

Transforming dementia research into policy change: a case study of the multi-country STRiDE project

Abstract:

STRiDE was an ambitious four-year project in seven countries aiming to build capacity around generating and using research to support the development of policies to improve quality of life of people with dementia and their carers. The project's innovative approach combined rigorous academic research and hands-on civil society advocacy. This paper explores the project's unique strategy for policy change and compiles case-studies from several of the STRiDE countries. Finally, we share lessons learned and next steps to keep momentum for policy change going in each of these countries – and beyond.

Introduction

The Strengthening responses to dementia in developing countries (STRiDE) project was a bold, ambitious four-year project in seven different countries (Brazil, India, Indonesia, Jamaica, Kenya, Mexico, & South Africa) across ten different research work-packages. STRiDE was funded by the UK Research and Innovation Global Challenges Research Fund (UKRI) and led by the London School of Economics and Political Science (LSE) in partnership with Alzheimer's Disease International (ADI), Dementia Alliance International (DAI) and other key universities in the seven countries.

The primary aim of STRiDE was to build research capacity to support policies improving quality of life of people with dementia and their carers (family or other caregivers). Country teams produced research evidence to better understand the impacts of dementia in their own cultural, social, and economic contexts to help develop recommendations for planning, financing, and implementation of national dementia plans.

The STRiDE project took an innovative approach to dementia research in that each country team was a partnership between civil society (Alzheimer's or dementia associations) and academic researchers. This unique combination of rigorous academic research and hands-on advocacy recognized that each partner could bring skills to the table that reinforced each other; that advocates need data to make their case to governments and researchers need advocates to identify important research questions, gather and interpret data and present research in a way that is likely to increase impact.

This paper focuses on that unique journey. First, it explores how STRiDE planned a strategy for policy change in each country using theory of change (ToC) workshops and then developed a methodology to help country teams transform research into policy impact. Second, it compiles case-studies from several of the STRiDE countries, describing their unique experiences of pulling together research data and evidence, and how they synthesized these into relevant and persuasive policy messages and recommendations to support the development of national dementia plans. Finally, we share reflections from the entire STRiDE project team regarding lessons learned, outside factors that impacted project progress, and next steps to keep momentum for policy change going in each of the STRiDE countries – and beyond.

Turning research into policy – the STRiDE way

It all started with a Theory of Change (ToC)

In order to develop a strategic pathway for how STRiDE would reach its impact, we embarked on a ToC development process. ToC is a structured approach that clarifies how a project, programme or policy is expected to achieve impact (De Silva et al., 2014). The process defines short-, medium- and long-term outcomes the project plans to achieve, the activities required to achieve them, the assumptions to be upheld for the project to achieve them and the indicators which measure whether the outcomes have been achieved. It is a highly interactive process, enabling team members to co-develop the project as a whole.

The ToC took place at the start of the project in March 2018, when all STRiDE partners participated in a two-day workshop. First, STRiDE partners identified key challenges for developing appropriate dementia care, treatment and support for people living with dementia and carers. Next, the teams focused on STRiDE's intended impact – that people with dementia and their carers live well and do not shoulder excessive costs, risk impoverishment or health problems. Then, in small groups, the partners considered the key steps (outcomes) necessary to achieve this impact in light of the challenges identified. These outcomes were then mapped onto a ToC map together with the STRiDE research activities (specifically the ten work-packages) that were expected to lead to the outcomes. The ToC map became a visual representation of the STRiDE project strategy, describing a pathway with clear outcomes and indicators to measure success.

This process was then repeated in each STRiDE country, enabling a more focused and country-specific pathway for each local team. Key stakeholders across health, long-term care and policy sectors and people with dementia and their carers were invited to participate.

The ToC focused on collaboration with stakeholders, building research capacity and gathering evidence. We also focused explicitly on knowledge exchange, impact, and engagement (KEIE) activities that enabled researchers and civil society partners to disseminate project learning to increase impact and to use this as an advocacy tool for policy change. A substantive section of the ToC map focused on what, beyond the project itself, needed to be in place for people with dementia to live well in each of the STRiDE countries. Important factors were inclusion of people with dementia, policies and plans, accountability and monitoring, political will, government leadership, financing, health and social care systems, workforce and training, identification and treatment/care and unpaid care. The process and resulting ToC maps have been described elsewhere in detail by Breuer et al. (2022a).

Developing a strategy for policy impact

To bring about policy change identified in the programme ToC, we recognised that persuading governments to change or adapt new policy is a complex, multi-faceted process. There are multiple factors that contribute to success of a policy process, each playing a supporting role to achieve change.

The Population Reference Bureau (PRB) developed a model of policy change which describes the policy process as an interaction between three key spheres (Ashford et al., 2006): *issues or problems* are identified, possible *solutions* are formulated, and the *political environment* in which events are often happening independently, not necessarily related to specific problems or solutions. It is when these three spheres come together that a *window of opportunity* is created, in which policy change can take place (Fig. 1).

