



STRiDE Dementia

Theory of Change Workshop in Brazil: Report and Pathway to Change Map



January 2019

Contents

1. Background and Aim	3
1.2. The STRiDE Programme	3
1.2. What is this document about?	3
2. Context.....	4
2.1. Country characteristics	4
2.1. Dementia in Brazil.....	4
3. The Development of a Theory of Change for Brazil	5
3.1. Date and location.....	5
3.2. Attendees	5
3.5. Programme	8
3.6. Findings	10
Current challenges: where are we coming from?.....	10
Looking at the future: where do we want to be/go?.....	11
Overcoming challenges: what do we need to change and how do we do it?	11
Summary of the ToC-Brazil Map	14
Future directions	15
References.....	16

1. Background and Aim

1.2. The STRiDE Programme

The STRiDE programme is aimed at contributing to the improvement of dementia care, treatment and support systems in Low- and Middle- Income Countries (LMICs) so that people living with dementia are able to live well, and family and other carers do not shoulder excessive costs, risk impoverishment or compromise their own health.

STRiDE has 10 Work Packages (WP) in total. WP1 is aimed at to co-developing the research and training agenda for STRiDE across and within countries by developing a Theory of Change (ToC) which can be used to identify 1. pathways to impact; 2. strategies and interventions and the evidence for them; and 3. assumptions. A ToC explains the process of change of a scenario by outlining causal linkages in an initiative (shorter-term, intermediate, and longer-term outcomes). The identified changes are mapped as the “outcomes pathway” which shows each outcome in logical relationship to all the others, as well as chronological flow. Each country’s ToC and the overarching STRiDE ToC maps can then be used to measure the progress and impact of the entire STRiDE programme.

The core STRiDE team in Brazil is based at the Federal University of Sao Paulo (UNIFESP) and is led by Professor Cleusa Ferri, who is a Psychiatrist and an Epidemiologist. Dr Deborah Oliveira, who is a Nurse by background, is the Early Stage Researcher in the team. The group is also supported by Professor Jerson Laks, who is a Psychiatrist based at the Federal University of Rio de Janeiro (UFRJ) and by the Federal Brazilian Association of Alzheimer’s Disease (FEBRAZ) represented at the time by Maria Aparecida Guimarães.

1.2. What is this document about?

This document aims to describe the development process of the Brazilian ToC and its respective ToC Map. First, a brief description of the Brazilian population and the current statistics on dementia in Brazil will be provided. After that, the process of planning and conduction of the workshop based on which the ToC was created is described. Each of the essential components of the ToC (e.g. impact, outcomes, assumptions, rationale, indicators of success, interventions, key activities) is detailed in bullet points, narrative and as a ToC Map. Additional documentation is provided in the Appendices at the end of the report.

2. Context

2.1. Country characteristics

Brazil is the largest country in both South America and Latin America (8.5 million square kilometres \approx 3.2 million square miles) and has over 208 million people. It is the world's fifth-largest country by area and the fifth most populous in the world. Brasilia is Brazil's capital and the most populated city is São Paulo. Brazil has 26 states, a Federal District, and around 5,570 cities (

Figure 1). It is one of the most multicultural and ethnically diverse nations due to over a century of mass immigration from around the world. Around 84% of the population of Brazil is defined as urban and is heavily concentrated in the South-eastern and North-eastern regions.



Figure 1. Map of Brazil - 26 states with their respective capitals, and the Federal District

2.1. Dementia in Brazil

Current estimates on dementia prevalence in Brazil is inconsistent. The Alzheimer's Disease International report of 2015¹ states that around 8.3% of people aged 60 and over in Latin America have dementia, however a systematic review has indicated that the prevalence of dementia in Brazil varies between 5.1 and 19.0%². Other studies have shown general prevalence rates of 12.5% among

those aged 65 and over³, 16.9% (private health sector age group>67)⁴ and 17.5% (aged 60 and over)⁵. Such differences might be due to e.g. the current high rates of undiagnosed individuals in Brazil⁶ and the huge cultural, economical and social diversity across the nation, and methodology employed. Most people living with dementia in Brazil are supported and cared for at home by their family members.

