Opportunities to Engage Patients in Diagnostic Safety through Open Notes

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No relevant disclosures

How can open notes improve patient safety and advance diagnostic excellence?

1. Increase completion of ambulatory diagnostic tests and referrals
2. Strengthen patient-clinician communication and relationships
3. Detect EHR errors, prevent diagnostic blindspots

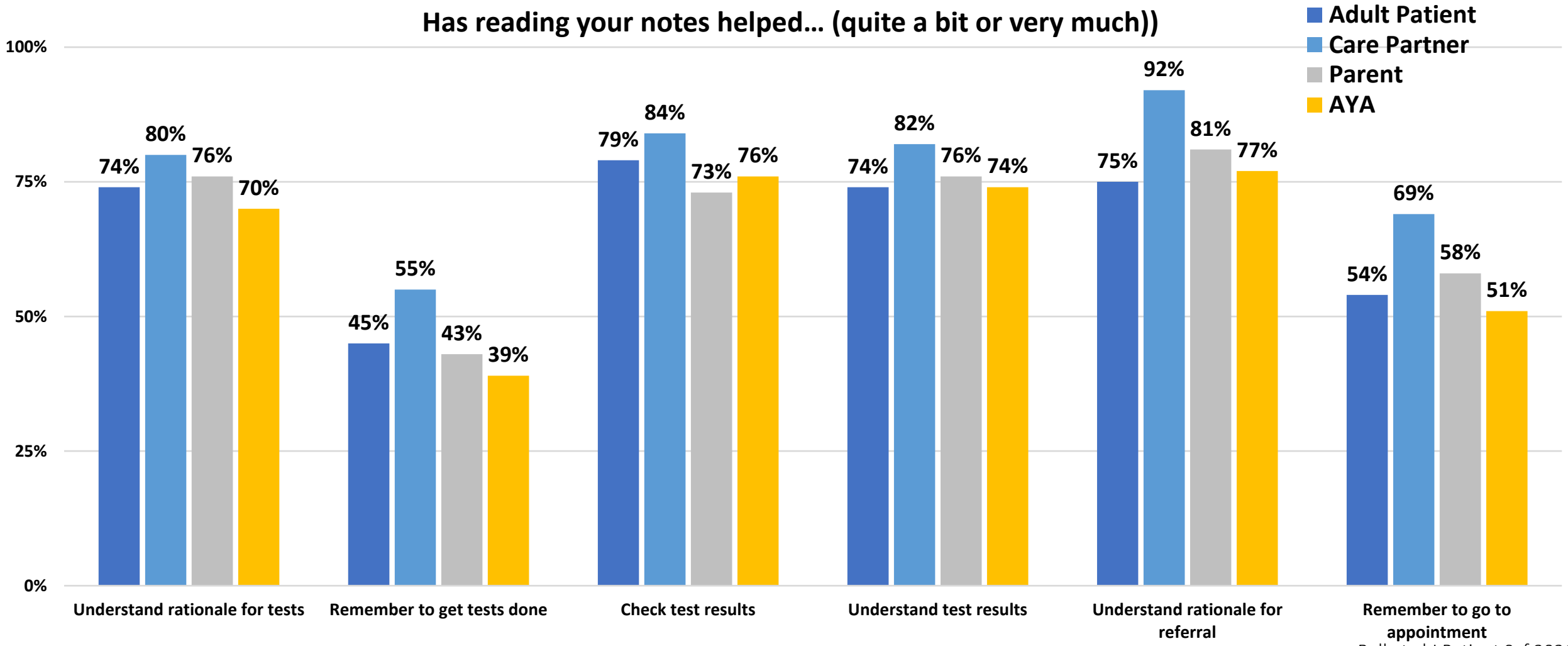
Why is data access important to patients and families?

