



Leveraging Integrated Digital Infrastructure to Modernize Remote-Enabled ALS Research: Lessons from the ALL ALS Study

Renu Kadali¹, Praveena Mohan¹, Courtney Igne², ALL ALS Consortium, James Berry², and Robert Bowser¹
Barrow Neurological Institute, Phoenix, AZ 85013, Massachusetts General Hospital, Boston, MA 02114

TRANSFORMING ALS RESEARCH THROUGH DIGITAL INNOVATION

Traditional ALS trials are often constrained by in-clinic demands, slow enrollment, and participant burden—limiting retention and data quality. The ALL ALS Consortium addresses these barriers through a participant-centered, digital-first approach across 36 U.S. sites and two linked studies: ASSESS and PREVENT.

This poster highlights how ALL ALS:

- Advances inclusive, remote-enabled study participation
- Reduces burden for both participants and sites
- Enhances geographic and demographic reach
- Demonstrates early operational success with digital tools
- Establishes a scalable, replicable model for decentralized ALS research

ALL ALS reimagines research to meet participants where they are—physically and experientially.

CORE COMPONENT OF ALL ALS DIGITAL INFRASTRUCTURE

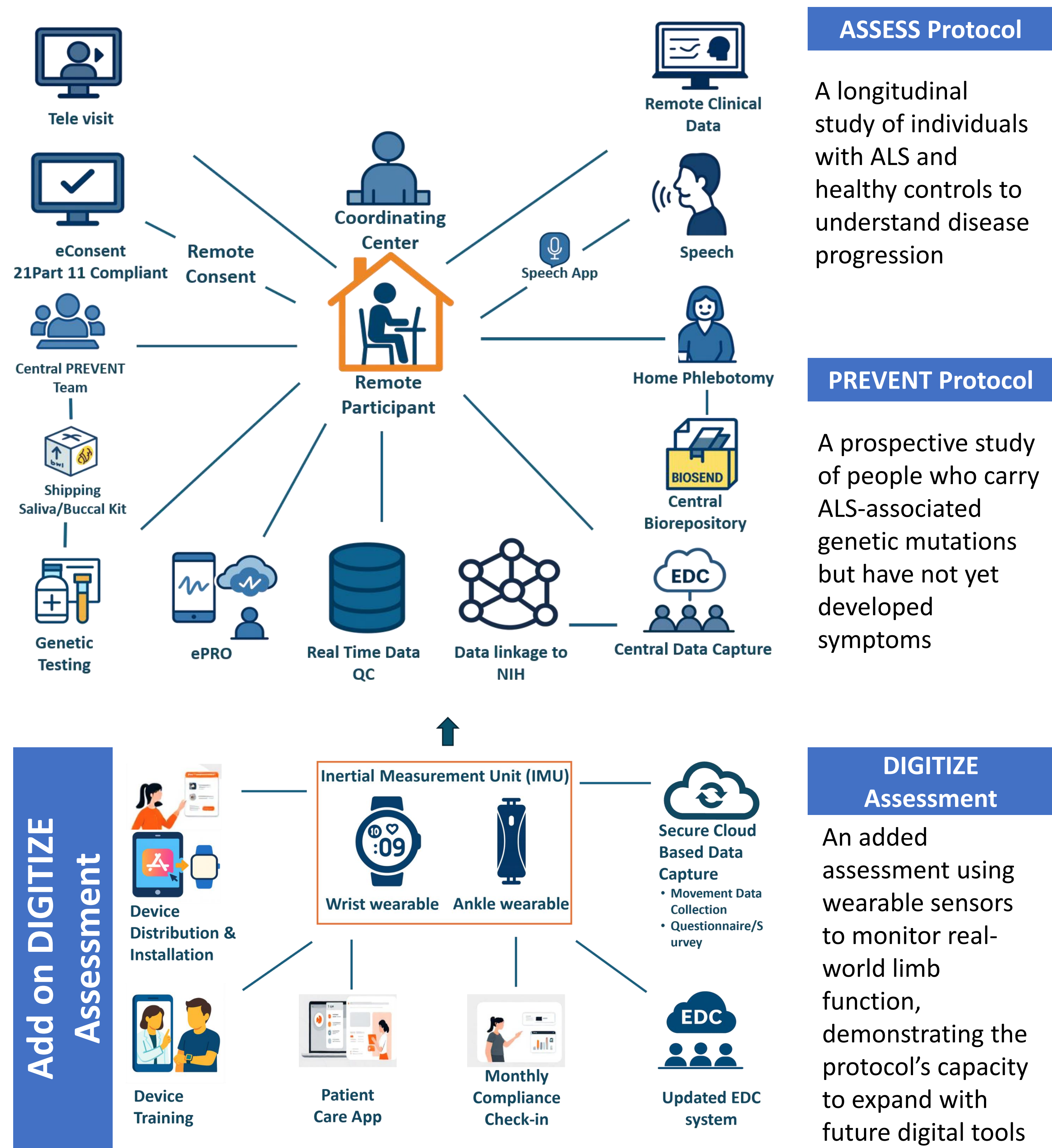


Figure 1: Digital Tools in ALL ALS ASSESS and PREVENT study

Tools	Advantages