3. The Development of a Theory of Change for Brazil

A one-day workshop was conducted to create a ToC Map for dementia in Brazil. This involved several stakeholders from across the country, as well as people living with dementia and family carers, and foreign researchers involved in STRiDE.

3.1. Date and location

The workshop took place on 28 June 2018 in the central area of the city of Sao Paulo, which is located in the South-eastern area of Brazil.

3.2. Attendees

The ToC workshop was led and facilitated by the Brazilian Stride team and attended by several individuals with different backgrounds (e.g. psychology, medicine, pharmacy, volunteers, people with lived experience) and who are currently working/acting on different areas/levels (e.g. university, ministry of health, health services, voluntary organizations) and were originally from different areas of Brazil (

Figure 1). Table 1 shows the names, roles, background and where each workshop attendee was originally from.



Figure 2. ToC workshop attendees

Table 1. Workshop attendee's names, background and area of origin in Brazil

Workshop role	Background/Training	State/Country
Workshop leaders		
Anna Beatriz Howat-Rodrigues	Psychologist	Rio de Janeiro
Cleusa Ferri	Psychiatrist and Epidemiologist, UNIFESP	Sao Paulo
Workshop facilitators		
Danusa Machado	PhD student- UNIFESP	Sao Paulo
Davi Opaleye	Geriatrician, MSc student - UNIFESP	Sao Paulo
Jerson Laks	Psychiatrist, Professor -UFRJ	Rio de Janeiro
Leonardo Jun Otuyama	Pharmacist - UNIFESP	Sao Paulo
Maria Aparecida Guimaraes	Carer -Federal Association of Alzheimer's Disease	Rio de Janeiro
Sarah Evans-Lacko	Mental Health Services Researcher, Associate Professorial Research Fellow	United Kingdom
Tatiani Piedade	MSc student - UNIFESP	Sao Paulo
Workshop contributors		
Airton Stein	General Practitioner (Medic), Dean of the Federal University of Health Sciences (RS)	Rio Grande do Sul
Alexandre Kalache	President of the International Longevity Centre	Rio de Janeiro
Caroline Ziebold	PhD – student UNIFESP	Brazil/Chile/United Kingdom
Elaine Fernandes Mateus	President of the Alzheimer's Association (Instituto Não me Esqueças)	Paraná
Elizabeth de Fátima B. Piovesan	President of the Alzheimer's Association	Paraná
Fabiana Carvalho	Family carer	Sao Jose dos Campos - SP
Gilberto Alves	Old Age Psychiatrist - Brazilian Association of Psychiatry	Maranhão
Jerusa Smid	Brazilian Academy of Neurology	Campinas SP
Joao Batista FantatoFilho	Person with dementia	Sao Paulo
Joost Martens	Regional Director of the Alzheimer's Disease International Americas	El Salvador
Jose Ronaldo Oliveira	Family Carer	Sao Jose dos Campos - SP
Karla Giacomini	Professor and Geriatrician, FioCruz – Instituto Rene Rachou	Minas Gerais
Luciana M. V. Sardinha	Department of Chronic Condition, PanAmerican Health Organization (PAHO)	Brasilia
Maria Cristina Hoffmann	Coordinator for Older People's Health, Ministry of Health	Brasilia
Maria Fernanda Lima Costa	Professor and Coordinator of the Longitudinal Brazilian Study (ELSI)	Minas Gerais
Norberto A. F. Frota	Neurologist, Brazilian Academy of Neurology	Ceará
Ricardo Nitrini	Professor, Neurologist	São Paulo
Rodrigo R. Schultz	President of the Alzheimer's Association	São Paulo
Sergio Blay	Psychiatrist, Brazilian Association of Psychiatry	São Paulo
Simone Fantano da Silva	Family carer	São Paulo
Sonia Brucki	Neurologist, Professor	São Paulo
Talita Rosa	General Practitioner (Medic), Post-Graduate Researcher	EUA (San Francisco)

Workshop attendees were purposively selected according to their expertise and experience in dementia. Participants were invited around one month prior to the workshop date and had their transport/accommodation costs reimbursed (see invitation letter model in Appendix 1). In total, 31 individuals were present on the day. Other four people who had accepted to take part in the workshop could not be present (two neurologists, one primary care clinician, and a representative of the Inter-American Development Bank). Individuals from the mainstream media in Brazil, a member from the Ministry of Social Development, and people from the local governments (council level) were invited but declined participation due to time constraints.



