



Automated Disclosure Portals for Alzheimer's Disease and Dementia Risk in a Community-Based Longitudinal Cohort

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Automated disclosure of research results can safely improve participant understanding while reducing staff burden, providing a scalable approach to research engagement. As expectations for research result access continue to grow, automated disclosure offers a practical solution that maintains safety, comprehension, and accessibility.

INTRODUCTION

METHODS

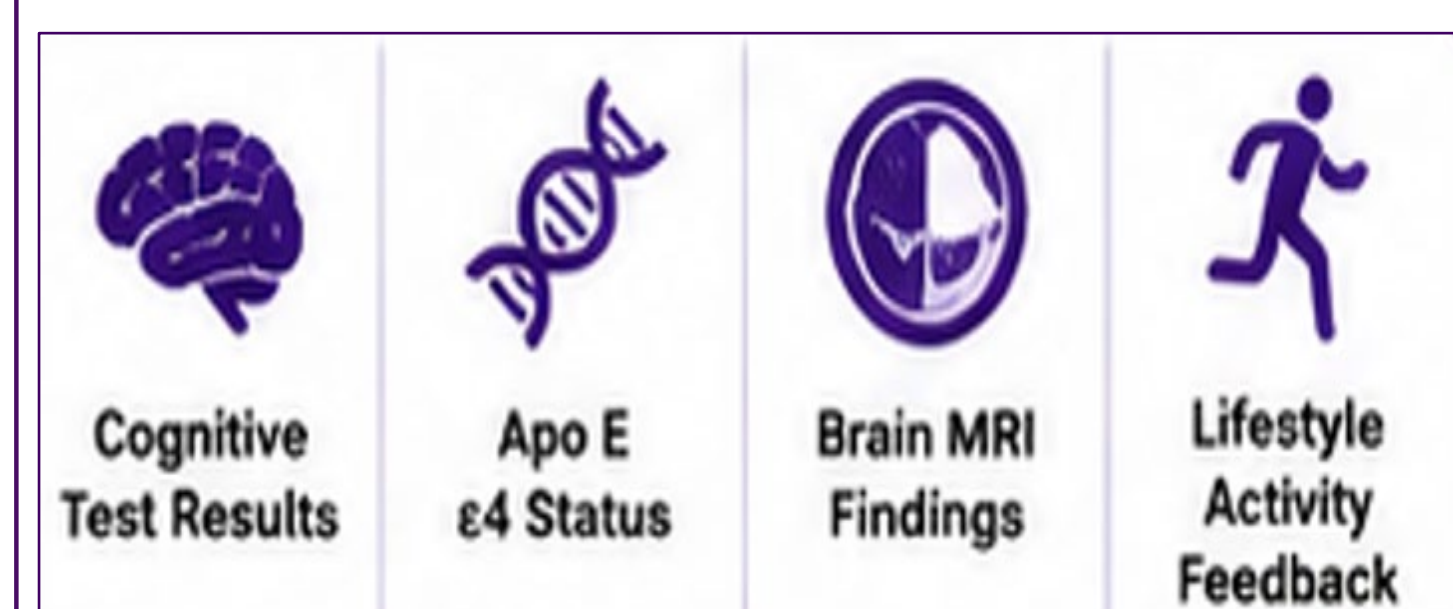
RESULTS

CONCLUSIONS

- As biological and genetic markers for Alzheimer's disease become more widely available, participants in observational studies increasingly expect access to their research results.
- Inadequate or unsafe disclosure can cause harm, while traditional clinician-led disclosure places significant burden on clinical staff.
- This study evaluated an electronic, automated disclosure process designed to deliver informed, voluntary research result disclosure while minimizing potential harm and staff burden.

- Conducted at the University of Kentucky Alzheimer Disease Center (UK-ADC) longitudinal cohort.

