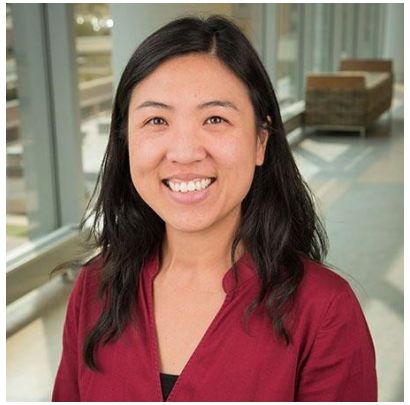
Grand Rounds

NIA IMPACT COLLABORATORY
TRANSFORMING DEMENTIA CARE

Identifying and Engaging Care Partners Through Electronic Health Records for Pragmatic Research



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Housekeeping

- All participants will be muted upon entry
- Enter **all questions** in the Zoom **Q&A/chat box** and send to Everyone
- Moderator will review questions from chat box and ask them at the end
- Visit impactcollaboratory.org
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KAISER PERMANENTE®
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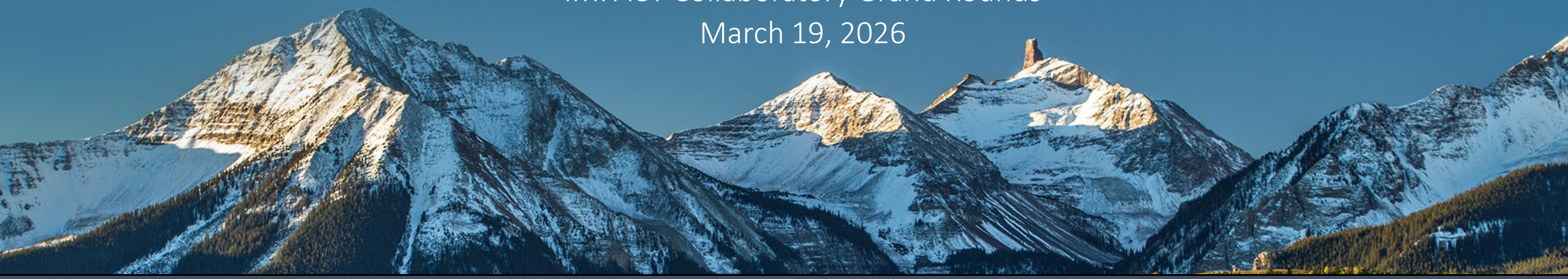
mHealthImpact
CREATING AND CURATING DIGITAL HEALTH SOLUTIONS

Identifying Care Partners of Persons Living with Dementia Using Electronic Health Record Data (ID-CARE)

Jennifer Portz, PhD, MSW

IMPACT Collaboratory Grand Rounds
March 19, 2026



NIA @2Collective/PennAITech P30AG073105 and NIA K76AG059934

Care Partners Play a Critical Role in ADRD Care

- Care partners provide essential support, including:
  - Coordinating medical care
  - Managing medications and behavioral symptoms
  - Assisting with daily activities
  - Communicating with clinicians
- Care partners often identify behavioral changes and safety concerns first, making the care partner–clinician partnership essential.
- ADRD caregiving is especially challenging due to:
  - Long disease course
  - Multiple chronic conditions
  - Progressive care needs

Current Care Partner Identification is Not Scalable

- National policies emphasize caregiver identification:
  - CARE Act
  - RAISE Family Caregivers Act

- Despite policy mandates:
  - Only ~50% of hospital patients were asked to identify a caregiver (2019 data).
  - Caregiver assessments occur <10% of the time in primary care for ADRD.
  - 40% of caregivers report providers do not know who they are.

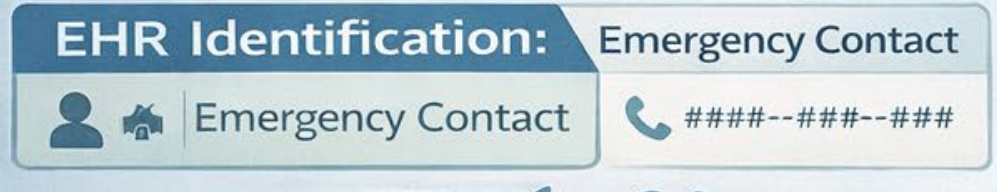
- Manual identification requires clinician time, specialized staff, and limited reimbursement, limiting widespread implementation.

- EHR-Based Care Partner Identification Enables System-Level Action
  - Unbefriended patients
  - Patients with unmet caregiving needs
  - Safety concerns

Care Partners Are Largely Invisible in the EHR

⚠ Minimal Caregiving Information Captured

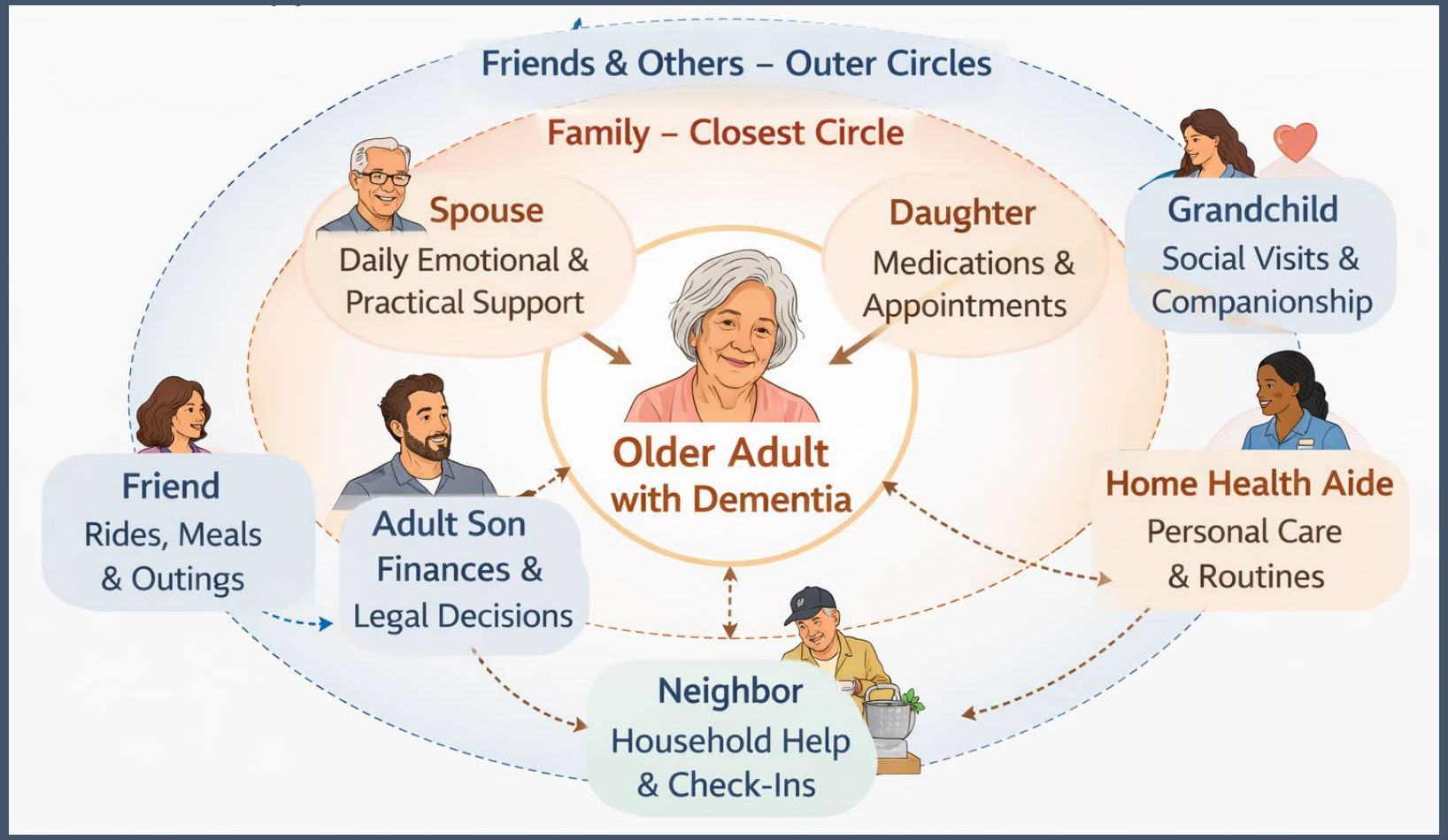
Only One Care Partner Recorded
+ multiple real-world caregivers involved



