JMIR Data

Volume 5 (2024) ISSN

Contents

Original Papers

Development of Depression Data Sets and a Language Model for Depression Detection: Mixed Methods Study (e53365)	
Faye Tumaliuan, Lorelie Grepo, Eugene Jalao	
A Database of Randomized Trials on the HIV Care Cascade (CASCADE Database): Descriptive Study (e36874)	
Lawrence Mbuagbaw, Diya Jhuti, Gohar Zakaryan, Hussein El-Kechen, Nadia Rehman, Mark Youssef, Michael Garcia, Vaibhav Arora, Babalwa	2



Original Paper

Development of Depression Data Sets and a Language Model for Depression Detection: Mixed Methods Study

Faye Beatriz Tumaliuan^{1*}, MSc, MS; Lorelie Grepo^{1*}, MS; Eugene Rex Jalao^{1*}, MS, PhD

Department of Industrial Engineering and Operations Research, University of the Philippines Diliman, Quezon City, Philippines *all authors contributed equally

Corresponding Author:

Faye Beatriz Tumaliuan, MSc, MS Department of Industrial Engineering and Operations Research University of the Philippines Diliman Melchor Hall, Magsaysay Avenue Quezon City, 1101 Philippines

Phone: 63 9176593613

Email: fayetumaliuan@gmail.com

Abstract

Background: Depression detection in social media has gained attention in recent years with the help of natural language processing (NLP) techniques. Because of the low-resource standing of Filipino depression data, valid data sets need to be created to aid various machine learning techniques in depression detection classification tasks.

Objective: The primary objective is to build a depression corpus of Philippine Twitter users who were clinically diagnosed with depression by mental health professionals and develop from this a corpus of depression symptoms that can later serve as a baseline for predicting depression symptoms in the Filipino and English languages.

Methods: The proposed process included the implementation of clinical screening methods with the help of clinical psychologists in the recruitment of study participants who were young adults aged 18 to 30 years. A total of 72 participants were assessed by clinical psychologists and provided their Twitter data: 60 with depression and 12 with no depression. Six participants provided 2 Twitter accounts each, making 78 Twitter accounts. A data set was developed consisting of depression symptom—annotated tweets with 13 depression categories. These were created through manual annotation in a process constructed, guided, and validated by clinical psychologists.

Results: Three annotators completed the process for approximately 79,614 tweets, resulting in a substantial interannotator agreement score of 0.735 using Fleiss κ and a 95.59% psychologist validation score. A word2vec language model was developed using Filipino and English data sets to create a 300-feature word embedding that can be used in various machine learning techniques for NLP.

Conclusions: This study contributes to depression research by constructing depression data sets from social media to aid NLP in the Philippine setting. These 2 validated data sets can be significant in user detection or tweet-level detection of depression in young adults in further studies.

(JMIR Data 2024;5:e53365) doi:10.2196/53365

KEYWORDS

depression data set; depression detection; social media; natural language processing; Filipino

Introduction

Background

Depression is a health condition involving changes in emotion, thinking, or behavior. It represents a substantial part of mental health discussions. It affects a wide range of the public, as it can be experienced by anyone to some degree regardless of nationality, culture, gender, age, financial status, or lifestyle. The World Health Organization reported that the Philippines has one of the highest numbers of persons with depression in Southeast Asia, affecting 3.3 million Filipinos [1]. In recent years, the country has become helpless from the negative impacts of the public health emergency and economic crisis from the COVID-19 pandemic. The Philippines' National Center for Mental Health reported an increase in suicide-related calls



received on their hotlines, from an average daily call volume of 400 in 2019 to 700 from March to August 2020. The Philippine Statistics Authority in July 2021 also reported an increase of 57% in the suicide rate between 2019 and 2020, during the height of the pandemic [2]. The World Health Organization assessed in 2011 that, by 2030, depression will be the chief source of the worldwide disease burden.

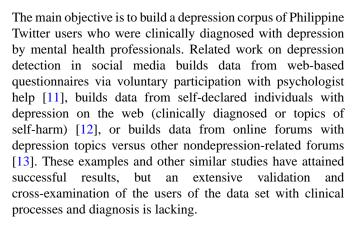
Social Media and Natural Language Processing for Depression Detection

Although depression and other mental illnesses may lead to social withdrawal and isolation, it was found that social media platforms are indeed increasingly used by affected individuals to connect with others, share experiences, and support each other [3]. A similar study in the United States concluded that internet users with stigmatized illnesses such as depression are more likely to use online resources for health-related information and communication about their illness than people with another chronic illness [4]. It was found that depressed individuals perceived social media as a means of maintaining social awareness and consoling themselves, while nondepressed individuals perceived it as a means of information sharing and consumption [5]. Moreover, because of the amount of complex behavioral data generated by users in social media, it has been explored in mental health research using pattern recognition, predictive modeling, classification, and categorization techniques to predict the presence of mental disorders, such as depression, suicidality, eating disorders, schizophrenia, and anxiety [6] in social network platforms such as Facebook, Twitter, Reddit, Weibo, and Sina Microblog.

Most of the methods mentioned are techniques used in natural language processing (NLP), which is the ability of computers to understand written or spoken language. It requires an extensive amount of data to build such models for a specific language. A language is considered a high-resource language if many available data resources exist (dictionaries, lexicons, treebanks of syntactically annotated data, all types of digitized text data such as news reports, books, social media, and other web-based data and annotated data for training depending on the NLP objective), making it possible to train machine learning models with these amounts of data. The national language of the Philippines, which is called Filipino, is based on an Austronesian language called Tagalog [7]. English is also considered a second language in the Philippines, with both English and Filipino used in written or spoken conversation, and most of the time used together in informal conversation, which forms "Taglish" (the combination of the 2 languages). Although English is a high-resource language, Filipino is considered a low-resource language. Because Filipino is a low-resource language, most NLP tasks and studies on mental health research focus on corpus building (or building depression vocabularies) to be used for other studies that need language processing [8-10].

Objectives

In this work, we aim to construct depression data sets from social media data to improve Philippine resources on depression research to aid in NLP.



We also aim to develop a corpus of depression symptoms that can later serve as a baseline for predicting depression symptoms in the Filipino and English languages. Because of the low-resource standing of Filipino depression data, this corpus of depression symptoms needs to be developed to perform and measure the predictive performance of various machine learning techniques in classification tasks.

Finally, we aim to develop a language model on the basis of Filipino and English social media data, which can be used to represent text data as vectors to aid in various downstream tasks in NLP.

Given the aforementioned objectives, we first constructed a data set of Twitter users validated by licensed clinical psychologists, and from these data, we constructed another data set of depression symptoms using a manual annotation process. We proposed a language model using the word2vec [14] algorithm using web-based texts in English and Filipino.

Related Work

Natural Language Processing

NLP is used by several studies to determine depression patterns or detect depression in social networks. Social media data are cleansed, segmented (separated into documents or sentences), tokenized (split into words or groups of words), and normalized (broken down into parts-of-speech, stemmed, or lemmatized to achieve root words or synsets for spelling correction and reducing complexity) in preparation for analysis. Sentiment analysis, a technique used to determine the sentiments of texts through data, is usually performed by classifying texts on the basis of polarity (positive and negative), valence or intensity, emotions, or subject dependency. Analysis may also be performed by categorizing data into ≥1 sets of "classes," which are called "classifiers." Such classifiers for machine learning used include regression, support vector machines, naive Bayes, and decision trees. Most recent methods convert words into embeddings or vectors (number representation of words) to perform deep learning analysis [11,13,15]. Deep learning uses networks that imitate the way neurons in the brain work to solve complex problems. Using deep learning methods can determine word similarity and analogy from well-trained corpora, which can be hard to achieve from the previously mentioned methods, such as accurately determining negation cues and word context and relationships. Results from social media studies that use



these methods suggest that language use has been found to be a predictor of depression [16].

Word Embeddings

For text data to be inputted as features into machine learning or neural network models, text data will need to be translated or represented into numbered vectors. Doing so makes it easier to represent words in a vector space and enables computations to be performed. It also enables words or text to be presented in several dimensions.

Several word embedding algorithms are available, and each has its strengths and weaknesses. Most of these algorithms need considerable training data to learn and create a language model. A vocabulary is created from all words existing in the training data, words are one-hot encoded (represented as 0 and 1), and probabilities of co-occurrence are computed between all the words in the training sample. One example is the word2vec model [14], which uses Continuous Bag of Words (CBOW) and skip-gram techniques to train a language model. CBOW aims to predict a target word from a set of words, while skip-gram is the opposite, wherein it tries to predict the probability of a given word being present when an input word is present. While training this model, a hidden layer of n-dimensions is created, which act as features that represent a word and its relationship to other words, thereby enabling the model to learn the semantic relationship between words, such as synonyms, antonyms, superclass, and neighboring or similar words. Other algorithms are available, such as global vectors [17], efficient learning of word representations and sentence classification (FastText), and BERT (Bidirectional Encoder Representations from Transformers) tokenizers. These models are trained repeatedly through the number of epochs, in which 1 epoch is a complete pass of the training data through the algorithm.

Word embeddings can serve as an input to machine learning algorithms to be used in downstream tasks such as classification or prediction tasks for depression detection in text data.

Depression Detection in Social Media

The most common social networks used for studying depression include Twitter [12,18-21], Reddit [13,22,23], Facebook [11,15], Weibo [20,24,25], and Sina Microblog [16]. Owing to being high-resource languages, most of this research is for languages in English and Chinese. Detecting depressed users from these social networks is a common theme (user-level detection), with depressed users [11,12,15,16,18,20,24,25], self-harm [26], and suicidal risk [23]. Some explored the detection from depression comments or texts [13,27], which are not on a user level (tweet level or comment level). Some studies also focused on detecting the degree of depression (ie, mild, moderate, or severe [19,21,26]) and early detection [22,26,28].

User-Level Versus Tweet-Level Depression Symptom Detection

Overview

Linguistic patterns, such as the use of positive or negative words, and social media behavior patterns, such as posting and user interaction behavior, are shown to have positive results in detecting depression [11,16,20]. Although several studies focus on depression screening, most studies focus on screening the users (user level) and do not focus on the emergence of depression symptoms in social media language. The social media data that users create can help doctors have a glimpse of their mental state through daily activities [5]. For example, on a tweet-level basis, passive daily activities can show known signs of psychological depression symptoms, such as changes in mood, activity level, sleeping and eating patterns, and suicidal ideation. This level of granularity by looking at the symptom level can aid the depression symptom tracking process and can open up opportunities to closely study depression patterns. It can also eventually lead to detection on a user level, determine the severity of depression through tweet-level symptoms [21], or help with early detection studies.

Tumaliuan et al

Data Collection Methods

The data collection methods for social media use specific application programming interfaces (APIs), which are a set of programmable commands that allow software interaction with certain websites.

User-Declared or Self-Declared Depression

In this method, users are identified as depressed when the self-reported sentence pattern "I'm diagnosed with depression" is matched or other patterns such as "(I'm/I was/I am/I've been) diagnosed depression" [12,20,22,28]. For the control group, users are labeled as nondepressed if no tweets containing "depress" were published in the sampling period or by selecting random users.

Group or Topic Involvement or Keyword Search

Studies that made use of group involvement performed data collection for depressed users by crawling subtopic groups catered to each social media platform, for example, Reddit subreddit groups such as r/depression, r/SuicideWatch [23], and r/selfharm [26] and Weibo's subtopic function "SuperTopic" [24,25]. The control group for nondepressed users is from other topics not related to depression or random users. Other studies use keyword search and apply it on Twitter and Sina Microblog using seed word generation methods from words extracted from each of the symptoms of the Patient Health Questionnaire-9 (PHQ-9), also with the help of psychologists [21].

Use of Depression Questionnaires

In the clinical setting, most initial screening tools make use of questionnaires for assessment by mental health experts or primary care physicians. A sample of the questionnaires from some of the previous studies that looked into depression detection are the Center for Epidemiologic Studies Depression Scale screening test [18,19], Beck Depression Inventory [26], Thai Mental Health Questionnaire [11], and PHQ-9 [21].

Manual Annotations

Looking at the previous data collection methods mentioned, it is crucial to note that each method has its limitations and biases. Some of the studies address this through manual checking or annotation of data by psychologists or trained personnel [21,22,24,25].



Interviews With Experts

From all the other data collection methods previously discussed, the "ground truth" method would be clinical interviews with mental health experts, as they serve as valid clinical assessments or diagnoses. Wang et al [16] used this method in their study, in which a group of psychologists diagnosed hundreds of volunteers using questionnaires and interviews. This method is the most costly and time consuming because mental health experts need to assess every participant in the study, but this removes the biases from the previous methods and makes sure that the 2 groups studied (with or without depression) are labeled correctly.