- 40-80% of health encounter information is forgotten or misremembered
- Worse with stress, bad news, complexity, language barrier…
- Sharing visit notes (open notes) provide an artifact; can help connect patients to next steps

Kessels J R Soc Med 2003
Barton Laws M et al PLoS One 2018

Ambulatory Diagnostic Safety: A vexing challenge

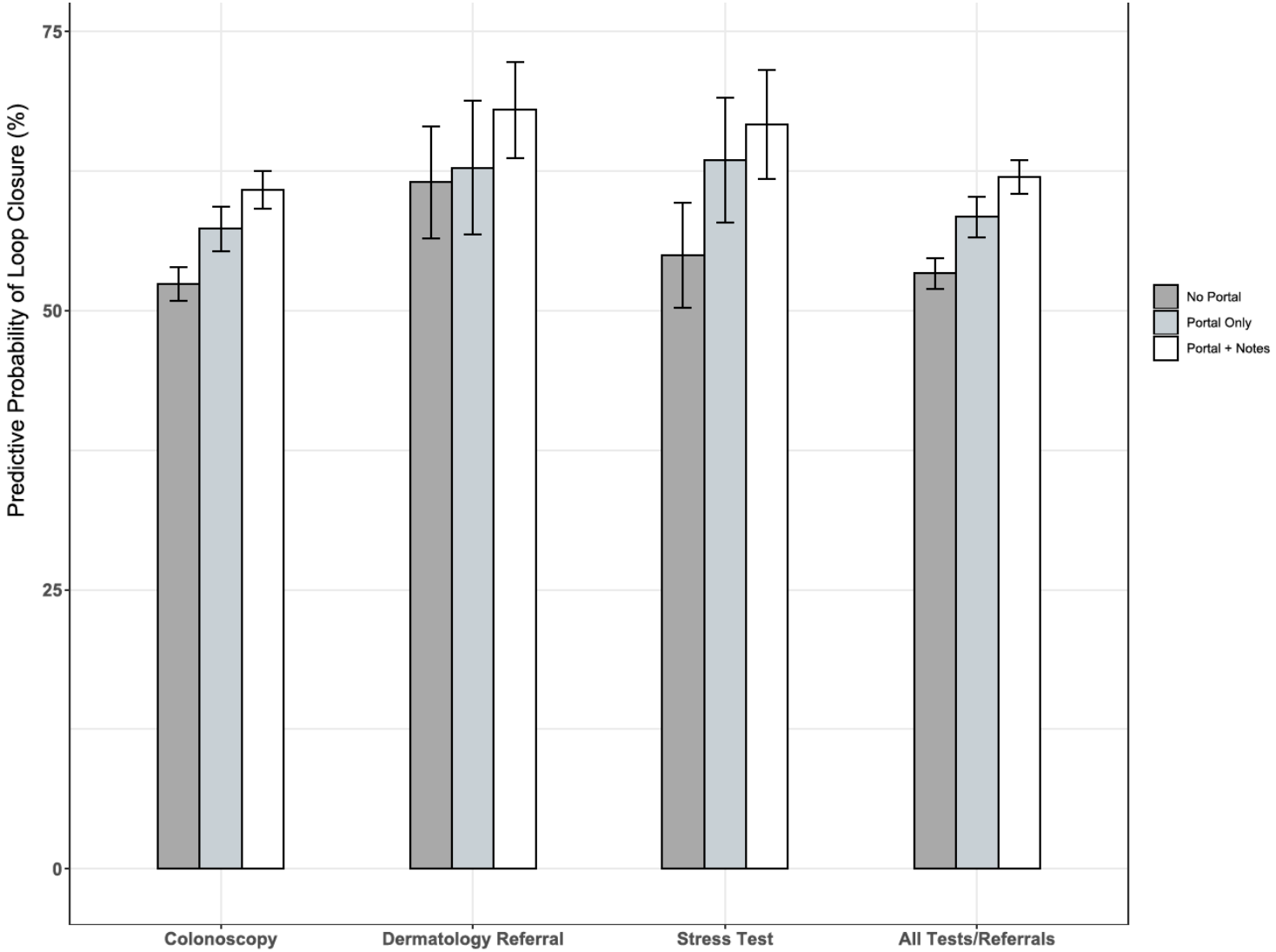
What 10,000 patients and families say about notes, tests, and referrals