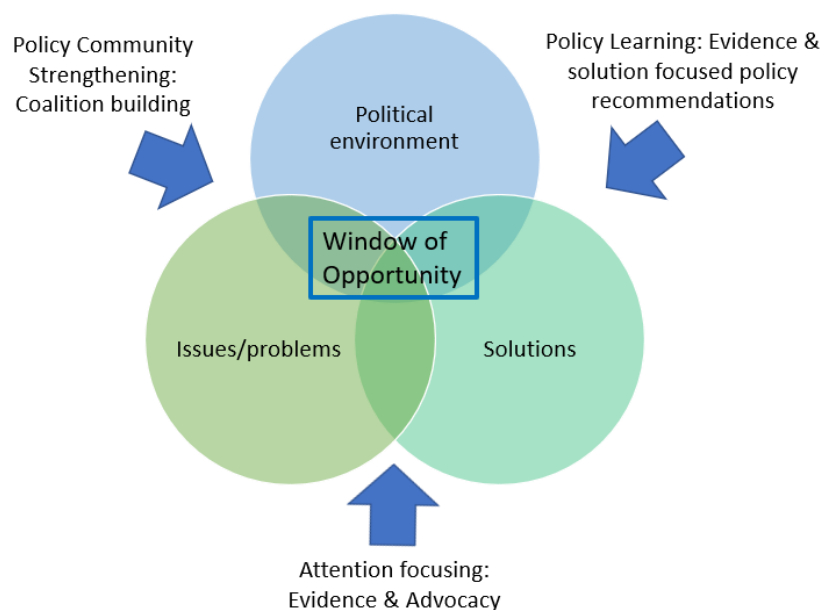


Figure 1 Turning research into policy action. [Adapted from Ashford et al, WHO Bulletin \(Ashford et al., 2006\)](#)

During STRiDE we actively worked to create these windows of opportunity in each country in line with PRB's model of policy change by defining the problem, suggesting solutions, and obtaining political consensus (Porter, 1995).

To do this, STRiDE country teams used research to undertake three types of activities to create policy windows (Ashford et al., 2006):

- 1) **Evidence and advocacy** Teams were encouraged to use evidence and advocacy to help with *attention focusing* to emphasise key issues and get them onto their government's political agenda. For example, one work package of STRiDE focused on stigma, with country teams gathering data to highlight gaps in knowledge and attitudes toward people with dementia. Stigma was also the theme of ADI's 2019 World Alzheimer's Month and country teams dovetailed their advocacy efforts to underpin the global ADI campaign theme with local evidence on stigma; resulting in more relevant and impactful advocacy and focused social media campaigns to garner public support and pressurize governments to react.
- 2) **Policy community strengthening** STRiDE conducted two important stakeholder mapping exercises that helped identify opportunities for *coalition building*, creating and/or strengthening these partnerships to ensure sustained interest in a specific policy issue. First, key stakeholders were mapped out and included in the ToC process. Second, as part of KEIE activities, valuable stakeholders were mapped to build alliances around communication, dissemination, and advocacy. Many of these stakeholders were then invited to take part in National Advisory Groups (NAG) established in each country to advise and guide project work. The NAGs met regularly and were highly interactive, with stakeholders sharing their expertise and encouraged to use their sphere of influence as champions for policy impact.
- 3) **Policy learning** STRiDE teams were encouraged to use research data to enable *policy learning*; helping to increase the knowledge that policy makers have around dementia based on evidence and solution-focused recommendations. STRiDE teams used data gathered throughout the project and evidence garnered through interviews and focus groups to pinpoint policy priorities. Country teams then developed focused policy messaging. Some countries were able to develop policy briefs that highlighted key issues and

recommendations for policy makers. The Indonesia team was able to present STRiDE data to their Minister of Health, which led to a working group to evaluate Indonesia's current dementia plan. Changes based on these recommendations will be piloted nationally.

Building advocacy through solid policy messaging

We worked from the understanding that policy messaging, underpinned by robust evidence was the first step in building momentum and consensus around new research that could be used in formal policy recommendations. Good policy messaging can be a powerful tool not only to influence policy makers, but also to capture public attention and galvanise support.

Figure 2 Action areas of the global action plan on dementia. From *Plan to impact V, 2021 (Alzheimer's Disease International, 2022)*



The project fostered four important components of effective policy messaging. First, there must be a *clear policy goal*. STRiDE encouraged the development and implementation of national dementia plans that align with the [World Health Organization's Global Action Plan on Dementia \(GAPD\)](#) which was passed unanimously by member states in 2017, focusing on the seven action areas listed in Figure 2. Second, policy messaging must be *evidence-based* and linked directly to STRiDE *research findings*. Third, policy messaging needs *context*: STRiDE teams needed to ensure they demonstrated *why* their research findings are important and what the *implications* could be if nothing is done. Finally, the policy message needed to be *action-oriented* with specific and solution-focused *recommendations* (Population Reference Bureau, 2016).