Combined Modalities

Overview

The studies above show that NLP and machine learning techniques can classify depression in users or depression in user comments on social media. It can be used to identify early risks and crises as well. Combining different modalities such as text, images, social media behavior, and results from psychological studies can improve detection capability. The accuracies of the techniques discussed in this review range from 0.69 [19] to 0.925 [13] using support vector machines, random forests, and other sentiment analysis techniques and have improved to up to 0.98 [23] in the last 2 to 3 years with the improvement of deep learning and word embedding techniques.

Philippine Studies for NLP and Depression

Initial studies for Filipino NLP act as an enabling resource for computational linguistics. This includes the Filipino wordnet project (FilWordNet) developed by Borra et al [29], which can serve as a basis for a stemmer, lemmatizer, or development of a named entity recognition system because of its manually created synsets and root words created in a dictionary format. Keen et al [9] developed FilCon, a generated subjective lexicon that contains subjectivity scores, positivity, negativity, and neutrality polarity values. Andrei [8] developed a Linguistic Inquiry and Word Count dictionary for positive and negative emotions using tweets, while Lapita et al [10] developed an emotion-annotated corpus of disaster-relevant tweets.

Bitsch et al [30] identified depression symptoms and categorized depression symptom categories to create a depression lexicon for pattern matching of the presence of depression symptoms. It is used as a mobile app solution. Nartia et al [31] developed a predictive model using a decision tree for identifying the mental health condition of university students, whereas Aliman et al [27] developed a bot that classifies potential mental health

crisis tweets using logistic regression. Aperocho [32] used a qualitative analysis approach to understand the use of Philippine English in the depressive language by analyzing the discourses posted by netizens on Facebook.

Research Gaps

One of the challenges in depression detection in social media is the collection of training data. Social media offers a huge opportunity in data science as it offers a huge amount of data that can be easily collected through available APIs. The downside is that it suffers from ethical concerns, validity, and credibility. Studies must ensure that users are informed of the data collection process, in which case, most of the previous studies scraped data from free APIs and did not involve the consent of users in the process. Another issue is the validation of whether the users have experienced depression. Questionnaire methods and clinical interviews increase the validity and are most credible but are costly and challenging to implement, which is the reason why most studies can only focus on data science methods or involve psychological experts in improving the data science methodologies in these studies.

Most studies discussed are also focused on user-level detection. User-level detection not based on symptom tracking can mimic screening methods but is not efficient to implement because clinical diagnosis still needs expert help. However, a depression symptom detection model on a text or tweet-level detection that can identify symptoms over time can help identify symptoms that can complement clinical practice and improve its efficiency. Aside from this, the current Philippine studies discussed can aid depression research in NLP if the goal is to determine how polarity, emotion, or sentence structure in text data relates to depression. As per similar studies abroad that use social media to determine patterns of depression, there is a lack of data set of social media users with clinically validated depression cases and a lack of depression symptom text data sets in Filipino and English, which can act as a baseline for depression symptom detection.

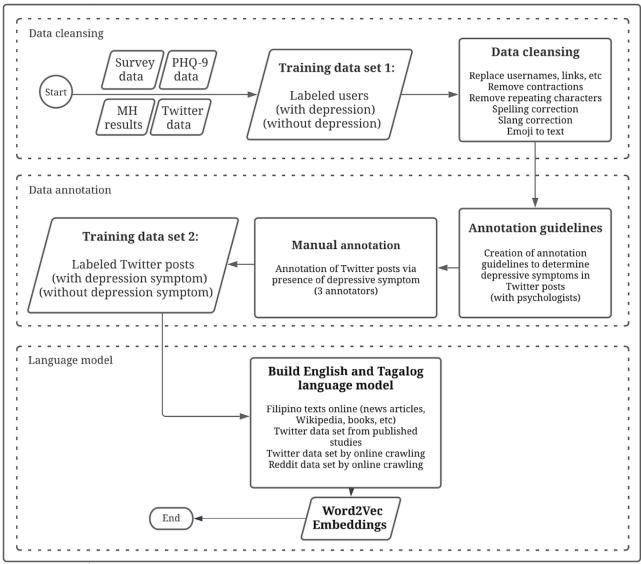
Methods

Overview

This section describes the data collection and methods for data set creation for this study. Figure 1 illustrates the whole methodology framework for this study. It includes the criteria for participant collection, sampling design, annotation guidelines and processes, and Filipino and English language model creation.



Figure 1. Methodology—this figure shows the different steps performed in this methodology, from data cleansing, data annotation process, and language model creation. It shows the creation of data sets 1 and 2 and word2vec embeddings, which are the major outputs and objectives of this study. MH: mental health; PHQ-9: Patient Health Questionnaire-9.



Study Design

This study is a 2-stage research that aims to detect depression symptom patterns in social media. It involves stage 1 (data generation) and stage 2 (depression symptom detection). This paper focuses on the first stage of generating depression data sets to be used for detecting depression symptoms in the second stage. The second stage is intended for future research in another paper.

Ethical Considerations

There are numerous ethical questions in mental health research, especially with regard to this study, which deals with social media and its various issues with privacy concerns. All participants signed an informed consent form, aiming participant understanding on what data was collected, and the privacy considerations and confidentiality measures that were applied, in addition to having complete control on what part of their data they wanted to share. Participant data were anonymized and any personal identifiable information were removed before any analysis was performed. Tweet text data were cleansed of

participant names, usernames, links, and hashtags, which ensures no tweets can be identifiable and traced back to a particular user.

The UP Manila Research Ethics Board (UPMREB 2022-0135-01) have reviewed and approved all methodologies and recruitment materials before the start of participant recruitment.

Recruitment

The inclusion criteria for participants in this study are Filipino Twitter users living in the Philippines who speak or write mainly in English or Filipino aged between 18 and 30 years. This age group is chosen for this study as the young adults' age group has been studied for mental health conditions and social media use (aged 18-24 years) [3], and the prevalence of suicide and depression in young adults in the Philippines (aged 15-29 and 18-24 years) [1,33].

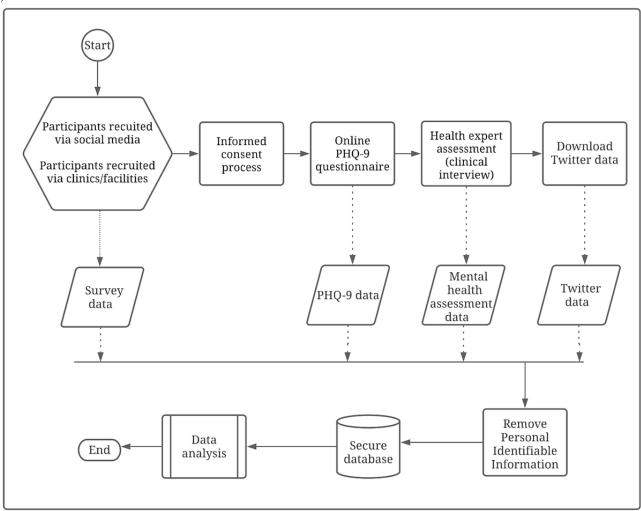
Participants are recruited from clinics and social media platforms and are asked to answer a survey form and a web-based self-assessment form which is the PHQ-9 depression



questionnaire. After the web-based self-assessment, all participants are assessed by a psychologist if experiencing or diagnosed with clinical depression (in any form or severity) or otherwise. The control group is the participants not assessed with depression or any other mental health conditions. Participants who were not assessed with depression but were assessed with other mental health conditions are excluded from this study. If assessed with any other mental health conditions (posttraumatic stress disorder, obsessive-compulsive disorder, bipolar disorder, schizophrenia, etc), they are included in the study as part of the depression group as long as the participant is experiencing depression because these are symptoms that are said to cause or can coexist with depression [34]. In short, the control group consists of participants who are assessed to have "usual" or "typical" mental health behaviors and the depressed group consists of participants assessed with depression.

Figure 2 illustrates the data collection workflow for this study. The participants were asked to sign a consent form for the collection of their social media data. This step informed the participants about what data will be collected and the privacy considerations and confidentiality measures that will be applied to their data. All participants were asked to share their data via the "Download an archive of your data" feature of Twitter in their account settings, which includes all historical data for an account. This step also makes sure that participants have complete control over what part of their data they want to share. Interactions with participants were performed by a mental health expert who was also on standby throughout the data collection phase should the participants experience distress and need support from a mental health professional.

Figure 2. Data collection workflow and generated data—each participant who completed the data collection process is expected to have 4 types of data collected. These are the survey data (which includes demographics and personal information), Patient Health Questionnaire-9 (PHQ-9) results, Mental Health Assessment results (includes symptoms, medical history, and depression assessment), and Twitter data archive (all historical Twitter data).



Sampling Design

Nonvalidated study data sets on depression on social media (those which are either scraped from the internet via self-declared users or self-assessment questionnaires) vary from a minimum of 20 [11] to 137 users with depression data [26]. As there are no known studies on this topic that use a data set

with validated users (those whose users were examined by clinics or experts), the greatest number of validated data sets is from the study by Wang et al [16] with a data set size of 122 users with depression.

Our data collection process included an assessment session with a psychologist, thus restricting the cost of the total number of



participants. Puyat et al [33] estimated that 8.9% of young adults experience moderate to severe depression in the Philippines. To attain population-proportion sample sizes for the 2 groups (persons with depression and the control group) in the study, the aim was to achieve at least 10% of the depression group from the overall participant data in this study. We aimed to gather approximately 80 participants for this study; thus, we needed at least 10 participants in the depression group. For a user-level detection of depression, a balanced class distribution (40 participants for the depressed group and 40 participants for the control group) is ideal for most classification tasks. However, because the goal is to create a data set of depression symptoms in text data (tweet-level depression detection), the balanced class is not imposed as long as the minimum requirement of 10 participants in the depression group is met. The resulting data collected from this process was tagged as data set 1, which includes labeled data of users who were "assessed with depression" (mild, moderate, or severe) or "not assessed with depression."

Data Preparation

Data Cleansing

Tweet text data were cleansed of usernames, links, and hashtags. Participants' names are sometimes included in the tweet texts when referencing themselves during tweets; thus, these were

cleansed as well. Special tokens for these cases were created, namely "xxuser, xxlink, xxhashtag, xxname." All these types of texts were replaced via their corresponding tokens.

Some text data were removed, such as nonalphabet or nonemoji characters, punctuations, and numbers. All remaining texts were converted to lowercase. Tweet text data contain irregular words such as contractions, typographical errors, elongated words, and slang words. For English words, contractions are replaced using the Python "contraction" package. Using this package transforms the word "don't" into "do not." Words with repeating characters were normalized by removing the occurrence of consecutive single characters unless it is a valid English or Filipino word. Abbreviations, wrong spellings, and slang were also corrected by creating a list of words that usually occur in social media texts. Spelling correction examples are Filipino words such as "d" transformed to "hindi" or English words such as "some1" changed into "someone." Slang correction examples are "pov" into "point of view," "dasurb" into "deserve," and so on. Every word in a tweet is checked whether it exists in this list that was generated for spelling correction and slang correction and is replaced by the corresponding word equivalent using Python search. Finally, emojis are transformed into equivalent text using the Python "demoji" package and tokenized using the "TweetTokenizer" package, illustrated in

Figure 3. Data cleansing—this figure shows the data cleansing steps of collected tweets from the conversion of tokens, removal of text, transforming into lower case and irregular words, conversion of unknown words, and conversion of emojis.

Input:	"uy masaya ako 10x	toda	ay :) gagaguiy HAHAHA uyyyyy!!!. @username 🥪 lol #happy https://sample.html"
	@username	=	xxuser
Special tokens:	#happy	=	xxhashtag
	https://sample.html	=	xxlink
Remove	:)		
punctuations,	!!!.		
numbers, etc:	10		
Lowercase	НАНАНА	=	hahaha
Irregular words	НАНАНА	=	haha
and slang	uyyyyy	=	uy
	lol	=	laughing
Unknown words	gaagaguiy	=	unk
Emoji	w	=	pouting face
Cleansed input	["uy", "masaya", ' "xxhashtag", "xxli		", "unk", "today", "unk ", "haha", "uy", "xxuser", "pouting", "face", "laughing",

Annotation Guidelines and Process

To create a depression symptom data set, a training data set 2 needed to be created in which individual tweets were manually annotated as having depression symptoms or no symptoms. Annotation guidelines were needed for annotators to be in sync for data to be well labeled and valid for the next steps. The creation of annotation guidelines was held with 2 clinical psychologists in a series of web-based sessions. The objective was to create depression symptom categories and to determine rules and guidelines for annotating tweets into the respective

categories. The categories were not mutually exclusive, as they can simultaneously occur together in one given tweet.

