

Open Notes:

Increasing Transparency and Engagement in Care

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EHRs and Patient Portals

- EHR/EMR: Electronic Health Record/Electronic Medical Record
- Patient Portal: tied to EHR, an online portal for patients to access their medical information
- Patients must register to use their health care provider's patient portal via secure log-in
- Patients can also designate care partners as "proxies" to be able to see their information through the portal

Use of Patient Portals by Older Adults

45% of adults age 65-80 have not set up portal account (as of June 2020); slight improvement from March 2018 report of 49%

Reporting no portal account:

50% of Black older adults

54% of lower-income adults

53% of Hispanic older adults

35% of higher-income adults

39% of white older adults

53% of less than HS education

Men less likely than women

31% of college graduates

Reasons Not Using Portal

2018 poll reported the following reasons older adults say they aren't registered for the portal:

- Lack of awareness (also of proxy access)
- Lack of need
- Lack of comfort using technology
- Dislike communicating about their health online

However-now more awareness/need due to telehealth, COVID test results, COVID vaccinations

Information on Portal

2018 poll found following uses among older adults:

- See test results (84%)
- Request prescription refill (43%)
- Schedule appointment (37%)
- Requesting upcoming appointment reminders (34%)
- Getting advice on health problem (26%)
- Updating insurance or contact info (22%)
- Requesting a referral (13%)

OpenNotes (the organization):

A philanthropically supported initiative focused on increasing transparency in health care.

open notes (the practice):

When patients can easily read progress notes.

Not a technology or an app. Not a product.



Robert Wood Johnson Foundation



The John A. Hartford Foundation



The Commonwealth Fund



What a patient sees

Back [Redacted] Past Visit Close

[Redacted]

After Visit Summary

[Redacted]

11/28/2017 2:15 PM

[Redacted]

Instructions from [Redacted] MD

Return in about 9 months
(around 8/28/2018).

Today's Visit

You saw [Redacted] MD on Tuesday November 28, 2017. The following issues were addressed:

- Astrocytoma, grade II (CMS code)

Blood Pressure 124/65	Height 5' 7"
Temperature (Oral) 98.2 °F	Pulse 69
Respiration 16	Oxygen Saturation 100%

vs. What the doctor writes aka *notes*

ASSESSMENT AND PLAN:

In summary, Ms. [Redacted] is a 38 y.o. year old woman with grade II astrocytoma that is stable on imaging in follow-up. Neurologically, she has stably reduced sensation on the R side of her body, as well as occasional focal R hand seizures.

IMAGING SCORE: 0

NEUROLOGICAL SCORE: 0

STEROID SCORE: 0

OVERALL TUMOR ASSESSMENT: 0

1. Grade II astrocytoma: As such, we will simply continue to monitor her. It has been > 5 years since she completed chemotherapy, and so we will extend the interval between scans to 9 months. I would be comfortable with her continuing to do the scans locally, and we can plan to do the next appointment as a phone consultation.

2. Seizures: We discussed whether she might be able to taper down one of her seizure medications, but given that she continues to have focal events, I would be concerned that she might have a larger breakthrough event so I would recommend that we keep the doses stable for the moment, and she is in agreement with this plan.

Follow-up:

- 9 months for next MRI and appointment. This scan is critical because based on the results, a change in the management plan for the patient may need to be made especially if there is any evidence to suggest tumor progression.

- All questions of [Redacted] and her family were answered to the best of my ability. They have our contact information and will call with further questions.

I spent a total of 26 minutes face-to-face with the patient and 14 minutes of that time was spent reviewing the imaging with the patient, review of management options, side effects, counseling and coordination of care

Original study: 2010

- **105** primary care clinicians
- **20,000** patients:
 - **Boston** (BIDMC)
 - Rural **Pennsylvania** (Geisinger)
 - **Seattle** safety net hospital (Harborview)
- *Now replicated at numerous sites around the country*



Surveyed *before* study

Physicians

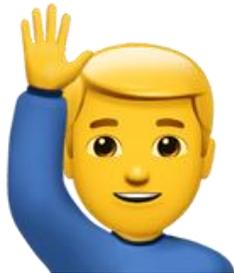


Patients



Surveyed *after* the study

Physicians



Patients



Results for patients

- ✓ 80% read a note initially, **50-60% long term**
- ✓ **75% reported benefits** (replicated multiple times) in Engagement, Medication Adherence, Planning, Control, Understanding
- ✓ **99% wanted to continue** (replicated multiple times)
- ✓ 85% would use OpenNotes as a **criterion for selecting providers**
- ✓ 20-42% reported **sharing their notes with care partners**

Results for Clinicians

- ✓ **Little impact** on workflow, email volume unchanged
- ✓ **Worries** about negative patient effects **didn't materialize**
- ✓ After study, **no clinicians stopped**
- ✓ Most **would recommend** the practice to colleagues
- ✓ Majority said sharing notes is **helpful for engaging patients**

7 years later...