⚠ Reality of Dementia Caregiving:

Social Convoy Theory

- Framework for complex relationships-give and receive care- over the lifespan
    - Improved health outcomes
    - Reduced mortality
    - Increased quality of life



ID-CARE Pilot Objective

Examine	Examine provider free-text notes and patient portal messages to find diverse types of caregivers.
Develop	Develop a framework for best analyzing this unstructured EMR and patient portal data to automate a prediction model for caregiver identification.

Study Design and Methods

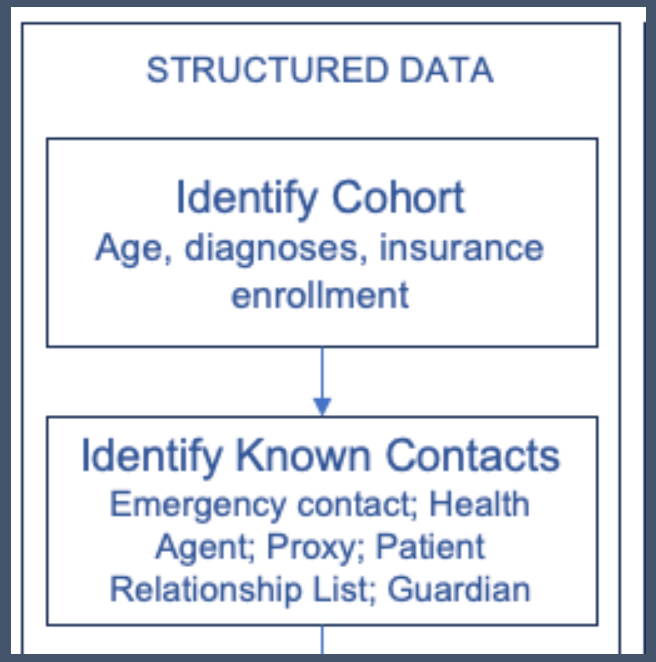
Retrospective Cohort Study

- N=789 people living with dementia
  - Age 60+
  - Dementia with behavioral disturbances
  - Enrolled in KPCO from 1/1/2020 – 11/2/2022
  - 1+ in-person or telehealth visit after initial ICD code
- Data Sources:
  - Virtual Data Warehouse – Patient data to establish cohort
  - KPCO EHR – Structured patient contact data, unstructured notes and portal messages

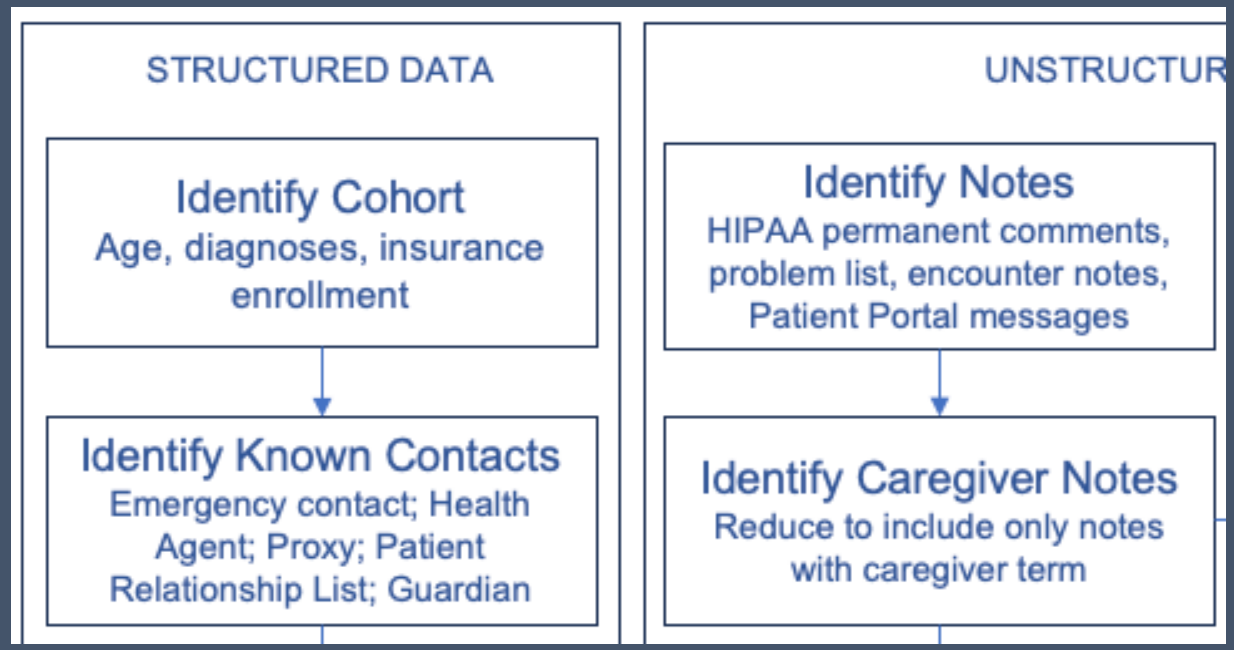
To Identify the Care Partner Network

1. Identification of known contacts from structured EHR data fields
2. Identification of unstructured notes and patient portal messaging that include caregiving text
3. Identification of names of potential caregivers that are not listed as known contacts from caregiving text