To target policy makers who are generally non-specialists and have limited time, we kept messages short, easy to read, succinct and solution-focused with clear recommendations (Green, 2014). We used different ways to compile evidence from STRiDE into coherent and compelling policy recommendations to governments. As project evidence grew, we were able to expand our policy

messaging into policy papers and short policy briefs outlining key research findings and providing a call to action and recommendations for policy reform as a way to facilitate initial discussions with governments.

The following case-studies describe the journey of several STRiDE country teams as they moved from identifying key gaps in dementia care to gathering data to form evidence-based, solution-focused messaging and policy recommendations.

Country case studies

Brazil

Identifying gaps and key issues

Brazil is a country with 208 million inhabitants, and an estimated 1.8 million people with dementia. By 2050, Brazil will have the world's fourth-largest older population, and an expected prevalence of dementia of approximately 5.7 million (GBD 2019 Dementia Forecasting Collaborators, 2022)

The Brazilian healthcare system is poorly prepared to deal with the challenges faced by people with dementia (Mattke et al., 2023). Access and pathways to care, care standards, and the built environment are inadequate (Alzheimer's Disease International & Global Coalition on Ageing, 2018)

and almost non-existent (Da Mata et al., 2022). Stigma and discrimination related to dementia are pervasive producing shame, symptom and diagnosis concealment, negative social interactions, reduced access to care networks and social participation, and even suicide (Oliveira et al., 2023). Effects are extended to carers and include managing health and finance risks (Ibanez et al., 2021).

Currently, there are no national strategies or plans that prioritise dementia. Recently, a bill was put before the Brazilian Chamber of Deputies (Bill 4,364/2020) regarding dementia, but it lacks comprehensive and humanized care for people with dementia and their families. Despite some local governments outpacing the national agenda in responding to dementia, the number of initiatives and their scope are insufficient to give access and quality support to the estimated number of people with dementia in the country.

Gathering data to build evidence-base

The Brazil team, together with members of the NAG and other key-stakeholders, explored the dementia care landscape (Da Mata et al., 2022), perceptions of stigma (Oliveira et al., 2023), and care pathways and experiences of people with dementia and their families (Da Mata et al., 2022).

Throughout the STRiDE project, data-gathering and network-building were critical to inform actions, interventions, and policy recommendations. Some of the key findings from the work packages were grouped into three main issues: (1) stigma related to dementia; (2) dementia care pathways; and (3) evidence informed recommendations (Table 1).

Table 1: Solution-focused policy recommendations

Dementia care gaps	Recommendations
Stigma related to dementia	<ul style="list-style-type: none"> • As part of a national educational programme, implement an anti-stigma intervention to improve knowledge, attitudes, and behaviours in relation to people with dementia among community health workers (Oliveira et al., 2023). • Include people with dementia and their families in awareness raising campaigns, research design, and anti-stigma programmes and activities (Lorenz-Dant et al., n.d.). • Increase public education and awareness by working together with other civil society organizations (i.e., other chronic diseases).
Dementia care pathways	<ul style="list-style-type: none"> • Include dementia in the national law Statute for the Person with Disability. • Encourage the development and implementation of care pathway protocols integrated to the MoH’s existing national Family Health Strategy Program - a state-funded free health programme with the potential to provide care and support for people living with dementia, from pre-diagnosis until end-of-life. • Review the MoH’s Clinical Protocol and Therapeutical Guidelines – Alzheimer’s disease, to include referrals to non-pharmacological interventions.

Evidence informed recommendations	<ul style="list-style-type: none"> • Keep providing knowledge translation into effective evidence-informed policy and programming. • Continue to assist in developing a national dementia plan.
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Barriers and facilitators for a dementia policy and plan

Political instability, the social and economic consequences of COVID-19 pandemic, low levels of awareness and stigma are barriers to the development of policies and programmes which concern people with dementia and their families in Brazil. Currently, there are low public funding levels available for dementia-specific programmes, no government-led national dementia campaigns, poor political will, poor health professional dementia training, and lack of integrated health systems. However, we believe the recent political changes, moving away from extreme right-wing ideologies (The Lancet Editorial 2022, Nature Editorial, 2022), coupled with contextualized research evidence and an enlarged community of stakeholders will facilitate advocacy strategies to increase social engagement and garner more support for our recommendations.

