De-Identification of Free-Text Medical Records

User Manual version 1.1

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Introduction

About this Document

This is the user's manual for the de-identification software developed at the Harvard/MIT Division of Health Sciences and Technology. It describes the dictionaries used by the software, file format used for various input/output files, PHI tag types generated, and an overview of the top-level API of the software. This document does not attempt to provide an exhaustive description of the software's purpose, structure or inner workings. For these details consult references listed in the bibliography. Consult the README.txt file for a summary of the software's installation and execution instructions.

About the De-Identification Software

The de-identification software is the product of a study at the Harvard-MIT Division of Health Science and Technology (HST) to automatically de-identify confidential patient information from text medical records used in intensive care units (ICUs). Patient records are a vital resource in medical research. Before such records can be made available for research studies, protected health information (PHI) must be thoroughly scrubbed according to HIPAA specifications to preserve patient confidentiality. Manual de-identification on large databases tends to be prohibitively expensive, time-consuming and prone to error, making a computerized algorithm an urgent need for large-scale de-identification purposes. We have developed an automated patternmatching de-identification algorithm that uses medical and hospital-specific information. The current version of the algorithm has an overall recall/sensitivity of around 0.967 and a precision (or positive predictive value) of 0.748.

Software Installation and Execution

Platforms

Perl 5.8 or 5.10 under Fedora Core 10, Linux 2.6.27 (development and testing). The code is also expected to run on Windows but have not been tested on that platform.

Code organization

The source code is contained in a single file (deid.pl). Each de-identification run can be configured using deid.config. Associated dictionaries used for de-identification are in folders /lists and /dict. We suggest extending or modifying all other lists and dictionaries to suit your particular needs. A comprehensive description of all lists and dictionaries follows in the next section.

Installation and Execution

Please see the README.txt file.

File Formats

The input to the code needs to be a single text-file containing the gold standard corpus with an extension .text.

Format for id.text

Each record in the corpus starts with the following format: START_OF_RECORD=<Patient-ID>||||<Record-Number>||||

The record must end with: ||||END_OF_RECORD

It is assumed that each patient has a unique patient ID, and each note has a unique record number for the patient. Note that in this current release of the gold standard corpus, the record date is not supplied. A default date is used in the perl code for date shifting when the record date is not supplied in the header. If you would like the deid code to date shift the dates within the medical records properly, you need to supply a record date for each record in the header as follows:

```
START_OF_RECORD=<Patient-ID>||||<Record-Number>||||<Record-Date>||||
```

The <Record-Date> should be in the format of <MM/DD/YYYY>.

Format for id.deid

The PHI location file (id.deid), containing all gold standard PHI locations, does not need to be passed into the code as an argument. When the user requests performance statistics, the algorithm assumes that a PHI locations file called <filename>.deid exists in the directory.

```
The format of this .deid is as follows:
Patient <Patient-ID><TAB>Note <Record-Number>
<PHI-Start><TAB><PHI-Start><TAB><PHI-End>
Patient <Patient-ID><TAB>Note <Record-Number>
<PHI-Start><TAB><PHI-Start><TAB><PHI-End>
```

An example follows for notes 1 and 2 for a patient with ID 1100:

Patient 1100 Note 1 12 12 15 24 24 29 Patient 1100 Note 2 10 10 18 245 245 251 310 310 312

Note: The first <PHI-Start> is the character index of the beginning of the word with the PHI. The second <PHI-Start> is the index of the beginning of the PHI selection. In the Gold Standard corpus, they are the same number. The third number <PHI-End> is the index of the last character selected as PHI.

Format for id.phi

This file has same format as id.deid.

Format for id.types

The PHI type/category file (id.types) contains the category of each PHI that appears in the gold standard corpus. PHIs are classified into the following categories: PTName, PTNameInitial, HCPName, RelativeProxyName,

Location, Date, DateYear, Phone, etc. See Appendix B for a complete listing of the PHI types. Some of the common PHI types are described as follows.

- PTName: Patient names (first, middle, or last names)
- PTNameInitial: Patient name initials
- RelativeProxyName: Names of patient's family members or proxies
- HCPName: Health Care Professional Names (doctors, nurses, hospital workers, etc.)
- Location: locations which include hospitals, company names, street addresses.
- Date: dates with day/month/year.
- DateYear: stand-alone year (without day or month).
- Phone: this includes telephone, pager and fax numbers.

The format of the PHI category file is as follows: <Patient-ID> <Record-Number> <PHI-Start> <PHI-End> <Type>

where *<*Type*>* is one of the PHI categories.