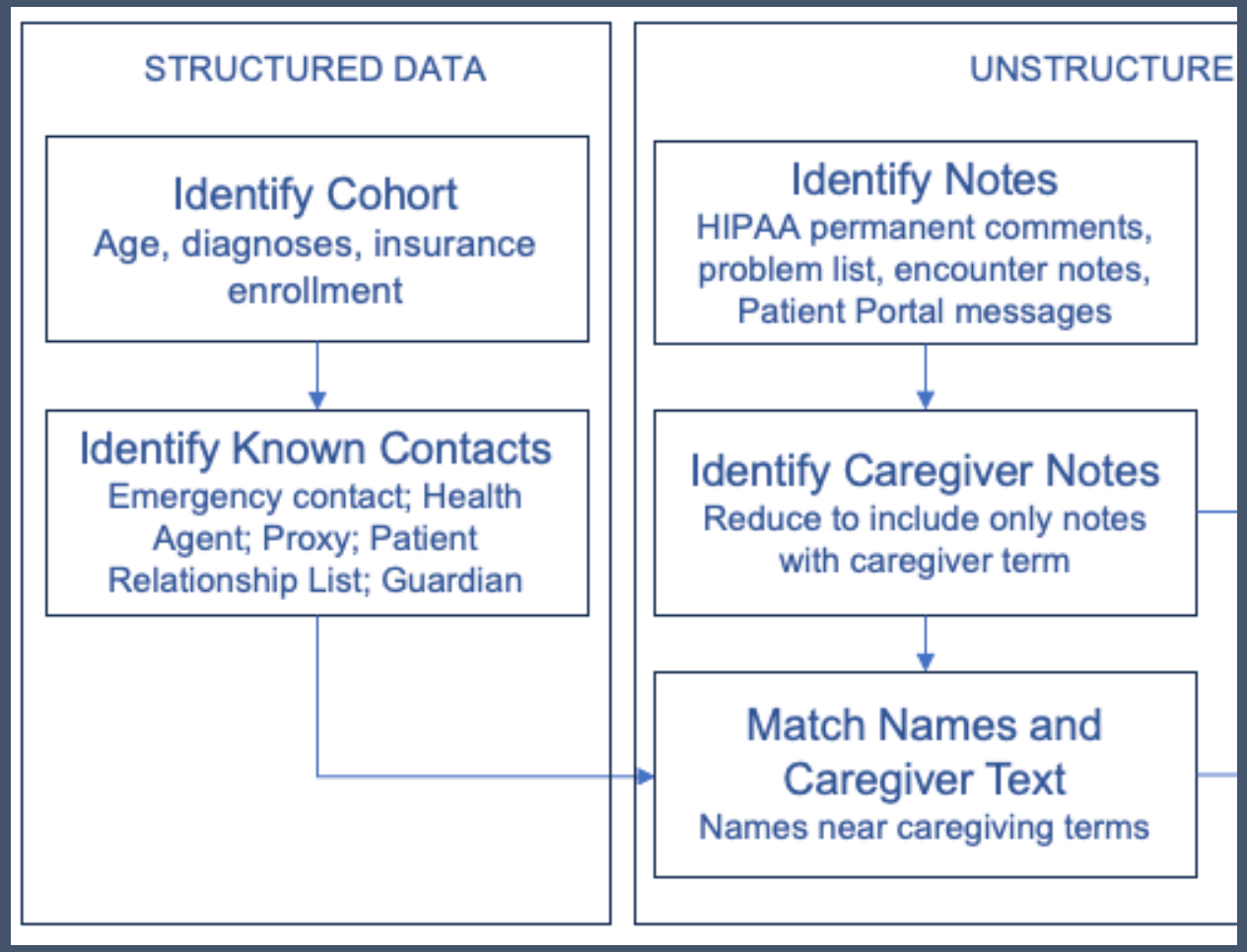
Structured Data Extraction – Known Contacts



Unstructured Data – Related to Caregiving



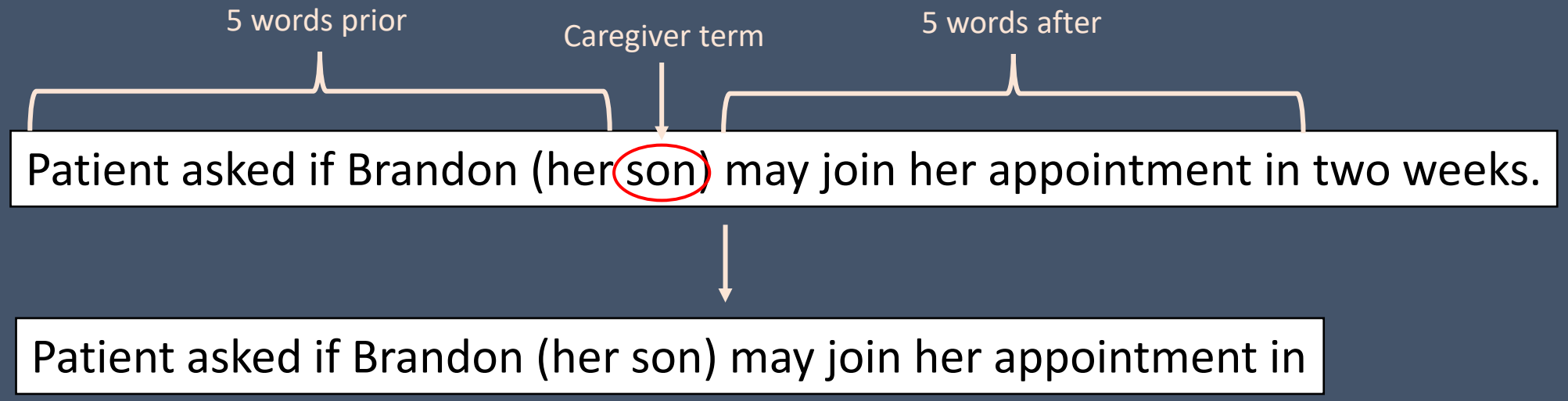
Matching Known Contacts and Caregiver Text