India

Identifying gaps and key issues

The STRiDE India team included members from Alzheimer’s & Related Disorders Society of India (ARDSI), a neurologist, a psychiatric social worker, a psychologist, and a researcher. Following the country ToC workshops, the STRiDE India project focussed on the following areas:

- Conducting a situational analysis involving a desk review, stakeholder interviews, case vignettes, Strengths, Weaknesses, Opportunities and Threats (SWOT) analysis and consultative interviews with experts/National Advisory Group members.
- Estimating the costs of dementia care in India and use simulation modeling to project the resources needed for its improvement.
- Investigating the impact of stigma around dementia with views from the general public, health care practitioners and the person with dementias’ families through focus group discussions with stakeholders in Chennai and Delhi.
- Ascertaining unpaid carer costs through interaction with family carers of people with dementia in Bengaluru and Hyderabad

Gathering data to build evidence-base

The ToC clearly highlighted the need for a dementia policy, improved diagnosis, carer economic support initiatives, and enhanced dementia care services to improve the quality of life. A review of the initial ToC by the ARDSI team will provide guidance for the next five-year phase of work.

The situational analysis is a comprehensive document contextualizing the dementia landscape. Together with the case vignettes, it revealed existing but fragmented support services and service providers and gaps to be addressed. The SWOT analysis presents a framework of needs and demands addressing dementia care, capacity building and allied activities.

The stigma research findings showed that there is poor understanding of dementia across different sections of society, leading to discrimination and a lack of empathy and the requisite caregiving skills. There is an immediate need to strengthen awareness and dementia friendly initiatives. Videos and short clips were prepared which could help in changing attitudes and increasing understanding.

Initial results from the unpaid carer costs study show high levels of emotional impact, and important economic burden on families. These findings will be used as evidence to advocate for carer support packages in a holistic policy.

Solution-focused policy recommendations

The STRiDE outcomes shall be used as evidence to showcase pressing gaps and to help devise strategic actions, while making a clear case for allocation of resources to policy makers in India. Globally, the similarity of findings across the STRiDE countries would help in creating synergy inviting attention of global development agencies aimed at encouraging resource allocation to address seven action areas as listed in WHO's Global Action Plan.

Inputs from STRiDE will also help provide evidence to support initiatives that can have a large impact in public health domain such as the Karnataka Brain Health Initiative (KBHI), the Kerala State Initiative of Dementia (KSID), and District Mental Health Programme under the National Health Mission.

Table 2: Priorities in addressing dementia care gaps in India

Dementia care gaps	Recommendations
Stigma and discrimination due to poor awareness	<ul style="list-style-type: none"> • The work package 3 study has highlighted the need to raise knowledge of dementia across different sections of - the general public, family carers and health professionals. • The findings throw light on the existence of derogatory references, incidents of patient abuse and lack of professional ability to handle persons with dementia. These findings indicate the need for awareness, training to improve knowledge, attitude, behaviour, and best practices to handle people living with all forms of dementia.
Present Risk reduction measures	The situational analysis reveals the present policies and measures ensuring risk reduction as part of the national non-communicable diseases policy. The need to explore complementing strategies to cater to the needs of patients with dementia is important.
Diagnostic and Institutional care requirements	The Theory of change clearly illustrates lack of diagnosis and the situational analysis under the SWOT re-affirms the strategies required to enhance diagnostic facilities for timely diagnosis, creation of care facilities and demand for low resource later stage dementia care. All this has to be included as part of policy framework for dementia.
Training for better dementia care management	The unpaid carer costs work package and work package on stigma clearly shows the need for person centered care management, training for both family members and professional carers for quality care management of people with dementia and the need for strengthening existing professional care capacities.

Jamaica

Identifying gaps and key issues

Jamaica's population of people over 60 is projected to be 18% of the total population by 2050; with increased prevalence comes increased costs. To date, there is no national dementia policy, plan, strategy, or dementia-specific public health guidelines. The STRiDE Jamaica team carried out a multi-pronged methodology with data gathering via stakeholder engagement, document review for a country-specific situation analysis and in-depth interviews with local and regional policymakers on the feasibility of implementing dementia policies and plan(s) in Jamaica. The team also prioritised

KEIE activities throughout the entire period of the project. Between 2018 through 2022, we engaged in over 90 educational events including information booths at ministry and university events, talks at churches, media appearances, and presentations at policy meetings and professional and community organisations. The team, including two members trained in Advanced Clinical Practice in Dementia Care, also provided free virtual dementia care management consultations to over 70 Jamaican families since 2020, many of them repeat clients.

Gathering data to build evidence-base

Key findings from the various work packages are summarised in terms of our lessons learnt regarding (1) stigma and dementia in Jamaica; (2) the costs informal carers bear; (3) long-term care; and (4) barriers and facilitators to a dementia policy and plan. Recommendations are summarised in Table 2.

Stigma and dementia in Jamaica

Stigma is a major barrier for people with dementia and their families. While many interviewees and KEIE activity participants shared that community reactions to the disease have improved in past decades, they noted that fear or discomfort remain and can lead to social isolation or mistreatment of persons living with dementia. In keeping with global data, many – including healthcare practitioners themselves – shared that healthcare practitioners, including general practitioners who are often the first port of call, still generally believe that dementia is a normal part of ageing. Many therefore never receive a formal diagnosis. There was a general call for increased public education and awareness.