The result of this exercise is the reviewed and finalized depression symptom categories with the psychologists. These categories are based on the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)* criteria for depression (The Structured Clinical Interview for DSM-5), PHQ-9 results, and Mental Health Assessment results from this study. Textbox 1 shows the depression categories from the annotation guidelines developed in Textbox 2.



Textbox 1. Depression categories for annotation.

Thinking, concentration, and decisions

- Unable to handle minor problems and daily activities—procrastination and academics
- Diminished ability to think or concentrate, indecisiveness, unorganized thinking, forgetfulness, slow

Interest and motivation

- · Loss of energy or motivation
- · Loss of interest or enjoyment of activities, such as sex, hobbies or sports

Physical: sleep

• Insomnia or sleeping too much

Physical: fatigue

- Fatigue, tiredness, or lack of energy
- Emotional, mental, or physical fatigue
- Example: Filipino context—"Pagod na ako" (in English: "I am already tired")

Physical: appetite

· Weight loss or gain, no appetite, or increased cravings

Physical: movement

- Moving or speaking slowly
- Feelings of restlessness or agitation
- Movement issues or wanting to stay in bed
- Example: Filipino context—"Hindi makakilos, gusto lang sa kama, hindi mapakali" (in English: "I cannot move, I want to stay in bed, I feel restless")

Substance use

- Using recreational drugs or alcohol, etc (excluding coffee, melatonin, etc)
- If a substance is used as a coping mechanism
- If the deed is already done, not if intention only

Patient Health Questionnaire-9 (PHQ-9)—suicidal tendencies

- · Recurrent thoughts of death, suicide attempts, or suicide
- Self-harm
- Overelaborate or strange ideas

PHQ-9—emotional: depressed and sadness

- Depressed mood or lonely
- · Feelings of hopelessness, tearfulness, emptiness, or grief
- Breakdowns
- Emotions not induced by movies, events, or other outside triggers

PHQ-9—emotional: worthlessness and worry

- Feelings of worthlessness or no confidence, feeling misunderstood, self-doubt, or hypercritical toward self
- · Feelings of guilt, fixating on past failures or self-blame, worry, discouragement, demotivation, or disappointment
- Stress, overthinking, or anxiety
- Negative thoughts and existential questions

Physical: pains



- Headache, back pains, stomachache or sexual dysfunction, tremors, or cold hands and feet
- Panic, choking, or numbness
- Pains triggered by stress (with the context of stress [eg, allergies, acid reflux, or gastroesophageal reflux disease])
- Exclude premenstrual syndrome signs or pains induced by known causes (accidents, etc), as said in the tweet

Social

- Social withdrawal or avoiding social interaction
- Sensitivity to criticism, irritability, agitation, or angry outbursts
- Detachment or isolation

Mental health-related issues

• Tweets not pertaining to any symptoms previously mentioned but denote that the user is associated with any mental health issues, such as talking to psychologists or being aware of mental health issues, or reminiscing traumas

No symptom

- The tweet has no symptom
- The tweet does not have enough context to be determined as a symptom



Textbox 2. Annotation guidelines.

Tweet annotations

• Tweet annotated as a whole, not by subsentences

Multiple symptoms

- A maximum of 3 symptoms can be annotated per tweet
- Example: "I cannot sleep nor move my body in this bed. Brb gonna die of starvation"
- Symptoms: Physical: sleep; Physical: movement; Physical: appetite

Speaker's view

Refrain from viewing the tweet as an outside person

Cause and effect relationship

• If any sentence builds upon a cause and reflects an effect, the underlying context or symptom in that tweet should be judged on the basis of the effect, for example, "If he wins, I will kill myself"; this will be judged as a symptom regardless of the said cause

Quotes, song titles, lyrics, etc

 Users sometimes portray their emotions or thoughts using these methods. As such, if the text suggests enough context, these are annotated as symptoms

Jokes and sarcasm

- On the basis of the context, jokes and sarcasm are annotated as symptoms
- Jokes (eg, "I will kill myself. Kidding"); symptom
- Sarcasm (eg, "Kill me now I am so bored"); no symptom

Rants

Treated as irritability symptoms

Politics

• These are treated as a symptom if a tweet suggests a strong emotional context that denotes a symptom, for example, "I am so angry at this government it makes me worry about my future"; social, PHQ-9—emotional: worthlessness and worry

Sadness over movies, events, "missing" people, places, or things

• These are not treated as symptoms because these are triggered by outside events

Metaphors or expressions

- These are examined depending on context; with enough context, they are treated as symptoms.
- Example: "Ang sakit mo sa ulo" (in English: "You are a headache"); no symptom
- Example: "Sakit ng ulo ko" (in English: "I have a headache"); symptom

Annotation Process

The process started with the selection of tweets to be annotated. All participants were included in this selection; included tweets are dated January 1, 2021, to November 30, 2022. Retweets and non-English and non-Filipino tweets were removed. Some tweets that were empty after data preparation and cleansing steps were discarded. The tool used for annotating tweets is Microsoft Excel. After tweet selection, these tweets were all annotated by the first-pass annotator. Tweets without depression symptoms are treated as "no symptom," and tweets that denote a depression symptom are passed on to the next 2 annotators.

These tweets checked by the first-pass annotator are tweets that significantly do not denote any depression symptoms. Examples

of these texts were tweets with incomplete contexts, such as emoticon or emoji replies, responses to other tweets (random conversations in a thread), tweets with only photos, links, or other media, one-worded or vague tweets, and third-party application—related tweets (eg, Wordle).

Tweets were annotated anonymously, individually, and in a randomized order. Annotators had no knowledge of the users and of the tweets being annotated, and the annotations are based solely on professional experience, together with the guidelines provided to them. This process is repeated in 4 iterations with different subsets of the data sets in each iteration, and all annotators provided their annotations in 10 days. Tweet label categories were considered correct if at least 2 annotators selected the same symptom category. After each iteration, an



annotation review is conducted within the annotators for tweets that do not have 2 agreeing annotations on the symptom category. A thorough discussion for each tweet is held until a consensus is reached among the annotators. Most tweets that are reviewed during this annotation review are due to human error, as the annotators expressed their sentiment that they intended to select a category but mistakenly selected the neighboring category. The remaining tweets needed some thorough discussions, and annotators decided together which category was most appropriate.

After the annotation process, an annotation validation is held wherein 4 to 5 random samples per category were chosen, a total of 68 tweets. These tweets were reviewed by the psychologists together with the annotators.

Measuring Annotation Reliability

The data set produced in the annotation step served as the baseline or "ground truth" when predicting depression symptoms in downstream tasks. The reliability of the annotation task can be measured by an interannotator agreement score, which measures how well multiple annotators can make the same decision for the given annotation labels or categories. This measure determines how well the annotation guidelines have been established, how well the annotation labels or categories have been identified, and how well the annotators have grasped the annotation rules. It can also measure the reproducibility of the annotation task at hand.

Textbox 3. Language model training data.

For this annotation task, the Fleiss κ measurement is used, as this can consider multiple annotators. This measurement also considers the possibility of the agreement occurring by chance. Raters having complete agreement will have an output of κ =1, and rates with no agreement will have κ <0. The following equation is used to compute the Fleiss κ score [35]:

$$= (\rho_o - \rho_e)/(1 - \rho_e)$$

Where $\rho_o =$ observed agreement of raters and $\rho_e =$ expected agreement of raters.

The annotation results were aggregated, and the interannotator Fleiss κ was computed using the Python package "statsmodels."

English and Filipino Word2vec Language Model

To train a language model, several text data gathered from various sources were used. A combination of English and Filipino texts is collected. A total of approximately 4.7 GB of data were collected and trained for this model. Textbox 3 summarizes the sources of the data used for this language model.

A word2vec model [14] was trained using the language model training data in the previous textbox as the training data set. The CBOW algorithm was used as a configuration. The model is trained with 300 features and 20 epochs with a window of 5. The window means the algorithm checks 5 words before and 5 words after the target word, which is predicted in every hidden node in the network. The algorithm outputs a word embedding, which is a 300-dimensional vector for every word included in the training data set vocabulary.

Filipino Texts online (News articles, Wikipedia, books, etc)

- PALITO corpus [36]
- Leipzig corpus [37]
- Isawika lexicon [38]

Twitter data set from published studies

- Yolanda data set [39]
- Gay language data set [40]
- Election data set [41]
- Hate speech data set [42]
- Emotion-annotated Tweets for Disaster Risk Assessment [EMOTERA] data set [10]

Twitter data set by web-based crawling (created by this study)

- Mental Health PH seed words
- Self-declared depression data set from 2019

Reddit data from the program which this study is a part of

Mental health discussions on Reddit



Results

Overview

The first objective of this study is to construct a data set of Philippine Twitter users who are assessed by mental health experts. The second objective is to develop a data set of depression symptoms that can serve as a baseline for predicting depression symptoms in Filipino and English, and the third objective is to create a language model that can represent Filipino and English text through vector representations. The following sections discuss the data collected, constructed data sets for this study, and the language model results, which address the objectives of this study.

Data

A total of 75 participants were assessed by psychologists and had a complete set of data categorized at the user level, with 60 assessed with depression, 12 not assessed with depression, and 3 not assessed with depression but have other mental health conditions and are excluded from the study. Further statistics in this study will include only these 72 participants (60 assessed with depression, 12 not assessed with depression). Six of these participants assessed with depression provided 2 accounts for Twitter. In total, 78 Twitter users have 577,202 tweets; 433,029 liked tweets; and a total of 1,010,231 tweets. This is the training data set 1. Figures 4 and 5 show the data collection results including the distribution and statistics of the collected data.

Tables 1 to 3 show the count of Twitter users, considering the 6 dummy Twitter accounts from the participants. Table 1 shows the statistical summaries for the Twitter data between the depressed group and control group for tweet and retweet counts. Table 2 shows the statistical summaries between the depressed group and control group for account age and mentions count. Table 3 shows the statistical summaries between the depressed group and control group for follower and following count.

During the annotation task, an initial number of 438,718 tweets were selected and preprocessed. A total of 102,262 tweets were annotated by the first-pass annotator and from this data set, 11,335 tweets have been annotated by all 3 annotators. The final data set generated in this study is 79,614 tweets, with 11,163 labeled with depression symptoms (13 categories) and 68,451 labeled with no symptoms, and is named as data set 2.

During the validation for data set 2, there were only 3 tweets out of 68 randomly chosen validation tweets in which the psychologists disagreed with the category label, reaching 95.59% psychologist validation score. Figure 6 shows the total counts of symptom categories resulting from the annotation task.

Another validation step is used using the Fleiss κ to measure the interannotator score using the 11,335 tweets annotated by 3 annotators and 14 label categories. The agreement score is 0.735, interpreted as "substantial agreement" on the basis of Figure 7 [43] interpretation of the Fleiss κ measurement.



Figure 4. Data collection results (part 1). The distribution of depression assessment results shows the imbalance of data, as more users are assessed with depression. Regarding severity, 26 individuals were assessed with "severe" depression, whereas 20 were assessed with "mild" and 14 with "moderate" depression. The distribution of gender in our collected data is also imbalanced, with more female participants recruited for this study. For the distribution of age, most users were aged 18 to 25 years.

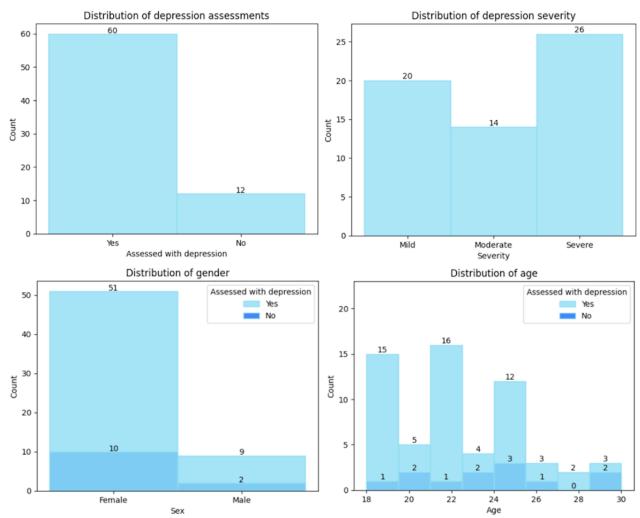
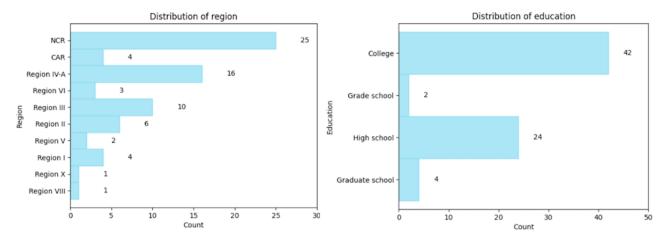




Figure 5. Data collection results (part 2). The distribution of regions shows most participants were from the National Capital Region (NCR), IV-A, and III regions and other parts of the Luzon area. In the distribution of education, most are college and high school graduates. Most participants are either employed or students as shown by the distribution of employment. CAR: Cordillera Administrative Region.



