Moving Pictures: Using film and digital media to increase dementia awareness in multicultural communities

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Moving Pictures
Dementia awareness for CALD communities

Moving Pictures is a collaboration between

Bringing research to life

Team

Principal investigator: A/Prof Bianca Brijnath

Project manager: Dr Josefine Antoniades

Project investigator team
- Professor Jon Adams, University of Technology Sydney.
- Dr Dianne Goeman, Adjunct Senior Research Fellow, University of Newcastle.
- Professor Colette Browning, Honorary Professor Peking University.
- Professor Katie Ellis, Curtin University.
- Professor Mike Kent, Curtin University.
- Dr Andrew Simon Gilbert
- Dr Samantha Croy

Bilingual staff
- Dr Nick Lee (Mandarin/Cantonese)
- Mariam Yousif (Arabic)
- Anu Krishnan (Hindi/Tamil)
- Dr Carolina Navarro Medel (Spanish)
- Julieta Sabates (Spanish)
- Phuong Lan Do (Vietnamese)
- Thu Ha Dang (Vietnamese)
- Carlo Guaia (Italian)
- Silvia Teani (Italian)
- Dr Antonia Thodis (Greek)

Services:
- Dementia Australia
- Assisi Aged Care
- Australian Multicultural Community Services (AMCS)
- Carers VIC
- Chinese Community Social Services Centre Inc.
- Circle Health
- Ethnic Communities Council of Victoria
- Federation of the Indian Association of Victoria
- Fronditha Care
- Hellenic Medical Society of Australia
- Monash University, Department of General Practice
- Myhealth Box Hill Medical Centre
- Pronia
- Ross Court Medical Complex
- United, Spanish Latin American Welfare Centre
- Victorian Arabic Social Services
- Victorian Multicultural Commission
- Migrant Resource Centre
- Wicking Dementia Research and Education Centre
- Alzheimer's WA
- Australian Arab Association
- Carers WA
- Chung Wah Association
- City of Melville
- Fortis consulting
- Hall & Prior Aged Care
- Italian Village Fremantle
- Multicultural Services Centre of Western Australia
- MYVISTA
- Rainbow Aged Care
- Australian Nursing Home Foundation
- Bridgeview Medical Practice
- Co.As.It. Sydney
- Co.As.It.
- Dementia Support Group for Indian Australian Inc.
- Itsowel
- Maronite Villages
- Multicultural Communities Council of Illawara (MCCI)
- Shellharbour Medical Centre
- Dr Ernest Tam
- SEWA Australia
- Centre for Cultural Diversity in Ageing
- And many, many more …

Rationale

Timely diagnosis for dementia essential

- Maintain independence

- Obtaining early intervention

- Better health outcomes

- Planning for the future

- Engage support for carers & families

In ethnic communities delayed access common

- Occurring at the point of crisis

- Illness beliefs

- Poor dementia literacy/system knowledge

- Language/ses disadvantage

Why is this important?

- 1 in 3 Australian over 65 is from a culturally and linguistically diverse (CALD) background and this number will grow

- To ensure health equity for all in the Australian community

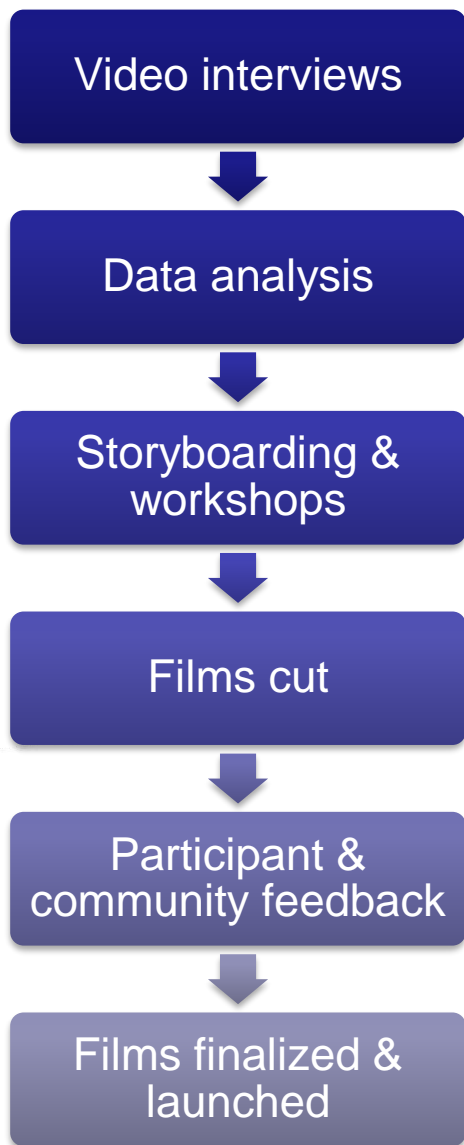- Urgent need to inform CALD families about dementia, to avoid delayed diagnosis and timely access to care