<u>Format for id.info</u>

This file contains information on PHI locations and de-identification process for debugging purposes. The format is <PHI-Start> <PHI-End> <PHI_Text> <PHI_TYPE>

The <PHI_Text> is the string from the text that corresponds to the PHI start end locations indicated in the first two numbers. If it is preceded by #, it is NOT a PHI. This means that the string was considered by the deid code as a potential PHI, but the algorithm ultimately decided that it's not a PHI. If it is not preceded by #, then it is considered a PHI. In this case, the <PHI_Text> will be followed by the <PHI_TYPE> string.

Dictionaries and Lists

The code uses multiple lists of known PHI and dictionaries of words and medical terms. We present the specific format of each list/dictionary in the following table. Multi-word names are allowed in the dictionary unless specified otherwise. In the case of multi-word names, the code will scan for the pattern in the note--all words in the name must appear (in the order listed in the dictionary) for there to be a match.

Name of list/dictionary	Dire ctory locat ion	Description	Format	Use in code	Notes
company_names_unambig.t xt	/lists	Unambiguous names of companies	1 name per line	Each line is hashed and scrubbed directly.	
company_names_ambig.txt	/lists	Ambiguous names of companies	1 name per line	Each line is hashed and marked as potential PHI.	
countries_unambig.txt	/lists	Unambiguous names of countries	1 name per line	Each line is hashed and scrubbed directly.	
doctor_first_names.txt	/lists	Unambiguous first names of doctors (hospital- specific)	1 name per line	Each line is hashed and scrubbed directly.	This file contains a list of unambiguous, surrogate doctors' names in gold standard corpus.
doctor_last_names.txt	/lists	Unambiguous last names of doctors (hospital- specific)	1 name per line	Each line is hashed and scrubbed directly.	This file contains a list of unambiguous, surrogate doctors' names in gold standard corpus.
ethnicities_unambig.txt	/lists	Unambiguous names of ethnicities	1 name per line	Each line is hashed and scrubbed directly.	
female_names_unambig.txt	/lists	Unambiguous female first names	1 name per line	Each line is hashed and scrubbed directly. Also used in name filter to determine if a word is a first name.	
male_names_unambig.txt	/lists	Unambiguous male first names	1 name per line	Each line is hashed and scrubbed directly. Also used in name filter to determine if a word is a first name.	

Name of list/dictionary	Dire ctory locat ion	Description	Format	Use in code	Notes
last_names_unambig.txt	/lists	Unambiguous last names	1 name per line	Each line is hashed and scrubbed directly.	
female_names_ambig.txt	/lists	Ambiguous female first names	1 name per line	Each line is hashed and marked as potential PHI. Also used in name filter to determine if a word is a first name.	
male_names_ambig.txt	/lists	Ambiguous male first names	1 name per line	Each line is hashed and marked as potential PHI. Also used in name filter to determine if a word is a first name.	
last_names_ambig.txt	/lists	Ambiguous last names	1 name per line	Each line is hashed and marked as potential PHI. Also used in name filter to determine if a word is a last name.	
female_names_popular.txt, male_names_popular.txt, last_names_popular.txt	/lists	Popular female/male first names and last names	1 name per line	Each line is hashed and marked as potential PHI. Also used in name filter to determine if an ambiguous name is also a popular name.	
last_name_prefixes.txt, prefixes_unambig.txt	/lists	Prefixes that may appear before a last name	1 prefix per line	Used to identify name patterns.	
locations_unambig.txt	/lists	Unambiguous location names	1 location name per line	Each line is hashed and scrubbed directly. Multiple words are scrubbed in the context of the whole location name, i.e. each word in a multi-word location will not be removed when occurring in isolation.	
locations_ambig.txt	/lists	Ambiguous location names	1 location name per line	Each line is hashed and marked as potential PHI. Multiple words are scrubbed in the context of the whole location name, i.e. each word in	

Name of list/dictionary	Dire ctory locat ion	Description	Format	Use in code	Notes
				a multi-word location will not be removed when occurring in isolation.	
local_places_unambig.txt	/lists	Towns and cities around the hospital	1 location name per line	Each line is hashed and scrubbed directly. Multiple words are scrubbed in the context of the whole location name, i.e. each word in a multi-word location will not be removed when occurring in isolation.	
local_places_ambig.txt	/lists	Ambiguous town and city names around the hospital	1 location name per line	Each line is hashed and marked as potential PHI. Multiple words are scrubbed in the context of the whole location name, i.e. each word in a multi-word location will not be removed when occurring in isolation.	
pid_patientname.txt	/lists	Patient ID (PID), patient first names, patient last names	Per line: PID firstname1 firstname2 lastname1 lastname2 Max 2 words for first names; max 2 words for last names	For the PID of the processed record, each patient name (first or last) is removed directly.	This file contains a list of surrogate patient names that appear in the gold standard corpus. For names exceeding 4 words modify existing code segment at the beginning of deid() to extend this functionality.
stripped_hospitals.txt	/lists	Unambiguous hospital names	1 name per line	Each line is hashed and scrubbed directly. Multiple words are scrubbed in the context of the whole location name, i.e. each word in a multi-word location will not be removed when occurring in	