- Results disclosed by category:

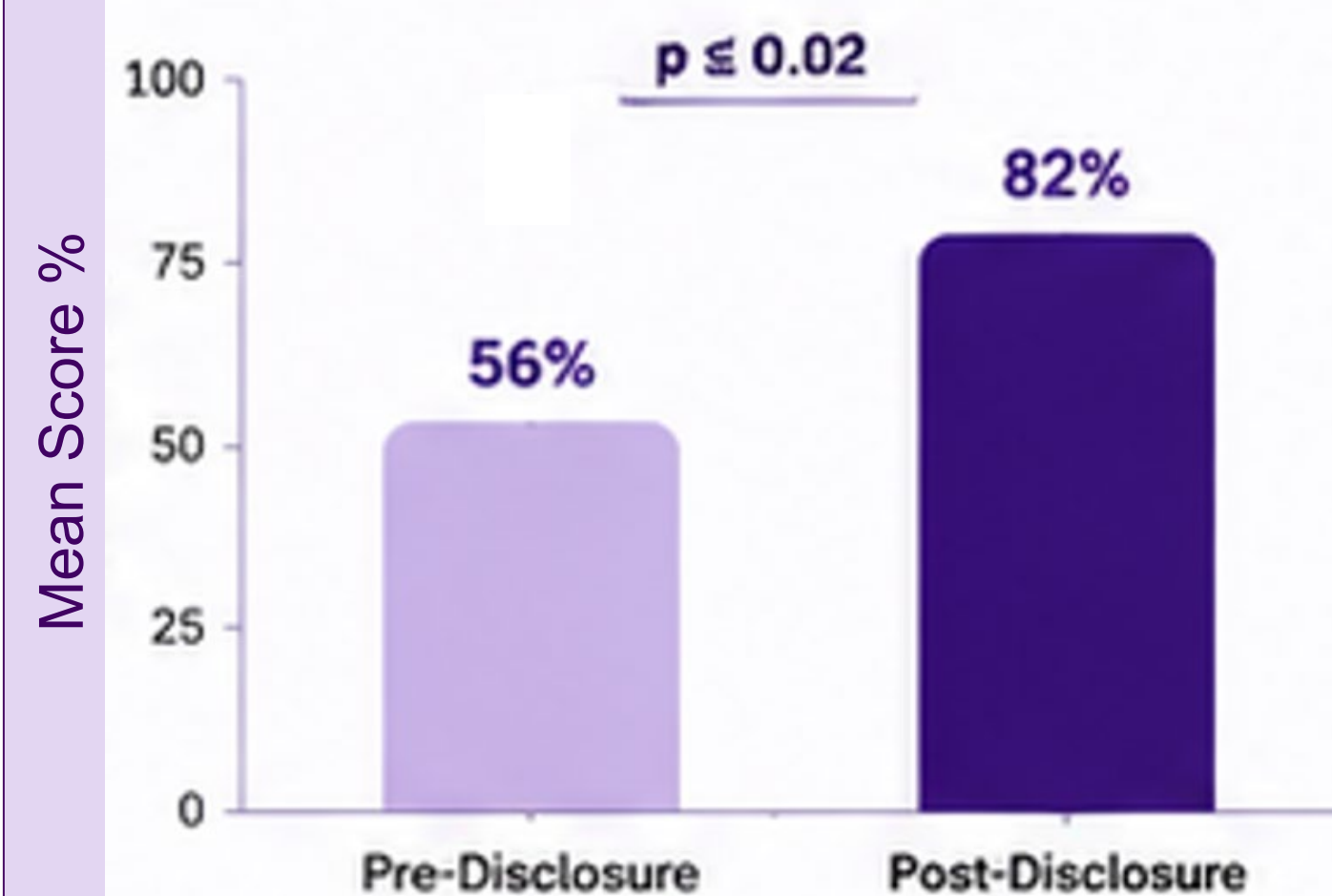


- An automated REDCap system delivered educational materials, comprehension checks, and voluntary disclosure.
- Pre- and post-disclosure measures assessed efficacy (knowledge/ understanding) and potential harm (worry, perceived dementia risk, anxiety).

Distribution of Pilot Participants diagnoses.

Dx Groups	N (%)
Normal Cognition	10(45%)
MCI	9(41%)
Dementia	4(18%)
Total	23(100%)

Knowledge & Understanding (Pre- vs Post-Disclosure)



Knowledge and understanding increased significantly following disclosure

Interest in Receiving Disclosure of Research Results



Interest did not significantly change after the disclosure process across all diagnostic groups.