Aim

Moving Pictures, a national project that aims to use film and digital media to raise dementia awareness in Australia's culturally and linguistically diverse (CALD) communities.

Methods

Video interviews → Data analysis → Storyboarding & workshops → Films cut → Participant & community feedback → Films finalized & launched
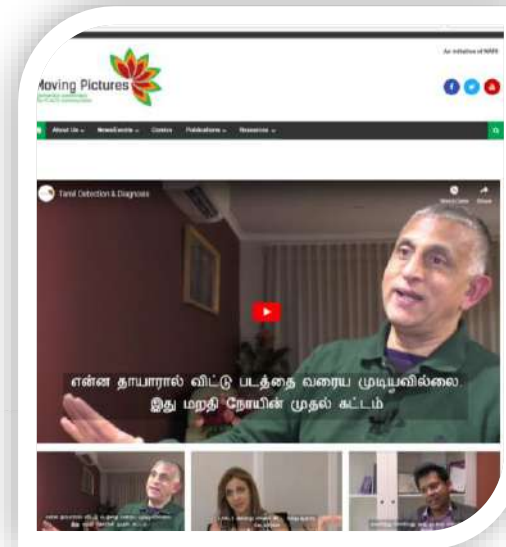
- **Mixed methods** comprising co-production & data analytics
- **Video interviews :** With carers (n=112) and Health professionals (n=41) from around Australia in language (9 languages) & English.
- **Data analysis:** Interviews transcribed & translated verbatim, data analysed using nVivo to form the basis for film storyboards
- **Storyboards** workshopped with representative steering committee
  – *Carer Journey*
  – *Navigating care*
  – *Detection & diagnosis*
- **15 films:** 5 languages, 3 films each: Tamil, Hindi, Mandarin, Cantonese and Arabic| 12 additional films in production (Greek, Italian, Spanish, Vietnamese.
- **Feedback:** Focus groups x 5: n=51 (MPI) |Member checking
- **Community screenings MPI** post-launch (<500 community members)
- **Online Community screening MPII** (current)

Moving Pictures
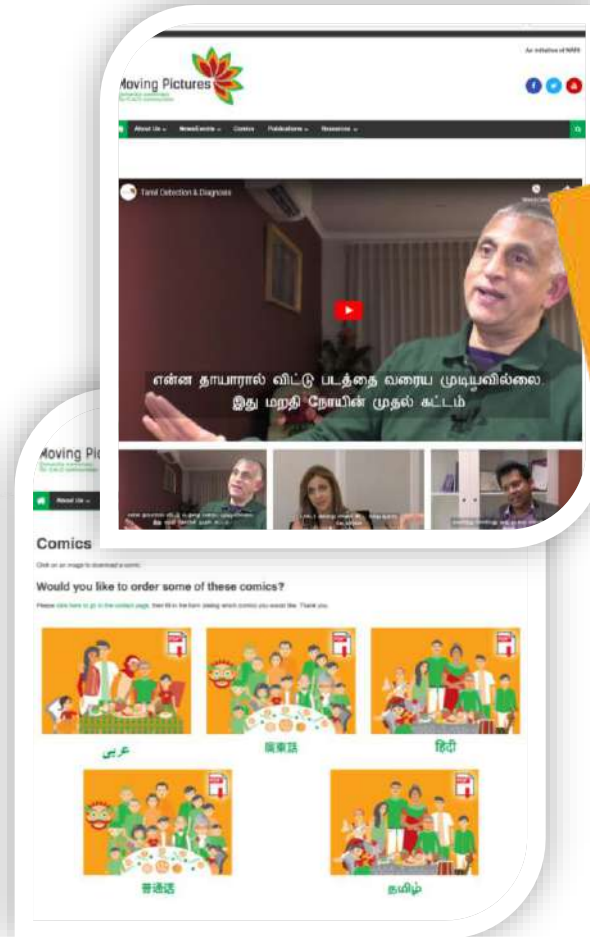Dementia awareness for CALD communities