Name of list/dictionary	Dire ctory locat ion	Description	Format	Use in code	Notes
us_area_code.txt	/lists	US area codes	1 area code per line	isolation. Used to validate if certain numeric patterns are phone numbers.	
us_states.txt, us_states_abbre.txt, more_us_state_abbreviation s.txt	/lists	US state names	1 name per line	Used to check for zipcodes, and potential locations.	
commonest_words.txt	/dict	Words that are very common in medical records	1 word per line	Used in multiple places to check whether possible names are commonest words.	
common_words.txt	/dict	Words that are common in medical records	1 word per line	Used in multiple places to check whether possible names are common words.	
sno_edited.txt	/dict	Medical terms that generally should not be removed	1 word per line	Used in multiple places to check whether possible names are medical terms.	
medical_phrases.txt	/dict	Multi-word medical terms that should not be removed	Multiple words per line	Used to check whether possible names are part of a medical phrase.	
notes_common.txt	/dict	Really common words or medical terms observed in notes that should not be removed.	1 word per line	Used to check for potential names and locations.	
shift.txt	Top- level direct ory	PID to date offset mapping	PID Number of days of forward shift	Used in re-identifying dates.	

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APPENDIX A. De-Identification Code Description

In this Appendix, we document the major Perl subroutines in our de-identification software. The code was implemented in Perl (version 5.8.8 and upgraded to version 5.10) and tested under Fedora Core 10, Linux 2.6.27. De-identification involves scanning the entire text to identify PHI, classifying each item of PHI based on the PHI categories, and replacing it with a PHI category tag (see Appendix B for the PHI category tags used by the software).

An input configuration file is used to allow users to enable/disable the following filter types: Name, SSN, URL, Email, Telephone, Unit Number (hospital patient identification number), Age (age over 89), Location, Date, and U.S. State. There are also flags in the configuration file that can be used to control whether certain dictionaries are to be loaded and used by the code for de-identification. The dictionaries that can be enabled/disabled in the configuration file include: patient identification number (PID) to patient name mapping, PID to date offset mapping (with a date shift value for each patient), country names, company names, hospital names, location names, doctor names, U.S. city names, U.S. state names, and ethnicity.

An overview of the main functions in the software follows in order of execution. The main function responsible for de-identification is **deid()**, which calls **findPHI()** on each paragraph of text. **findPHI()** scans through the paragraph of text and identifies PHI. After **deid()** has run each paragraph through **findPHI()**, the software calls **outputText()** to create the de- and re-identified output of the paragraph. We list the API of the major functions in the software below to provide an idea about its general structure.

TOP MOST LEVEL OF CODE

Returns: None

Called by: Command at command prompt

Function synopsis:

The de-identification software initially sets the paths of lists and dictionaries in the working directory that will be used in de-identification. Many of these lists and dictionaries are provided in a package along with the software. The software declares arrays of context words that can be used to identify PHI. The software calls the function **setup()** to create some lookup lists of known PHI in memory for fast comparison with individual words during de-identification of text. It then calls the function **deid()** to de-identify the text.

setup()

Arguments: None Returns: None Called by: Topmost level of code Description: Creates some lookup lists to have in memory Function synopsis: The function sets up hashes of known PHI lists and dictionaries for direct identification of words in text, e.g. last names, hospital names. The function preloads some PHI dictionaries into corresponding arrays, e.g. locations, states, and generates associations between PHI in some lists and PHI categories.

deid()

Arguments: None Returns: None Called by: Topmost level of code

Description: This function reads in the text file to be de-identified, calls subroutine findPHI() to deidentify text paragraph-by-paragraph, and outputs the de-identified text to a file. Function synopsis:

The function opens the data file that contains the text to be de-identified. It reads in the data file paragraph by paragraph so that items that extend over lines are not missed. It calls the function **findPHI()** with each paragraph as the argument for the de-identification of the paragraph. The function subsequently obtains and stores the PHI locations in the paragraph identified by **findPHI()**. The function finally calls the function **outputText()** with hashes of identified PHI location to obtain the de-identified text.

findPHI()

Arguments: paragraph of text

Returns: hash of PHI found

Called by: deid()

Description: Dispatched from the **deid()** function that perform de-identification. Reads in a paragraph of text and runs the de-identification filters on it.