Similar results, **replicated numerous times...**



After 7 years... **patient views**

- ✓ Patients still say **notes are very important** for taking care of their health, feeling in control of their care, and remembering their care plans
- ✓ **Almost all** patients say they *understood all or nearly all* of their notes
- ✓ Reading notes **helps them understand their medications**
- ✓ Patients with less education or limited English proficiency reported the most benefit

Walker J, et al. OpenNotes After 7 Years: Patient Experiences With Ongoing Access to Their Clinicians' Outpatient Visit Notes. *J Med Internet Res* 2019;21(5):e13876. DOI: 10.2196/13876

Leveille, SG, et al. Patients Evaluate Visit Notes Written by Their Clinicians: a Mixed Methods Investigation. *J GEN INTERN MED* (2020). <https://doi.org/10.1007/s11606-020-06014-7>

Desroches CM, et al. Patients Managing Medications and Reading Their Visit Notes: A Survey of OpenNotes Participants. *Annals of Internal Medicine*. 2019;171(1):69. doi:10.7326/m18-3197

3197

Views of Older Patients (age 65+)

40% shared a note with someone (most often a family member)

4.5% reported a note was very confusing

4.2% said they were more worried after reading a note (29% said less worried and 56% said no change)

74% said reading notes is important for taking care of their health

69% said helps them feel in control of their care

65% said helps them remember plan of care

52% said helps them prepare for visits

After 7 years... **clinician views**

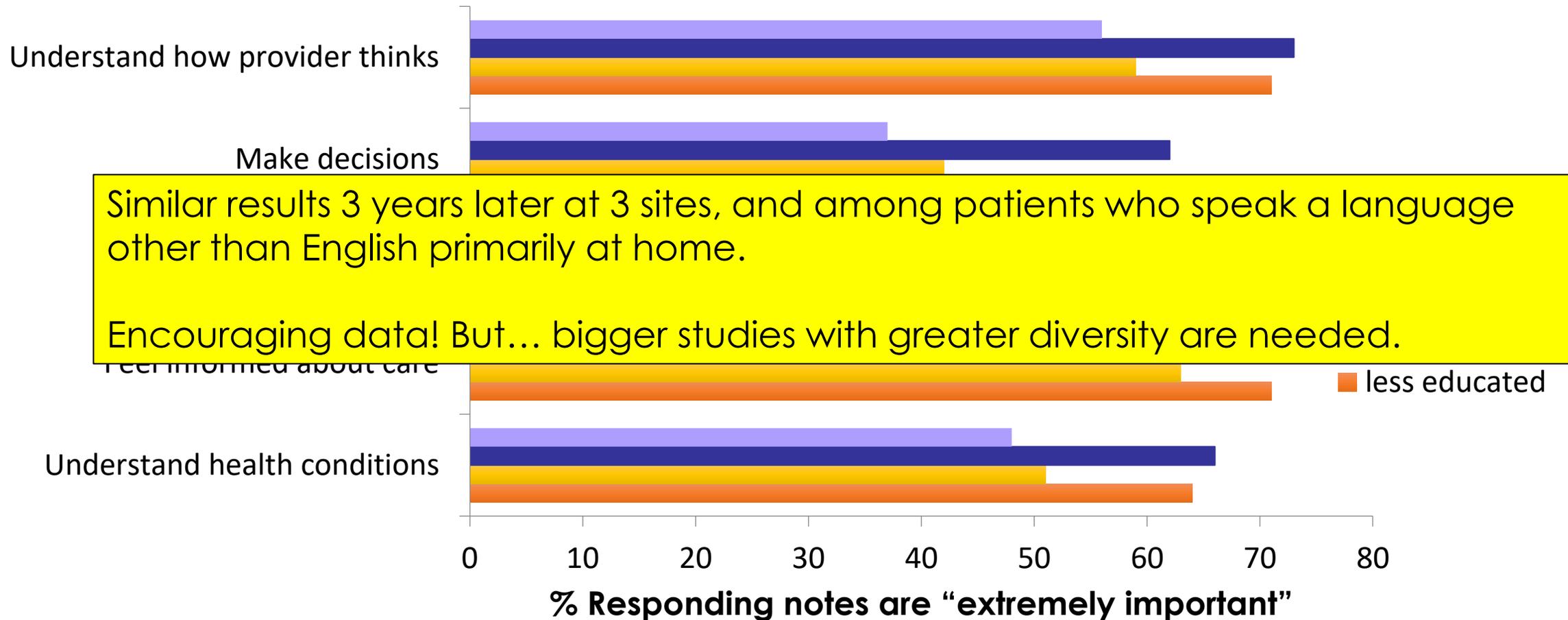
- ✓ Majority say sharing notes with patients is a **good idea** and **helpful for engaging patients**
- ✓ Most would **recommend** the practice to colleagues
- ✓ Few report questions or concerns from patients about notes
- ✓ 1/3 say they spend at least “somewhat” more time in documentation