Figure 3. Group activities for the ToC-Brazil

3.5. Programme

The workshop programme is shown in Appendix 2. Sessions were planned and designed to collect the attendees' views around the *current challenges* faced by people with dementia in Brazil (assumptions/rationale), what would be the *ideal scenario* for people with dementia to live dignified, healthy and fulfilled lives (outcomes/indicators of success/impact), as well as *what we need* and *how we can achieve* this (interventions/key activities).

First, presentations were delivered by Cleusa Ferri and Sarah Evans to give an overview about dementia worldwide and more specifically in Brazil and to explain the objectives of STRiDE, what we meant by ToC, how we could create a ToC Map, and what was expected from participants and from the overall workshop activity. Upon arrival, participants were given an ID with different colours which identified the table they were going to work. This distribution was purposively planned to ensure a good mix of backgrounds in each working group (Figure 4).



Figure 4. Group discussions for the ToC Brazil.

As shown in Appendix 2, the workshop included four main activities. These were introduced to participants as being the stages of a ‘group trip’ which participants were going to experience during that day. Participants worked on the specific activities in groups and each group presented their final key points to the other groups. Group leads also added their main points into the wallboard, which would be linked to the overall workshop findings at the end. Each activity ended with an open discussion, which facilitators took note of the main points raised.

The workshop ended with a general group discussion led by Cleusa Ferri who encouraged participants to order the ‘post its’ in the wallboard in a sequence that was appropriate to create a ToC model. Individuals were asked to identify which aspects were challenges to be overcome, were outcomes, or indicators, etc.

3.6. Findings

Key findings from the workshop discussions are summarised in bullet points below. A Map demonstrating the relationships between the various challenges/outcomes/solutions/etc. is shown in Figure 5. A narrative of the main points included in the ToC-Brazil is provided after that.

Current challenges: where are we coming from?

a. Social participation

- People with dementia are mostly excluded from society and are unable to fulfil their potential;
- People with dementia are disempowered to advocate for their own rights;
- Dementia associations are not well known among all people living with dementia, their families/carers, and in Brazilian society, and are currently unable to advocate for all people living with dementia.

b. Equity and government stewardship

- Brazil currently lacks a National Dementia Plan;
- Dementia is not included as a priority on the agenda of chronic conditions for older people and social protection organisations;
- Lack of access of people with dementia to early diagnosis, which impedes decision-making regarding future plans and care;
- Unequal distribution of healthcare spending across the population lifespan;
- Civil society, researchers, associations do not currently ensure that governments are accountable for their actions, decisions and policies;
- Older adults have free bus pass, but not their carers;
- Gender inequity in dementia prevalence and family caregiving;
- Large number of people who are illiterate, which contributes to poor access to appropriate care, information, and support.

c. Research and technology

- Limited high-quality research available on dementia which impedes the development and implementation of interventions and evaluation of costs;
- Lack of innovative solutions for the care provision for people with dementia in the community;

- Limited amount of data on dementia from the national health system for the purpose of service monitoring.

d. Intersectoral collaboration

- Lack of intersectoral collaboration between Ministries of Health, Education, Social development and Science and technology;
- Lack of collaboration among multiple health professionals for the care provision of people living and dying with dementia.

e. Capacity building

- Professional carers are undervalued by society and caregiving is regulated by a professional association;
- There is a lack of dementia training in the curriculum of health professionals and continuing professional development.

f. Service organisation

- Lack of protocols for the diagnosis, treatment, long term care and referral of people living with dementia in primary care;
- Lack of monitoring and surveillance of the care provided for people with dementia;
- Insufficient number of services for people with dementia and their families across the various phases of the disease and geographical areas of Brazil.

Looking at the future: where do we want to be/go?

- People with dementia, their carers and families live and die well;
- People with dementia are included in society without discrimination and are able to fulfil their potentials;
- Older people in the early stages of dementia are able to access early diagnosis to make decisions about their future and care; and can advocate for their rights.

Overcoming challenges: what do we need to change and how do we do it?