Consent & Outreach	• Electronic record maintenance • Self-paced and reduces errors in Consent process • Secure messaging • Website and Participant Interest form helps with tracking and engage in broad recruitment activities
Remote Bio-sample Collection	• Participants who are unable to travel or do not have access to clinical sites can still participate in the study
Remote Clinical Data Capture	• Reduced Participant Burden • Enhanced Data Completeness & Quality • Improved Access to Specialized Services • Scalability & Flexibility • Operational Efficiency
Data Integration & Monitoring	• Risk-based monitoring, audit-trails • Live query • Data export to NIH

Table 1: Advantages of Digital Infrastructure and tools

OPERATIONAL SUCCESS AT SCALE (DATA PULLED FROM AUGUST 2025)

Key Operation Metrics	ASSESS	PREVENT
# of states with minimum of one participant enrolled	47 and Puerto Rico	
# of Participant Interest Form	340	
# of eConsents completed	149	84
# of genetic testing results returned	N/A	45
# of successful remote phlebotomy visits	216	160
# of Blood vial samples	~24,000	~15,000
# of CSF samples	~2500	~2500
Average time from sample collection to biorepository (days)	4.7	5.2

Table 3: Key operational metrics of ALL ALS Digital Infrastructure

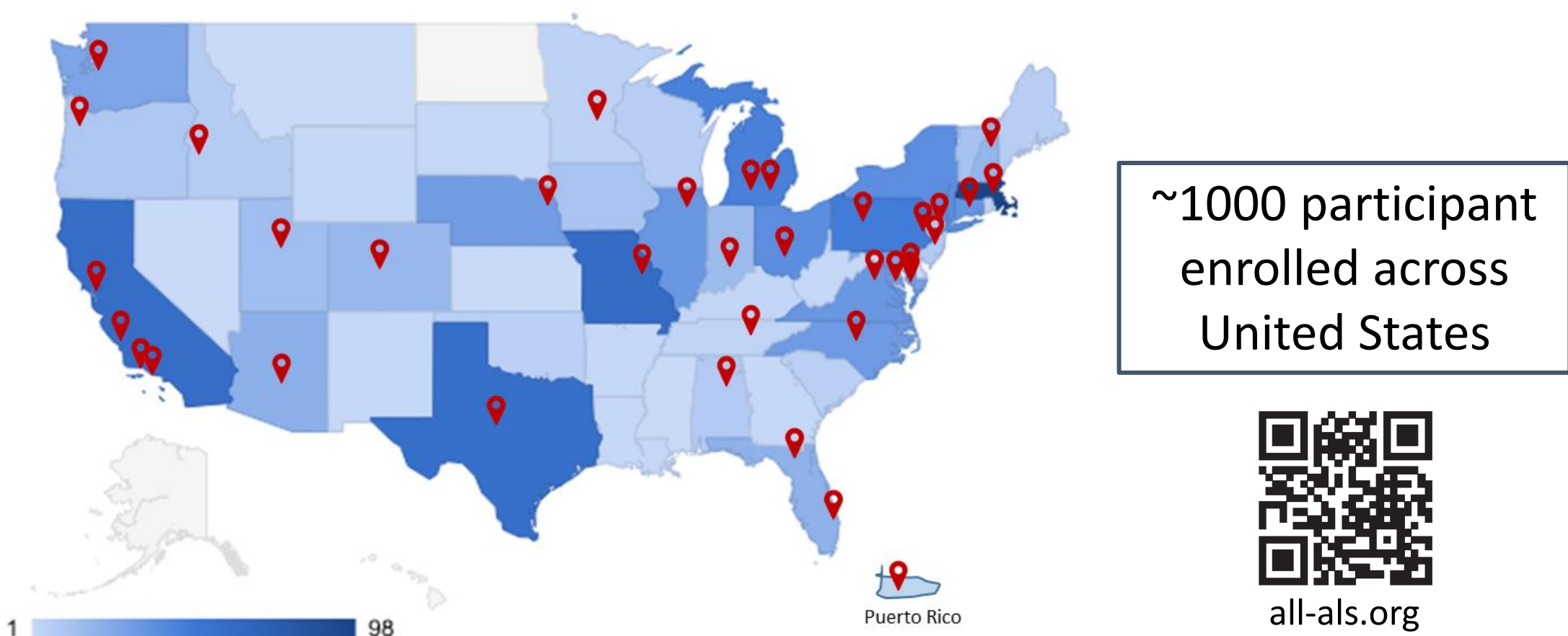


Figure 2: Deployment of ALL ALS Digital Infrastructure Across 36 Clinical Sites (32 currently active for enrollment)