Bell et al J Patient Saf 2021
Chimowitz et al,JCJQPS 2018
Lam et al F Hlthcre J 2021

Do patients who read visit notes on the patient portal have a higher rate of "loop closure" on diagnostic tests and referrals in primary care? A retrospective cohort study

- >10,000 primary care studies at 1 center
  - ➢ Colonoscopy, Derm ref, Cardiac stress test
- 2 clinics (academic hosp, community)
  - ➢ "No Portal": No portal registration
  - ➢ "Portal Only": portal account, no notes read
  - ➢ "Portal+ Notes": Read at least one note



Bell et al JAMIA 2023

Detecting EHR errors: Patient-reported breakdowns

- **Missed main concern:** "Doctor reported that I did not claim to have pain in my hand. I am a pianist and I went specifically because pain was in my hand."
- **Wrong symptoms/history:** "The notes regarding sinus pain were not accurate as to the area of my upper jaw being affected... It mattered to me because I had recently had dental work in the actual area of the pain."
- **Tests/Wron** …her patient"
- **Diagnosis:** "…
- **Copy/Paste:** "… of a headache in a year. This … made based on inaccurate …
- **A different taxonomy**: Not feeling heard, misalignments, access problems, omissions, didn't know who to call or when (or no response), experiences of disrespect/discrimination/bias, events between visits…

Patients identified breakdowns in every step of the diagnostic process; >50% of these were potential blindspots

Important events we were missing, and important opportunities to coproduce safety with patients

How do we get this vital information back to clinicians?

Bell et al JAMA Netw Open 2020
Bell et al BMJ Qual Saf 2021
Bell et al Milbank Q 2022

OurDX Tool: co-developed with patients/families, UCD, Pt Experience experts

Goal: streamlined tool that captured relevant, actionable info while minimizing patient and provider work

What matters most to you

Visit Priorities: What are the most important things you would like to talk about at your visit?

- Alignment

Tell us about your health

Over the last 6 months have you had: (structured)

Please tell us more… (unstructured)

- Quick flag of higher risk DxP; Medical history in the patient's own words (accuracy)

Getting it right

Did you feel heard…?

Problems/delays with tests/referrals?

Any other problems or delays…?

…something specific that is **going well**…?

- Capture common, actionable diagnostic concerns and reinforce what is going well