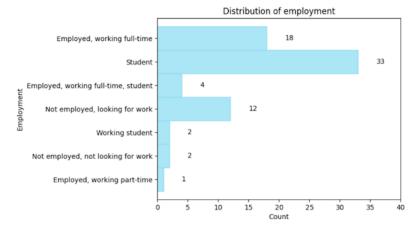


 Table 1. Data collection results (part 3).

	tweet_count							retweet_count						
	Count	Mean (SD)	Mini- mum	25%	50%	75%	Maximum	Count	Mean (SD)	Mini- mum	25%	50%	75%	Maxi- mum
Assessed	with d	epression		•		,	,	•	•		•		•	
No	12	3498.42 (3982.08)	80	461.5	1606.00	5477.25	10,843.00	12	313.75 (569.71)	0	5.25	29	405.75	1960.00
Yes	66	6146.03 (9198.76)	3	404.75	2313.50	6724.75	47,644.00	66	605.94 (1395.77)	0	1	30.5	232	6670.00

Table 2. Data collection results (part 4).

tweet_age_days								mentions_count						
	Count	Mean (SD)	Mini- mum	25%	50%	75%	Maximum	Count	Mean (SD)	Mini- mum	25%	50%	75%	Maxi- mum
Assessed	with d	epression		•			•		•		•			
No	12	2429.17 (1614.81)	599	904.5	2284.00	3564.75	5480.00	12	1674.25 (2049.69)	24	169.75	909	2448.50	6664.00
Yes	66	1780.61 (1389.65)	101	609.5	1470.50	2581.75	4860.00	66	2959.41 (5634.60)	1	145.25	853	2596.25	37,315.00



Table 3. Data collection results (part 5).

	Follower							Following							
	Count	Mean (SD)	Mini- mum	25%	50%	75%	Maximum	Count	Mean (SD)	Mini- mum	25%	50%	75%	Maxi- mum	
Assessed	l with d	epression				•		•	•					,	
No	12	218.17 (175.73)	7	61	178	370	490	12	330 (364.07)	53	113.5	174	395.5	1,169.00	
Yes	66	252.53 (380.18)	0	29	98.5	276.75	1,839.00	66	321.65 (393.44)	0	64	156	406.75	1,787.00	

Figure 6. Annotation task results. Total counts per symptom category for all the 11,163 tweets labeled with depression symptoms and their corresponding symptom categories are shown here. Social, PHQ-9-emotional: worthlessness and worry, PHQ-9-emotional: depressed and sadness have the most number of tweets, whereas Physical: movement and Substance use and PHQ-9-suicidal tendencies have the least number of tweets. MH: mental health; PHQ-9: Patient Health Questionnaire-9.

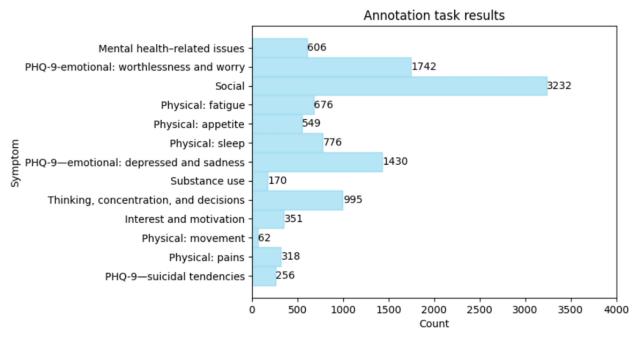


Figure 7. Interpretation of Fleiss κ . The resulting Fleiss κ is 0.735, denoting the annotation task agreement score as "substantial agreement". Used with permission of John Wiley & Sons - Books, from "The measurement of observer agreement for categorical data. Landis JR, Koch GG, 33(1):159-174, Mar 1977" [43]; permission conveyed through Copyright Clearance Center, Inc.".

Kappa Statistic	Strength of Agreement
< 0.00	\mathbf{Poor}
0.00-0.20	Slight
0.21 – 0.40	Fair
0.41 – 0.60	$\operatorname{Moderate}$
0.61 - 0.80	Substantial
0.81-1.00	Almost Perfect

Constructed Data Sets

From all 4 types of data collected in this study, 2 labeling mechanisms are applied: labeled data at a user level and tweet

level. The data set of user-level annotated data is a combination of survey data, PHQ-9 questionnaire results, and Mental Health Assessment results (data set 1). The other tweet-level annotated data set was created from the previous annotation tasks from



the Twitter archive data of participants (data set 2). Both data sets share the same number of Twitter users (78 users).

A complete list of data per data set is provided in Textbox 4, and the summary is shown in Table 4.

Data sets collected and processed in this study can greatly help both the mental health research and the Filipino language processing research in the country.

We have created a data set that includes demographic data, PHQ-9 questionnaire data, and Mental Health Assessment data. It is important to mention that all participants in this data collection were assessed by psychologists via clinical interviews.

These data can be used to explore user-level depression detection of users in social media.

The annotated training data set created by this study is also a good starting point for exploring the development of depression symptom detection models because annotation rules were constructed with mental health experts and processed by 3 annotators, with guidance and validation from the experts as well. The interannotation agreement score achieved a Fleiss κ score of 0.735, which is interpreted as "substantial agreement." This data set has also reached a 95.59% psychologist validation score on the validation data set.



Textbox 4. Data set information.

Survey data (data set 1)

- Age
- Sex
- Region
- Education
- Employment
- MentalHealth_SelfRating
- MentalHealth_Services

Patient Health Questionnaire-9 (PHQ-9) data (data set 1)

• PHQ-9 score

Mental health assessment data (data set 1)

- Symptom_ThinkingConcentrationDecisions
- Symptom_InterestMotivation
- Symptom_Sleep
- Symptom_Fatigue
- Symptom_Appetite
- Symptom_Movement
- Symptom_Substance
- Symptom_SuicidalTendencies
- Symptom_DepressedSadness
- Symptom_WorthlessnessWorry
- Symptoms_Pain
- Symptoms_Social
- Symptoms
- Medical history
- Psychiatric History (current)
- Psychiatric History (past)
- History of Mental Ilness in Family
- History of Family Illness
- Religion
- Sexual Orientation
- Substance Use History
- Other providers
- Self Harm
- Suicidal Behavior
- Final Assessment
- Assessed with Depression
- Severity
- Assessment time (mins)

Twitter data (data set 1)

- tweet_daily_mean
- tweet_daily_max tweet_min_dt



- tweet_max_dt
- is_retweet
- is_reply
- mentions_count
- tweet_count
- retweet_count
- favorite_count
- tweet_age_days
- isretweet_percentage
- isreply_percentage
- isowntweet
- isowntweet_percentage
- createdAt
- blocked
- follower
- following
- mute
- lists_created
- lists_member
- lists_subscribed
- protectedHistory
- twitterCircle

Twitter data (data set 2)

- id
- full_text_cleaned
- Final Symptom Category 1
- Final Symptom Category 2
- Final Symptom Category 3

Table 4. Data set summaries.

Raw data	Data set 1: User-level depressed vs nondepressed	Data set 2: Tweet-level depression symptom category
Survey data	1	a
PHQ-9 ^b	1	_
Mental health assessment	✓	_
Twitter data archive	✓ (summarized—means, averages, etc)	✓ (annotated)
Summary	72 users (78 Twitter users): 60 assessed with depression; 12 not assessed with depression	78 Twitter users (6 dummy accounts); 11,163 tweets (depression symptom); 68,451 tweets (no symptom)

^aNot applicable.



^bPHQ-9: Patient Health Questionnaire-9.

Discussion

Depression Symptom Between Depressed and Control Groups

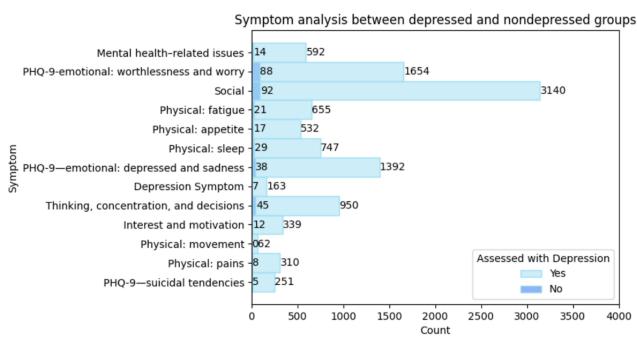
Data set 2 (tweet-level depression symptom category) was created by annotating depression symptoms of anonymized data from both the depressed and nondepressed groups. By doing this, we remove the bias that these symptoms can only be experienced by the depressed group. Depression still faces many challenges with the diagnosis because the symptoms also occur in other conditions, and these symptoms can be experienced by nondepressed users all the same. Every person experiences a lack of sleep or common emotions such as sadness, worry,

disappointment, rage, and physical symptoms of headache and fatigue every now and then.

Figure 8 shows this comparison of the amount of depression symptoms recorded for depressed and nondepressed groups. Further studies can be done on analyzing these depression symptom patterns and comparing the differences in how both groups experience these symptoms and how these symptoms are revealed through language use.

It is interesting to note that some symptoms of PHQ-9-suicidal tendencies, are also detected in the nondepressed group. These are tweets containing talks about death, for example, "if i die i die i do not even care anymore" or "i just want to be dead face with tongue xxlink."

Figure 8. Symptom analysis between depressed and nondepressed groups. This figure shows the number of symptoms recorded for both groups, as depression symptoms occur for both but differ in intensity and frequency. Social symptoms are the most recorded symptom being experienced by the nondepression group, which may include sensitivity to criticism, irritability, and anger. The next common symptom for the nondepression group was the PHQ-9-emotional: worthlessness and worry, which includes texts about daily worries such as school and work-related problems. MH: mental health; PHQ-9: Patient Health Questionnaire-9.



Word2vec Language Model Results

A language model trained with ample data can be a powerful tool if it can capture semantic relationships between words. Because word embedding features can capture a word's representation in several dimensions, the more it can capture these features, the better results we can achieve when training our models on downstream tasks such as classification and prediction tasks. Figure 9 illustrates a sample word vector output from this algorithm.

The language model created is a combination of Wikipedia articles, news articles, books, and data sets specific to web-based language, such as Twitter and Reddit data sets. There are also depression-specific topics included in these data sets to better model the depression patterns in natural language in social media. Finally, English and Filipino are both included in the data sets, with purely English text, Filipino texts, and a combination of the two. This is to model both languages in a

single vector space, because "Taglish" is the common language used on the web, with direct code switching between words in both languages.

To check the language model's ability to capture both languages, the cluster embeddings of words and how they look in a 2D space are presented subsequently. To plot these words, each word is transformed into its 300-dimensional vector and is fit into a KMeans model of ≥2 clusters. In KMeans, data points are grouped together based on certain similarities. Centroids are determined, which are representations of the location of the center of each cluster, and observations are assigned to each cluster with the nearest mean. In this test case, we check if certain words belong to a cluster, specifically comparing if the language model can determine words from symptoms and cluster them correctly. Figure 10 illustrates our first test case to show word relationships.



We also look at semantic relationships captured by the language model. Several examples below show word analogies using cosine similarities between word vectors. Neighboring words are words that are most similar to a target word in the vocabulary on the basis of this cosine similarity. Positive words contribute positively toward similarity, and negative words contribute negatively. Figure 11 illustrates our second test case to show similar words.

Looking at the analogies captured by the language model using cosine similarities to compute positive and negative word relationships through word vectors, Figure 12 shows examples of correctly captured relationships by the language model.

A language model can never fully capture a language as it can only learn what it has been trained on. Some aspects may not be captured, such as examples in Figure 13. There are also some issues with biases, for example, with gender bias in the training data, as shown in Figure 13.

The Filipino and English language models developed in this study can be used for research on other downstream tasks such as classification, labeling, and named entity recognition tasks. It can also be used on non-mental health research tasks and is best for tasks focusing on the Filipino and English languages in social media data.