Costs informal carers bear for dementia care

In addition to the emotional and psychological costs of care, our findings indicated the significant financial costs that informal carers bear for dementia care – both direct (e.g., out of pocket expenditures) and indirect (e.g., productivity costs). Currently, Jamaicans lack equitable access to medication for common non-communicable diseases (NCDs), and only about 20% of the population has any insurance. Yet less than 30% of persons aged 60 and older are enrolled in the National Health Fund's (NHF) Jamaica Drugs for the Elderly (JADEP) medication subsidisation programme, with a much higher participation by the better off sectors of the population, who should be able to afford private insurance. Furthermore, no type of dementia is listed as an NCD covered by the NHF. In terms of where care is provided, even though care homes may seem like a logical option, the average cost of a private nursing home is very expensive, generally unregulated and lacking the infrastructure and the capacity to effectively care for dementia patients.

Long-term care (LTC) policy and programming

LTC is not yet common or widely understood nor are there any LTC policies in the Caribbean. Over 70% of older Jamaicans have a chronic illness, a dementia risk factor. Persons over 65 who have dementia are likely to have up to four other NCDs and shared risk factors. Our assessment of existing guidelines, regulations, services, and programmes indicated that the landscape designed to serve older adults, persons with mental health challenges, those with or at risk of developing NCDs and persons living with a disability is characterised by siloes and under-funding. In a paper mapping the long-term care sector in Jamaica, we concluded that a formal LTC policy or strategy is especially crucial, and that factors such as affordability, stage of dementia, in-home infrastructure, and the ability to remain in the labour market impact decisions about placing a family member in a care facility (Govia et al., 2021). Given the transnational nature of Jamaican life, another non-traditional yet crucial support to the informal LTC sector in Jamaica is remittances.

Table 3: Key findings, lessons learned and initial recommendations

Dementia care gaps	Recommendations
Stigma and dementia	<ul style="list-style-type: none">• Formal dementia-specific training for nurses, care home workers and health and social practitioners.• Dementia sensitisation that begins in schools so knowledge and awareness can be cultivated with young people.• Public-private partnerships to raise awareness.• Funding for dementia education and support for caregivers.
Costs informal carers bear for dementia care	<ul style="list-style-type: none">• Encourage and enable Jamaicans aged 60 and older to enroll in the National Health Fund's (NHF) Jamaica Drugs for the Elderly (JADEP) medication subsidisation programme.• Ensure equitable access to medication for common NCDs and include dementia as a listed NCD under the NHF.• Add anti-dementia medication to the JADEP programme.
Long-term care	<ul style="list-style-type: none">• A formal long-term care policy is crucial.

Barriers and facilitators for a dementia policy and plan

Our research on policy making processes has revealed that factors such as lack of political will, low levels of awareness, absence of legislation relevant to dementia-inclusive communities and services coupled with high levels of stigma among policymakers themselves affect policy decisions. Jamaica may, therefore, be well positioned for the implementation of a standalone national dementia plan which focuses on the most contextually relevant and urgent areas of the WHO seven priority areas. Despite these barriers, there are strong champions and advocates and a growing community of stakeholders pushing for funded dementia policy.

Solution-focused policy recommendations

Policy briefs focusing on the long-term care sector, stigma, and public awareness, and stand-alone versus integrated approaches to a dementia policy are being finalised. However, Jamaica is still in need of systematic data collection on dementia to better grasp the scale of dementia. The addition of anti-dementia medication to the JADEP programme can be a helpful data capture tool as it registers rates of usage. The disaggregation of public mental health clinic data to specify dementia diagnosis with an attention to differential diagnosis was also recommended to facilitate improvements in the Jamaican dementia care landscape. Research with informal caregivers revealed a pressing need for post-diagnostic support (carer support groups, caregiver relief and clearer signposting to trustworthy sources of information and advice). In addition, large scale and targeted

public education campaigns in tandem with legislation are needed to help families navigate the issue of reduced capacity in dementia and guide financial institutions in protecting clients living with dementia.

Kenya

Identifying gaps and key issues

During the course of the STRiDE project, the Kenya team conducted a situational analysis (Musyimi et al., 2022a) to map dementia care pathways, identifying gaps related to supporting people with dementia and their carers. The team also developed a policy summary (Musyimi et al., 2022c) with key messages that were important for setting dementia care priorities, helping to develop policy recommendations to improve dementia care in Kenya.

