

Developing The Republic of Armenia's First National Dementia Registry

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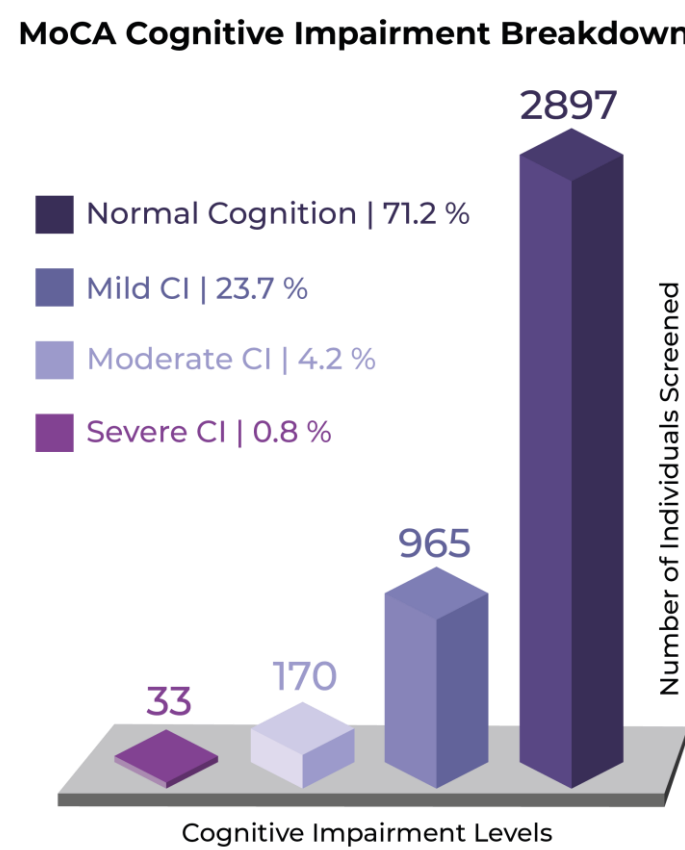
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Why Armenia Needs a Dementia Registry?

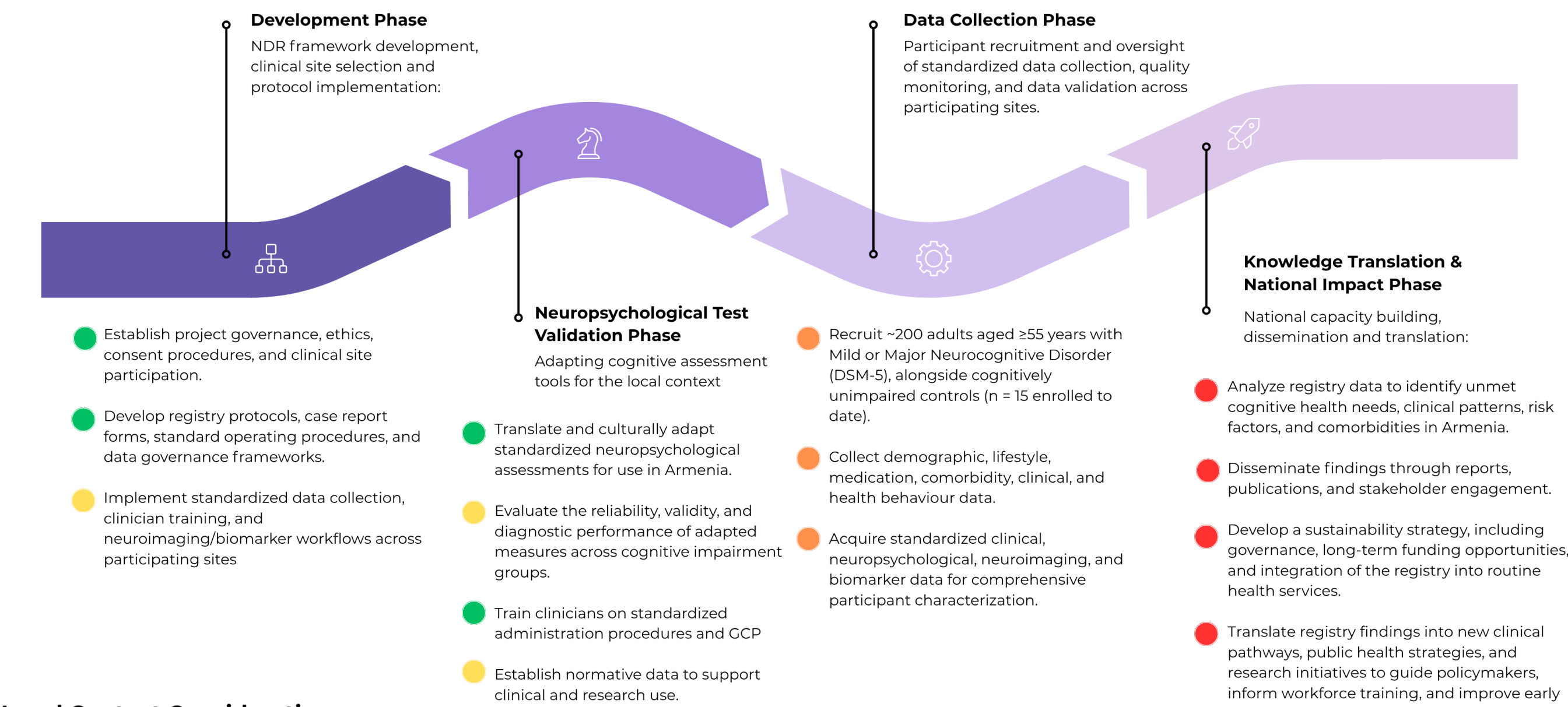
Armenia is currently experiencing a compressed demographic transition with its proportion of older adults ≥65 years projected to reach almost 22-23% by 2050. Despite the country's recent classification as an Upper middle-income country (UMIC), the growing burden of non-communicable diseases (NCD) and widespread lack of awareness about cognitive impairment (CI) highlight critical public health concerns among this rapidly aging population.