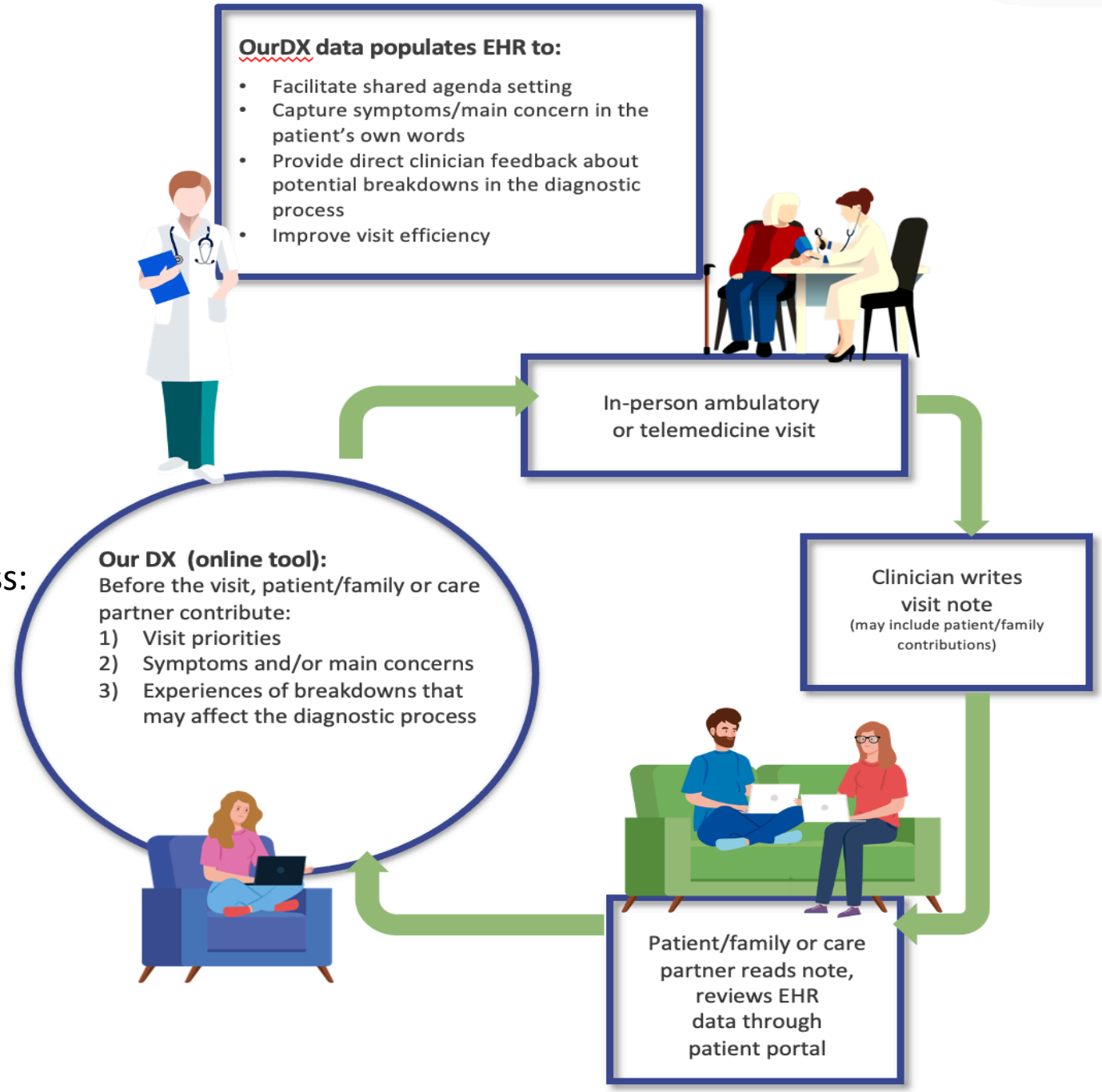
Bell et al BMJ Qual Saf 2023

OurDx Engagement Cycle

Patients and families as Diagnostic Partners

Focus on patients with chronic illness:

- Multidisciplinary care
- Multiple providers
- Unique knowledge



What did they say….? Contributions

- >7500 reports in 4 clinics
- Chart review: 450 ->qual analysis
- Average of 3 contribution categories/report
- Most common: Clinical symptoms, Tests/referrals, Dx/next steps, Communication

1. Access barriers
2. Clinical symptoms/history
3. Information about meds (DxP-related)
4. Recent visits for same problem
5. Multidisciplinary information
6. Tests/referrals
7. Diagnosis/next steps
8. Care coordination
9. Communication issue
10. Other

