Systems for Helping Veterans Comprehend Electronic Health Record Notes

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Outline

- Background
- The NoteAid System
- Evaluation: 3 Pilot Studies
  - Self-reported comprehension
  - Paraphrase note: "…in your own words"
  - Patient interviews
- Conclusion & Future Work

Background

- Patients reading their EHR notes has the potential to
  - Enhance medical understanding
  - Improve healthcare management and outcomes
- **Blue Button:** The Department of Veterans Affairs (VA) Blue Button enables Veterans to view, print, and download their EHRs, including clinical notes (e.g., progress notes).
  - As of April, 2013, over 750K registered users and over 3.6 million Blue Button download requests

The Challenge

- Physicians' notes are difficult to comprehend (Keselman et al)
- Many Veterans have limited health literacy (Schapira et al)

"The patient will be scheduled for a repeat **EGD** in one year for surveillance purposes of **Barrett's esophagus**. From a **GI** standpoint, we recommend to proceed with **bariatric surgery**. However, he will need to continue daily **PPI** administration to maximize acid reduction. Otherwise, there are no additional recommendations. The patient was treated with **myocardial infarction**."

The NoteAid System

- A system for helping patients comprehend electronic health record notes
- Automatically
  - Identifies clinically relevant concepts
  - Links concepts to their definitions
  - Translates medical jargon into lay language that patients understand
  - Links notes to other education material

NoteAid Demonstration

- http://www.clinicalnotesaid.org

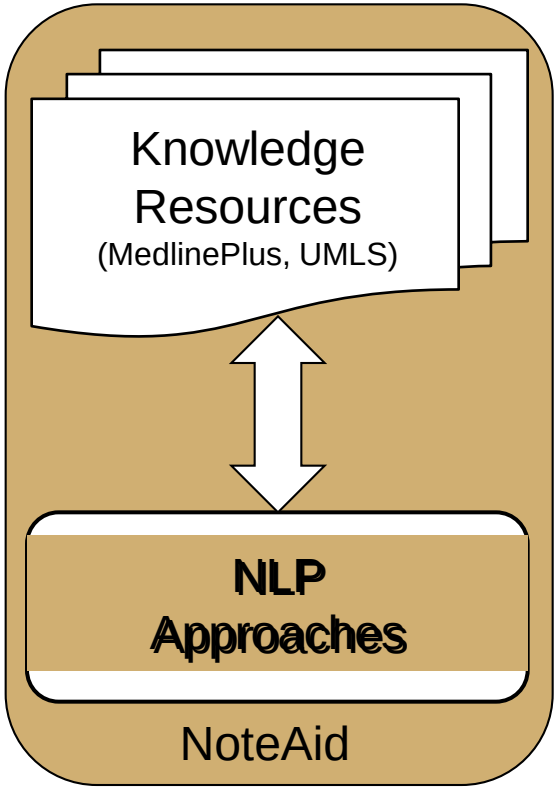
Poll Question #1

- What is your primary role in VA?
  - student, trainee, or fellow
  - clinician
  - researcher
  - manager or policy-maker
  - Other

Poll Question #2

- Which best describes your research experience?
  - have not done informatics research
  - have some informatics research experience
  - have some informatics and some NLP research experience
  - Have extensive NLP research experience