Doctor-patient relationship

- ✓ **99% of patients felt better (37%) or the same (62%)** about their clinician after reading at least one note
- ✓ Older, racially diverse patients, with poorer health, or lower formal education were **more likely to feel better about the doctor**
- ✓ **> 97% of patients reported same or greater trust** in their clinicians
- ✓ **> 50% of doctors believed shared notes increased patient satisfaction and trust (50+%)**
- ✓ No doctors reported ordering more tests or referrals

Vulnerable populations:

How important are notes to engage in care (0-10)
by Race and Education? (Single site, n=6913)



Gerard et al, JMIR 2018

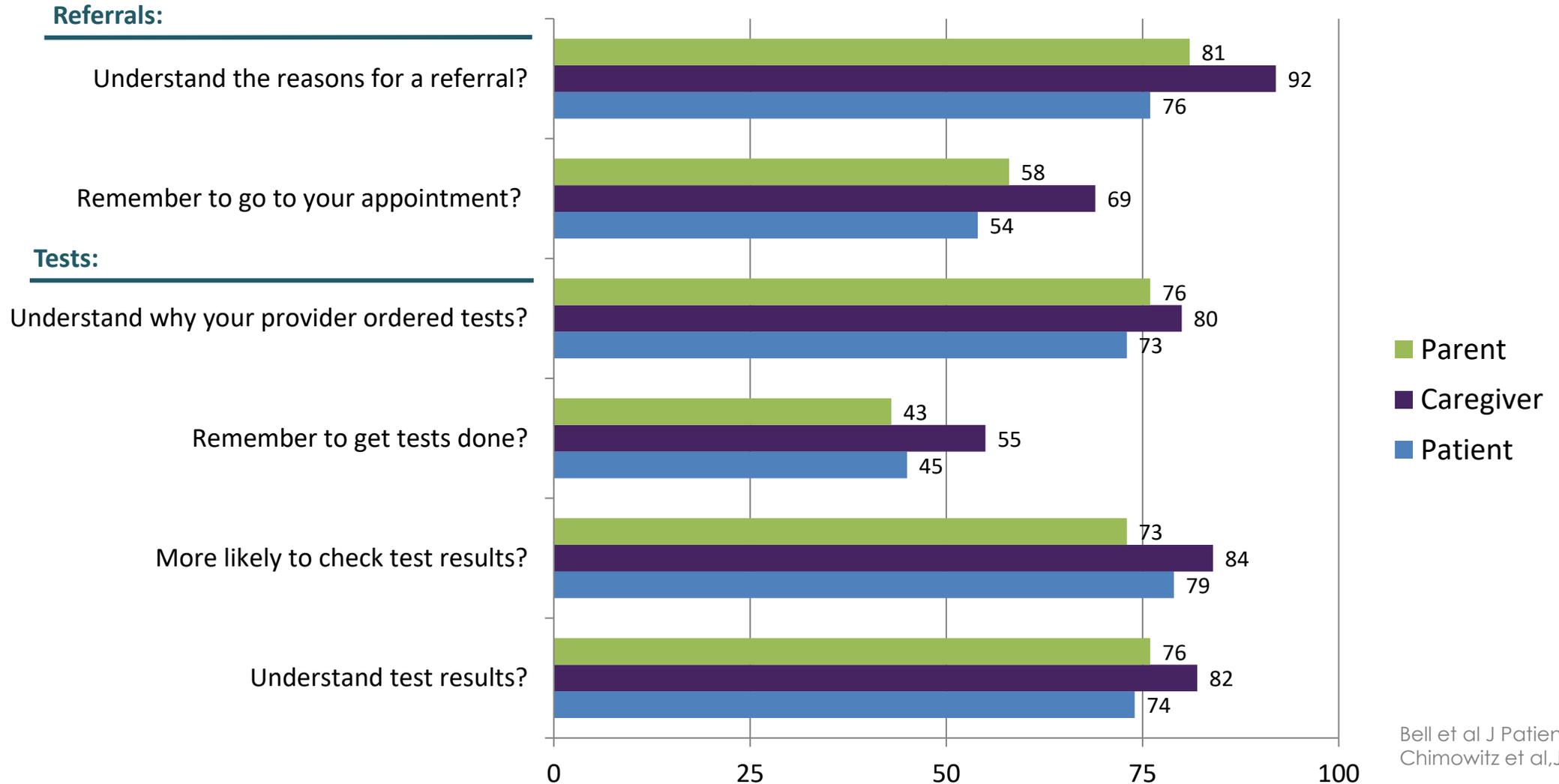
multivariable regression:

individuals self-identifying as black/African American, Asian, Hispanic/Latino, "other" or "multiple" races; or \leq high school education; were 2-3 x more likely to report notes were extremely important to engage in care than their counterparts