Bell et al BMJ Qual Saf 2023

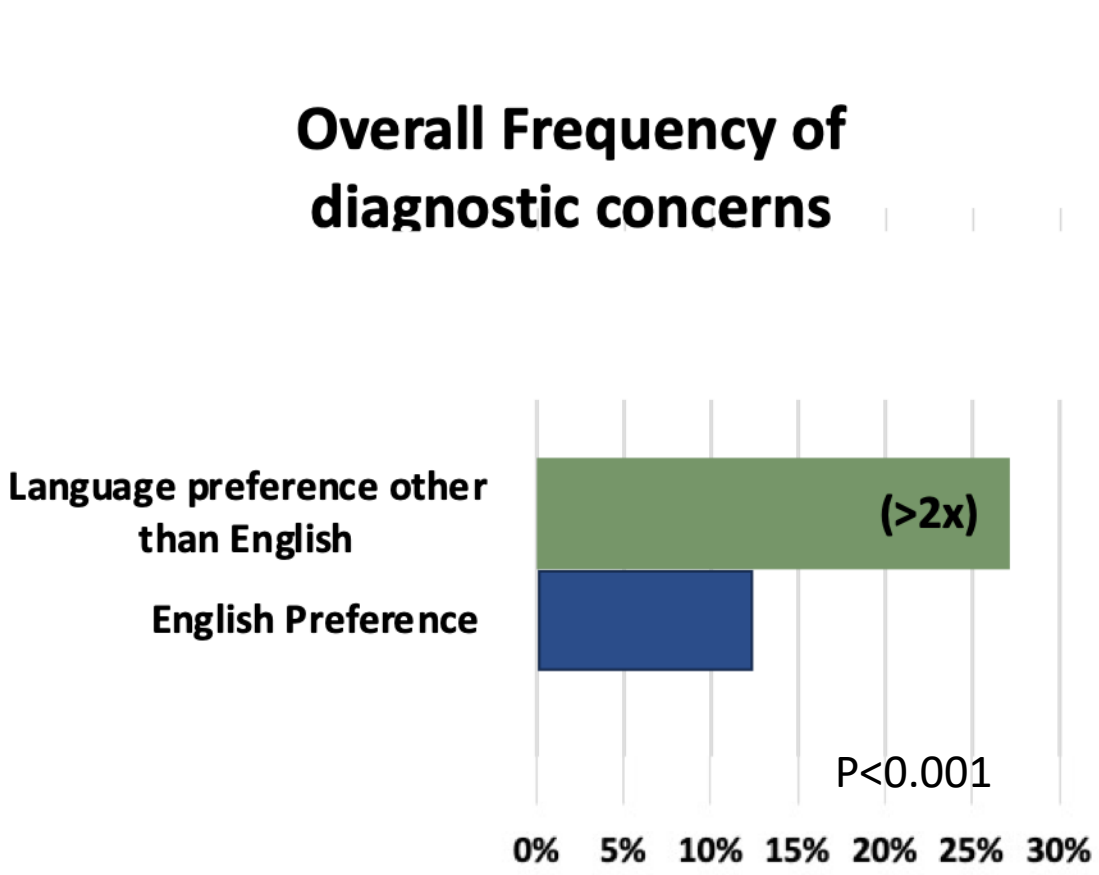
What did they say….? Contributions

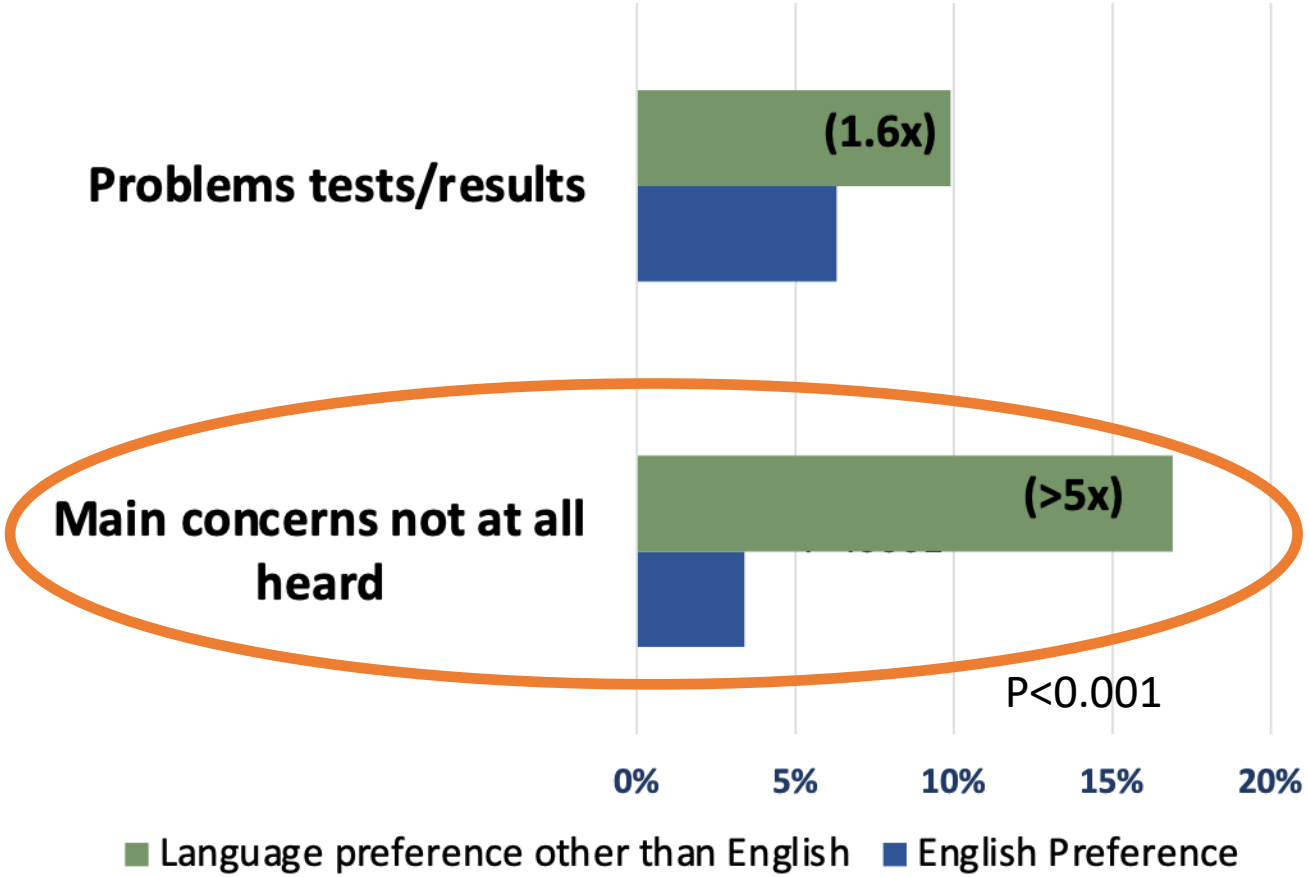
Contribution categories that were significantly more common **in patients/families with diagnostic concerns**

1. Access barriers
2. Clinical symptoms/history
3. Information about meds(DxP-related
4. Recent visits for same problem
5. Multidisciplinary information
6. Tests/referrals
7. Diagnosis/next steps
8. Care coordination
9. Communication issue
10. Other problem or delay

