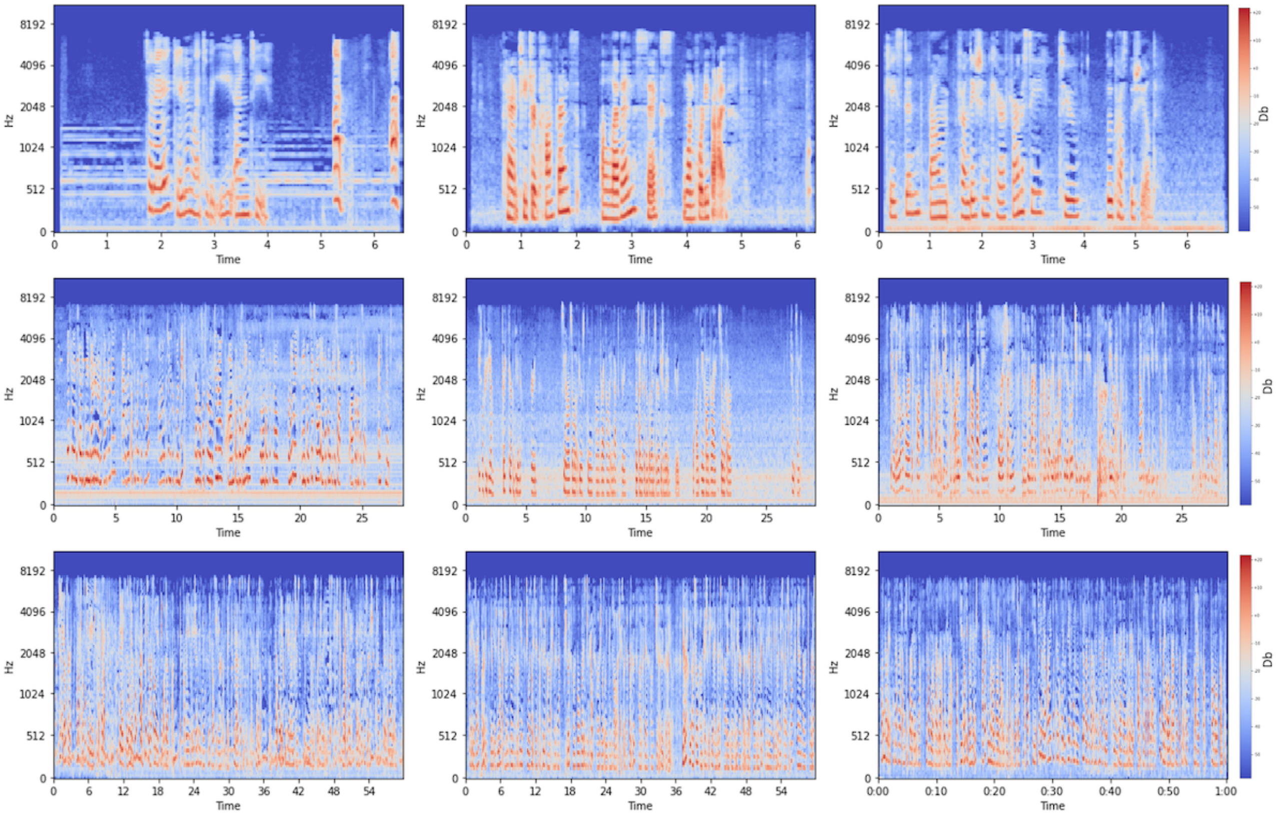
Future work will focus on building and fine-tuning condition-specific models, ontologies, and vocabularies, prototyping PGHD integration to clinical workflow, and improving clinical decision support mechanisms through PGHD-informed visuals.

In addition, we plan to analyze voice and audio characteristics and extract-related features (such as pause rates, pitch, loudness, acoustic and spectral features, and multiple speakers, such as parent and child) [51,52]. Voice analytics will add a new dimension to PGHD analytics by investigating vocal and environmental audio features (markers) with patient notes and building a multimodal pipeline, such as improving transcription quality, improving sentiment analysis, identifying the environmental factors [53,54], and guiding future data collection protocols. Textbox 2 provides a glimpse at the data for the proposed future work with voice analytics.

**Textbox 2.** Augmenting patient-generated health data with voice analytics pipeline in addition to natural language processing pipeline.