“Fuzzy” Matching Example

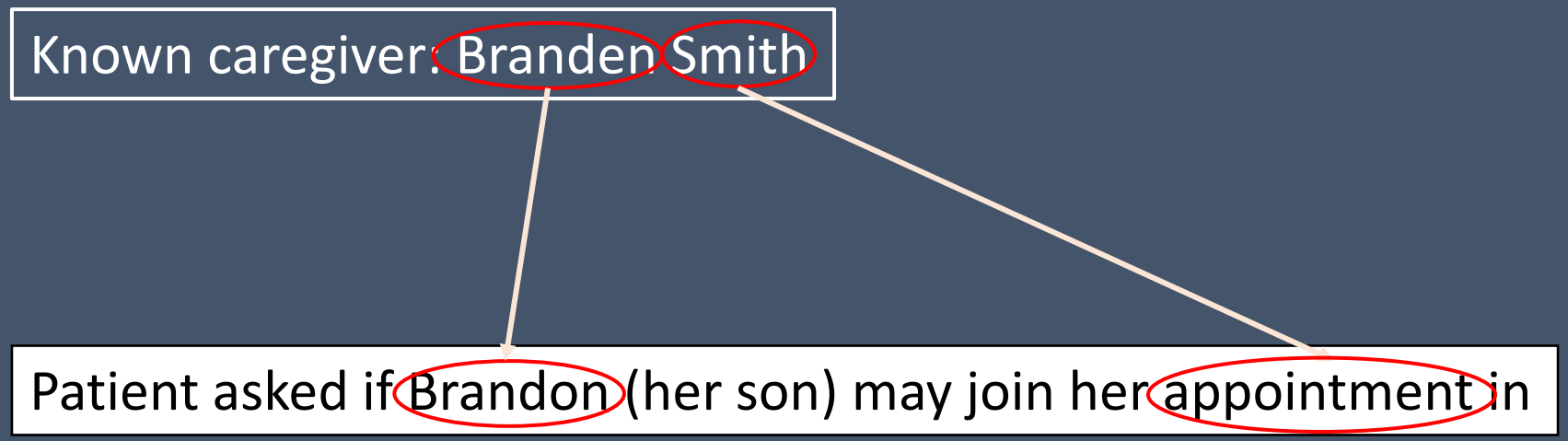
Search for caregiver key terms and create text snippets of 5 words before and after key term.

Known caregiver: Branden Smith



“Fuzzy” Matching Example

Score each possible combination of first/last name x word in text snippet using string edit distance algorithm

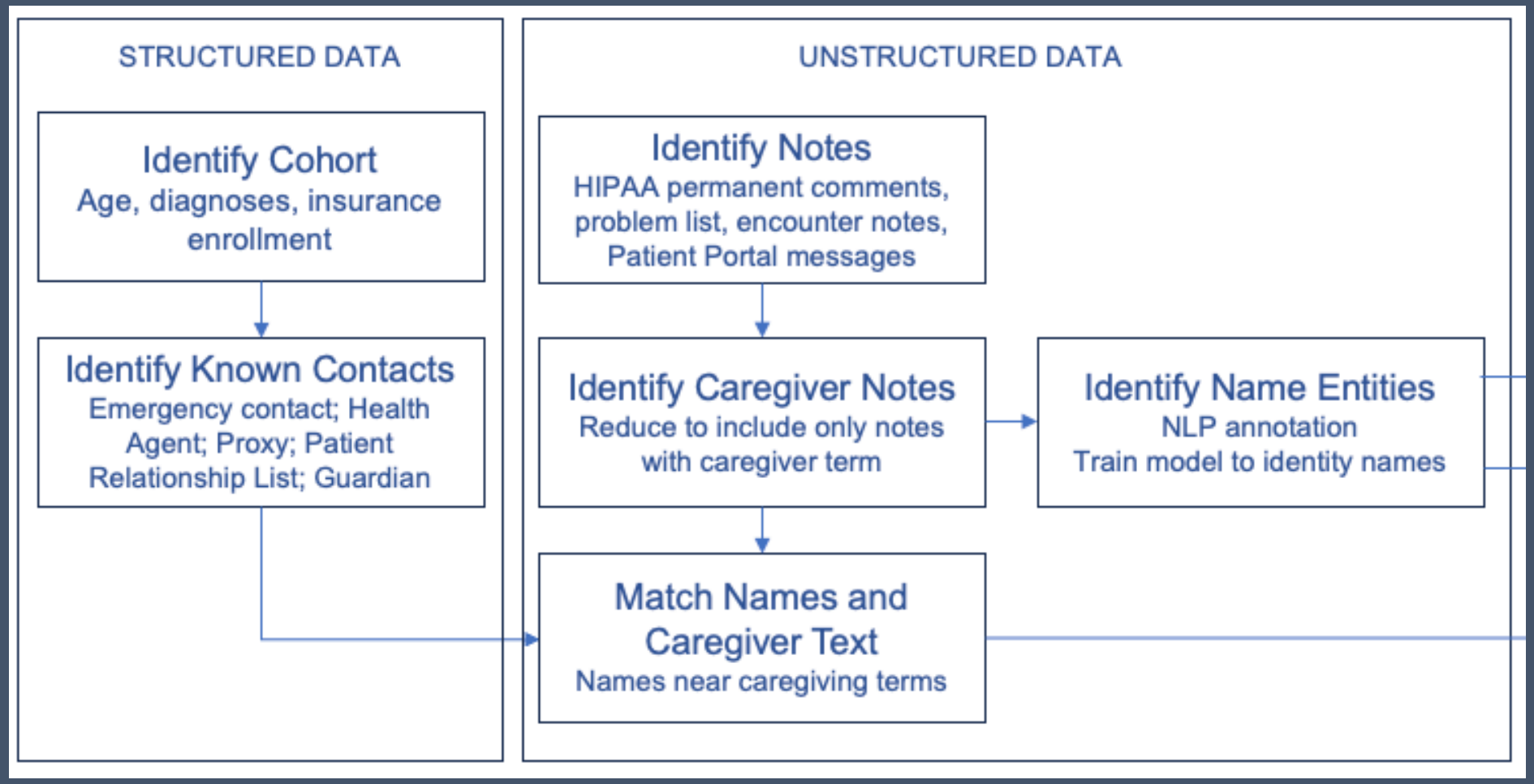


Closest first name match, score = 14
(letter replacement “e” → “o” = score 100
Divide by word length, round down: 7, 100/7 = 14)

Other operations have different scores, e.g.,
swapping order of two letters = score 50

Closest last name match, score = 71
(closest match may not be close at all!)

