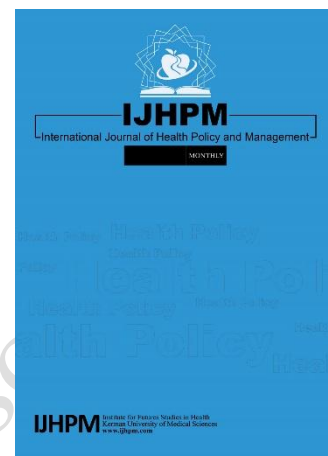


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Zahra Mortazavi, Keramat Yousofi, Shahriar Dabiri, Mohammad Khaksari

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Innovative Collaboration for a Longitudinal Cohort Study on the Health of Visually Impaired Individuals in Iran: A Partnership of NGOs, Private Entities, and Academia

Zahra Mortazavi¹, Keramat Yousofi², Shahriar Dabiri³, Mohammad Khaksari*⁴

1. Negahe Aftab Mehr Non-governmental Institute of Kerman for Supporting Individuals with Severe Low Vision and Blindness, Kerman, Iran
2. Clinical Research Development Unit Mehrigan Hospital, Kerman University of Medical Sciences, Kerman, Iran
3. Dabiri Medical Diagnostic Laboratory, Kerman, Iran
4. Physiology Research Center, Institute of Neuropharmacology, Kerman University of Medical Sciences, Kerman, Iran

Correspondence to: Mohammad Khaksari; mkhaksari@kmu.ac.ir

Dear Editor,

We wish to share our experience launching a pioneering longitudinal cohort study in Iran, exemplifying a tripartite collaboration among academic, private, and non-governmental sectors. This initiative, titled "A 5-Year Prospective Cohort Study on the Physical, Mental, and Social Health of Individuals with Severe Visual Impairment and Blindness in Kerman, Iran," represents a novel approach to addressing gaps in health research for vulnerable populations.

Background and Rationale

Globally, longitudinal studies focusing on the health of blind and severely visually impaired individuals remain scarce, particularly in low- and middle-income countries (LMICs) ¹. In LMICs, challenges such as limited funding, inadequate infrastructure, and low awareness of the issue hinder the effective development and implementation of programs. These factors make it difficult to establish sustainable solutions. In Iran, no comparable model exists to track the health trajectories of this population systematically. This absence makes it challenging to identify emerging health issues, allocate resources effectively, and design targeted interventions to reduce health disparities within this group. Existing research highlights significant unmet needs, including the progression of non-communicable diseases (NCDs), mental health challenges (e.g., depression, anxiety), and social determinants of health in visually impaired individuals². This cohort study aims to fill these knowledge gaps while testing a collaborative framework for multisectoral health research.

Study Design and Collaborative Framework

The study is a 5-year prospective cohort involving at least 700 participants registered with the Negahe Aftab Mehr Institute (a nonprofit supporting the visually impaired) and the Kerman Association of the Blind. The tripartite collaboration includes:

1. Academic Sector (Kerman University of Medical Sciences - KUMS): Responsible for technical oversight, ethical governance, and partial financial support.
2. Private Sector (Mehrgan Hospital and Dr. Dabiri Diagnostic Laboratory): Provide clinical infrastructure and diagnostic services, contributing financially to the study.
3. NGOs (Negahe Aftab Mehr Institute and Kerman Association of the Blind): Facilitate participant recruitment and community engagement and provide partial funding

A memorandum of understanding (MoU) formalizes the roles of this collaboration, including shared financial responsibilities, data collection, and dissemination of findings. This model ensures sustainability and equitable participation, addressing common challenges in LMIC-based research, such as fragmented funding and institutional silos³.



Photo 1: Signing of the Memorandum of Understanding among Kerman University of Medical Sciences, the private sector, and NGO, March 13, 2025

Innovation and Anticipated Outcomes

This study introduces two key innovations. These innovations aim to bridge gaps in the research on the health of visually impaired individuals and have the potential to inform policies for better healthcare services.

Furthermore, this study directly impacts the health of the target group by detecting health problems and facilitating medical care. Collected biobank samples will also be stored for potential future research or clinical use.

1. Methodological

It is the first Iranian cohort to integrate physical, mental, and social health metrics for visually impaired individuals using validated tools^{4,5}.

We will measure demographic and anthropometric variables, general and psychological health, and lifestyle factors, including physical activity, sleep patterns, nutrition, smoking, alcohol and drug use, and medical history. An ophthalmologist will examine all participants and record key findings⁶⁻¹².

Simultaneously, a blood sample will be collected for routine lab tests, biobanking for future research, and assessment of specific biomarkers relevant to this group, such as melatonin, cortisol, thyroid and liver functions, and insulin levels. Subjects will receive a report containing interview results, lab tests, and physician records, and any abnormalities will be addressed. Annual assessments will track outcomes such as NCD progression, accident-related injuries, and mental health trends. The study will also assess vision trends in visually impaired subjects and ophthalmic complications in all subjects.

2. Operational

This study benefited from a partnership in which the NGO provided the study site and equipment and recruited visually impaired participants. Private sector contributions included partial funding, technical support, lab tests, and participant incentives. Kerman Medical University covered additional study costs, addressed methodological concerns, and provided scientific and ethical approval of the research proposal.¹³.

Initial data (first-year data) will establish baseline health profiles. Subsequent years' data will reveal health trends and their relationship to lifestyles and baseline risk factors. The archived biological samples provide a valuable resource for future research.

Challenges and Lessons Learned

Initially, coordination and establishing a shared language posed a significant challenge. However, an open dialogue platform enabled partners to comprehensively understand each other's interests, capabilities, and limitations, culminating in a signed MOU.¹⁴

Conclusion and Call for Action

Collaboration between academic, private, and NGO sectors offers an efficient model for organizing large, complex, and longitudinal studies, even in low-income countries. This cohort demonstrates the feasibility of such a multisectoral collaboration in resource-constrained settings, and we urge researchers and policymakers to adopt similar frameworks to address health disparities in vulnerable groups.

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