> Our study reveals that the voice data have been created in different environments (eg, alone in a silent room, while driving, or in a room with children). This affects the quality of transcriptions and, hence, NLP performance. We plan to transform and analyze audio or voice data with melspectrograms that can help decompose complex features or magnitude of signals of the voice and help extract features efficiently [51]. Eventually, we plan to use convolutional neural network models to extract features and classify them [53]. Figure 2 provides melspectrograms of nine participants' voice recordings.

**Figure 2.** Melspectrogram of participants' voices. Librosa library was used via Anaconda Spyder (Python 3.10; n_fft=2048, hop_length=512, n_mels=128; audio bitrate at 24 kbps and 20 Hz to 20 kHz frequency range). The top row is from 3 different participants with 6 seconds of recording, the middle row is from 3 different participants with 28 seconds of recording, and the bottom row is from 3 different participants with 60 seconds of recording. The first, third, and sixth melspectograms have higher noise or children sound in the background.



## Conclusion

We present the feasibility of an NLP pipeline with real-world data in a low-resource setting, focusing on medication and symptom information extraction. Unstructured PGHD can inform decision-making and support remote monitoring and self-care. With customizable information extraction methods using NER and medical ontologies, NLP models can feasibly extract a broad range of clinical information from unstructured PGHD in low-resource settings. We suggest future work to build medical condition-specific models, test the integration to clinical workflow, and use audio features in the analysis.

## Acknowledgments

This study was supported by Award Number UL1TR002733 from the National Center for Advancing Translational Sciences. The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Center for Advancing Translational Sciences or the National Institutes of Health.

## Data Availability

Because the data sets analyzed during the current study contain personally identifiable information and sensitive health information, they are not publicly available. Research consent did not include making the data available publicly.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Medication and symptom names captured.
[DOCX File , 10 KB-Multimedia Appendix 1]

## References

1. What are patient-generated health data? HealthIT. URL: https://www.healthit.gov/topic/otherhot-topics/what-are-patient-generated-health-data [accessed 2022-07-22]