The NoteAid System



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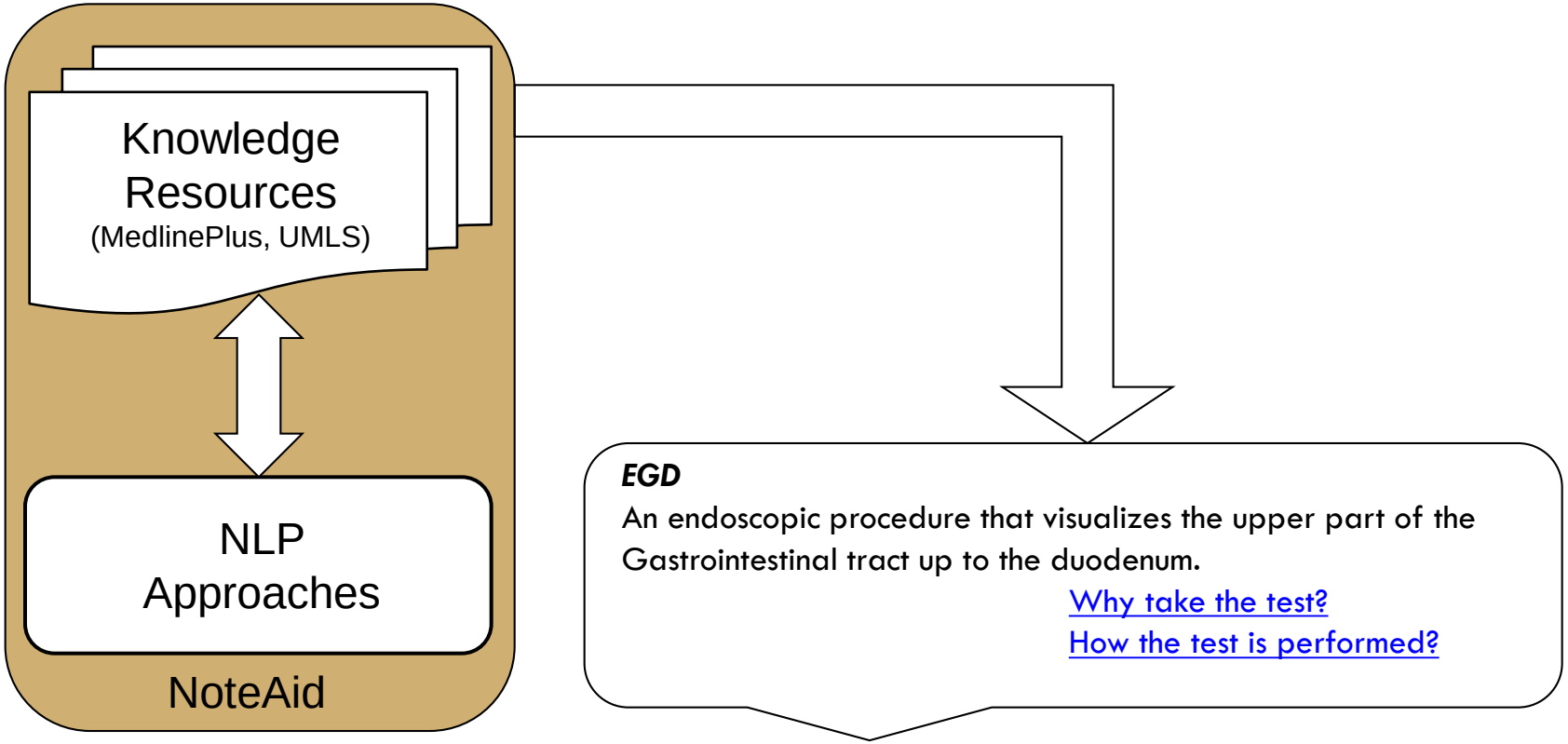

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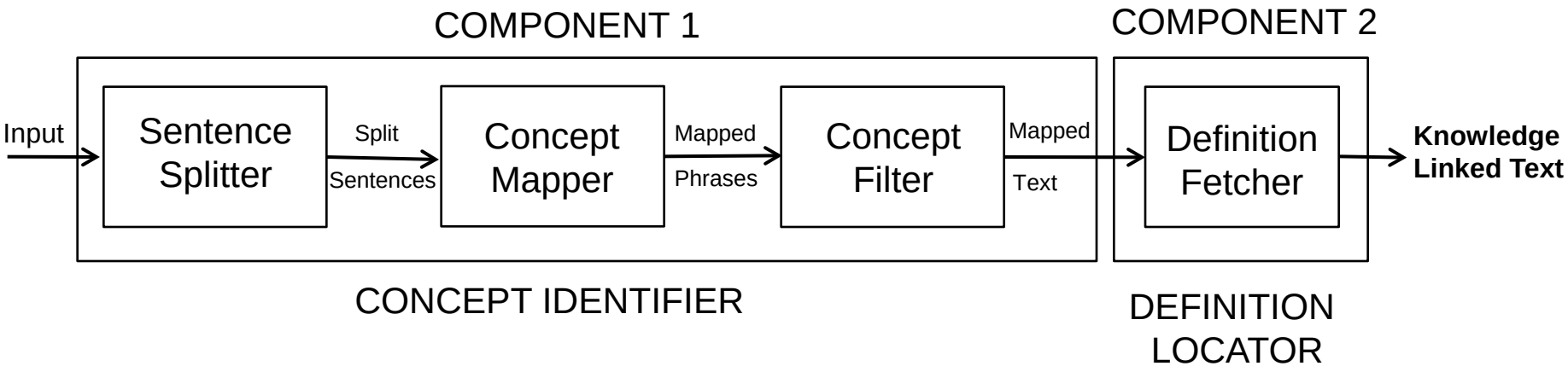
NoteAid