Sharing evidence-base and solution-focused policy recommendations

The team held a final project dissemination workshop, where the STRiDE Kenya team shared project findings and reviewed progress to date. The various stakeholders affirmed that STRiDE contributed to a great extent in creating awareness and reducing stigma on dementia through working with community health workers (Musyimi et al., 2022b) and assisting in developing the National Dementia plan (ongoing). They acknowledged that there is no single strategy that can solve dementia care gaps in Kenya. Nevertheless, there are a number of lessons and actions that can be garnered from the STRiDE Kenya project to inform decision-making at the individual, community, and policy levels. Working together, the STRiDE Kenya team and key stakeholders specifically identified four priorities and recommendations to address dementia care gaps; increasing the health care workforce, reducing stigma and discrimination in communities and health care settings and improving knowledge sharing (*table 4*). This could be further enhanced beyond STRiDE through more policy actions, resilience in stakeholder engagement and funding through local and international partnerships to improve dementia care.

Table 4: Priorities in addressing dementia care gaps

Dementia care gaps	Recommendations
Limited dementia-care workforce and support	<ul style="list-style-type: none"> • Improve collaborative dementia care including palliative care, social development sectors and members of the general public. • Integrate dementia care screening at the community level (empower traditional and faith healers, community health workers and primary health care settings) and training in institutions.
Dementia knowledge sharing gaps	Share lessons learnt and evidence-based practices with policy makers in order to align their agendas with ongoing activities and stimulate data-informed policy making.
Self and public stigma	Create awareness through STRiDE output materials, across multiple platforms i.e., print and electronic e.g., social media, YouTube channels, mobile applications etc.
Exclusion of people living with dementia and their carers	Amplify the voices of people living with dementia and their carers by providing opportunities for individuals to share experiences with dementia during intervention development and policy discussions whilst acknowledging their strengths, capabilities, interests, aspirations and encouraging people living with dementia to live their best lives.

Although there are competing developmental and health needs at the policy levels, we plan to work with various stakeholders in academia, government, private and civil organizations to prioritize dementia care nationally and locally.

One highlight of the STRiDE project was the contribution of evidence to the ongoing development of Kenya's national dementia plan, while acknowledging the gaps identified in the plan such as lack of data and late dementia detection resulting in delayed care. A new grant, building on STRiDE, through the Davos Alzheimer's Collaborative will redeploy community health workers trained within STRiDE to screen 2,400 individuals aged 60 and above for dementia. The aim is to increase early dementia detection in community and primary health care settings. This will contribute towards data-informed policy making and identify areas of intervention focus for improved quality of life.

Mexico

Identifying gaps and key issues

There are approximately 1.6 million people with dementia in Mexico (de Langavant et al., 2020), however, dementia is not recognized as a public health priority and no national-level dementia diagnosis and management strategies are in place. As a result, unpaid family carers and civil society associations provide most of the care and support needed by people with dementia. Stigma and lack of knowledge about dementia represent major constraints to timely diagnosis, with the majority of individuals and family members seeking health services in late stages when symptoms are most challenging (Gutierrez-Robledo & Arrieta-Cruz, 2015).

New services to support those living with dementia and their families are needed urgently; however, this takes time to plan, finance and implement. In the immediate future, actions to increase knowledge and awareness of dementia and its social impact should be taken. It is important at the societal level and in public and private health and social services, that individuals know the full impact of dementia; its risk factors and how to reduce them, its symptoms and how best to communicate with those affected. As long as society lacks information and policy makers remain indifferent, it will be harder to take any action.

Gathering data to build evidence-base

After four years of participation in STRiDE, the Mexican Alzheimer's Federation (FEDMA) and its affiliated associations, recognise the importance of collaborating with academia and public institutions for the voices of people with dementia and their carers to be heard. Sharing experiences and data, building capacity, and generating communication materials helps to promote and improve our work and creates a friendly environment for people with dementia, their caregivers and family members. Through FEDMA's collaboration with the National Institute of Geriatrics in Mexico and colleagues across the seven STRiDE countries, we have acquired training, tools, and evidence that can be passed on to relevant decision makers in government. We will use the data and materials generated to reinforce our role as main stakeholders representing civil society and strengthening networks with other governmental and non-governmental sectors.

Solution-focused policy recommendations

Based on the information from the situational analysis, including a SWOT analysis and interviews with key stakeholders, we are generating four policy briefs, each for a targeted audience: the 21 Alzheimer associations affiliated to FEDMA; primary care health professionals; public mental health services; and professionals from various fields. Considering each group's profile, these will include basic information on dementia, the needs of both people with dementia and their environment, how to cater specific services to better support them. Additionally, we will continue our collaborative network to increase knowledge, fight stigma, and create more dementia-friendly spaces. Specific

opportunities identified in the SWOT that may enable implementation of dementia care strategies include the reform that unifies psychiatric and mental health services at the MoH that would bring a more comprehensive care of mental/brain health. Key recommendations are summarised in Table 5.