2. Nittas V, Lun P, Ehrler F, Puhan MA, Mütsch M. Electronic patient-generated health data to facilitate disease prevention and health promotion: scoping review. J Med Internet Res 2019;21(10):e13320. [doi: 10.2196/13320] [Medline: 31613225]
3. Tiase VL, Hull W, McFarland MM, Sward KA, Del Fiol G, Staes C, et al. Patient-generated health data and electronic health record integration: a scoping review. JAMIA Open 2020;3(4):619-627 [FREE Full text] [doi: 10.1093/jamiaopen/ooaa052] [Medline: 33758798]
4. Jim HSL, Hoogland AI, Brownstein NC, Barata A, Dicker AP, Knoop H, et al. Innovations in research and clinical care using patient-generated health data. CA Cancer J Clin 2020;70(3):182-199 [FREE Full text] [doi: 10.3322/caac.21608] [Medline: 32311776]
5. Marwaha JS, Landman AB, Brat GA, Dunn T, Gordon WJ. Deploying digital health tools within large, complex health systems: key considerations for adoption and implementation. NPJ Digit Med 2022;5(1):13 [FREE Full text] [doi: 10.1038/s41746-022-00557-1] [Medline: 35087160]
6. Cercato MC, Vari S, Maggi G, Faltyn W, Onesti CE, Baldi J, et al. Narrative medicine: a digital diary in the management of bone and soft tissue sarcoma patients. Preliminary results of a multidisciplinary pilot study. J Clin Med 2022;11(2):406 [FREE Full text] [doi: 10.3390/jcm11020406] [Medline: 35054100]
7. van Buchem MM, Boosman H, Bauer MP, Kant IMJ, Cammel SA, Steyerberg EW. The digital scribe in clinical practice: a scoping review and research agenda. NPJ Digit Med 2021;4(1):57 [FREE Full text] [doi: 10.1038/s41746-021-00432-5] [Medline: 33772070]
8. Coiera E, Kocaballi B, Halamka J, Laranjo L. The digital scribe. NPJ Digit Med 2018;1:58 [FREE Full text] [doi: 10.1038/s41746-018-0066-9] [Medline: 31304337]
9. Bin Sawad A, Narayan B, Alnefaie A, Maqbool A, Mckie I, Smith J, et al. A systematic review on healthcare artificial intelligent conversational agents for chronic conditions. Sensors (Basel) 2022;22(7):2625 [FREE Full text] [doi: 10.3390/s22072625] [Medline: 35408238]
10. Haggstrom DA, Carr T. Uses of personal health records for communication among colorectal cancer survivors, caregivers, and providers: interview and observational study in a human-computer interaction laboratory. JMIR Hum Factors 2022;9(1):e16447 [FREE Full text] [doi: 10.2196/16447] [Medline: 35076406]
11. Walker J, Leveille S, Kriegel G, Lin CT, Liu SK, Payne TH, et al. Patients contributing to visit notes: mixed methods evaluation of ournotes. J Med Internet Res 2021;23(11):e29951 [FREE Full text] [doi: 10.2196/29951] [Medline: 34747710]
12. Sezgin E, Noritz G, Lin S, Huang Y. Feasibility of a voice-enabled medical diary app (SpeakHealth) for caregivers of children with special health care needs and health care providers: mixed methods study. JMIR Form Res 2021;5(5):e25503 [FREE Full text] [doi: 10.2196/25503] [Medline: 33865233]
13. Seinen TM, Fridgeirsson EA, Ioannou S, Jeannetot D, John LH, Kors JA, et al. Use of unstructured text in prognostic clinical prediction models: a systematic review. J Am Med Inform Assoc 2022;29(7):1292-1302 [FREE Full text] [doi: 10.1093/jamia/ocac058] [Medline: 35475536]
14. Gaudet-Blavignac C, Foufi V, Bjelogrlic M, Lovis C. Use of the systematized nomenclature of medicine clinical terms (SNOMED CT) for processing free text in health care: systematic scoping review. J Med Internet Res 2021;23(1):e24594 [FREE Full text] [doi: 10.2196/24594] [Medline: 33496673]
15. Dreisbach C, Koleck TA, Bourne PE, Bakken S. A systematic review of natural language processing and text mining of symptoms from electronic patient-authored text data. Int J Med Inform 2019;125:37-46 [FREE Full text] [doi: 10.1016/j.ijmedinf.2019.02.008] [Medline: 30914179]
16. Wei Q, Ji Z, Li Z, Du J, Wang J, Xu J, et al. A study of deep learning approaches for medication and adverse drug event extraction from clinical text. J Am Med Inform Assoc 2020;27(1):13-21 [FREE Full text] [doi: 10.1093/jamia/ocz063] [Medline: 31135882]
17. Li X, Cui M, Li J, Bai R, Lu Z, Aickelin U. A hybrid medical text classification framework: integrating attentive rule construction and neural network. Neurocomputing 2021 Jul;443:345-355. [doi: 10.1016/j.neucom.2021.02.069]
18. Cronin RM, Fabbri D, Denny JC, Rosenbloom ST, Jackson GP. A comparison of rule-based and machine learning approaches for classifying patient portal messages. Int J Med Inform 2017;105:110-120 [FREE Full text] [doi: 10.1016/j.ijmedinf.2017.06.004] [Medline: 28750904]
19. Hussain SA, Sezgin E, Krivchenia K, Luna J, Rust S, Huang Y. A natural language processing pipeline to synthesize patient-generated notes toward improving remote care and chronic disease management: a cystic fibrosis case study. JAMIA Open 2021;4(3):ooab084 [FREE Full text] [doi: 10.1093/jamiaopen/ooab084] [Medline: 34604710]
20. Nelson SJ, Zeng K, Kilbourne J, Powell T, Moore R. Normalized names for clinical drugs: RxNorm at 6 years. J Am Med Inform Assoc 2011;18(4):441-448 [FREE Full text] [doi: 10.1136/amiajnl-2011-000116] [Medline: 21515544]
21. Sezgin E, Oiler B, Abbott B, Noritz G, Huang Y. "Hey Siri, help me take care of my child": a feasibility study with caregivers of children with special healthcare needs using voice interaction and automatic speech recognition in remote care management. Front Public Health 2022;10:849322 [FREE Full text] [doi: 10.3389/fpubh.2022.849322] [Medline: 35309210]
22. Amazon Web Services (AWS). URL: https://aws.amazon.com/products/ [accessed 2023-02-10]
23. dateparser 1.1.7. PyPl. URL: https://pypi.org/project/dateparser/ [accessed 2022-08-27]
24. scispacy. GitHub. URL: https://allenai.github.io/scispacy/ [accessed 2022-08-27]