NLP to Identify Names of Caregivers



Predicting Names of Caregivers

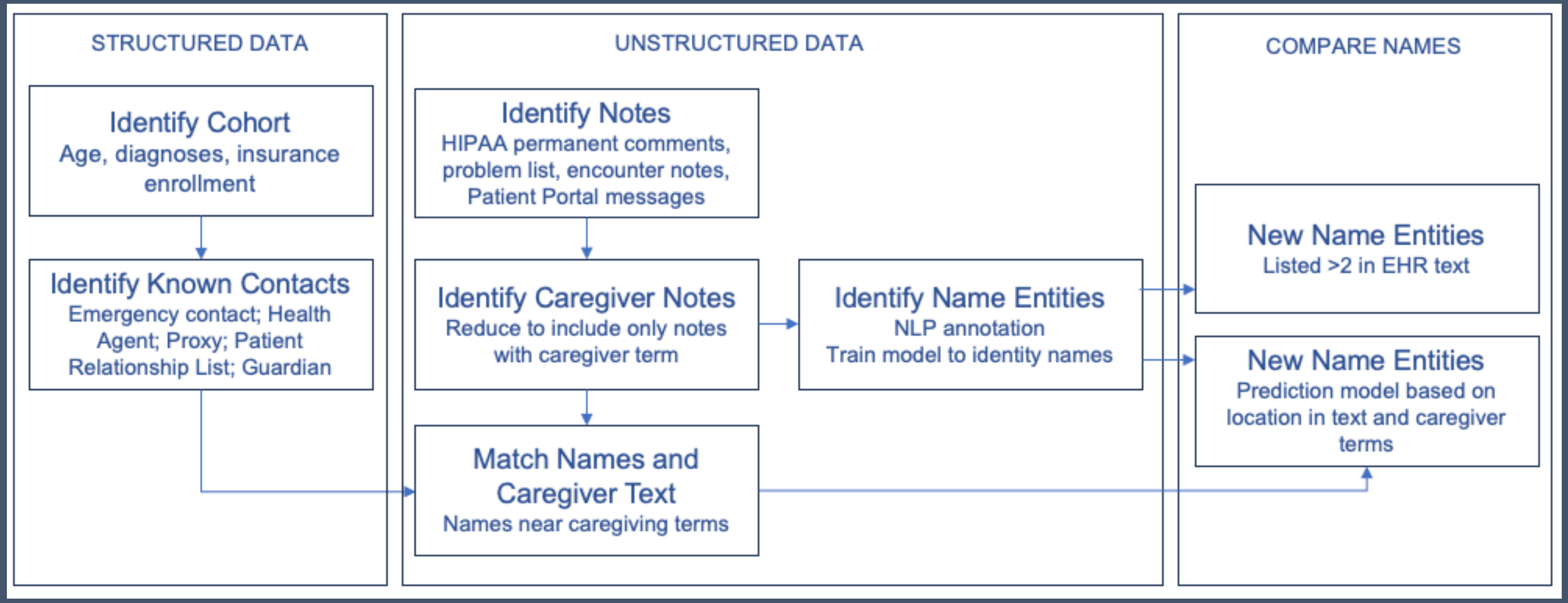


Table 1. Demographics of patients living with dementia (n=789)

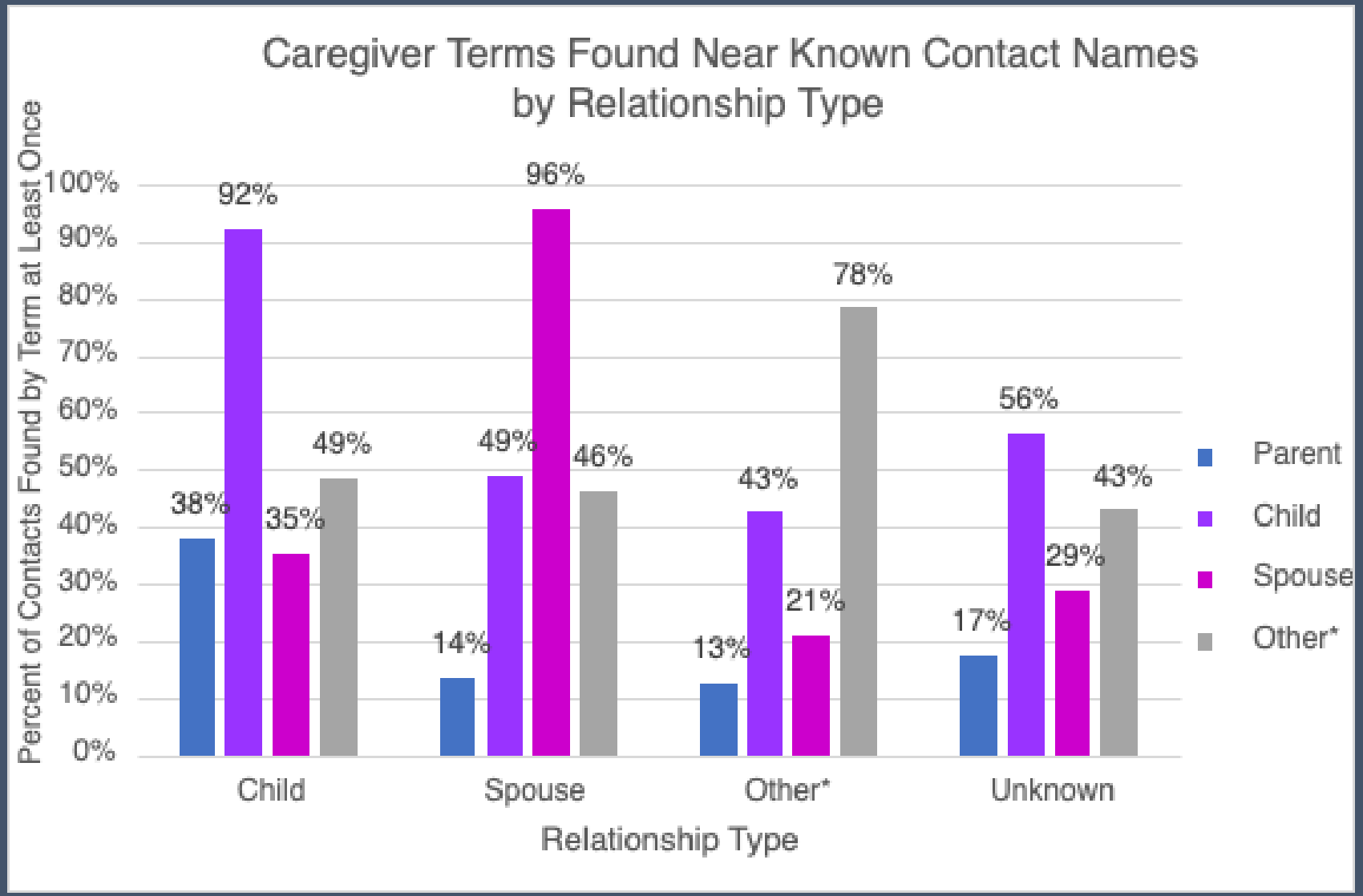
Demographics	PLWD Cohort	PLWD with Contacts/ Relations Recorded
PLWD Cohort Size	(N = 789)	(N = 749)
Demographics		
Age, mean (SD)	84.3 (8.1)	84.3 (8.1)
Sex, % female	62.3%	63.3%
Race, %		
American Indian/Alaskan Native	1.3%	1.2%
Asian	2.0%	1.9%
Black or African American	3.7%	3.7%
White	79.5%	80.2%
Other*	3.7%	3.2%
Unknown or not reported	9.9%	9.5%
Hispanic, %	11.3%	10.9%
Contacts/Relationships in EHR		
Mean (SD) # contacts/relationships	--	2.1 (1.2)
Has any contact/relationship	--	94.9%
Has relationship recorded	--	94.9%
Has emergency contact	--	93.4%
Has guardian	--	7.1%
Has healthcare agent	--	37.6%
Has portal proxy	--	9.9%