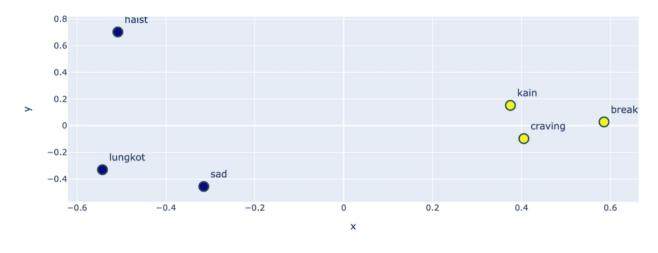
Figure 9. Word2vec vector embeddings: the word vector output for the word "kumain" or in English "ate." Each dimension represents an extracted feature of the text data that is extracted from this unsupervised learning algorithm.

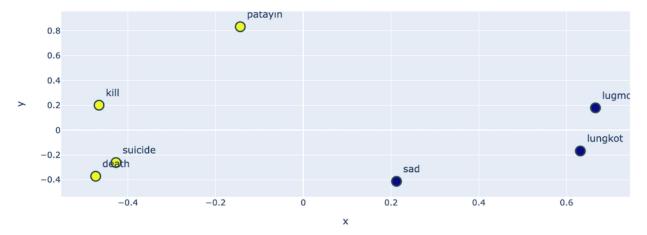
```
word_to_vec_map['kumain']
```

```
array([-4.6646464e-01, -1.1932397e+00, 2.0376454e-01, -6.9477897e+00,
       6.8528533e+00, -4.0141077e+00, -2.6217785e+00, 1.2687764e+00,
       2.4475107e+00, 3.0928826e+00, -8.9264240e-01, -3.4816718e+00,
      -7.9303944e-01, 5.8815236e+00, 5.4919034e-01, -2.4795973e+00,
       8.0929970e-02, -8.2169850e-01, -2.1571820e+00, -4.6831360e+00,
       1.9985547e+00, -1.1311437e+00, 2.9914450e-01, -1.0269141e+00,
      -8.6227745e-01, -1.5426064e-01, 2.3333588e+00, -1.2600807e+00,
      -2.8032188e+00, 4.0651120e-01, -2.5040119e+00, 6.1281043e-01,
       2.3040133e+00, -5.0824030e-01, -3.0578492e+00, 3.1929898e+00,
      -7.9413210e-01, 5.4897947e+00, -4.4051343e-01, -1.3072422e+00,
      -5.2493796e+00, 5.3285130e+00, 1.9485309e+00, -6.1531990e-01,
       2.1112802e+00, -6.5582485e+00, -1.9110060e+00, 2.6409228e+00,
       6.8613260e-01,
                      7.5624890e+00, 4.9788246e+00, 1.4587379e-01,
                       1.6982244e+00, -2.3851380e-03, 8.6924900e-01,
       3.2714430e+00,
      -3.9199150e+00,
                       5.3642535e-01, 5.4603790e-01, 1.7235978e+00,
      -5.2639080e+00, -3.7997308e-01, -3.0113642e+00, 2.5522470e+00,
                       4.9247180e+00, 1.8904795e-01, -1.6870737e+00,
      -2.6990805e+00,
                       6.0770516e+00, -6.0710490e-01, 1.1515030e+00,
       8.2331330e-01,
      -2.9365516e+00,
                       1.6321912e+00, 1.5102484e+00, 1.8770980e+00,
      -4.4962960e+00, -4.1229987e+00, 1.2450608e+00, -2.3276122e-01,
                       1.7394879e+00, -6.1742520e-01, 4.6056250e-02,
      -2.2191203e+00,
       6.3919444e+00, 2.1739416e+00, 5.5815850e-01, -3.4518380e+00,
      -6.5538930e-01,
                       2.4520788e-01, 4.4339757e+00, 2.3791358e+00,
       3.3539867e+00, -3.8426826e+00, -5.4825860e-01, 4.0342380e+00,
      -4.7092104e+00, 2.2370725e+00, 9.3078494e-02, -1.1788568e+00,
```



Figure 10. Language model word symptom relationships. The first figure shows the appetite versus sadness symptoms, with test cases "craving, kain (eat), breakfast, lungkot (sadness), haist (expression of sigh), sad," which are combinations of English and Filipino words. We notice here that they are also a combination of expressions (haist), emotions (craving, lungkot, and sad), or action words (kain). These examples show that these are correctly clustered into appetite and sadness clusters. The second figure shows suicidal tendency—related words "kill, suicide, death, patayin (kill)" are clustered together versus sadness words "sad, lungkot, lugmok (sunken)." In addition, the third figure shows mental health issue—related words "psychologist, therapy, and trauma" are clustered together versus movement-related words "tamad (lazy), galaw (move), kama (bed).".





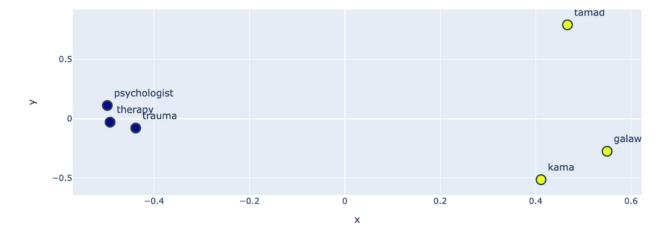




Figure 11. Language models for similar words. From this figure, we can see that the most similar words for "Bulacan," which is a province in the central Luzon region in the Philippines, has similar words "Pampanga, Laguna, Hagonoy, Calumpit, etc" which are also places (provinces, municipalities), Pampanga, Hagonoy, and Calumpit being geographically in close boundaries with Bulacan, and "Bocaue, Pulilan, Hangonoy" being towns and municipalities in Bulacan. We also see the word neighbors for "suicide," which includes "sucide," which is a common wrong spelling for "suicide," "magpakamatay," which is the Filipino translation, and other "suicide" related words in both languages. We can also see "bombing and kidnapping," which are common words seen with suicide as per news articles such as "suicide bombing." We also see the words mostly associated with symptoms such as "anxiety, worry, pain, galit (mad), irita (irritated), and magbigti (hang)."

```
word = "bulacan"
                                            word = "suicide"
[('pampanga', 0.7358443737030029),
                                        [('sucide', 0.5407605767250061),
('laguna', 0.7199677228927612),
                                         ('pagpapakamatay', 0.5233020186424255),
('hagonoy', 0.6931978464126587),
                                         ('death', 0.49004361033439636),
('cavite', 0.6815253496170044),
                                         ('pagpapatiwakal', 0.47800150513648987),
('batangas', 0.6798783540725708),
                                         ('murder', 0.46966496109962463),
('bocaue', 0.6739640235900879),
                                         ('hysteria', 0.4609432518482208),
('bulakan', 0.6643749475479126),
                                         ('bombing', 0.45023512840270996),
('pulilan', 0.6537086367607117),
                                         ('nagpakamatay', 0.4378076195716858),
('calumpit', 0.644932210445404),
                                         ('panic', 0.4366177022457123),
('pangasinan', 0.6382399797439575)]
                                         ('kidnapping', 0.4298591613769531)]
                                             word = "galit"
    word = "anxiety"
                                          [('inis', 0.7204680442810059),
[('depression', 0.6644597053527832),
 ('migraine', 0.6080722212791443),
                                           ('nagagalit', 0.6484684348106384),
 ('depresyon', 0.5789698958396912),
                                           ('poot', 0.6338117122650146),
   word = "worry"
                                             word = "irita"
[('wori', 0.5607364177703857),
                                          [('inis', 0.6198936104774475),
 ('promise', 0.5451393723487854),
                                           ('naiirita', 0.5976190567016602),
 ('sure', 0.5236937999725342),
                                           ('imbyerna', 0.559351921081543),
                                             word = "magbigti"
    word = "pain"
[('pains', 0.6610055565834045),
                                          [('magpatiwakal', 0.7025496363639832),
  ('sadness', 0.6096132397651672),
                                           ('magpakamatay', 0.6339846253395081),
  ('discomfort', 0.5701459050178528),
                                           ('saksakin', 0.5900859236717224),
```



Figure 12. Language model analogies. Synonyms were captured, such as "maganda" (beautiful) is to "pretty" and "ugly" is to "pangit" (ugly). This is another example of the model capturing word similarities in Filipino and English code switching. Antonyms were also captured, "gusto" (want) is to "ayaw" (do not want) and "want" is to "need." In addition, part-whole and superclass were captured, "gulong" (tire) is to "tela" (fabric) and "kotse" (car) is to "sinulid" (thread). Other examples captured: "pagkain" (food) is to "aso" (dog), "takoyaki" (octopus balls) is to "hayop" (animal), "Nanay" (mother) is to "babae" (woman), and "tatay" (father) is to "lalaki" (man).

```
positive=['maganda', 'ugly'], negative=['pretty']
[('pangit', 0.5525190234184265)]

positive=['gusto', 'want'], negative=['ayaw']
[('need', 0.6499773263931274)]

positive=['gulong', 'tela'], negative=['kotse']
[('sinulid', 0.5436260104179382)]

positive=['pagkain', 'aso'], negative=['takoyaki']
[('hayop', 0.508664071559906)]

positive=['nanay', 'babae'], negative=['tatay']
[('lalaki', 0.7116712927818298)]
```

Figure 13. Language model faults and biases: the first 2 examples show some faults with currency and geography, which gave incorrect results. Gender biases are also shown in the last 2 examples; if "captain" is to "man," the model results in a "woman" as a "villain." In addition, if "doctor" is to "man," the model outputs "woman" is to "psychiatrist.".

```
positive=['peso', 'baht'], negative=['philippines']
[('dollar', 0.583448588848114)]

positive=['manila', 'bangkok'], negative=['philippines']
[('maynila', 0.5512936115264893)]

positive=['captain', 'woman'], negative=['man']
[('villain', 0.43109777569770813)]

positive=['doctor', 'woman'], negative=['man']
[('psychiatrist', 0.5288854241371155)]
```



Data Set Limitations

Age Group Limitation

The population included in this study focuses on the young adult population (aged 18-30 years). The created data set may not be generalizable to other population samples as the language and social media use of individuals may be different within different age demographics.

Tweet Symptom Annotation Limit

In this study, a maximum limit of 3 symptoms per tweet is enforced as part of the annotation guideline. This is aimed at simplicity because of the complex nature of the annotation task. Aside from the number of tweets to be annotated, several depression categories are also considered, which proved quite challenging for the annotators. For binary label classification tasks (depression symptom vs nondepression symptom), this limitation may be ignored as the presence of at least one symptom is considered a depression symptom label. Multilabel classification tasks (14 symptom depression categories) should be considered as a limitation of the created data set, as some symptoms may not be included in some tweets.

Data Imbalance

This study ensures the validity of depression screening for each participant, requiring multiple data collection workflow steps and the participation of both participants and mental health experts. Because of the limited slots for expert assessment, the data collected shows an imbalance between the participants for the depressed and control groups. This data set imbalance might be worth noting for user-level depression detection studies, but because the goal of this study is to create a tweet-level annotation of depression and not on a user level, the data imbalance on the user level is insignificant. However, it is useful that all participants were assessed by experts, so the results of all tweet-level analyses can be routed back or compared with user-level analyses, which unfortunately is not a scope of this paper but can be explored in the future.

Another class imbalance in this data set is the distribution of sex. In this data set, 85% are female participants (61 female and 11 male participants). This may be attributed to the higher prevalence of depression in female individuals among young adults in the Philippines [33], while some similar studies on web-based mental health intervention show similar patterns of gender imbalance where participants are mostly female [44].

These data set limitations should be noted when doing data analysis on the resulting data set.

Conclusions and Future Work

Valid data sets need to be constructed to develop solutions to identify depression patterns through NLP and machine learning. This study aimed to help in the area of depression research through the construction of depression data sets from social media to aid NLP in the Philippine setting. The proposed process included interdisciplinary methods between psychology and data science methods, implementing clinical screening methods with the help of psychologists. A total of 72 participants were assessed by psychologists and provided their Twitter data, with 60 assessed with depression and 12 not assessed with depression. A baseline data set of depression symptoms in tweets was created by manual annotation in a process constructed, guided, and validated by psychologists. In total, 13 depression categories and 1 no symptom category were identified during this process. This annotation process was done by 3 annotators, accomplishing a substantial interannotator agreement score of Fleiss κ of 0.735 and a 95.59% psychologist validation score. From this task, a total of 79,614 depression symptom-annotated tweets are created. A language model using the word2vec algorithm is also created, which can represent text into numbered vectors and can be used in various machine learning techniques for NLP. This study created several validated data sets that can be used further to enhance depression research in the Philippines.