- Knowledge Resources
  - MedlinePlus
    - the National Institutes of Health's Web site for patients and their families and friends
  - UMLS – Unified Medical Language System
    - Files and software integrating biomedical vocabularies
      - Consumer Health Vocabulary (Qing et al)
      - Definitions
  - Others
    - Other NIH resources
    - Other consumer health resources
- NLP approaches

NLP Approach

- Two system components –
  - Concept Identifier
    - Process input text and identify clinically relevant concept
  - Definition Locator
    - Fetch definitions from MedlinePlus, UMLS and Wikipedia



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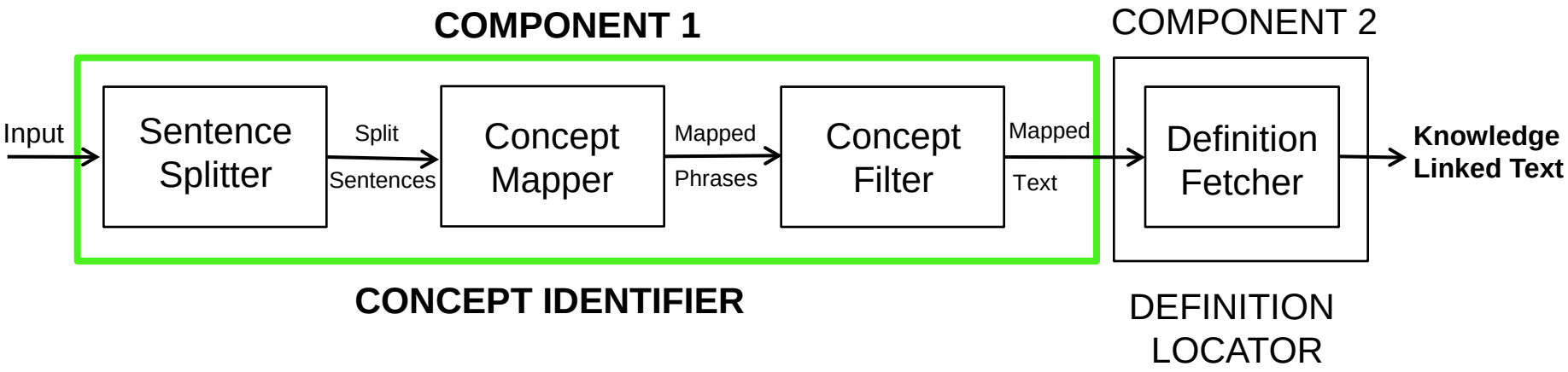

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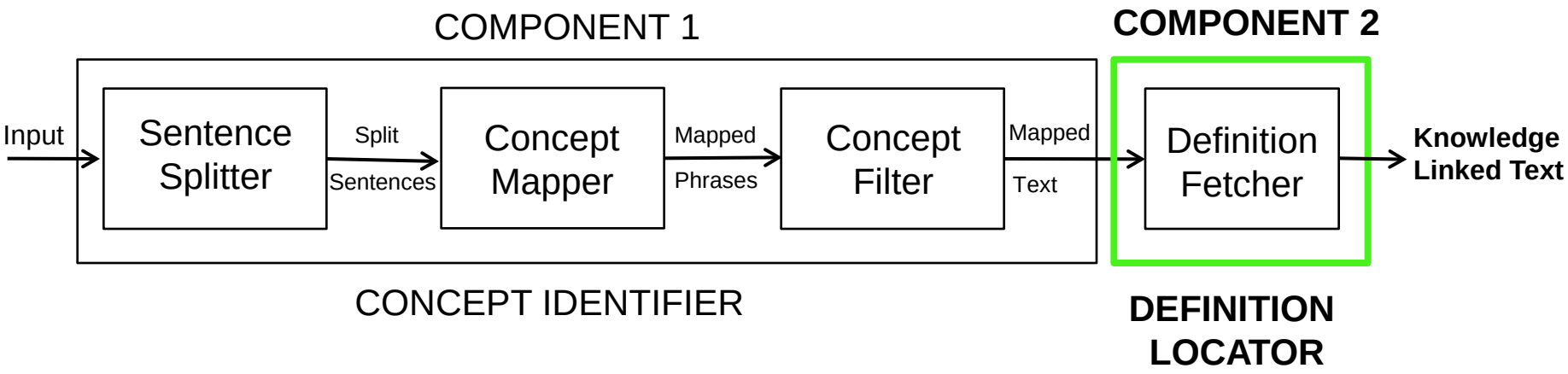