Function synopsis:

The function splits the data text into items demarcated by spaces. It performs an exact matching of each item with lists of known PHI, e.g. proper names. The function then calls each filter function, e.g. name, age, date filters, sequentially. The function returns a hash of approved PHI.

outputText()

Arguments: hash of PHI locations

Returns: None

Called by: deid()

Description: Creates the de-identified version of the text. Replaces dates with shifted dates, and other PHI with their PHI types.

Function synopsis:

The function prints all the identified PHI locations to the output file. If a PHI is a date, the function shifts the date and replaces it in the de-identified text. This shift may be a predetermined value or a random value. If a PHI is not a date, the function replaces it in the de-identified text with a tag of the PHI type. The function then prints the remaining non-PHI text to the de-identified text. Thus, the function outputs a de-identified text file that is the original data file with all the identified PHI replaced with PHI tags or shifted dates.

stat()

Arguments: filenames of file containing Gold Standard PHI locations and file containing PHI locations of current de-identification run

Returns: None

Called by: Topmost level of code

Description: Calculates code performance statistics if comparison mode is set to 1 and if Gold Standard is available.

Function Synopsis:

The function compares the PHI locations contained in the gold standard database and in the output from the de-identification software, determines the recall and precision of the de-identification results, and prints them on the screen.

APPENDIX B. PHI Tag Types

The de-identification algorithm replaces each PHI found in the medical notes with a PHI category tag. In this section, we list the PHI tags defined in the code.

Name

The name filter replaces each name instance found in the medical notes with a PHI tag that indicates the type of name replaced (e.g., first/last, female/male). In some cases, the pattern used to detect the name is specified in parenthesis following the name type. For example, the tag [*** Name (PTitle) ***] indicates that the name matches patterns defined by plural titles such as "Drs." and "Professors". Example name PHI tags are as follow.

[** Known patient firstname **] Name matched the patient's first name listed in the dictionary.

[** Known patient lastname **] Name matched the patient's last name in the dictionary.

[** Doctor First Name **] Doctor first name.

[** Doctor Last Name **] Doctor last name.

[** Female First Name (un) **] Unambiguous female first name.

[** Male First Name (un) **] Unambiguous male first name.

[** Name(LF) **] Last name followed by a comma and then a first name.

[** Name (MD) **] Doctor names followed by "MD".

[** Name (PRE) **] Doctor name initial preceded by words such as "physician", "PCP", "provider", etc.

[** Name (NI) **] Names preceded by name indicators, such as "mother", "brother", "husband".

[** Name (NameIs) **] Name preceded by the term "name is".

[** Name Prefix (Prefixes) **] Name prefixes such as "de la", or "van der".

[** Last Name (Prefixes) **] Name preceded by prefixes such as "de la" or "van der".

[** Name (STitle) **] Name followed by specific titles, such as "DR", "MR" or "MS".

[** Name (PTitle) **] Name followed by plural titles such as "Drs." And "Professors".

[** Name (NamePattern) **] Various name patterns that involve a first name, followed by an optional 1 or 2 middle initial(s), and then a last name.

Location

PHI category tags generated by the location filters include the following.

[** Street Address **] Street address.

[** Location **] Location in general, such as town, city names.

[** Location (Universities) **] University names.

- [** Hospital **] Hospital names.
- [** Wardname **] Hospital ward names.
- [** PO BOX **] PO Box number.

[** State/Zipcode **] Zipcode preceded by state names.

[** State **] U.S. state names.

[** Country **] Country name.

[** Company **] Company name.

Telephone

The phone filter generates the following two types of PHI category tags.

- [** Telephone/Fax **] Telephone or fax numbers.
- [** Pager number **] Pager or beeper numbers.

Other

- [** Social Security Number **] Social security numbers.
- [** Medical Record Number **] Number associated with the medical record.
- [** Unit Number **] Unique patient number.
- [** Age over 90 **] Age equal to 90 or older.
- [** E-mail address **] Email address.
- [** URL **] Web URL address.
- [** Holiday ^{**}] Holiday such as Christmas, Hanukah, Ramadan.
- [** Ethnicity **] Words that indicate ethnicity or nationality, such as American, African, Spanish, etc.