For future research, 4 directions can be explored. (1) This study suggests future research to apply the methodologies performed in this study to improve the class imbalance and size of the data sets. The data sets can be further expanded to collect more users and Twitter data, and the annotation process of detection symptoms can be expanded into more tweets. (2) The data sets in this study can be used to explore the creation of depression symptom detection models in social media data using machine learning techniques on a tweet-level detection. (3) The data sets in this study can also be used to explore the creation of user-level depression detection using social media behavior data, PHQ-9 data, and demographic data. (4) Finally, depression symptom patterns can be explored further in depth between the depression and nondepression groups in this data set, as both groups contribute to the depression symptoms data set, and both show some level of depression symptoms.

Acknowledgments

The authors are grateful to all participants for their interest and contribution, who believe this research will open doors to mental health research opportunities in the country. Furthermore, the authors would like to thank reviewers for their support and influence in shaping our methods and results and #MentalHealthPH and other clinics and organizations for helping them in participant recruitment. This work was funded by the University of the Philippines (UP) System Emerging Inter-Disciplinary Research Program (OVPAA-EIDR-C09-07).

Data Availability

The data sets generated during and analyzed during this study are not publicly available due to the sensitive nature of the respondents in this study, but are available from the corresponding author on reasonable request.



Conflicts of Interest

None declared.

References

1. Depression and other common mental disorders: global health estimates. World Health Organization. 2017 Jan 3. URL: https://www.who.int/publications/i/item/depression-global-health-estimates [accessed 2024-07-28]

- 2. Pandemic year sees 57% rise in suicide rate in Philippines. Philstar Global. 2021 Jul 6. URL: https://www.philstar.com/headlines/2021/07/06/2110596/pandemic-year-sees-57-rise-suicide-rate-philippines [accessed 2024-07-28]
- 3. Gowen K, Deschaine M, Gruttadara D, Markey D. Young adults with mental health conditions and social networking websites: seeking tools to build community. Psychiatr Rehabil J 2012;35(3):245-250. [doi: 10.2975/35.3.2012.245.250] [Medline: 22246123]
- 4. Berger M, Wagner TH, Baker LC. Internet use and stigmatized illness. Soc Sci Med 2005 Oct;61(8):1821-1827. [doi: 10.1016/j.socscimed.2005.03.025] [Medline: 16029778]
- 5. Park M, McDonald D, Cha M. Perception differences between the depressed and non-depressed users in Twitter. In: Proceedings of the International AAAI Conference on Web and Social Media. 2013 Presented at: ICWSM-13; July 8-11, 2013; Cambridge, MA. [doi: 10.1609/icwsm.v7i1.14425]
- 6. Guntuku SC, Yaden DB, Kern ML, Ungar LH, Eichstaedt JC. Detecting depression and mental illness on social media: an integrative review. Curr Opin Behav Sci 2017 Dec;18:43-49 [FREE Full text] [doi: 10.1016/j.cobeha.2017.07.005]
- 7. Eberhard DM, Simons GF, Fennig CD. Ethnologue: languages of the world. Twenty-seventh edition. SIL International. 2024. URL: https://www.ethnologue.com/ethnoblog/welcome-27th-edition/ [accessed 2024-08-03]
- 8. Andrei AL. Development and evaluation of Tagalog linguistic inquiry and word count (LIWC) dictionaries for negative and positive emotion. The MITRE Corporation. 2014 Dec 23. URL: https://www.mitre.org/sites/default/files/publications/pr_14-3858-development-evaluation-of-tagalog-linguistic-inquiry.pdf [accessed 2024-07-29]
- 9. Keen D, King NM, Lopez JL, Mondares A, Ponay C. FilCon: Filipino sentiment lexicon generation using word level-annotated dictionary-based and corpus-based cross lingual approach. In: Proceedings of the 9th International Conference of Asian Association of Lexicography. 2015 Presented at: ASIALEX 2015; June 25-27, 2015; Hong Kong, China.
- 10. Lapita FR, Batista-Navarro RT, Albacea E. Crowdsourcing-based annotation of emotions in Filipino and English tweets. In: Proceedings of the 6th Workshop on South and Southeast Asian Natural Language Processing. 2016 Presented at: WSSANLP2016; December 11, 2016; Osaka, Japan.
- 11. Katchapakirin K, Wongpatikaseree K, Yomabootand P, Kaewpitakkun Y. Facebook social media for depression detection in the Thai community. In: Proceedings of the 15th International Joint Conference on Computer Science and Software Engineering. 2018 Presented at: JCSSE 2018; July 11-13, 2018; Nakhonpathom, Thailand. [doi: 10.1109/jcsse.2018.8457362]
- 12. Shen G, Jia J, Nie L, Feng F, Zhang C, Hu T, et al. Depression detection via harvesting social media: a multimodal dictionary learning solution. In: Proceedings of the 26th International Joint Conference on Artificial Intelligence. 2017 Presented at: IJCAI'17; August 19-25, 2017; Melbourne, Australia. [doi: 10.24963/ijcai.2017/536]
- 13. Cornn K. Identifying depression on social media. Stanford University. URL: https://web.stanford.edu/class/archive/cs/cs224n/cs224n.1194/reports/custom/15712307.pdf [accessed 2024-07-29]
- 14. Mikolov T, Sutskever I, Chen K, Corrado G, Dean J. Distributed representations of words and phrases and their compositionality. In: Proceedings of the 26th International Conference on Neural Information Processing Systems Volume 2. 2013 Presented at: NIPS'13; December 5-10, 2013; Lake Tahoe, NV.
- 15. Rosa RL, Schwartz GM, Ruggiero WV, Rodriguez DZ. A knowledge-based recommendation system that includes sentiment analysis and deep learning. IEEE Trans Industr Inform 2019 Apr;15(4):2124-2135. [doi: 10.1109/tii.2018.2867174]
- Wang X, Zhang C, Ji Y, Sun L, Wu L, Bao Z. A depression detection model based on sentiment analysis in micro-blog social network. In: Proceedings of the 17th Pacific-Asia Conference on Knowledge Discovery and Data Mining. 2013 Presented at: PAKDD 2013; April 14-17, 2013; Gold Coast, Australia. [doi: 10.1007/978-3-642-40319-4_18]
- 17. Pennington J, Socher R, Manning C. GloVe: global vectors for word representation. In: Proceedings of the 2014 Conference on Empirical Methods in Natural Language Processing. 2014 Presented at: EMNLP 2014; October 25-29, 2014; Doha, Qatar. [doi: 10.3115/v1/d14-1162]
- 18. De Choudhury M, Gamon M, Counts S, Horvitz E. Predicting depression via social media. In: Proceedings of the Seventh International AAAI Conference on Weblogs and Social Media. 2013 Presented at: ICWSM-13; July 8–11, 2013; Cambridge, MA. [doi: 10.1609/icwsm.v7i1.14432]
- 19. Tsugawa S, Kikuchi Y, Kishino F, Nakajima K, Itoh Y, Ohsaki H. Recognizing depression from Twitter activity. In: Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems. 2015 Presented at: CHI '15; April 18-23, 2015; Seoul, Republic of Korea. [doi: 10.1145/2702123.2702280]
- 20. Shen T, Jia J, Shen G, Feng F, He X, Luan H, et al. Cross-domain depression detection via harvesting social media. In: Proceedings of the Twenty-Seventh International Joint Conference on Artificial Intelligence. 2018 Presented at: IJCAI'18; July 13-19, 2018; Stockholm, Sweden. [doi: 10.24963/ijcai.2018/223]



21. Kabir M, Ahmed T, Hasan MB, Laskar MT, Joarder TK, Mahmud H, et al. DEPTWEET: a typology for social media texts to detect depression severities. Comput Hum Behav 2023 Feb;139:107503 [FREE Full text] [doi: 10.1016/j.chb.2022.107503]

- 22. Losada DE, Crestani F, Parapar J. eRISK 2017: CLEF lab on early risk prediction on the internet: experimental foundations. In: Proceedings of the 8th International Conference of the CLEF Association. 2017 Presented at: CLEF 2017; September 11-14, 2017; Dublin, Ireland. [doi: 10.1007/978-3-319-65813-1 30]
- 23. Adarsh V, Arun Kumar P, Lavanya V, Gangadharan GR. Fair and explainable depression detection in social media. Inf Process Manag 2023 Jan;60(1):103168 [FREE Full text] [doi: 10.1016/j.ipm.2022.103168]
- 24. Wang Y, Wang Z, Li C, Zhang Y, Wang H. Online social network individual depression detection using a multitask heterogenous modality fusion approach. Inf Sci 2022 Sep;609:727-749 [FREE Full text] [doi: 10.1016/j.ins.2022.07.109]
- 25. Li Z, An Z, Cheng W, Zhou J, Zheng F, Hu B. MHA: a multimodal hierarchical attention model for depression detection in social media. Health Inf Sci Syst 2023 Dec 18;11(1):6 [FREE Full text] [doi: 10.1007/s13755-022-00197-5] [Medline: 36660408]
- 26. Losada DE, Crestani F, Parapar J. Overview of eRisk 2020: early risk prediction on the internet. In: Proceedings of the Conference and Labs of the Evaluation Forum. 2020 Presented at: CLEF 2020; September 22-25, 2020; Thessaloniki, Greece. [doi: 10.1007/978-3-030-58219-7_20]
- 27. Aliman GB, Nivera TF, Olazo JC, Ramos DJ, Sanchez CD, Amado TM, et al. Sentiment analysis using logistic regression. J Comput Innov Eng Appl 2022 Jul:35-40 [FREE Full text]
- 28. Parapar J, Martín-Rodilla P, Losada DE, Crestani F. Overview of eRisk 2022: early risk prediction on the internet. In: Proceedings of the Conference and Labs of the Evaluation Forum. 2022 Presented at: CLEF 2022; September 5-8, 2022; Bologna, Italy. [doi: 10.1007/978-3-031-13643-6_18]
- 29. Borra A, Pease A, Edita R, Roxas O, Dita S. Introducing Filipino wordnet. In: Proceedings of the 5th Global WordNet Conference. 2010 Presented at: GWC2010; January 31-February 4, 2010; Mumbai, India.
- 30. Bitsch J, Ramos R, Ix T, Ferrer-Cheng PG, Wehrle K. Psychologist in a pocket: towards depression screening on mobile phones. Stud Health Technol Inform 2015;211:153-159. [Medline: <u>25980862</u>]
- 31. Nartia EJ, Paragas JR, Pascual N. Detection of students' mental health status: a decision support system. In: Proceedings of the 3rd International Conference on Research and Academic Community Services. 2021 Presented at: ICRACOS 2021; October 9-10, 2021; Surabaya, Indonesia. [doi: 10.1109/icracos53680.2021.9701996]
- 32. Aperocho MD. Philippine English in online depressive language. Psychol Educ Multidiscip J 2022;4(3):1-12. [doi: 10.5281/zenodo.7065807]
- 33. Puyat JH, Gastardo-Conaco MC, Natividad J, Banal MA. Depressive symptoms among young adults in the Philippines: results from a nationwide cross-sectional survey. J Affect Disord Rep 2021 Jan;3:100073 [FREE Full text] [doi: 10.1016/j.jadr.2020.100073]
- 34. Hofmeijer-Sevink MK, Batelaan NM, van Megen HJ, Penninx BW, Cath DC, van den Hout MA, et al. Clinical relevance of comorbidity in anxiety disorders: a report from the Netherlands Study of Depression and Anxiety (NESDA). J Affect Disord 2012 Mar;137(1-3):106-112 [FREE Full text] [doi: 10.1016/j.jad.2011.12.008] [Medline: 22240085]
- 35. Fleiss JL. Measuring nominal scale agreement among many raters. Psychol Bull 1971;76(5):378-382 [FREE Full text] [doi: 10.1037/h0031619]
- 36. Dita SN, Roxas RE, Inventado P. Building online corpora of Philippine languages. In: Proceedings of the 23rd Pacific Asia Conference on Language, Information and Computation. 2009 Presented at: PACLIC 2009; December 3-5, 2009; Hong Kong, China.
- 37. Leipzig corpora collection Tagalog. Leipzig University. 2017. URL: https://corpora.wortschatz-leipzig.de/en?corpusId=tgl_community_2017 [accessed 2024-07-29]
- 38. Roxas RE, Borra A. Computational linguistics research on Philippine languages. In: Proceedings of the 38th Annual Meeting on Association for Computational Linguistics. 2000 Presented at: ACL '00; October 3-6, 2000; Hong Kong, China. [doi: 10.3115/1075218.1075292]
- 39. Soriano CR, Roldan MD, Cheng C, Oco N. Social media and civic engagement during calamities: the case of Twitter use during typhoon Yolanda. Philipp Polit Sci J 2016 Feb 26;37(1):6-25. [doi: 10.1080/01154451.2016.1146486]
- 40. Oco N, Fajutagana R, Lim CM, Miñon JD, Morano JA, Tinoco RC. Witchebelles anata magcharot kay mudra na nagsusuba si akech: developing a rule-based unidirectional beki lingo to Filipino translator. J Sci Technol Arts Res 2015;1(1):29-37 [FREE Full text]
- 41. Pablo ZC, Oco N, Roldan MD, Cheng C, Roxas RE. Toward an enriched understanding of factors influencing Filipino behavior during elections through the analysis of Twitter data. Philipp Polit Sci J 2014 Nov 27;35(2):203-224. [doi: 10.1080/01154451.2014.964794]
- 42. Cabasag NV, Chan VP, Lim SC, Gonzales ME, Cheng CK. Hate speech in Philippine election-related tweets: automatic detection and classification using natural language processing. Philipp Comput J 2019 Aug;XIV(1):1-14.
- 43. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977 Mar;33(1):159-174. [Medline: 843571]