Identification of Known Contacts

Table 2. Sources and Relationship Type for Known contacts

Known Contacts from Structured Fields	N = 1,667
Sources	
Patient relationships	96.6%
Emergency contacts	44.2%
Legal guardians	3.4%
Healthcare agents	30.1%
Portal proxy	5.3%
Relationship type (from patient relationships table)	
Child	54.1%
Spouse	15.6%
Parent	0.1%
Other	17.1%
Unknown	13.1%
Same last name as patient	47.1%

Known Contacts in Caregiving Text



			to Caregiver Term(s) in EHR Text by Text Type				Percent Found Near Caregiver Terms by Caregiver Term Category				
	Denominato	N	Encounter Notes	Permanent Comments	Portal Messages	Problem List	Parent	Child	Spouse	Other‡	Any
Known Contacts: Matched by First Name	*Cohort**	789	93.7%	67.8%	46.1%	70.8%	46.0%	79.6%	56.7%	70.8%	94.4%
	Contacts†	1,667	88.4%	43.9%	29.2%	49.6%	27.0%	72.2%	41.4%	52.5%	89.4%
Known Contacts: Matched by Full Name	*Cohort**	789	88.2%	48.3%	34.7%	54.2%	9.8%	69.8%	35.0%	34.5%	90.1%
	Contacts†	1,667	73.7%	28.4%	19.3%	35.2%	4.9%	54.9%	22.5%	22.9%	77.0%
New Names: All names found next to caregiver terms	*Cohort**	789	99.2%	36.6%	40.6%	24.8%	44.6%	81.7%	63.8%	80.9%	99.2%
	Names†	7,556	89.8%	5.6%	10.0%	3.5%	9.5%	46.2%	28.5%	36.0%	100.0%
New Names: Found next to caregiver term twice or more	*Cohort**	789	86.8%	18.9%	29.4%	21.5%	30.8%	65.0%	48.3%	58.2%	88.5%
	Names†	2,614	94.0%	7.1%	15.7%	8.7%	14.4%	53.9%	31.6%	44.0%	100.0%
New Names: Model predicted to be similar to known contacts	*Cohort**	789	87.7%	33.3%	22.3%	24.7%	21.9%	81.2%	42.5%	54.8%	89.7%
	Names†	3,706	93.5%	10.1%	7.1%	7.0%	6.4%	91.4%	16.8%	24.5%	100.0%

The NLP model identified 7,556 “new” names in the caregiver EHR text among 99% of the cohort with high accuracy and reliability (F1=.85, precision=.89, recall=.82).

Discussion

- First to use name-matching and a rule-based algorithm to identify names of care partners through patient EHR and portal messages
- Caregivers are present throughout the EHR – Caregiving information exists across multiple EHR locations
- Many caregivers participate in care, but are not formally documented
- Relationship patterns – most often adult children
- Study Limitations: Single health system, majority White, focus on behavioral disturbances, NLP identified names – not roles, requires human verification for clinical use

Next Steps

- Would love to:
  - Refine and further validate the prediction model
  - Qualitatively review context around caregiver terms and names to improve prediction and caregiving needs
  - Identify contact information of named care partners for outreach/intervention

- NIA R01 under review to update the model to identify relationship type, caregiving tasks, and caregiving needs.

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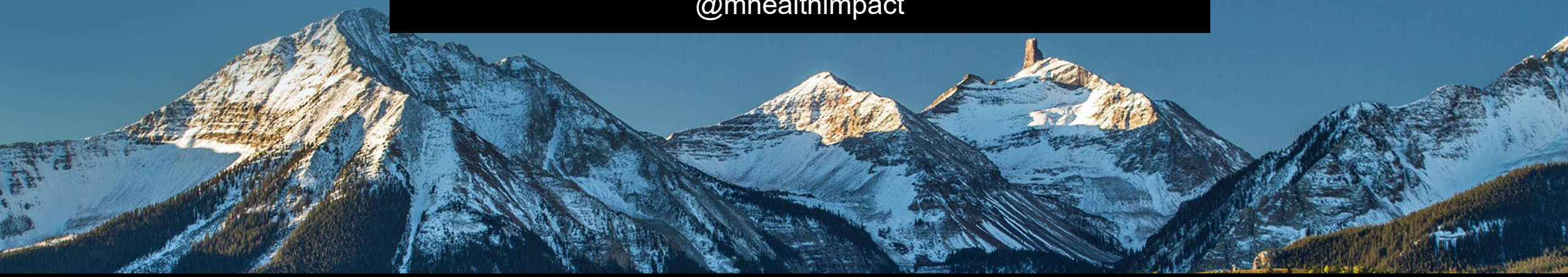

Center for Home Care Policy & Research

At VNS Health

Center for Home Care Policy & Research

- Independent research center affiliated with VNS Health
- Established 1993
- NIH and foundation funding
- Mission: *Conduct objective research that advances knowledge promoting the delivery of high-quality, cost-effective care in the home and community.*

VNS Health Services

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Behavioral Health

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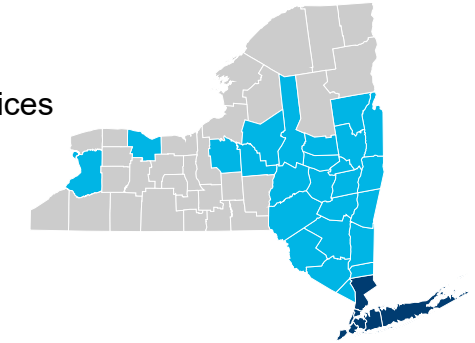
Care Management

Health Plans

Programs and services across New York.



VNS Health, by the Numbers

73,000

People in New York that VNS Health impacts every day.

970,000

Professional visits made in 2024 while providing care to over 117,000 patients.