- Development of a National Dementia Plan through intersectoral collaborative efforts;
- Make dementia a public health priority through specific policies and public investment;

- Improve investment on research and on public resources for people with dementia so that people can have access to early diagnosis; good-quality care; treatment;
- Reduce dementia-related stigma and empower people living with dementia to live more autonomous and dignified lives through e.g. provide more support to NGO's such as FEBRAZ (Brazilian Federation of Alzheimer Associations) and their associations; development of regular dementia-focused public campaigns; promote positive views about ageing and evidence-based information about cognitive health (dementia not part of ageing) through social media, TV, radio, schools;
- Improve professional training and knowledge about dementia, especially primary care providers;
- Reduce social inequality among older people and women through e.g. improving access to public benefits for the poorest; flexibilization of public taxation;
- Promote better integration among health professionals through the development of multidisciplinary training and protocols;
- Encourage partnerships between and health services/resources;
- To 'legalise' the paid carer role in Brazil;
- Development and standardisation of clinical tools for dementia;
- To establish the exact societal costs of dementia, including unpaid care;
- Provide better training and support to family carers in the community.

STRiDE Brazil: Draft Theory of Change map

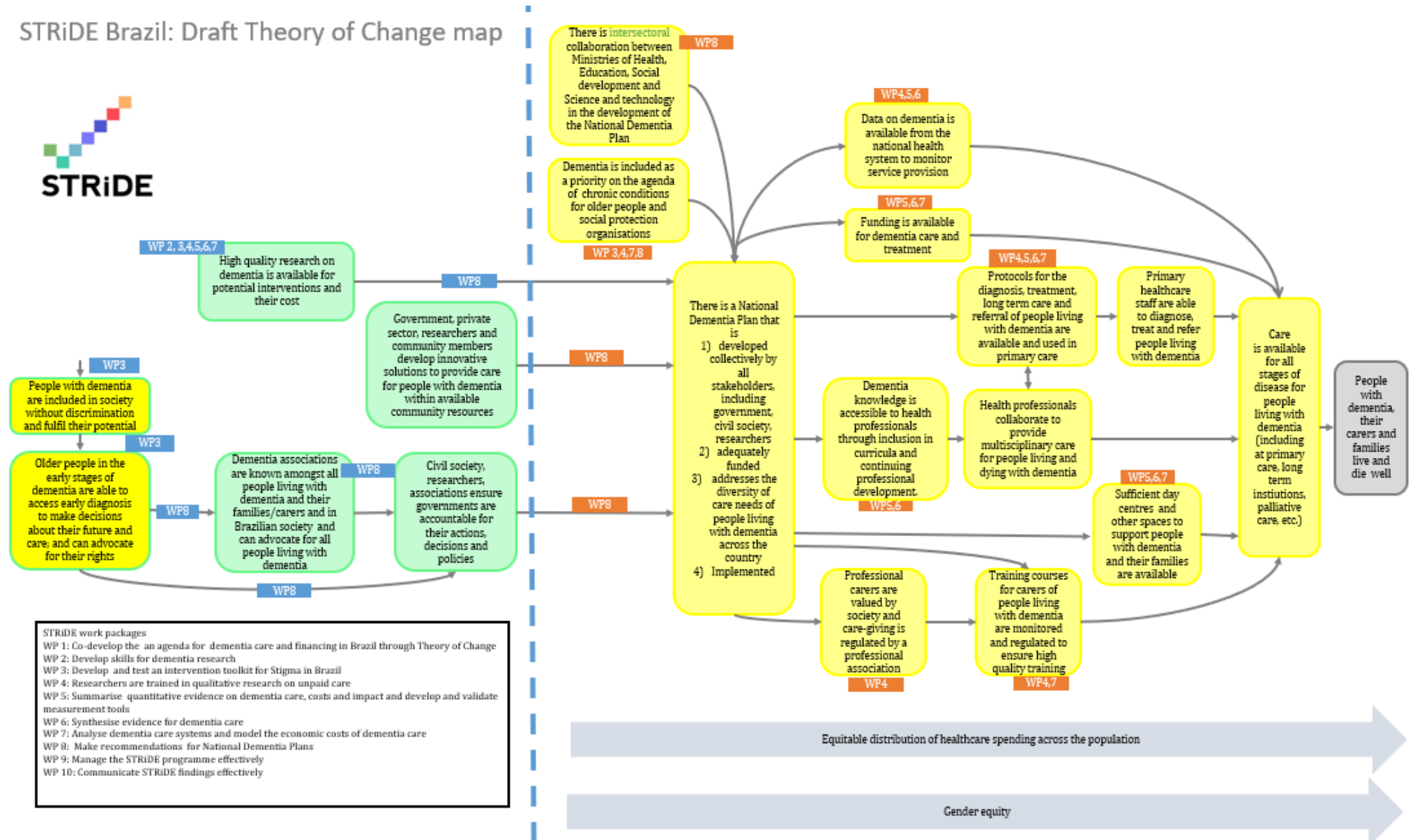


Figure 5. ToC-Brazil Map

Summary of the ToC-Brazil Map

Figure 5 shows the ToC Map created from the key aspects/outcomes raised by the workshop attendees. Outcomes were written in the form of statements and were displayed in the Map in a context/temporal sequence that was logical to participants (one particular outcome was thought by the attendees to be the prerequisite for another to happen). Outcomes were connected through specific STRiDE WPs, demonstrating how each can be achieved through the specific work planned to be carried out within the programme.

As seen in Figure 5, the priority outcomes for Brazil are linked to work to be carried out as part of all STRiDE project WPs and more specifically with WP8 which is focused on *making recommendations to a National Dementia Plan*. Brazil is to be involved especially with WP 3 (Stigma) and WP7 (costs). Working towards meeting these two central themes is likely to have high impact on most of the other outcomes identified as priorities for Brazil. For example, through an anti-stigma intervention (WP3), more people in the early stages of dementia might be able to access early diagnosis to make decisions about their future. This may also help these individuals to be included in