25. Neumann M, King D, Beltagy I, Ammar W. ScispaCy: fast and robust models for biomedical natural language processing. 2019 Presented at: The 18th BioNLP Workshop and Shared Task; August 2019; Florence, Italy. [doi: 10.18653/v1/w19-5034]
26. Honnibal M, Montani I. SpaCy 2: Natural language understanding with Bloom embeddings, convolutional neural networks and incremental parsing. SpaCy. 2017. URL: https://spacy.io/ [accessed 2023-02-12]
27. Wang W, Zheng VW, Yu H, Miao C. A survey of zero-shot learning. ACM Trans Intell Syst Technol 2019 Jan 16;10(2):1-37. [doi: 10.1145/3293318]
28. Papanikolaou Y, Staib M, Grace J, Bennett F. Slot filling for biomedical information extraction. ArXiv. Preprint posted online on September 17, 2021 [FREE Full text] [doi: 10.18653/v1/2022.bionlp-1.7]
29. Liao J, Eskimez SE, Lu L, Shi Y, Gong M, Shou L, et al. Improving readability for automatic speech recognition transcription. arXiv. Preprint posted online on April 9, 2020 [FREE Full text]
30. Khattak FK, Jeblee S, Pou-Prom C, Abdalla M, Meaney C, Rudzicz F. A survey of word embeddings for clinical text. J Biomed Inform 2019;100S:100057 [FREE Full text] [doi: 10.1016/j.yjbinx.2019.100057] [Medline: 34384583]
31. Sirrianni J, Sezgin E, Claman D, Linwood SL. Medical text prediction and suggestion using generative pretrained transformer models with dental medical notes. Methods Inf Med 2022;61(5-06):195-200. [doi: 10.1055/a-1900-7351] [Medline: 35835447]
32. Juhn Y, Liu H. Artificial intelligence approaches using natural language processing to advance EHR-based clinical research. J Allergy Clin Immunol 2020;145(2):463-469 [FREE Full text] [doi: 10.1016/j.jaci.2019.12.897] [Medline: 31883846]
33. Iqbal FM, Lam K, Joshi M, Khan S, Ashrafian H, Darzi A. Clinical outcomes of digital sensor alerting systems in remote monitoring: a systematic review and meta-analysis. NPJ Digit Med 2021;4(1):7 [FREE Full text] [doi: 10.1038/s41746-020-00378-0] [Medline: 33420338]
34. Celi LA, Marshall JD, Lai Y, Stone DJ. Disrupting electronic health records systems: the next generation. JMIR Med Inform 2015;3(4):e34 [FREE Full text] [doi: 10.2196/medinform.4192] [Medline: 26500106]
35. Ranade-Kharkar P, Weir C, Norlin C, Collins SA, Scarton LA, Baker GB, et al. Information needs of physicians, care coordinators, and families to support care coordination of children and youth with special health care needs (CYSHCN). J Am Med Inform Assoc 2017;24(5):933-941 [FREE Full text] [doi: 10.1093/jamia/ocx023] [Medline: 28371887]
36. Sezgin E, Noritz G, Elek A, Conkol K, Rust S, Bailey M, et al. Capturing at-home health and care information for children with medical complexity using voice interactive technologies: multi-stakeholder viewpoint. J Med Internet Res 2020;22(2):e14202 [FREE Full text] [doi: 10.2196/14202] [Medline: 32053114]
37. Richardson PA, Harrison LE, Heathcote LC, Rush G, Shear D, Lalloo C, et al. mHealth for pediatric chronic pain: state of the art and future directions. Expert Rev Neurother 2020;20(11):1177-1187 [FREE Full text] [doi: 10.1080/14737175.2020.1819792] [Medline: 32881587]
38. Jacob C, Sezgin E, Sanchez-Vazquez A, Ivory C. Sociotechnical factors affecting patients' adoption of mobile health tools: systematic literature review and narrative synthesis. JMIR Mhealth Uhealth 2022;10(5):e36284 [FREE Full text] [doi: 10.2196/36284] [Medline: 35318189]
39. Coughlin SS, Prochaska JJ, Williams LB, Besenyi GM, Heboyan V, Goggans DS, et al. Patient web portals, disease management, and primary prevention. Risk Manag Healthc Policy 2017;10:33-40 [FREE Full text] [doi: 10.2147/RMHP.S130431] [Medline: 28435342]
40. Debon R, Coleone JD, Bellei EA, De Marchi ACB. Mobile health applications for chronic diseases: a systematic review of features for lifestyle improvement. Diabetes Metab Syndr 2019;13(4):2507-2512. [doi: 10.1016/j.dsx.2019.07.016] [Medline: 31405669]
41. Marcolino MS, Oliveira JAQ, D'Agostino M, Ribeiro AL, Alkmim MBM, Novillo-Ortiz D. The impact of mHealth interventions: systematic review of systematic reviews. JMIR Mhealth Uhealth 2018;6(1):e23 [FREE Full text] [doi: 10.2196/mhealth.8873] [Medline: 29343463]
42. Baysari MT, Westbrook JI. Mobile applications for patient-centered care coordination: a review of human factors methods applied to their design, development, and evaluation. Yearb Med Inform 2015;10(1):47-54 [FREE Full text] [doi: 10.15265/IY-2015-011] [Medline: 26293851]
43. Gentles SJ, Lokker C, McKibbon KA. Health information technology to facilitate communication involving health care providers, caregivers, and pediatric patients: a scoping review. J Med Internet Res 2010;12(2):e22 [FREE Full text] [doi: 10.2196/jmir.1390] [Medline: 20562092]
44. Hartasanchez SA, Heen AF, Kunneman M, García-Bautista A, Hargraves IG, Prokop LJ, et al. Remote shared decision making through telemedicine: a systematic review of the literature. Patient Educ Couns 2022;105(2):356-365. [doi: 10.1016/j.pec.2021.06.012] [Medline: 34147314]
45. Militello L, Sezgin E, Huang Y, Lin S. Delivering delivering perinatal health information via a voice interactive app (SMILE): mixed methods feasibility study. JMIR Form Res 2021;5(3):e18240 [FREE Full text] [doi: 10.2196/18240] [Medline: 33646136]
46. Noh J, Kavuluru R. Joint learning for biomedical NER and entity normalization: encoding schemes, counterfactual examples, and zero-shot evaluation. ACM BCB 2021;2021:55 [FREE Full text] [doi: 10.1145/3459930.3469533] [Medline: 34505115]