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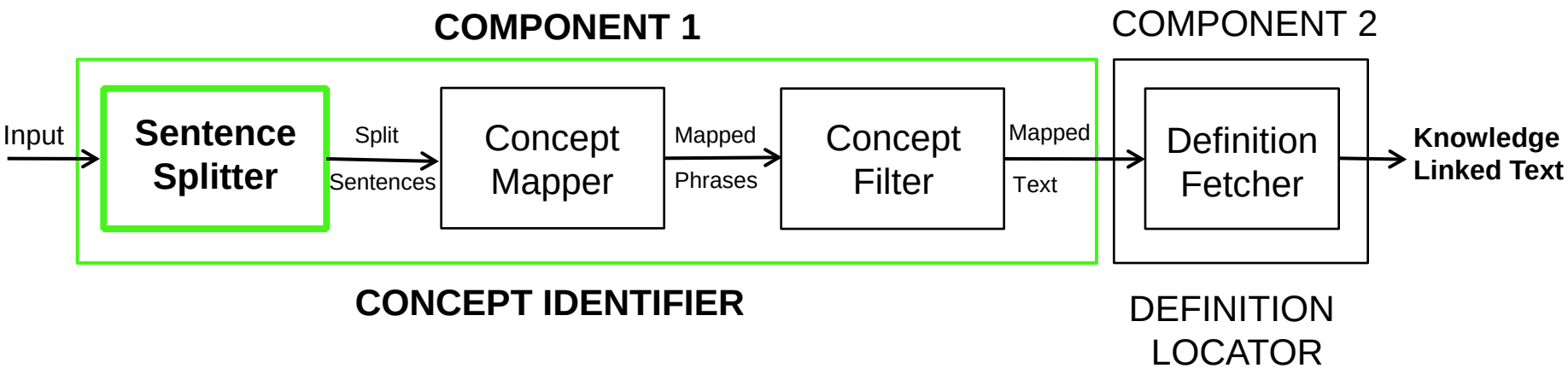

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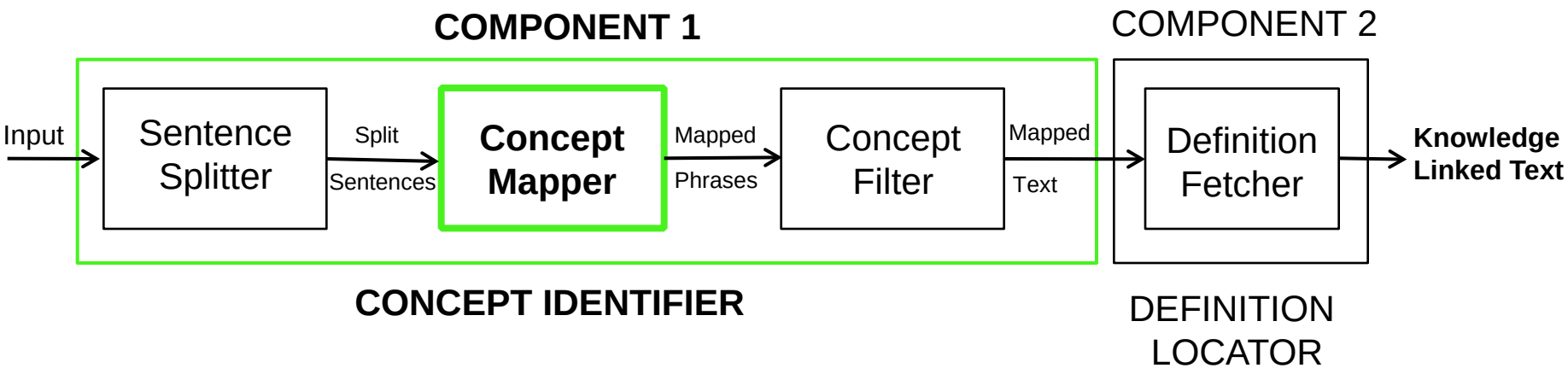