Bell et al BMJ Qual Saf 2023

Diagnostic concerns by Language Preference

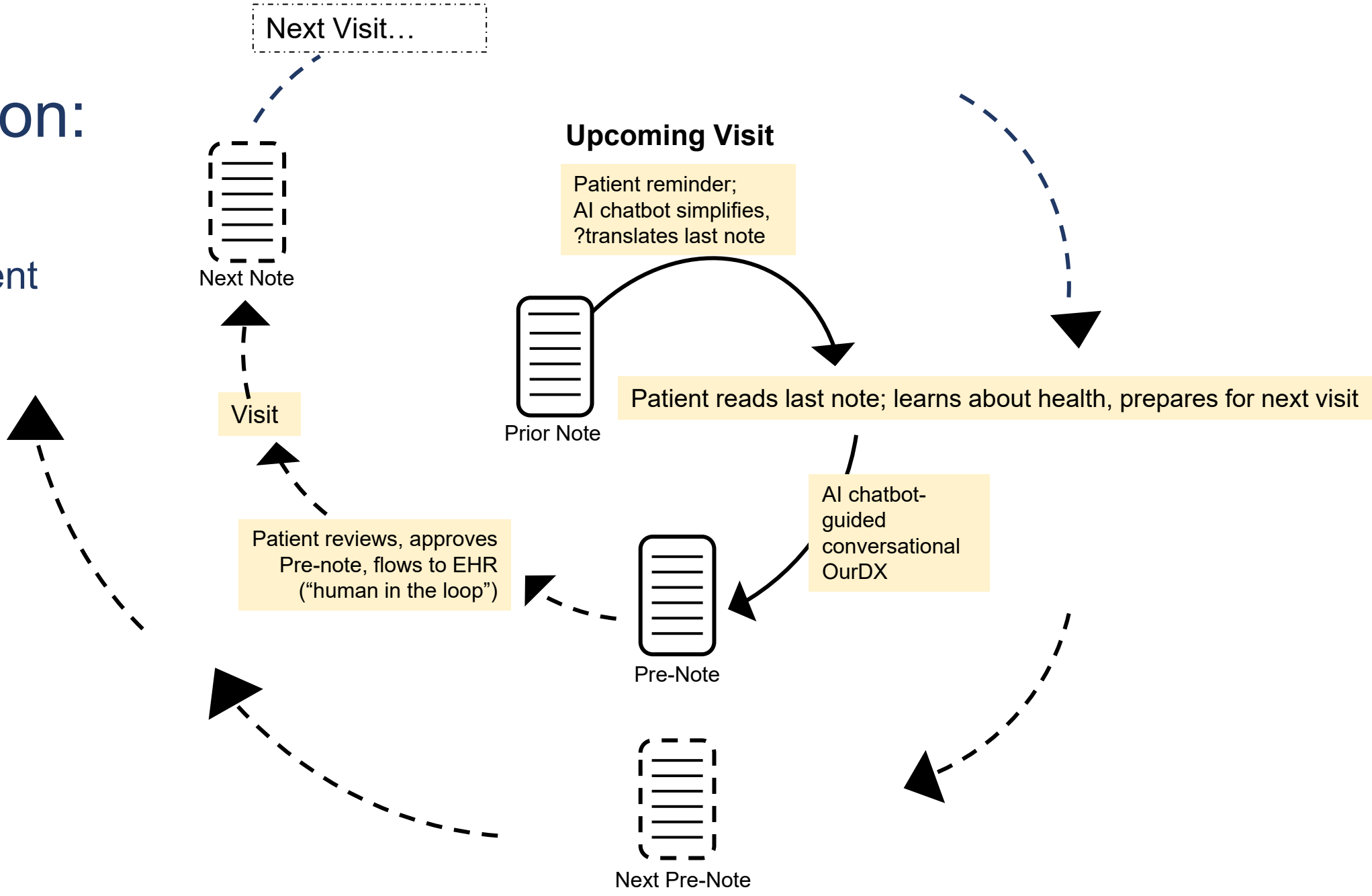




Bourgeois et al Appl Clin Inform 2023

OurDx AI integration:

A virtual cycle of patient engagement and learning?



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Tom Delbanco, Jan Walker,
Brianna Mahon, Sandy Novack,
Lisa Rubino, Michele Domey (not shown)

“Nervited”

Access, literacy/language, bias, error

Can we leverage AI to amplify what helps patients in the diagnostic process?

The Cost of Technology

© 2011 Thomas G. Murphy, MD.

Toll, JAMA 2012

The Gift of Technology

Chat GPT: Picture a drawing of a child standing confidently with a big smile on their face. They are surrounded by several figures—family members, friends, or [a doctor]—each depicted with attentive expressions. Speech bubbles or thought bubbles above each person could show phrases like "We're listening", "We hear you", or "You matter". The background might be a bright and warm setting, perhaps with a sunny sky or a cozy room, to convey a sense of comfort and support. This scene would illustrate the idea of feeling heard and understood, capturing the emotional connection and validation that comes from being truly listened to by others.

??? 2032