In 2022, Alzheimer's Care Armenia's nationwide CI screening program revealed a significant proportion of older adults (n = 4,066) living with CI (mild CI, 23.7%; moderate CI, 4.2%; severe CI, 0.8%). Despite this demonstrated and growing public health concern, Armenia currently lacks a national dementia registry to systematically capture, monitor, and plan for dementia and related cognitive disorders.

This absence of systematic dementia surveillance is not unique to Armenia but reflects a broader regional gap across Eastern Europe and the South Caucasus, where national dementia registries and standardized longitudinal data collection systems remain limited, particularly in low- and middle-income (LMIC) health systems.



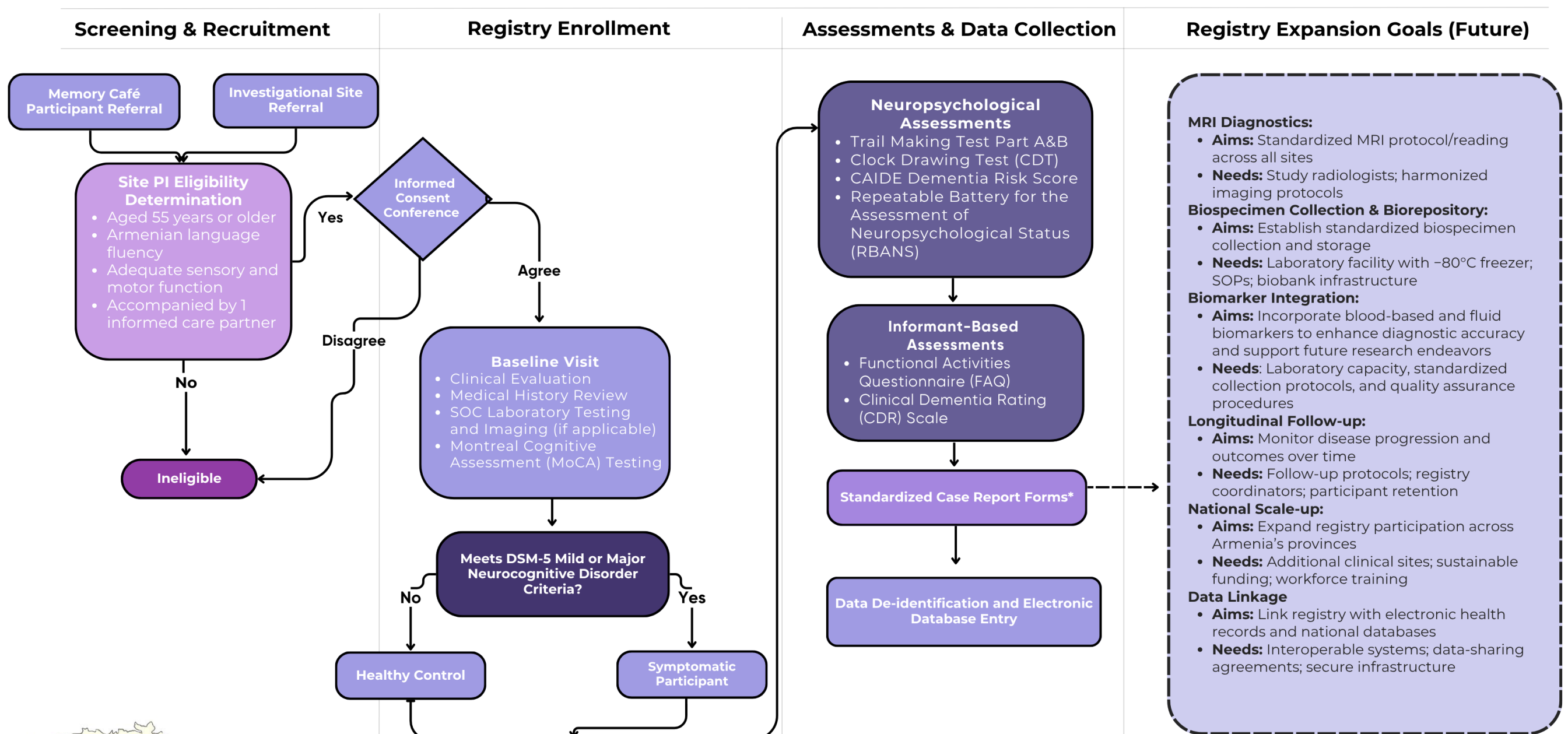
Methods: Phased Implementation-Informed Approach