society without discrimination and may help them fulfil their potential. Together with the development of a National Dementia Plan (WP8) that should be informed by evidence-based research (WPs 2, 3, 4, 5, 6 and 7 in STRiDE), this anti-stigma intervention (WP3) may help improve the work currently carried out by the Alzheimer's Associations in Brazil and may encourage people with dementia to advocate for their rights. A National Dementia Plan (WP8) in Brazil has the potential to stimulate stewardship from government, private sector, researchers and community members to develop innovative care solutions within available community resources for people with dementia. Civil society, researchers, associations may also be more encouraged to ensure that governments are accountable for their actions, decisions and policies.

Brazil needs a National Dementia Plan (WP8) that is i) developed collectively by all stakeholders, including government, civil society, researchers; ii) adequately funded; iii) addresses the diversity of care needs of people living with dementia across the country; and iv) is implemented successfully. This plan will help ensure that i) dementia is treated as a public health priority in Brazil; ii) knowledge is available to professionals and they can better collaborate; iii) paid and unpaid carers are supported and acknowledged in society; and iv) high quality care is available for all people with dementia so that they can live well from the early to the end stages of dementia ('vision'). The WPs 4, 5, 6 and 7 in STRiDE can help to ensure that the outcomes expected to result from an implemented National Dementia Plan in Brazil are effective and sustainable.

Future directions

Stigma was one of the most common issues mentioned during workshop discussions. As a result, Brazil was chosen to be one of the countries to test the efficacy of an anti-stigma intervention as part of WP3. This may contribute to improve social participation of people with dementia in Brazil, it may help improve access to early diagnosis, empower people with dementia to advocate for their rights, and ‘pressure’ governments to invest and better direct public resources to dementia. It is hoped that the work carried out by the other WPs, such as WP4 on unpaid care and WP5 on quantitative evidence, will also help establish e.g. costs and means for improving care for people with dementia in the community at large. A National Dementia Plan can be developed with the contribution of key stakeholders and is expected to have an impact in most outcomes identified as key priorities for Brazilians with dementia and their families. The next step will be to identify key indicators of success so that the STRiDE team in Brazil can demonstrate the impact of the work carried out towards meeting the outcomes proposed in the ToC-Brazil.