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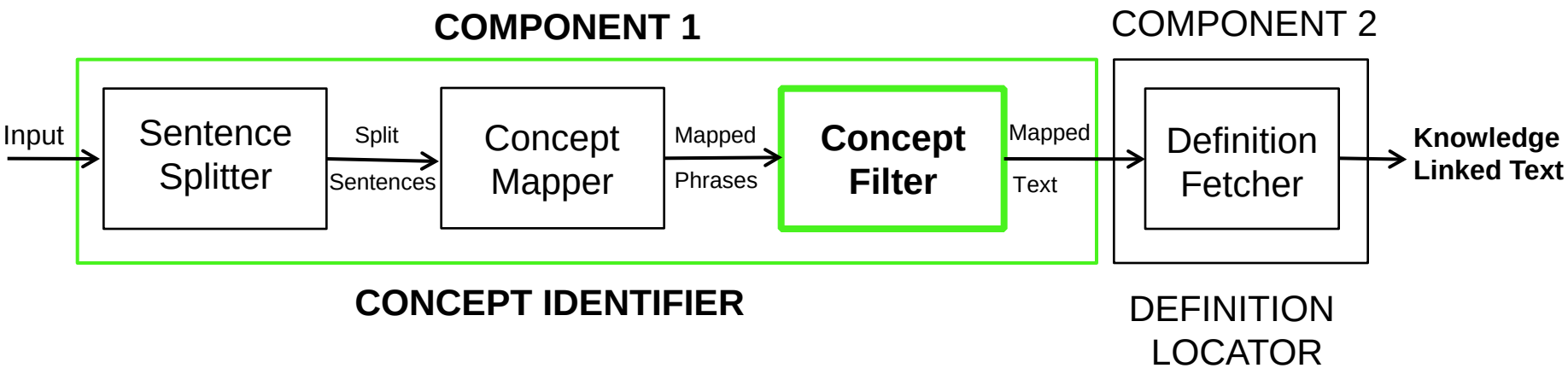

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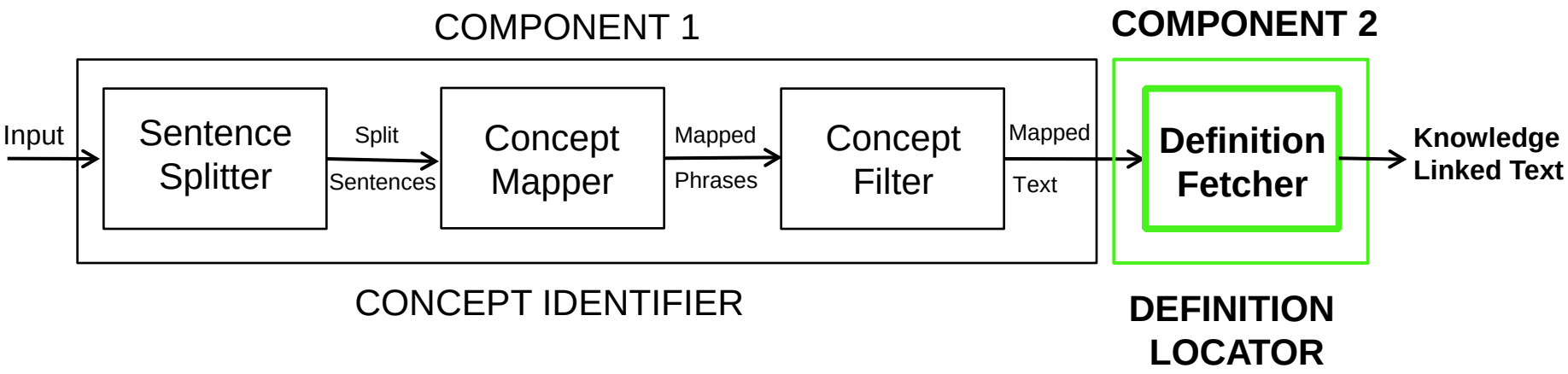