Table 5: Recommendations to address dementia care gaps in Mexico

Dementia care gaps	Recommendations
Lack of dementia diagnosis and management strategies	<ul style="list-style-type: none"> • Generate a National Dementia Action Plan for the detection, diagnosis and treatment/management of cognitive impairment and dementia based on primary care services. When generated, Action Plans are required to get a budget allocated. • Establish a national referral system so when cognitive impairment is detected, individuals can be referred to other services for confirmatory diagnosis impairment/dementia or discarding other conditions.
National Plan published but slow implementation	Generate a coordinated consensus within the STRiDE National Advisory Group to prioritise actions within the Plan that can be implemented in the short and medium term.
Knowledge and evidence gaps	<ul style="list-style-type: none"> • Increase social awareness and reduce stigma through communication campaigns and dissemination of information, making sure to include the voices of people with dementia. • Strengthen collaboration between Alzheimer’s associations and policy makers to share experiences and use this to inform policy planning and implementation process. • Train primary health care practitioners in cognitive impairment and dementia care • Generate research on the social and economic determinants and impacts of dementia and dementia care and make this information available to policymakers. • Integrate a national registry and information system to follow up on diagnosed cases and their management / treatment.
Need for capacity building within Alzheimer’s associations	<ul style="list-style-type: none"> • Build upon experience of the Alzheimer’s associations in STRiDE to strengthen their capacity building. • Support the professionalization of Alzheimer’s associations, allowing them to increase their financial autonomy and advocacy work to further support people living with dementia, their caregivers and family members. • Strengthen their capacity as advocacy groups by working together with policy makers.

South Africa

Identifying gaps and key issues

Dementia is currently not recognised as a policy priority in South Africa, with no national dementia plan or dementia-specific services provided at primary healthcare level. Existing health, care, and support services for people with dementia and their families are largely inadequate (Lloyd-Sherlock, 2019). Pathways to diagnosis and care are characterised by historical inequities in access, structural stigma, and disparities in skills and understanding to detect and manage dementia (Jacobs et al., 2022). Social care and support (including long-term care) for people with dementia, are largely provided by a severely under-funded non-governmental organisation (NGO) sector and a private sector that caters for the minority of South Africans who can afford expensive out-of-pocket

payments. Therefore, most people with dementia are cared for at home and supported by their families (Gurayah, 2015) who are negatively impacted by widespread poverty, inequality, and unemployment. There is no routine monitoring and evaluation of dementia within South Africa's health and social care sectors. Overall, there were no reliable data sources available to inform priority setting with only small, localised studies available (Marais et al., 2006; Bigala & Ayiga, 2014; De Jager et al., 2017; Meel, 2017; Kotze, 2018) highlighting the need for more information.

Gathering data to build evidence-base

STRiDE data provides the unique opportunity to inform policy prioritisation and development, with key findings from the work packages summarised in terms of our lessons learned regarding (1) stigma and dementia in South Africa; (2) prevalence and the impact of dementia at the household and community level; (3) risk of elder abuse among people with dementia; and (4) our multi-stakeholder engagements about dementia policy prioritisation and development. Recommendations are summarised below in Table 6.

Stigma and dementia

People with dementia and their informal, family carers experience high levels of internalised, public, and structural stigma (Lloyd-Sherlock, 2019). Stigma negatively impacts help-seeking behaviour, where service users tend to self-isolate (internalised stigma) or hide family members with dementia from negative community reactions or harmful beliefs (public stigma). Structural stigma within the public health sector included a lack of understanding and training on dementia affecting access to diagnostic services, post-diagnostic support, treatment and care while rendering the public health sector unprepared to meet the needs of people with dementia (Lloyd-Sherlock, 2019).

Local prevalence estimates and impact

Based on a household survey conducted in two areas in South Africa, prevalence of probable dementia for people aged 65 years and older is estimated at 13.7% (10.5-17.5) (unweighted), and when weighted by national age, sex and literacy estimates prevalence is estimated at 11.8% (95% CI = 8.9-15.2). Overall, people with dementia report poorer quality of life than those without dementia, with only 1 in 56 (i.e., 1.8%) people with dementia having accessed a formal diagnosis when compared to other conditions such as hypertension (55.1%), diabetes (20.6%), heart conditions (13.1), and stroke (3.1%). Most people identified with dementia (86%) reported needing care, of which 48.2% need care 'much of the time'. Most carers are female (80.4%) and economically inactive, exacerbating the impact of poverty, inequality, and unemployment.

Elder abuse and dementia

Elder abuse in South Africa is high, with people with dementia being particularly vulnerable. Survey data shows people with dementia are four times more likely to be at risk of abuse from carers than those without dementia (OR 3.96, 95% CI). Current health and social care structures locate most people with dementia within a household that is unsupported, fuelling known risk factors for elder abuse. There are insufficient services currently available to older persons who need help at household or community level; with no national helpline or NGO that offers information, protection services, legal counsel, and support outside of existing (and overburdened) public social care services.