47. Kuebler J, Tong L, Jiang M. Multi-round parsing-based multiword rules for scientific knowledge extraction. 2021 Presented at: 2021 IEEE International Conference on Big Knowledge; December 7-8, 2021; Auckland, New Zealand. [doi: 10.1109/ickg52313.2021.00051]
48. Liu X, Tan J, Fan J, Tan K, Hu J, Dong S. A Syntax-enhanced model based on category keywords for biomedical relation extraction. J Biomed Inform 2022;132:104135. [doi: 10.1016/j.jbi.2022.104135] [Medline: 35842217]
49. Peterson KJ, Liu H. Automating the transformation of free-text clinical problems into SNOMED CT expressions. AMIA Jt Summits Transl Sci Proc 2020;2020:497-506 [FREE Full text] [Medline: 32477671]
50. Wu X, Xiao L, Sun Y, Zhang J, Ma T, He L. A survey of human-in-the-loop for machine learning. Future Gener Comput Syst 2022 Oct;135:364-381. [doi: 10.1016/j.future.2022.05.014]
51. Kumar A, Jaquenoud T, Becker JH, Cho D, Mindt MR, Federman A, et al. Can you hear me now? Clinical applications of audio recordings. medRxiv. Preprint posted online on February 8, 2022. [doi: 10.1101/2022.02.07.22270598]
52. Zhang L, Chen X, Vakil A, Byott A, Ghomi R. DigiVoice: voice biomarker featurization and analysis pipeline. arXiv. Preprint posted online on June 17, 2019 [FREE Full text]
53. Purwins H, Li B, Virtanen T, Schlüter J, Chang S, Sainath T. Deep learning for audio signal processing. arXiv. Preprint posted online on May 25, 2019 [FREE Full text] [doi: 10.1109/jstsp.2019.2908700]
54. García-Ordás MT, Alaiz-Moretón H, Benítez-Andrades JA, García-Rodríguez I, García-Olalla O, Benavides C. Sentiment analysis in non-fixed length audios using a Fully Convolutional Neural Network. Biomed Signal Process Control 2021 Aug;69:102946. [doi: 10.1016/j.bspc.2021.102946]

## Abbreviations

**CSHCN:** children with special health care needs
**NER:** named entity recognition
**NLP:** natural language processing
**PGHD:** patient-generated health data
**PLM:** pretrained language model
**SNOMED CT:** Systematized Nomenclature of Medicine Clinical Terms

*Edited by A Mavragani; submitted 27.09.22; peer-reviewed by J Kim, D Whitehead; comments to author 09.12.22; revised version received 24.01.23; accepted 30.01.23; published 07.03.23*

*Please cite as:*
*Sezgin E, Hussain SA, Rust S, Huang Y*
*Extracting Medical Information From Free-Text and Unstructured Patient-Generated Health Data Using Natural Language Processing Methods: Feasibility Study With Real-world Data*
*JMIR Form Res 2023;7:e43014*
*URL: https://formative.jmir.org/2023/1/e43014*
*doi: 10.2196/43014*
*PMID:*