Safety opportunities in the space between visits: What 10,000 patients and family members say

Has reading your/the patient's notes helped you...
(% responding "quite a bit " or "very much")



Note errors: How often do clinicians and patients anticipate/find them?

24%

Clinicians anticipate non-trivial errors in notes

21%

Patient reports include a possible note mistake

21%

Patients report finding at least 1 error in a survey of >22,000 users

- ✓ 40% "somewhat or very serious"
- ✓ Older, sickest approximately 2x as likely to find a mistake

Patient-reported “very serious” errors

Diagnosis-specific:

- “Said I am BRCA positive when I am NOT BRCA [positive]”

Medical history/exam:

- “Wrong eye mentioned for upcoming surgery”
- “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 BMI; told I could not be placed on a heart lung transplant list”

Wrong patient:

- “Plan to change medication based on the lab results of another patient”

Meds:

- “I found an incorrect dosage on a note that was being used by a referred physician for an infusion. The dosage was incorrect by 10 fold.”



Strengthening partnerships with care partners

- ✓ >40 million Americans
- ✓ Costly, preventable, and high stakes errors and readmissions
- ✓ Often lack access to critical information
- ✓ Family members are among the most vigilant of health system stakeholders

Care partners are **more likely** than patients to report benefits from note-reading.



“It really is much easier to show my family who are also my caregivers the information in the notes than to try and explain myself. I find the notes more accurate than my recollections.”
-a patient

Care Partners as Portal Proxies

- Promoting portal proxy option:
 - Helps clinic staff know who communicating with
 - Clinic staff know who is completing questionnaires, etc.
 - Privacy of patient information
 - Patient has control-can grant and revoke access
- 2/3 of U.S. hospitals offer adult patients the option of granting portal access
- Not always easy process
- URMC example-what happens when educate/inform; flexibility of options (need even more)

21st Century Cures Act Information Blocking Rule

Did you know?

As of April 2021, a federal mandate requires that patients must have immediate electronic access to all of the information in their medical records at no charge.

More details here: <https://www.opennotes.org/onc-federal-rule/>

What Types of Notes Must Be Shared

Consultation notes

Discharge summary notes

History & physical

Imaging narratives

Laboratory report narratives

Pathology report narratives

Procedure notes

Progress notes

Do not have to be shared: psychotherapy notes

What Can Patients/Advocates Do? Accessing Notes

- Register for patient portal and encourage others to register for patient portals
- If you help someone manage their care and/or someone helps you, explore the option of portal proxy
- Look for your notes-go to patient portal and look for links to page with visit notes, look at individual visits (may be hard to find them)
- Read your notes before and after healthcare visits-to prep and to remind (also to catch any errors)
- Encourage others to find and read their notes
- <https://www.whereismymedicalrecord.org/>

What Can Patients/Advocates Do? Urging Sharing of Notes

- If hard to find notes, talk to someone at your doctor's office or contact someone in patient advocacy or Health Information Technology (HIT)
- If your clinician isn't sharing notes, ask them why and encourage them to do so; if clinic/health system isn't sharing make sure they know about the federal rule-can reach out to patient advocacy or clinic administrator
- If on a Patient and Family Advisory Council (PFAC): work with the health system to inform patients/care partners about the portal and about notes and how to find them and utilize them; work with the health system to determine how patients can report errors/concerns

OpenNotes Resources

New Federal Rules and Open Notes: <https://www.opennotes.org/onc-federal-rule/>

Finding Your Notes/Reporting Info Blocking:
<https://www.wherismymedicalrecord.org/>

Reading Your Notes: FAQs for Patients: <https://www.opennotes.org/reading-your-notes-faqs-for-patients/>

Webinars: <https://www.opennotes.org/webinars/>

Research: <https://www.opennotes.org/research/>

OpenNotes.org toolkits for patients:

- Pediatrics/Adolescents
- Mental Health
- Patient & Family Advisory Council
- Care Partners

Thank you

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Beth Israel Deaconess
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