Evaluation

- Three Pilot Evaluations, with the IRB approval from UMass
  - Lay people self-report comprehension
  - Lay people paraphrase notes
  - Patient interviews
- No Veterans, pending VA IRB approval

Pilot Evaluation: Self-Reported Comprehension

- Lay people
- De-identified notes (not own notes)
- With or without NoteAid
- Self-reported comprehension
  - 1 to 5
  - 1: impossible to understand
  - 5: understand completely

Four NoteAid Implementations

- NLP+Different Knowledge Resources
  - MedlinePlus
  - UMLS
  - Wikipedia
    - 50% physicians use Wiki (KevinMD.com, 2009)
    - 53% US population use Wiki (NBC News 2011)
  - Hybrid (MedlinePlus+UMLS+Wikipedia)

Readability: Flesch-Kincaid grade level

- Hypothyroidism
  - "Too little thyroid hormone. Symptoms include weight gain, constipation, dry skin, and sensitivity to the cold. Also called underactive thyroid" – From NCI
    - FK is 9 – corresponding to US 9th grade education
  - "deficiency of thyroid gland activity; characterized by decreased basal metabolic rate, fatigue and lethargy, sensitivity to cold, and menstrual disturbances; untreated it progresses to myxedema; in infants severe hypothyroidism leads to cretinism." – From NIH CSP
    - FK is 25, much more difficult to understand

Evaluation Data

- 20 de-identified progress notes

Type	Progress Notes
No of Reports	20
Total (Avg) # of sentences	473 (23.7)
Total (Avg) # of words	4862 (243)
Avg Flesch-Kincaid Grade Level	9.8

Subjects

- The Amazon Mechanical Turk
  - Has shown to be reliable for medical annotations and evaluations
- Recruited 25 subjects
  - 5 systems (4 implementations + 1 w/o NoteAid)
  - 5 subjects per system
- 21 subjects completed the evaluation

Demographic Information

- Gender
  - Female – 9 (42.9%)
  - **Male** – 12 (57.1%)

- Education
  - High School – 7 (33.3%)
  - Associates – 2 (9.5%)
  - **Bachelors** – 6 (28.6%)
  - Masters – 6 (28.6%)

57.2%

Evaluation Process

- Subjects randomly assigned to one of the following five systems to read 20 progress notes
  - Note only (no NoteAid)
  - NoteAid_MedlinePlus
  - NoteAid_UMLS
  - NoteAid_Wiki
  - NoteAid_Medline+UMLS+Wiki (hybrid)
- Self-reported comprehension
  - 1 – impossible to understand
  - 5 – understand completely

Readability and Self-Reported Comprehension

- The FK Grade Level of a note correlated with self-reported comprehension score
  - ρ=-0.77, $p<0.01$, Spearman rank correlation
- Lower FK Grade level notes associated with higher (better) comprehension

Results

- Average self-reported comprehension scores

System	Note Alone	MedlinePlus	UMLS	Wiki	Hybrid
Score	2.95±0.67	4.12±0.33*	3.63±0.57*	3.85±0.47*	3.92±0.40*

*p<0.01, Non-parametric Mann-Whitney Wilcoxon signed-rank test

Limitations

- Self-reported comprehension score
- Do lay people *really* understand the notes?
- Lay people--not patients--performed evaluation

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  - **Lay people self-report comprehension**
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Evaluation Process

- **Data:** 5 de-identified progress notes
- **Subjects:** 40 subjects recruited from the Amazon Mechanical Turk
- **Evaluation Process:**
  - Each subject was presented with 5 notes, one at a time, either with NoteAid (hybrid), or without.
  - Each subject paraphrased the main content of the note
  - 39 completed the evaluation (20 with NoteAid and 19 without)