44. Davies EB, Morriss R, Glazebrook C. Computer-delivered and web-based interventions to improve depression, anxiety, and psychological well-being of university students: a systematic review and meta-analysis. J Med Internet Res 2014 May 16;16(5):e130 [FREE Full text] [doi: 10.2196/jmir.3142] [Medline: 24836465]

Abbreviations

API: application programming interface **CBOW:** Continuous Bag of Words

DSM-5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

NLP: natural language processing **PHQ-9:** Patient Health Questionnaire-9

Edited by A Mavragani; submitted 10.10.23; peer-reviewed by J Magadia, M Remolana, AJ Li, C Entwistle, X Ren; comments to author 15.03.24; revised version received 29.04.24; accepted 02.07.24; published 04.09.24.

Please cite as:

Tumaliuan FB, Grepo L, Jalao ER

Development of Depression Data Sets and a Language Model for Depression Detection: Mixed Methods Study

JMIR Data 2024;5:e53365

URL: https://data.jmir.org/2024/1/e53365

doi:10.2196/53365

PMID:

©Faye Beatriz Tumaliuan, Lorelie Grepo, Eugene Rex Jalao. Originally published in JMIR Data (https://data.jmir.org), 04.09.2024. This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in JMIR Data, is properly cited. The complete bibliographic information, a link to the original publication on https://data.jmir.org/, as well as this copyright and license information must be included.



Original Paper

A Database of Randomized Trials on the HIV Care Cascade (CASCADE Database): Descriptive Study

Lawrence Mbuagbaw^{1,2,3,4}, MPH, MD, PhD; Diya Jhuti⁵, BHSc; Gohar Zakaryan⁵, BHSc; Hussein El-Kechen¹, MSc; Nadia Rehman¹, BDentSc; Mark Youssef⁶, MD; Michael Cristian Garcia¹, MSc; Vaibhav Arora⁵, BHSc; Babalwa Zani⁷, MSc; Alvin Leenus⁸, MMASc; Michael Wu⁹, BSc; Oluwatoni Makanjuola⁵, BHSc

Corresponding Author:

Lawrence Mbuagbaw, MPH, MD, PhD
Department of Health Research Methods, Evidence and Impact
McMaster University
1280 Main Street West
Hamilton, ON, L8S3L8
Canada

Phone: 1 905 962 2477

Email: mbuagblc@mcmaster.ca

Abstract

Background: The Joint United Nations Programme on HIV/AIDS has set targets for 2025 regarding people living with HIV. For these targets to be met, 95% of people with HIV would need to know their HIV status, 95% of people with HIV would need to be receiving antiretroviral therapy, and 95% of people on antiretroviral therapy would need to be virally suppressed. Some countries are on track to meet these targets. However, within and across countries, several vulnerable populations may not meet these targets. This is in part because several approaches to improving the cascade of care after an HIV diagnosis are not tailored to and are not appropriate for vulnerable populations, such as men who have sex with men, sex workers, people who inject drugs, Black people, people in prisons, women, and youth. To inform research, policy, and practice, there is a need for curated data on HIV care cascade research.

Objective: The CASCADE database is a repository of randomized clinical HIV trials. It was designed to inform, support, and improve HIV care cascade research, systematic reviews, and evidence maps.

Methods: PubMed, Embase, CINAHL, PsycINFO, Web of Science, and the Cochrane Library were searched to obtain randomized trials that were designed to address at least one of the following care cascade outcomes: the initiation of therapy, adherence to medication, retention in care, and engagement in care. Data were screened and extracted in duplicate using DistillerSR software (Evidence Partners Incorporated) and were cataloged based on the following features: year, income level, setting, the delivery of the intervention, the population receiving the intervention, intervention type, and the level of pragmatism of the intervention.

Results: A total of 298 HIV clinical trials are included in the CASCADE database, of which 162 (54.4%) were conducted in high-income countries, and 116 (38.9%) targeted vulnerable populations. Adherence to antiretroviral therapy was the most investigated HIV care cascade outcome (216/298, 72.5%), followed by retention in care (34/298, 11.4%). CASCADE has a user-friendly interface with simple and advanced search features. The CASCADE database has inspired 2 methodological papers and 13,567 website visits from over 10 countries.



¹Department of Health Research Methods, Evidence and Impact, McMaster University, Hamilton, ON, Canada

²Biostatistics Unit, Father Sean O'Sullivan Research Centre, St. Joseph's Healthcare, Hamilton, ON, Canada

³Centre for Development of Best Practices in Health, Yaoundé Central Hospital, Yaoundé, Cameroon

⁴Department of Global Health, Stellenbosch University, Cape Town, South Africa

⁵Faculty of Health Sciences, McMaster University, Hamilton, ON, Canada

⁶Department of Medicine, University of Toronto, Toronto, ON, Canada

⁷Nyasha Consulting, Cape Town, South Africa

⁸Faculty of Science, Western University, London, ON, Canada

⁹Michael DeGroote School of Medicine, McMaster University, Hamilton, ON, Canada

Conclusions: CASCADE is the first database dedicated to trials that focus on the HIV care cascade, and it can be used for systematic reviews, evidence maps, and methodological research. It is freely accessible, and the data can be downloaded in CSV format.

(JMIR Data 2022;3(1):e36874) doi:10.2196/36874

KEYWORDS

data set; database; cascade; HIV; antiretroviral therapy; adherence; retention; pragmatic; database; randomized controlled trial; randomized; clinical trial; review; evidence map; methodological research; open access

Introduction

From 2020 to 2021, about 37.7 million people were living with HIV worldwide, of which 28.2 million were accessing antiretroviral therapy (ART) [1]. Deaths from HIV-related causes have reduced by about 47% in the last decade [1]. People at higher risk of HIV infection, who are also referred to as *key populations* (eg, sex workers, men who have sex with men, people who inject drugs, and transgender people), account for 65% of all HIV infections [1].

Success in curbing morbidity and mortality due to HIV is measured based on the proportion of people achieving key steps in the HIV care cascade. The Joint United Nations Programme on HIV/AIDS (UNAIDS) has set targets for 2025 regarding people living with HIV. It is expected that by 2025, a total of 95% of people living with HIV will know their status, 95% of people who know their status will be on ART, and 95% of people on ART will achieve viral suppression [1]. For countries to meet these goals, targeted policies and interventions are required to enhance the uptake of testing for HIV; engagement in care; adherence to medication; and, ultimately, viral suppression. With close to 40 years of HIV research and innovation, enormous strides have been made toward reaching these targets in many countries [2-4]. However, there are concerns that even if countries meet these targets, stigma, discrimination, and structural barriers may prevent key subpopulations from meeting these targets. For instance, many countries have punitive laws and policies against people living with HIV, and gender inequalities and violence compromise access to care for many [5]. Further, successful research may never be implemented in the real world because the interventions are too complex, resource intensive, or insufficiently tailored [2].

As we strive to ensure that all of the UNAIDS targets are met globally (ie, across countries and within subpopulations), we must understand what needs to be done to ensure that all people living with HIV can meet these targets. Evidence syntheses can help with identifying knowledge gaps and shortcomings from the existing evidence base and highlighting areas where further research is needed [6]. To this end, and as part of an overview of systematic reviews to improve treatment initiation, adherence to ART, and retention in care for people living with HIV [5], we built the CASCADE database.

The CASCADE database [7] was born from efforts to create evidence maps on the HIV care cascade. This database is a "one-stop shop" for randomized trials of interventions that improve the initiation of treatment, adherence to medication,

and retention and engagement in care. The database can be used to write literature reviews, conduct systematic reviews, conduct methodological research, create evidence maps, or simply learn about HIV care cascade research.

Methods

Database Implementation

The trials were identified by using a standard evidence synthesis methodology. The first set of trials were identified from an overview of systematic reviews on strategies for improving the HIV care cascade [8,9]. In brief, we searched PubMed, Embase, CINAHL, PsycINFO, Web of Science, and the Cochrane Library for systematic reviews published from 1995 to 2018, including at least 1 randomized trial of an intervention that was designed to improve the initiation of ART, adherence to ART, or retention in care. The second and subsequent sets of trials were identified through targeted searches for trials on the HIV care cascade that were published in the same databases from 2018 to August 2021. Only trials that were published as full texts and had participants who were people living with HIV that reported at least 1 care cascade outcome were eligible. All retrieved searches were deduplicated. Screening and data extraction were conducted in duplicate using DistillerSR software (Evidence Partners Incorporated).

The database is composed of 1 back-end table, which includes the following data: year, income level, the vulnerable population of focus, who delivered the intervention, the setting in which the intervention was delivered, the intervention type, and the level of pragmatism of the intervention (ie, how close it is to real-world care). The vulnerable population, who delivered the intervention, the setting of the intervention, and the intervention type are not mutually exclusive (ie, trials may belong to more than 1 category).

Database Functionalities

Simple Search

The simple search function identifies any key words in the title or abstract, including author and journal names.

Advanced Search

The advanced search function allows users to filter the results of a search based on the following features:

- Year: The platform allows the user to specify a start year and end year for the search and is based on the year of publication of the trial.
- Income level: This drop-down menu allows the user to select trials from countries with different income levels, as



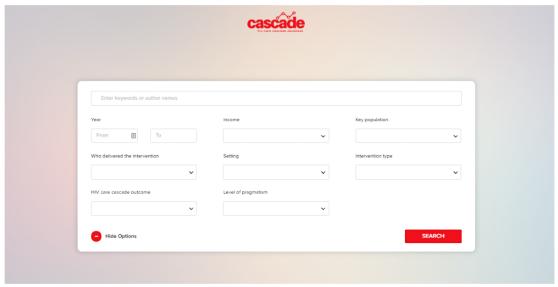
defined by the World Bank, and includes high-income, upper-middle-income, low-middle-income, and low-income countries [10]. There is also a mixed category for studies conducted in multiple countries with different income levels.

- Key population: Trials are organized according to whether they primarily included people from any key population (ie, African, Caribbean, or Black people; commercial sex workers; men who have sex with men; prisoners; people who inject drugs; women; and youth).
- The person who delivered the intervention: The database distinguishes among trials of interventions delivered by clinicians, lay workers, or peers.
- The setting: Trials may be for interventions delivered in a clinic or community-based setting.

- Intervention type: A variety of intervention types are included, such as changes in health care delivery, counseling, education, electronic interventions, incentives, mobile health, outreach, peer navigation or support, and psychotherapy.
- Care cascade outcome: Users may select 1 of 4 care cascade outcomes—the initiation of treatment, adherence to ART, retention in care, and engagement in care.
- Level of pragmatism: The level of pragmatism—a measure
 of how well a trial matches usual care—was determined
 for each trial by using the RITES (Rating of Included Trials
 on the Efficacy-Effectiveness Spectrum) tool [11]. Trials
 may be situated along a continuum ranging from having a
 strong emphasis on efficacy to having a strong emphasis
 on effectiveness.

The layout of the advanced search page is shown in Figure 1.

Figure 1. Image of the advanced search layout on the CASCADE website.



Tips

On the tips page, we display information on how to use the database and the types of trials that are included in each category. The layout of the tips page is shown in Figure 2.

Figure 2. Image of available tips on the CASCADE website.