NARI
NATIONAL AGEING RESEARCH INSTITUTE

Moving Pictures resources

MP Films

Detection & Diagnosis
Navigating Care
The Carer Journey

Moving Pictures resources

MP Films

MP comics

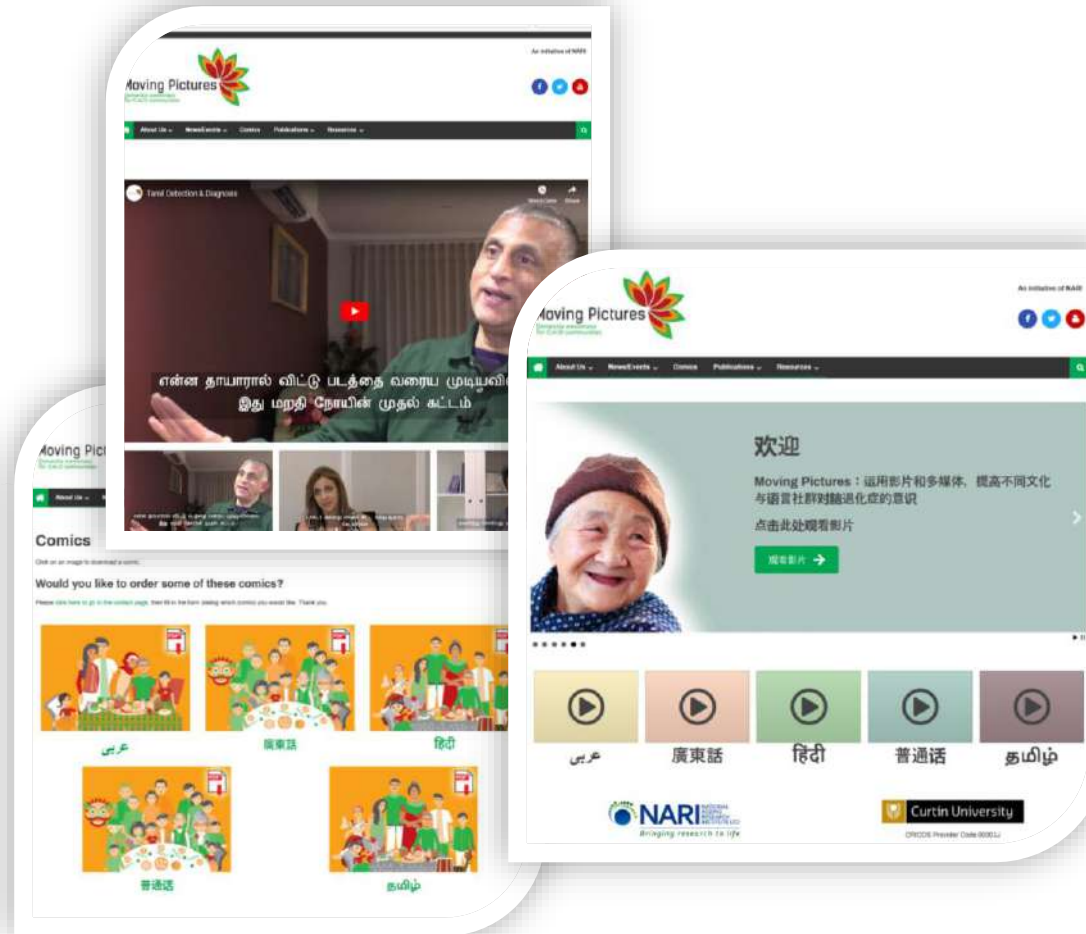# Moving Pictures resources

MP Films

MP comics

MP website

See the films for free at
www.movingpictures.org.au

Impact

- To date www.movingpictures.org.au has had 19,613 views
- >620 followers on Twitter and 207 followers on Facebook
- >9000 comics distributed
- >20 print and broadcast stories including in the ABC, SBS, and The Australian)

Impact

- MP listed on the Australian Commission on Safety and Quality in Health Care, Queensland Government Carer Directory and Queensland Government Health websites

- >30 ethno-specific organisations (e.g. Centre for Cultural Diversity) and industry newsletters.