References

1. Alzheimer's Disease International. World Alzheimer Report 2015: The Global Impact of Dementia. An analysis of prevalence, incidence, cost and trends. (2015).
2. Fagundes, S. D., Silva, M. T., Thees, M. F. R. S. & Pereira, M. G. Prevalence of dementia among elderly Brazilians: a systematic review. *Sao Paulo Med. J.* **129**, 46–50 (2011).
3. Lopes, M. A., Ferrioli, E., Nakano, E. Y., Litvoc, J. & Bottino, C. M. C. High prevalence of dementia in a community-based survey of older people from Brazil: association with intellectual activity rather than education. *J. Alzheimers Dis. JAD* **32**, 307–316 (2012).
4. Correa Ribeiro, P. C., de Souza Lopes, C. & Lourenco, R. A. Prevalence of dementia in elderly clients of a private health care plan: a study of the FIBRA-RJ, Brazil. *Dement. Geriatr. Cogn. Disord.* **35**, 77–86 (2013).
5. Cesar, K. G. *et al.* Prevalence of Cognitive Impairment Without Dementia and Dementia in Tremembe, Brazil. *Alzheimer Dis. Assoc. Disord.* **30**, 264–271 (2016).
6. Nakamura, A. E., Opaleye, D., Tani, G. & Ferri, C. P. Dementia underdiagnosis in Brazil. *The Lancet* **385**, 418–419 (2015).

APPENDIX 1

EXAMPLE OF INVITATION LETTER



Strengthening responses to dementia in developing countries

São Paulo, 06 de junho de 2018.

De: Equipe STRiDE

Para: !

Assunto: Convite para Reunião de Apresentação do Projeto e workshop Teoria de Mudança

Prezada

O projeto *Strengthening Responses to Dementia in Developing Countries* (STRiDE) é um estudo multicêntrico coordenado pelo Professor Martin Knapp, da *London School of Economics* no Reino Unido, com a subvenção da *Global Challenges Research Fund UK* (GCRF), para o aumento da capacidade de pesquisas econômicas, epidemiológicas e de políticas públicas para auxiliar países de renda média e baixa a responder às necessidades geradas pelo aumento do número de pessoas com demência de uma forma ética e sustentável.

O estudo tem duração de quatro anos e está sendo implementado no Brasil, África do Sul, Índia, Indonésia, Jamaica, Quênia e México. No Brasil, a Pesquisadora Principal é a Professora Cleusa Ferri, da Universidade Federal de São Paulo (UNIFESP), e o convênio conta também com a participação da Federação Brasileira de Associação para a Doença de Alzheimer (FEBRAZ).

Como parte do início das atividades, temos o prazer de convidá-los a participar de uma reunião no dia 28 de junho de 2018, de 08:30hs às 17:30hs, em São Paulo, no qual será apresentado o projeto e será conduzido um workshop (*Theory of Change Workshop*). O evento será totalmente em Português. Suas opiniões e participação serão fundamentais para o sucesso do projeto no nosso país.

Para tanto, oferecemos estadia na noite anterior ao evento, passagem aérea e almoço durante o dia do evento.

Por favor, confirme sua presença via email para ferricleusa@gmail.com e junotuyama@gmail.com com a sua preferência de voos.

Atenciosamente,

Prof Dra. Cleusa Ferri

Programa de pos graduacao do Departamento de Psicobiologia
Universidade Federal de Sao Paulo – UNIFESP
<http://lattes.cnpq.br/2524029270331859>

APPENDIX 2

WORKSHOP PROGRAMME

Date and time: Thursday, 28 June 2018, 8:30am to 5:00pm

Venue: Hotel Golden Tulip – Alameda Lorena, n° 360, Jardins. São Paulo – SP. CEP: 01424-000

Activities:

08:30 – Welcome

08:50 – Introduction to STRiDE and Theory of Change

09:30 – Participant introduction

10:00 – Activity 1: Identifying challenges – Where are we coming from?

10:30 – Coffee break

11:00 – Continuation of Activity 1

11:30 – Activity 2: Overcoming challenges – Where do we want to be/go?

12:30 – Lunch break

13:30 – Activity 3: What do we need to change?

14:30 – Activity 4: Interventions and strategies - How do we get where we want to be/go?

15:30 – Coffee break

16:00 – Collaborative construction of a ToC Map

17:00 – Closing remarks and end