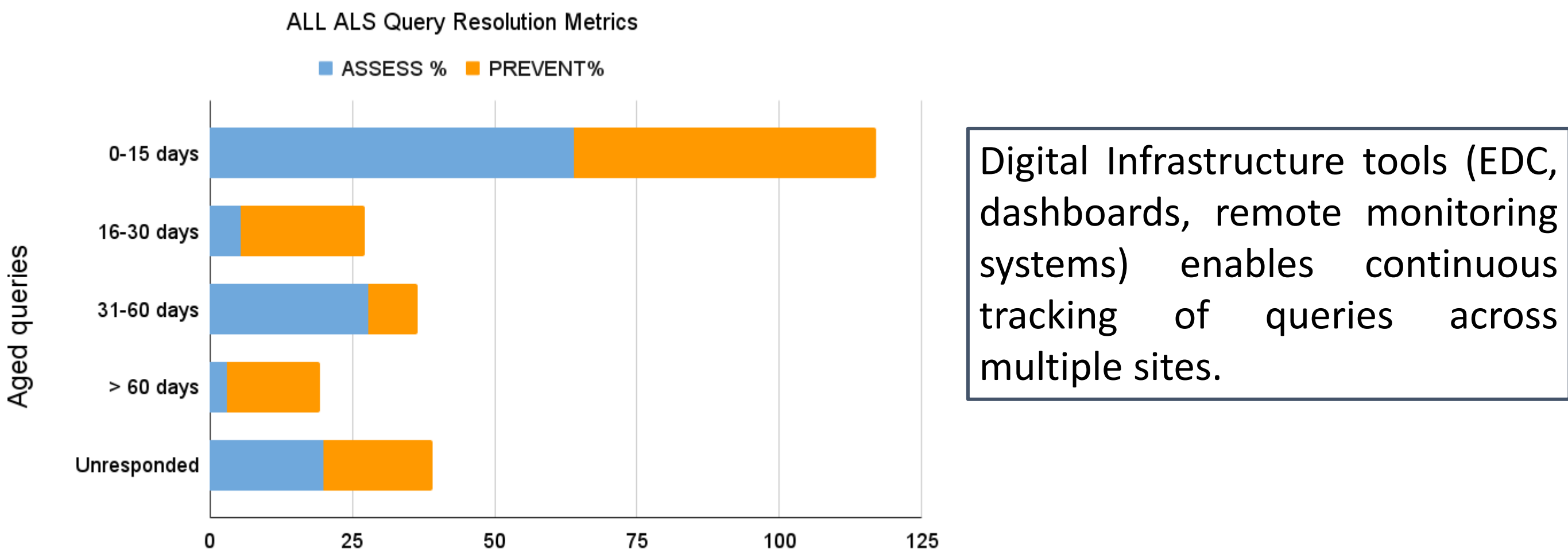


Figure 3: Management and tracking of data quality.

Digital Assessment		ASSESS	PREVENT
ePRO	Participant Enrolled	609 (84%)	273 (94%)
	No. of Survey Completion	~4000	400
	Compliance	82%	82%
Speech	Participant Enrolled	417 (82%)	245 (91%)
	No. of Survey Completion	417	245
	Compliance	62%	79%

Table 2: Compliance and metrics for ePRO and Speech assessments

DISCUSSION & CONCLUSION

- **Hybrid participation** reduced site burden and broadened access.
- **Integrated digital tools** enabled real-time QC across clinical, speech, and ePRO data.
- **DIGITIZE wearables** support modular, remote movement assessments.
- **High ePRO & speech compliance** shows feasibility and strong engagement.
- **Challenges:**
 - Institution-specific tech restrictions
 - Variability in participant digital literacy
 - Telehealth licensure complexities
 - Device shipping and deployment logistics
- **Takeaway:** The ALL ALS Consortium built a **scalable, digital-first infrastructure** with standardized tools, proactive site support, and real-time feedback—offering a future-ready model for decentralized ALS research.

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