- *Moving Pictures Australia* drew formal media releases from the Federal Minister for Aged Care and the Federation of Ethnic Communities Council of Australia.

Uptake and next steps

Publications to date

- Brijnath B, Gilbert AS, Kent M, et al. Beyond crisis: Enacted sense-making among ethnic minority carers of people with dementia in Australia. Dementia. November 2020. doi:10.1177/1471301220975641

- Bianca Brijnath, PhD, Andrew Simon Gilbert, PhD, Josefine Antoniades, PhD, Samantha Croy, PhD, Mike Kent, PhD, Katie Ellis, PhD, Colette Browning, PhD, Dianne Goeman, PhD, Jon Adams, PhD, Boundary-crossers: How providers facilitate ethnic minority families' access to dementia services, *The Journals of Gerontology: Series B*, 2021;, gbab073, https://doi.org/10.1093/geronb/gbab073

- Under review:
  - Emotions and care
  - Structural burden

- In preparation:
  - Positive aspects of care
  - History of migration on service availability
  - Awareness
  - Home-knitted strategies

Moving Pictures II

- Currently developing resources in Spanish, Greek, Italian & Vietnamese
- Greek & Italian resources will be completed by early 2021
- Spanish & Vietnamese by mid 2021

Coming Soon in New Languages

ADAPT
Animating Dementia Prevention for CALD Communities

Moving Pictures India

- Funded by Alzheimer's Association USA
- Starting in 2021
- Focus on dementia care in low and middle income countries

Moving Pictures GENIE

- Develop an online repository of evidence-based dementia resources developed for migrant communities sourced internationally.

- Systematic search & via crowdsourcing from experts and academics

- Hosted on Moving Pictures website as a searchable page

- Project initiated as a collaboration with MP team and ISTAART members (Sanne Franzen, Kylie Radcliff, Mario Parra, Jayashree Dasgupta, Louise Lavrencic)

- Masters students working towards developing a prototype (Jing Ye Ooi & Veronica Lay; Monash U.)

Thank you for listening!

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Dementia Care Navigator CALD – Specialist
Nina Catalano

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phn WESTERN SYDNEY
An Australian Government Initiative

Session overview

- Dementia Care Navigator
- What people need
- Facts and stats
- Dementia
- Key Findings
- Communicating
- Case studies
- Summary

Dementia Care Navigator
CALD Specialist
Western Sydney

- A better way to connect with services and support for culturally and linguistically diverse communities
- Provide education re funding and services

Dementia Care Navigator – CALD Specialist

- The Navigator role plays an integral part in the Western Sydney Primary Health Network
- Primarily for Australians from culturally and linguistically diverse backgrounds and special need communities where English is not their first language
- 2-year trial funded by Western Sydney Primary Health Network

Benefits to the client

- Dedicated Dementia Specialist
- Group sessions to help navigate living with dementia at all stages, including connecting with government-funded services (My Aged Care, National Disability Insurance Scheme, etc.) and other service providers
- Tailored and continuous one-on-one support available in person, via phone, email and other online forums

Benefits to the client

- Information about local services
- Expert and unbiased information
- Translated resources and ability to work with interpreters
- Support for people of all ages
- Support from pre-diagnosis to Palliative Care

Diversity in Action

Countries

Armenia **Indonesia**
Sri Lanka Turkey
Afghanistan **Greece**
Tokelau Samoa
Cyprus **China**
Lebanon **Italy** Sudan
Finland Korea **Spain**
Hong Kong **Malta**
Fiji **Egypt**

Languages

Farsi Dari **Hindi**
Arabic **Mandarin**
Cantonese Italian
Turkish Spanish
Fijian Hindi
Oceanic Languages
Samoan

Facts and stats

Every 3 seconds
someone in the world
develops dementia.

In Australia an estimated
250 people
join the population
with dementia each day.

There are more than
472,000 people
living with dementia
in Australia.

In 2021 there is an estimated
28,300 people
with younger onset
dementia in Australia.

By 2028 there will be
an estimated
590,000 people
with a diagnosis of
dementia in Australia.