Examples: Without NoteAid

- **Note** : The patient is doing okay today. He has some complaints of discomfort around his tracheostomy site but otherwise has no complaints of chest pain, shortness of breath, abdominal pain, nausea, or vomiting. OBJECTIVE : Vital Signs : Currently stable. Cardiac : Normal S1, S2. No murmurs, rubs, or gallops are present. Lungs : Clear to auscultation bilaterally. Abdomen : Soft, nontender, and nondistended. Normoactive bowel sounds are present. LABS : There are no new labs from today. ASSESSMENT AND PLAN : 1. Preoperative assessment from my prior note. 2. Hyponatremia likely to be SIADH related. Continue to monitor for now. 3. Leukocytosis. Likely to be reactive. No clear infectious source. 4. Thrombocytopenia. It is probably chronic in nature and appears to be stable. Although , we would continue to monitor this for now as well.
- **Paraphrase note 1**: "The patient seems to be doing alright despite some minor discomfort. His vital signs are stable and he hasn't had any labs today. The plan going forward is to keep monitoring the patient."
- **Paraphrase note 2**: "The patient appears to be doing well aside from minor discomfort around the site of where the tracheostomy was performed. Other than that, they do not appear to have any other discomfort. There are other apparent issues like **Hyponatremia** and **Leukocystosis** which appear to be a result of the procedure. The patient appears to be doing well, but should continue being monitored."

Examples: NoteAid

- **Note** : The patient is doing okay today. He has some complaints of discomfort around his tracheostomy site but otherwise has no complaints of chest pain, shortness of breath, abdominal pain, nausea, or vomiting. OBJECTIVE : Vital Signs : Currently stable. Cardiac : Normal S1, S2. No murmurs, rubs, or gallops are present. Lungs : Clear to auscultation bilaterally. Abdomen : Soft, nontender, and nondistended. Normoactive bowel sounds are present. LABS : There are no new labs from today. ASSESSMENT AND PLAN : 1. Preoperative assessment from my prior note. 2. Hyponatremia likely to be SIADH related. Continue to monitor for now. 3. Leukocytosis. Likely to be reactive. No clear infectious source. 4. Thrombocytopenia. It is probably chronic in nature and appears to be stable. Although , we would continue to monitor this for now as well

- **Paraphrase note**: "The patient is doing well although he has some discomfort around his tracheostomy area. The patient has stable vitals. Some conditions will continue to be monitored, including **low salt content** in the blood, **high white blood cell count**, and **low blood platelet count**."

Evaluation of Summary

Terms in 195 Summaries	With NoteAid	Without NoteAid
Number of medical jargon terms in lay language	**268**	68
Number of medical jargon terms copied and pasted	**70**	169

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A Pilot Study: Patient Evaluation with NoteAid

- Approved by the IRB board at UMMS
- Recruit 3 patients, all college graduates
  - One Type I diabetes, two Type II diabetes
  - Being treated for 5~15 years
- Each patient presented with 1~2 own progress notes of his/her most recent clinical visit
  - Ask what they don't understand
  - Present Note+NoteAid
  - Think-aloud
  - A list of questions

Concepts and Abbreviations

- The 3 patients did not understand 5~10 concepts in his/her own progress note
  - E.g., FT4, auscultation, post-ablative hypothyroidism

Questions

- **Do you want to read your EHR notes?** Yes (3)
- **When do you want to read your notes?**
  - Before and after a clinical visit (3)
- **Is there a specific part of notes that you would like to read?**
  - All notes (2), current plan (1)
- **Would you be willing to share your notes with your friends or family members?**
  - No (2), spouse if asked (1)
- **Is NoteAid helpful?** Yes (3)
- **Do you want to use NoteAid?** Yes (3)

How to Improve NoteAid

- More concepts included by NoteAid (3)
- Easy-to-read definitions (3)
- More education material (3)

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Limitations

- Main limitations
  - All pilot studies
    - Sample size is small
    - No Veteran population

Conclusion and Future Work

- NoteAid improved EHR note self-reported comprehension
- NoteAid helped patients comprehend their own notes
- Future Work
  - NLP: Improve concept coverage and filtering
  - NLP: Improve quality of the definitions
  - NLP: Add education material
  - Evaluate comprehension
  - Evaluate system in which Veterans read their own EHR notes

References

- Polepalli Ramesh B, Houston T, Brandt C, Fang H, **Yu H.** Improving Patients' Electronic Health Record Comprehension with NoteAid, Studies in Health Technology and Informatics Vol.192: MEDINFO 2013, pp 714 - 718. DOI:10.3233/978-1-61499-289-9-714. **Best Student Paper Award**

- Polepalli Ramesh B and **Yu H.** Systems for Improving Electronic Health Record Note Comprehension, In proceedings of Health Search and Discovery 2013 at ACM SIGIR 2013, pp 39-42.

Thanks and Questions

- The NoteAid Prototype Systems:
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