11,000

Team members make up our diverse workforce.

$2+ Billion

Annual revenues.

$69+ Million

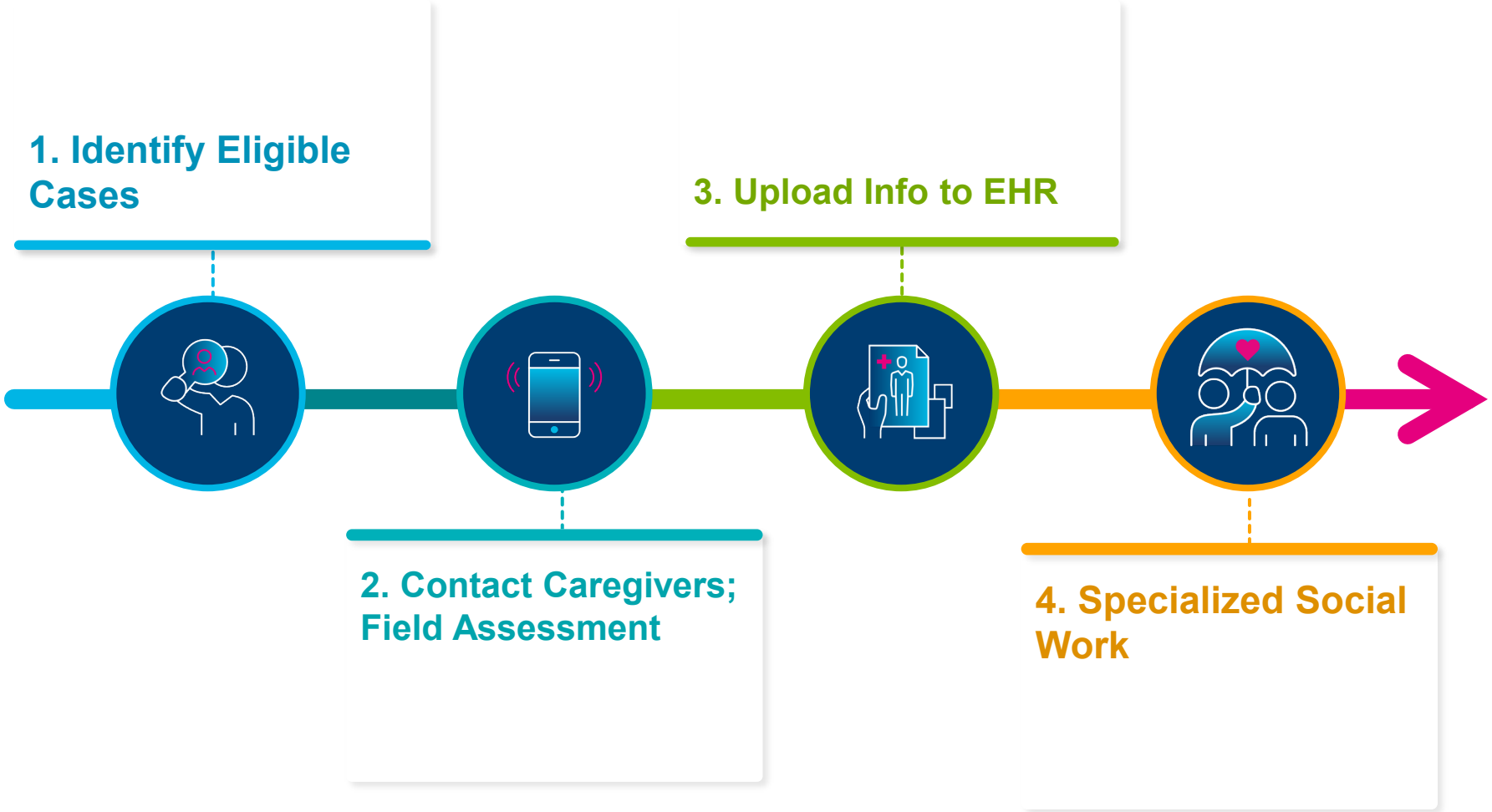
Provided in 2024 in charitable care and community impact programs.

VNS Health

Dementia Caregivers' Link to Assistance and Resources (DECLARE)

Ongoing ePCT (embedded Pragmatic Clinical Trial) in home health

DECLARE Intervention Protocol



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Dementia Caregivers' Link to Assistance and Resources (DECLARE)

Ongoing ePCT (embedded Pragmatic Clinical Trial) in home health

DECLARE Intervention Protocol

Program runs daily to identify new cases using existing data warehouse elements

1. Identify Eligible Cases

- Caregiver information (existence, name, number) gathered during scheduling process
- ≈13% incorrect -- doesn't count those we can't reach
- Not most relevant (e.g., power of attorney but lives out of state)
- Not complete (single point of contact for a network of paid and unpaid help – 80% have 2+ helpers)

VNS Health

Dementia Caregivers' Link to Assistance and Resources (DECLARE)

Ongoing ePCT (embedded Pragmatic Clinical Trial) in home health

DECLARE Intervention Protocol

2. Contact Caregivers; Field Assessment

Phone call from research team; 5-minute assessment of relationship / burden / tasks

- Phone calls rather than SMS text messaging due to compliance / legal concerns
- Ongoing discussion / interpretation of law
- More nuanced in context of (1) dementia diagnosis and (2) signed privacy agreement