By 2058 it is estimated that
1,076,000 people
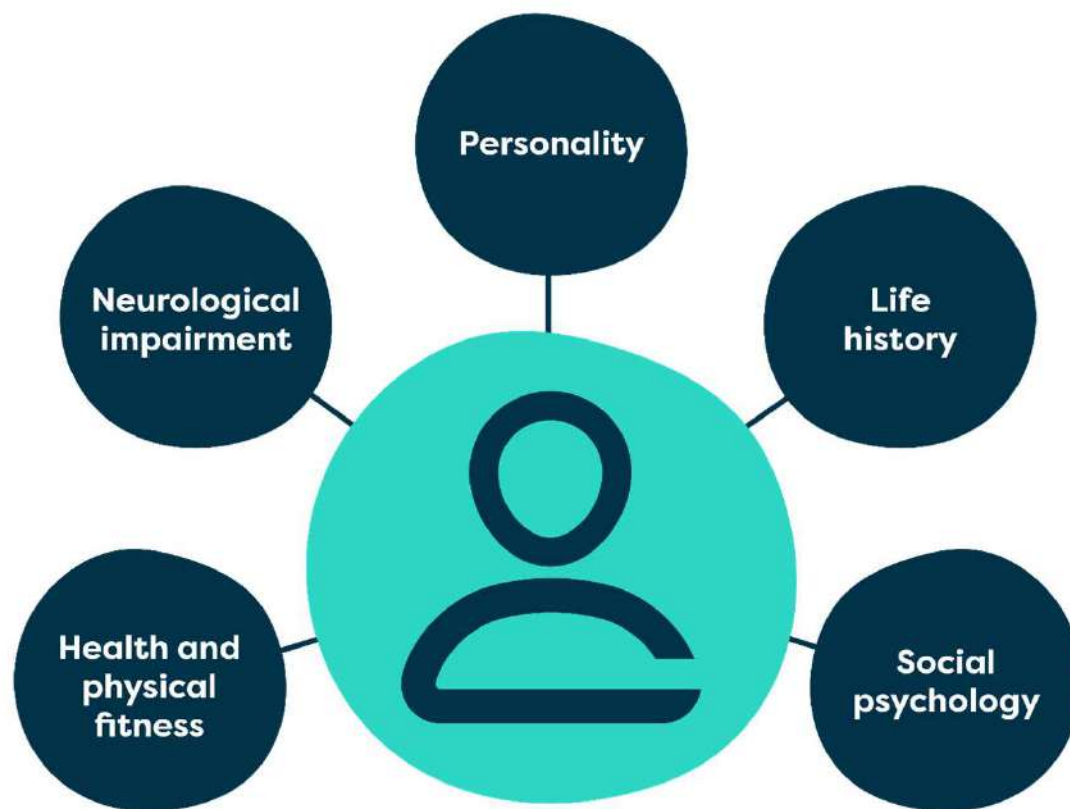will have a diagnosis of
dementia in Australia.

What is dementia

Dementia is an umbrella term to describe a **set of symptoms caused by brain disease.**

Typical signs of dementia are gradual **changes in thinking that get in the way of a person doing everyday things.**

No two people are affected in exactly the same way.

It is not a normal part of ageing.

Experience of dementia

Personality

Neurological impairment

Life history

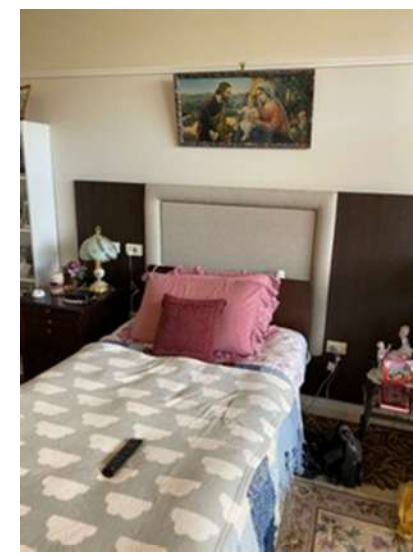Health and physical fitness

Social psychology

Person with dementia

The Enriched Model of
Dementia Brooker, D (2007)

Communication in the CALD space

- Connection
- Never presume
- Relationship building
- Trust
- What people need

Case Studies

Family Conference

Four siblings online across areas

Indian Zoom Information Session

- Information session on Dementia and services

CALD Link Workers

- Link worker model and partnership

Dementia Australia – Services and Information

- dementia.org.au
- dementia.org.au/resources/videos
- NSW.Referrals@dementia.org.au

Dementia
Australia™

National Dementia Helpline
1800 100 500

Interpreter

For language assistance
call **131 450**

Find us online
dementia.org.au