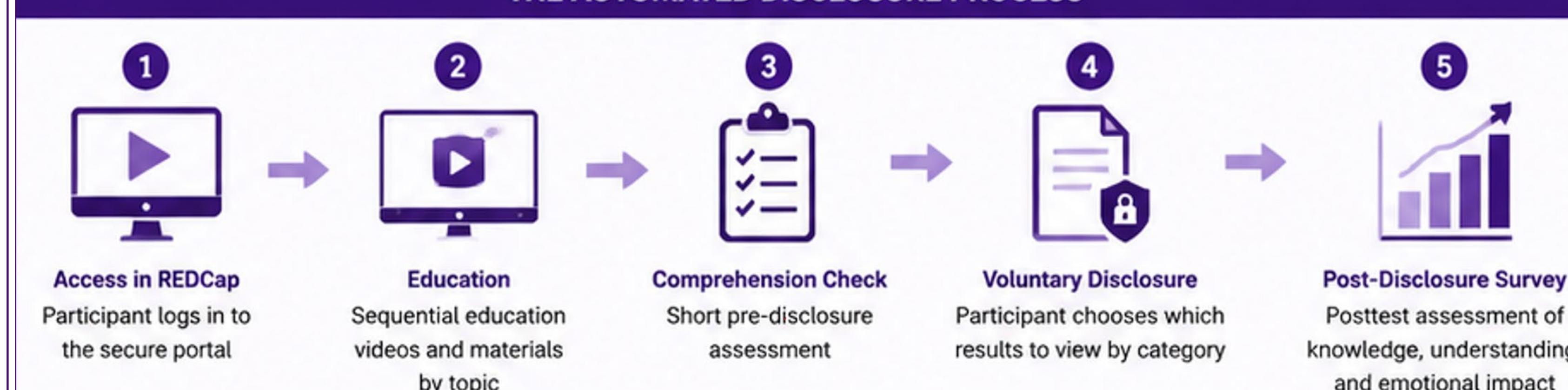
Impact of the disclosure on emotion

Outcome Measure	Change (Pre to Post)	p
Perceived Likelihood of developing Dementia	↔	NS
Worry about Dementia	↔	NS
Anxiety	↔	NS

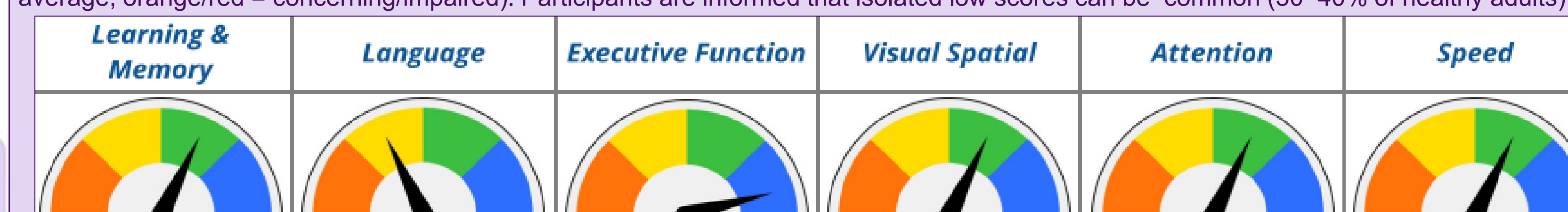
No significant pre- to post- disclosure difference in perceived risk, worry or anxiety.

- ✓ This automated disclosure process is safe, acceptable, and effective in a diverse cohort across the cognitive spectrum.
- ✓ Participants demonstrated improved knowledge and understanding without increased worry, perceived risk, or anxiety.
- ✓ The system is easy to navigate and provides flexible access to information.
- ✓ Automated disclosure substantially reduces staff and clinician burden while achieving outcomes comparable to clinician-led discussions.
- ✓ The process is now being implemented across approximately 800 research participants at the UK-ADC, and expanded results will be presented with the pilot findings.

THE AUTOMATED DISCLOSURE PROCESS



Example cognitive feedback display. Gauges show performance by cognitive domain (green = expected, blue = above average, yellow = below average, orange/red = concerning/impaired). Participants are informed that isolated low scores can be common (30–40% of healthy adults).



The automated disclosure process is HIPAA and Article 11 compliant.

INFO



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