# Challenges in conducting Dementia Research in Urban communities

S Revathi[1], Tejaswini S Manae[2], Renuka B R[3], Rakshith Maneshwar Hoskeri[4], Dr Ajit Deo Burma[5], Dr Girish N Rao[6], Dr Suvarna Alladi[7]

[1] PhD Scholar, Department of Neurology, National Institute of Mental Health And Neuro Sciences, Bangalore.

[2] Research Assistant, Department of Neurology, National Institute of Mental Health And Neuro Sciences, Bangalore.

[3] Field Worker, Department of Neurology, National Institute of Mental Health And Neuro Sciences, Bangalore.

[4] Assistant Professor, Department of Clinical Psychology, Dharwad Institute of Mental Health And Neuro Sciences, Dharwad.

[5] Project Officer, Department of Neurology, National Institute of Mental Health And Neuro Sciences, Bangalore.

[6] Professor, Department of Epidemiology, National Institute of Mental Health And Neuro Sciences, Bangalore.

[7] Professor, Department of Neurology, National Institute of Mental Health And Neuro Sciences, Bangalore.

# Introduction

Increase in elderly population and problems associated

Physical Dependencies, Health and Psychosocial Problems

Cognitive Decline

Poor social connectedness

Cultural diversity

Altering Family Structure

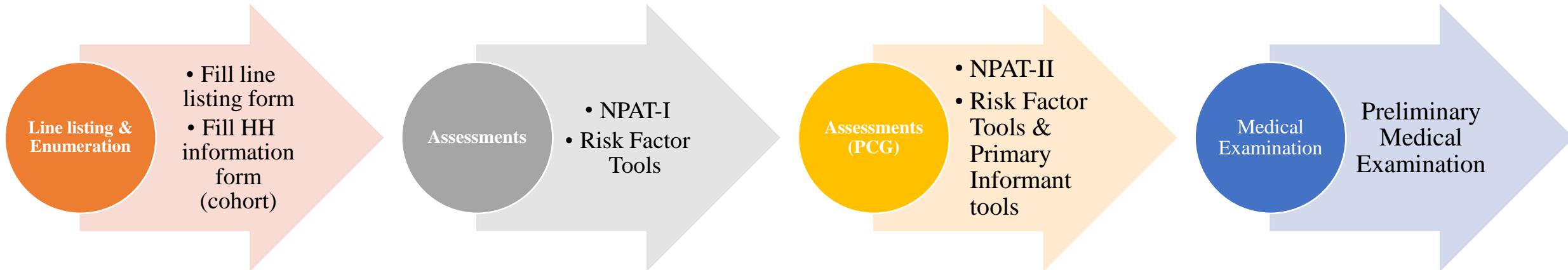Specific Problems with Ageing needs focused attention

Lack Of quality studies on Dementia-AADAR DSP

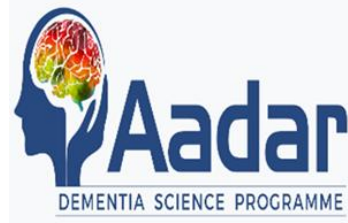# Advancing Approaches To Dementia Associated Research-Dementia Science Programme (AADAR-DSP)

- The AADAR DSP being undertaken by NIMHANS in Urban Bengaluru.

- Bengaluru south, Jayanagar and JP Nagar wards

- House to house survey



**Line listing & Enumeration**
- Fill line listing form
- Fill HH information form (cohort)

**Assessments**
- NPAT-I
- Risk Factor Tools

**Assessments (PCG)**
- NPAT-II
- Risk Factor Tools & Primary Informant tools

**Medical Examination**
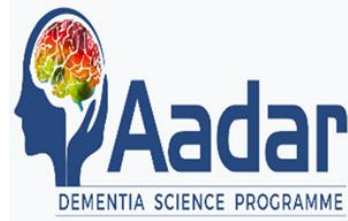Preliminary Medical Examination

# Objective of the study

To document the researchers' and participants' perception on community-based dementia research in an urban setting.

# Methodology

- AADAR DSP project team at NIMHANS
  - Psychologists
  - Doctors
  - Social workers
  - Public health professionals
- Thematic analysis: Inductive analysis
- Themes were formulated based on the feedback from the participants and staffs.

| More than 1200 participants interviewed | → | Feedback from participants and researchers | → | Inductive Thematic analysis |

# Results and Discussion

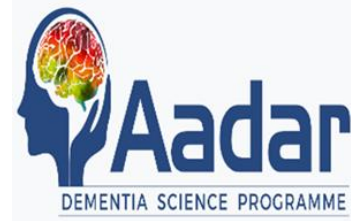- Households enumerated-5121
- Participants recruited- 1238

Psychologists- 9; Doctors- 4
- Social workers- 4; Public health and others professionals- 5

- Scientific advisory committee meetings- 02
- All principal investigators meeting- 03
- Training sessions for field staff- 02
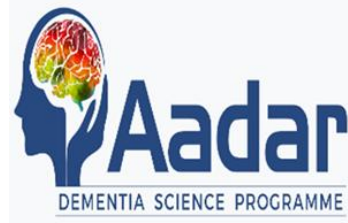- Weekly review meetings- 97
- Field visits- 25

# Results and Discussion

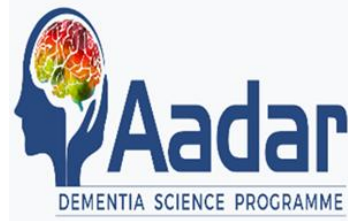| Themes | Details | Participants | Staffs |
|---|---|---|---|
| Frustrations | High refusals, language barrier, emotional breakdown | | ✓ |
| Safety and fear | Stray animals/pets, strangers inside home | ✓ | ✓ |
| Lack of support and motivation | Lack of basic amenities, mobility services, poor attitude towards health research, financial stress and lack of personal benefits | | ✓ |
| Exhaustion | Physical and mental exhaustion | ✓ | ✓ |
| Health and behavioral issues of the participants | Frail health of the participants and their caregivers | | ✓ |
| Pandemic | Risk of COVID-19 | ✓ | ✓ |
| Others | Poor environmental/weather conditions | | ✓ |

# Results and discussion

| Individual | Frustrations | Safety and fear | Lack of support and motivation | Exhaustion | Health and behavioral issues | Pandemic | Others |
|---|---|---|---|---|---|---|---|
| Researchers | Maximum | Moderate | Most | Moderate | Moderate | Most | Most |
| Participants | Minimum | Most | Moderate | Most | Most | Most | Moderate |

- Maximum
- Most
- Moderate
- Minimum

# Strategies



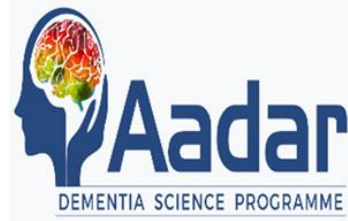Team building exercises

Defining Career Progression

Case Studies

Management Principles

Managing conflicts of interest

# Conclusion

❑Good quality data will come from good quality support.

❑Staff demands and requirements are rarely documented, understood and addressed.

❑First attempt to discuss on the same.

❑Training and sensitizing the staff and stakeholders on the importance of community-based dementia-research.

❑There need to develop innovative methods to engage the community and conduct research in urban settings.