Local Context Considerations:



Results: Registry Design & Workflow



Methods: Registry Development Process

International Registry Model Review

- Incorporate global perspectives from **Argentina (ReDeCAr)**, **Sweden (SveDem)** and **Australia (ADNeT)**
- Clarify potential implementation approaches, data standardization strategies and considerations for aligning with national clinical and policy priorities

Stakeholder Consultation

- Consulted local clinicians, Ministry of Health representatives, Medical University Professors, front line data collectors, social workers, caregivers, and persons living with dementia
- Identify best pathways for **health system integration, community engagement and long-term sustainability**

Expert Advisory Input

- Assembled an **international team of experts** including Neurologists, Neuropsychologists, Gerontologists, Public Health Practitioners, Clinical Researchers, Database developers to **oversee framework development and phased implementation**

Feasibility Assessments

- Data compiled on **existing dementia diagnostic pathways, workforce capacity and training, regional provider distribution, availability of screening and neuropsychological assessment tools and specialized diagnostic services** (e.g. advanced neuroimaging, laboratory and biomarker testing)

Registry Framework Development & Site Selection

- Framework **adjusted to local resource limitations and prioritized minimum core dataset**
- Local stakeholder and International Expert consultation utilized to develop **clear protocols, standardized case definitions, case report forms and SOPs**
- 3 clinical sites identified for pilot data collection** in light of diagnostic capacity and availability of trained professionals

Key Limitations

- Underrepresentation of rural and underserved populations.**
- Limited access to **specialized diagnostic services** (e.g., advanced neuroimaging, laboratory investigations, and biomarker testing).
- Lack of culturally and linguistically adapted, psychometrically **validated neuropsychological assessment tools.**
- Social stigma** surrounding dementia and societal perception of CI as a part of normal aging process, contributing to **delayed recognition and care-seeking.**
- Limited research infrastructure and clinical registries, creating **challenges for participant identification and recruitment.**

Together, these barriers contribute to **delayed diagnosis, variability in clinical assessment, and incomplete characterization of dementia across the country**, underscoring the need for standardized, nationally accessible diagnostic and data collection approaches.

Conclusion

By consolidating data on demographic characteristics, cognitive function, disease staging, and relevant comorbidities, this initiative represents a critical step in uncovering unmet needs for neurodegenerative disorders in Armenia and aims to provide guidance for clinical practice, public health interventions and health policy decisions. Furthermore, it will offer a scalable model for similar initiatives in neighboring low- and middle-income countries.

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Acknowledgements

We gratefully acknowledge the collaboration of our institutional partners in Armenia: Yerevan State Medical University, Erebouni Medical Center and RA National Institute of Health.

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