User Interaction

All of the trials have hyperlinks that take users to the PubMed page or journal page of the identified articles. Search results can also be downloaded as a CSV file. Users are encouraged to suggest studies that could be added by emailing hccd@mcmaster.ca.

Results

As of December 30, 2021, CASCADE includes 298 HIV clinical trials that were published between 2015 and 2021. About half of these trials were conducted in high income countries (n=162, 54.4%), and 116 (38.9%) focused on a vulnerable population. About half of the interventions were delivered exclusively by clinicians (158/298, 53%) and were clinic-based interventions (173/298, 58.1%). The most frequent types of interventions

were combinations (136/298, 45.6%), and adherence was the most common HIV care cascade outcome (216/298, 72.5%). About half of the trials (136/298, 45.6%) had a balanced emphasis on both efficacy and effectiveness. The key features of the trials in the database are outlined in Table 1.

In addition to the protocol for the overview of systematic reviews and the published overview [7,8], the CASCADE database has inspired 2 methodological papers. The first is an assessment of how HIV pilot studies are conducted [12], and the second evaluates the virological measures used in HIV clinical trials [13].

In the last year, as of June 24, 2022, the database has had 13,567 visits, with most visitors accessing the database from the United States, Canada, Singapore, Germany, the United Kingdom, China, Ireland, France, Lithuania, and the Netherlands.



Table 1. Characteristics of trials in the CASCADE database (N=298).

Variable	Trials, n (%)
Income level	
High	162 (54.4)
Upper middle	51 (17.1)
Low middle	39 (13.1)
Low	31 (10.4)
Mixed	15 (5)
Population	
General population of people with HIV	185 (61.1)
Vulnerable population	116 (38.9)
The people who delivered the intervention	
Clinicians exclusively	158 (53)
Laypersons exclusively	45 (15.1)
Peers exclusively	25 (8.4)
Combinations	70 (23.4)
Setting of intervention	
Clinic-based intervention	173 (58.1)
Community- and clinic-based intervention	44 (14.8)
Community-based intervention	46 (15.4)
Other	35 (11.7)
Type of intervention	
Changes in health care delivery	40 (13.4)
Counseling	36 (12.1)
Education	13 (4.4)
Incentives	9 (3)
Mobile health	34 (11.4)
Outreach	4 (1.3)
Peer navigation or support	9 (3)
Psychotherapy	17 (5.7)
Combinations of any types of interventions	136 (45.6)
Care cascade outcome	
Adherence	216 (72.5)
Retention	34 (11.4)
Engagement	8 (2.7)
Initiation	14 (4.6)
More than 1 cascade outcome	26 (8.7)
Level of pragmatism	
Strong emphasis on efficacy	1 (0.3)
Rather strong emphasis on efficacy	35 (11.7)
Balanced emphasis on both efficacy and effectiveness	136 (45.6)
Rather strong emphasis on effectiveness	80 (26.8)
Strong emphasis on effectiveness	46 (15.4)



Discussion

Principal Findings

CASCADE is a database of 298 HIV clinical trials that were published between 2015 and 2021. With 13,567 visits as of June 24, 2022, it is a widely used resource for clinical trials on the HIV care cascade. We plan to update the database on a semiannual basis, and we will continue to develop it based on user feedback. Updates will include formal searches for new trials and previously unpublished trials, and we will contact the authors of the included trials to suggest additional trials. Additional information that could be added for each trial include a detailed description of the intervention based on the TiDieR (Template for Intervention Description and Replication) checklist [14], risk of bias assessments, the indication of whether the study is a pilot study or a full trial, graphical displays, and other features. We will also validate the completion of the database against future systematic reviews. Further development is contingent on user interest and resources.

Comparison to Prior Work

To the best of our knowledge, there is no other database dedicated to randomized trials of the HIV care cascade. Other existing HIV databases either store data on the prevalence and incidence of HIV [15] or are dedicated to storing HIV genetic sequences [16,17]. Within the Cochrane Library, the Cochrane Controlled Register of Trials can be used to identify completed published and unpublished randomized trials, and ongoing trials.

Specific filters can be applied to identify HIV trials. However, these trials are not categorized by the following: income level, the vulnerable population of focus, who delivered the intervention, the setting in which the intervention was delivered, the intervention type, and the level of pragmatism of the intervention [18].

Limitations

We faced challenges in categorizing trials that were not accessible as full texts, either because they were only published as conference abstracts or because the full texts were not available through our institutional libraries and the interlibrary loan system. We will continue to seek these full-text articles to include and curate these trials. Further, as this database is focused on the HIV care cascade, it does not include research on preventive interventions, such as pre-exposure prophylaxis and postexposure prophylaxis.

Conclusion

CASCADE is the first database dedicated to trials on the HIV care cascade. It includes information that can be used to learn about interventions, supplement systematic reviews, create evidence maps, and conduct methodological research. By looking at the bigger picture, this database can help researchers explore the similarities and differences among HIV clinical trials that may help explain why some interventions are more successful than others, highlight knowledge gaps, and inform future research.

Acknowledgments

Data extraction was completed by Anisa Hajizadeh, Annie Wang, Rita Morassut, and Jessica Bartoszko. The database and website were built by the Webcapitan team [19]. This work was supported by The Ontario HIV Treatment Network (grant EFP-1096-Junior Inv) and the Canadian Institutes of Health Research Canadian HIV Trials Network.

Authors' Contributions

LM and DJ wrote the first draft. All other authors (GZ, HE-K, NR, MY, MCG, VA, BZ, AL, MW, and OM) reviewed subsequent drafts and approved the final version.

Conflicts of Interest

None declared.

References

- 1. Fact sheet 2022. UNAIDS. URL: https://www.unaids.org/sites/default/files/media asset/UNAIDS FactSheet en.pdf [accessed 2022-07-20]
- 2. 2025 AIDS targets. UNAIDS. URL: https://aidstargets2025.unaids.org/ [accessed 2022-11-26]
- 3. Lima V, St-Jean M, Rozada I, Shoveller JA, Nosyk B, Hogg RS, et al. Progress towards the United Nations 90-90-90 and 95-95-95 targets: the experience in British Columbia, Canada. J Int AIDS Soc 2017 Nov;20(3):e25011 [FREE Full text] [doi: 10.1002/jia2.25011] [Medline: 29130644]
- 4. Marinda E, Simbayi L, Zuma K, Zungu N, Moyo S, Kondlo L, et al. Towards achieving the 90-90-90 HIV targets: results from the south African 2017 national HIV survey. BMC Public Health 2020 Sep 09;20(1):1375 [FREE Full text] [doi: 10.1186/s12889-020-09457-z] [Medline: 32907565]
- 5. Lebelonyane R, Bachanas P, Block L, Ussery F, Alwano MG, Marukutira T, et al. To achieve 95-95-95 targets we must reach men and youth: High level of knowledge of HIV status, ART coverage, and viral suppression in the Botswana Combination Prevention Project through universal test and treat approach. PLoS One 2021 Aug 10;16(8):e0255227 [FREE Full text] [doi: 10.1371/journal.pone.0255227] [Medline: 34375343]



6. O'Leary BC, Woodcock P, Kaiser MJ, Pullin AS. Evidence maps and evidence gaps: evidence review mapping as a method for collating and appraising evidence reviews to inform research and policy. Environ Evid 2017 Jul 17;6(19):1-9 [FREE Full text] [doi: 10.1186/s13750-017-0096-9]

- 7. HIV care cascade database. CASCADE. URL: https://hivcarecascade.com/ [accessed 2022-01-02]
- 8. Mbuagbaw L, Hajizadeh A, Wang A, Mertz D, Lawson DO, Smieja M, et al. Overview of systematic reviews on strategies to improve treatment initiation, adherence to antiretroviral therapy and retention in care for people living with HIV: part 1. BMJ Open 2020 Sep 23;10(9):e034793 [FREE Full text] [doi: 10.1136/bmjopen-2019-034793] [Medline: 32967868]
- 9. Mbuagbaw L, Mertz D, Lawson DO, Smieja M, Benoit AC, Alvarez E, et al. Strategies to improve adherence to antiretroviral therapy and retention in care for people living with HIV in high-income countries: a protocol for an overview of systematic reviews. BMJ Open 2018 Sep 11;8(9):e022982 [FREE Full text] [doi: 10.1136/bmjopen-2018-022982] [Medline: 30206089]
- 10. World Bank open data. The World Bank. URL: https://data.worldbank.org/ [accessed 2019-06-21]
- 11. Wieland LS, Berman BM, Altman DG, Barth J, Bouter LM, D'Adamo CR, et al. Rating of included trials on the efficacy-effectiveness spectrum: development of a new tool for systematic reviews. J Clin Epidemiol 2017 Apr;84:95-104 [FREE Full text] [doi: 10.1016/j.jclinepi.2017.01.010] [Medline: 28188898]
- 12. El-Khechen HA, Khan MIU, Leenus S, Olaiya O, Durrani Z, Masood Z, et al. Design, analysis, and reporting of pilot studies in HIV: a systematic review and methodological study. Pilot Feasibility Stud 2021 Nov 30;7(1):211 [FREE Full text] [doi: 10.1186/s40814-021-00934-9] [Medline: 34847957]
- 13. Youssef M, Zani B, Olaiya O, Soliman M, Mbuagbaw L. Virological measures and factors associated with outcomes, and missing outcome data in HIV clinical trials: a methodological study. BMJ Open 2021 Oct 25;11(10):e039462 [FREE Full text] [doi: 10.1136/bmjopen-2020-039462] [Medline: 34697107]
- 14. Hoffmann TC, Glasziou PP, Boutron I, Milne R, Perera R, Moher D, et al. Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide. BMJ 2014 Mar 07;348:g1687. [doi: 10.1136/bmj.g1687] [Medline: 24609605]
- 15. HIV/AIDS surveillance data base. United States Census Bureau. URL: https://www.census.gov/programs-surveys/ international-programs/about/hiv.html [accessed 2022-07-20]
- 16. Foley BT, Korber BTM, Leitner TK, Apetrei C, Hahn B, Mizrachi I, et al. HIV sequence compendium 2018. Los Alamos National Laboratory. 2018. URL: https://permalink.lanl.gov/object/tr?what=info:lanl-repo/lareport/LA-UR-18-25673 [accessed 2022-07-20]
- 17. Kuiken C, Korber B, Shafer RW. HIV sequence databases. AIDS Rev 2003;5(1):52-61 [FREE Full text] [Medline: 12875108]
- 18. Dickersin K, Manheimer E, Wieland S, Robinson KA, Lefebvre C, McDonald S. Development of the Cochrane Collaboration's CENTRAL Register of controlled clinical trials. Eval Health Prof 2002 Mar;25(1):38-64. [doi: 10.1177/016327870202500104] [Medline: 11868444]
- 19. Webcapitan. Webcapitan. URL: https://webcapitan.com/en/ [accessed 2022-07-20]

Abbreviations

ART: antiretroviral therapy

RITES: Rating of Included Trials on the Efficacy-Effectiveness Spectrum

TiDieR: Template for Intervention Description and Replication **UNAIDS:** Joint United Nations Programme on HIV/AIDS

Edited by A Mavragani; submitted 29.01.22; peer-reviewed by FM Calisto, CMJ Wong; comments to author 19.05.22; revised version received 29.06.22; accepted 18.07.22; published 11.08.22.

Please cite as:

Mbuagbaw L, Jhuti D, Zakaryan G, El-Kechen H, Rehman N, Youssef M, Garcia MC, Arora V, Zani B, Leenus A, Wu M, Makanjuola

A Database of Randomized Trials on the HIV Care Cascade (CASCADE Database): Descriptive Study JMIR Data 2022;3(1):e36874

URL: https://data.jmir.org/2022/1/e36874

doi:10.2196/36874

PMID:

©Lawrence Mbuagbaw, Diya Jhuti, Gohar Zakaryan, Hussein El-Kechen, Nadia Rehman, Mark Youssef, Michael Cristian Garcia, Vaibhav Arora, Babalwa Zani, Alvin Leenus, Michael Wu, Oluwatoni Makanjuola. Originally published in JMIR Data (https://data.jmir.org), 11.08.2022. This is an open-access article distributed under the terms of the Creative Commons Attribution License (http://creativecommons.org/licenses/by/4.0/), which permits unrestricted use, distribution, and reproduction in any



medium, provided the original work, first published in JMIR Data, is properly cited. The complete bibliographic information, a link to the original publication on https://data.jmir.org/, as well as this copyright and license information must be included.



Publisher: JMIR Publications 130 Queens Quay East. Toronto, ON, M5A 3Y5 Phone: (+1) 416-583-2040

Email: support@jmir.org