VNS Health

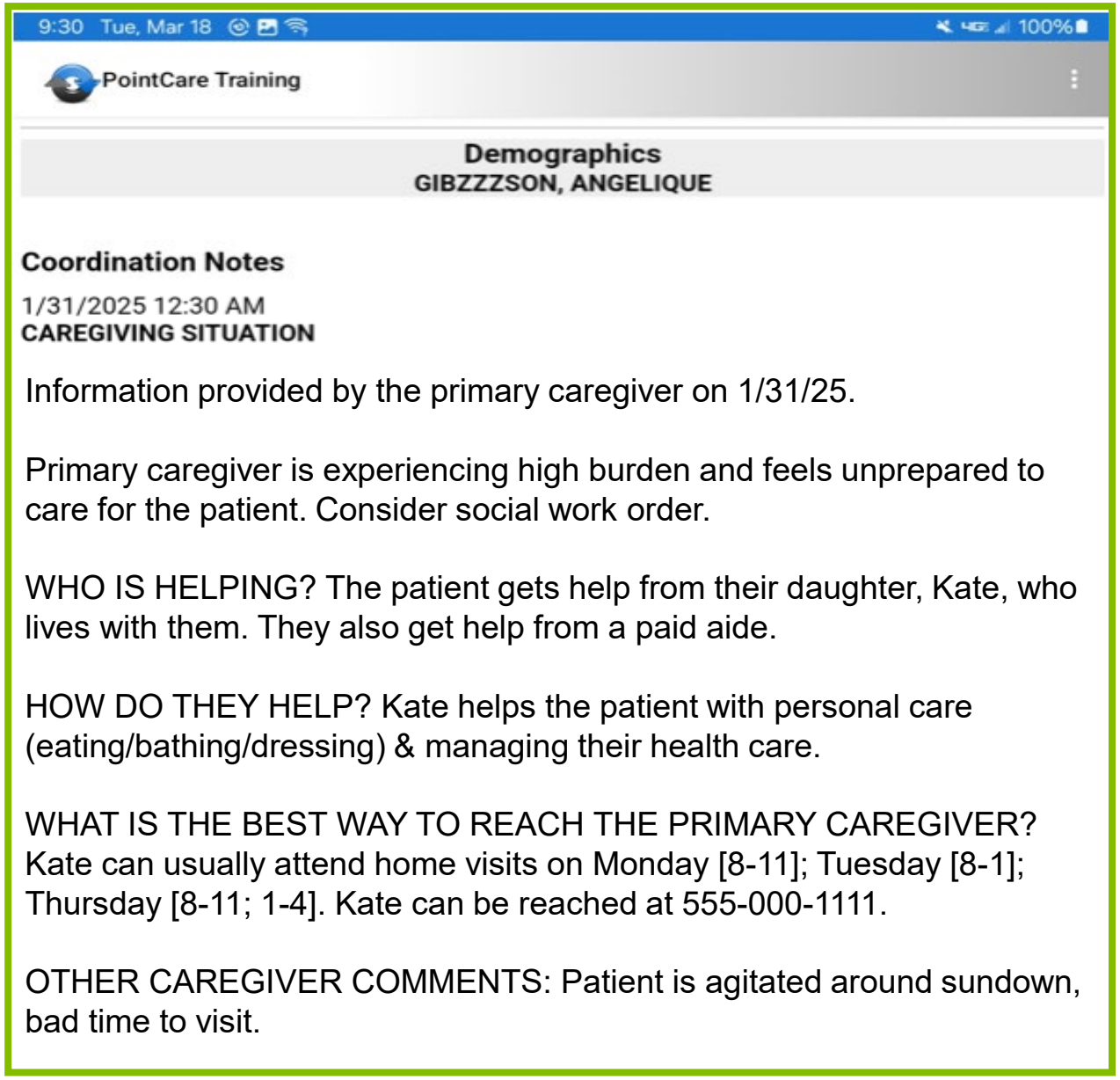
Dementia Caregivers' Link to Assistance and Resources (DECLARE)

Ongoing ePCT (embedded Pragmatic Clinical Trial) in home health

DECLARE Intervention Protocol

Caregiver responses uploaded automatically as formatted coordination note

3. Upload Info to EHR



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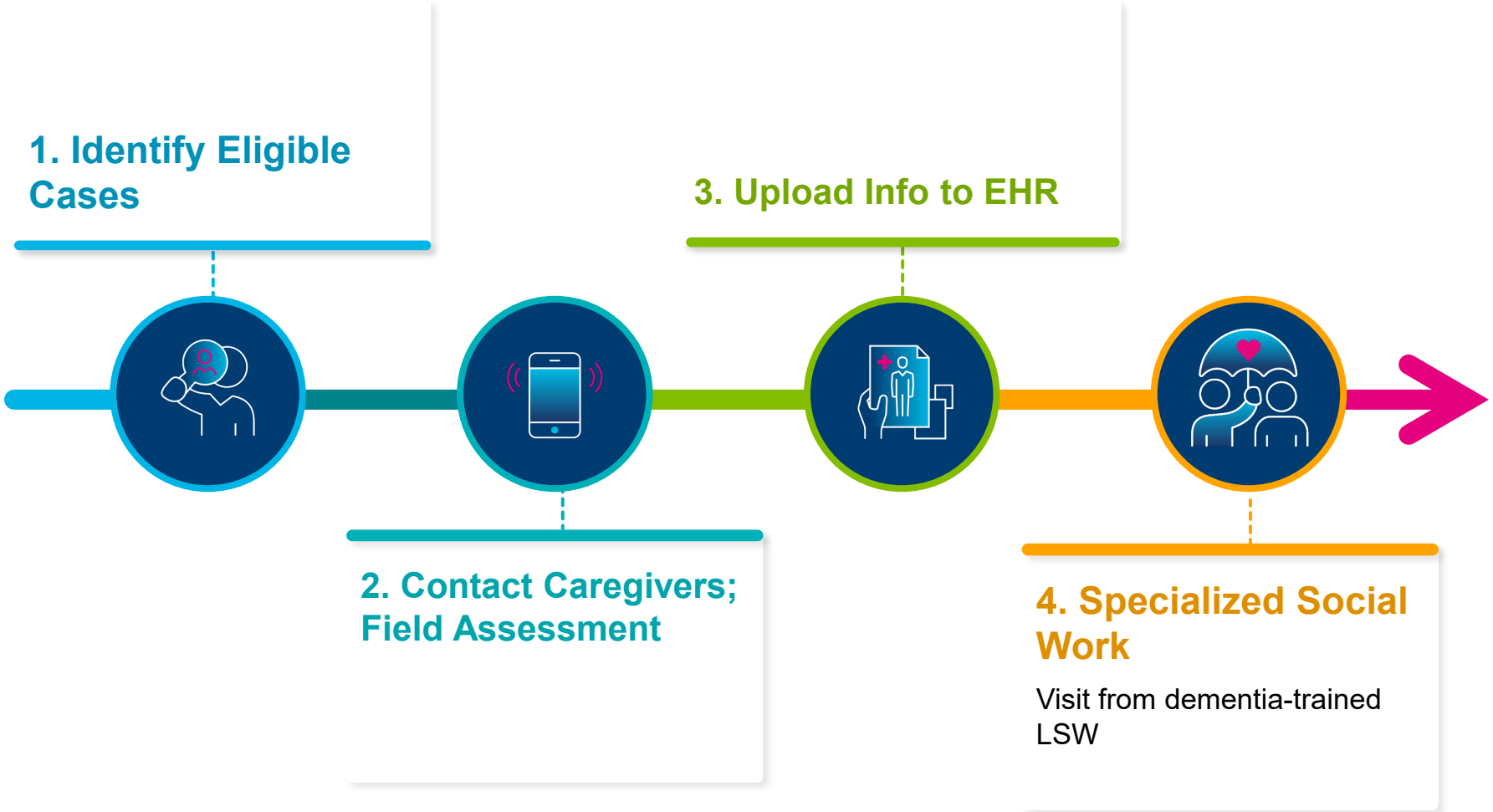

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