Multi-stakeholder engagement on policy prioritisation and development

Part of the research involved in the STRiDE project included stakeholder interviews and engagement to better understand priorities across the health and long-term care sector, particularly around policy impact. When advocating for dementia policy prioritisation and development, stakeholders from the social care and support sector stressed the importance of local data. Policy decision-makers

primarily respond to local data, with preference given to public health concerns that are prioritised and monitored by state entities such as Statistics South Africa (STATSSA). Therefore, lobbying for dementia should start with lobbying the correct partners and establishing dementia as a national public health concern by including dementia as a condition monitored and evaluated by existing surveillance entities. There was also considerable debate about whether a national dementia plan or strategy should be mobilised as a standalone policy or integrated into existing ones. While stakeholders from the social care and support sector were adamant that a standalone policy was needed to mobilise resources across sectors, many (including the health sector) felt that generating funding support for a standalone policy (especially in the context of competing priorities) is highly unlikely and that the most effective way to prioritize dementia would be to integrate it into existing policies such as the Older persons' Act (no.13 of 2006) (Government Gazette, 2006), the Health Act (no.61 of 2003) (Government Gazette, 2003), and the Mental Health Act (no.17 of 2002) (Government Gazette, 2002).

Currently the South African government does not have structures to which stakeholders can be held accountable for inter-sectoral plans. For example, the Department of Health cannot direct the Department of Social Development on any matters, or vice versa. Therefore, the government stakeholders consulted suggested that the dementia agenda must be led by top management and specifically sanctioned by the Director-General's office in each relevant department. Clear dialogue between stakeholders is needed and intersectoral collaboration with clear roles and responsibilities assigned to each sector, supported by structures in place to enforce accountability.

Solution-focused policy recommendations

Dementia prevalence in South Africa is high and increases with age. There is a critical need for awareness and understanding of dementia, and to lobby policy decision-makers to prioritise the development of a national strategy. Developing a standalone dementia policy may be a long-term goal, however short-to medium term goals can be achieved by integrating dementia into existing policies that strengthen current structures and services to identify, support and manage dementia from the ground up. Local STRiDE data supports this process and is the first step towards the mobilisation of policy decision-makers to (1) prioritise and strengthen responses to dementia in South Africa; and (2) set priorities that support intersectoral collaboration and developing a coordinated response to this public health concern.

Table 6: Evidence informing recommendations for policy prioritisation

Dementia care gaps	Recommendations
Stigma and dementia in South Africa	Addressing stigma at structural, community and inter-personal levels is critical to strengthen existing health systems, promote help-seeking behaviour, support timely diagnosis, and to improve quality of life for people living with dementia and their families in South Africa.
Prevalence and impact of dementia at household and community level	<ul style="list-style-type: none"> • Historical inequities in access to healthcare services in South Africa needs to be addressed to support people living with dementia and their families to access timely diagnostic services, supportive treatments and social care and support. • Project data demonstrates a need to strengthen community-based health and support services that alleviate social and economic pressures at the household-level.

Risk of elder abuse among people living with dementia	There is a need for integration of protection and justice services for older persons and particularly people living with dementia in South Africa, with clear referral and support structures in place.
Multi-stakeholder engagements about dementia policy prioritisation and development	<ul style="list-style-type: none"> • While some stakeholders supported the need for a standalone dementia policy, many felt the most effective way to approach dementia prioritisation would be to strengthen existing policies and integrate dementia into these. • There is a need for dialogue between stakeholders and intersectoral collaboration with clear roles and responsibilities assigned to each sector, supported by structures in place to enforce accountability.

Reflections, lessons learned, and next steps

As a final chapter to the STRiDE project, team members met one last time in June 2022 to revisit the original ToC and to reflect on progress, recognise barriers to certain outcomes and to plan next steps.

Partners agreed that most of the assumptions and outcomes of the original ToC remained relevant. Although issues highlighted as gaps in care still existed, STRiDE research had made inroads to raise awareness of these issues and to gather data and evidence to use in efforts to change policy. Most country teams agreed that the STRiDE project, including the initial ToC workshops, had been instrumental in focusing attention on dementia care gaps in their countries and that the interconnectedness of the different work packages enabled teams to develop an evidence base to make tailored, responsive recommendations to governments.

There were policy gains in Kenya and Indonesia, where STRiDE teams were able to meet with ministries of health and influence dementia policy drafts. In Kenya, the ministry of health had committed to developing a national plan at the ADI Africa regional conference in 2018 and this was advanced further by project evidence and advocacy. ADI sent a letter welcoming the new Indonesian Minister of Health and used this as an opportunity to make him aware of STRiDE's work. This opened a door for members of the project to meet directly with the minister to sensitise him to the impact of dementia and to recommend interventions to revise the current dementia plan and improve care across the country. In Brazil, a senior researcher from STRiDE was an advisor on a team putting together a dementia bill to be passed through the Senate. This enabled the STRiDE Brazil team to suggest input based on project evidence.

Policy progress was slower in the other four countries, much of this due to the impact of Covid-19, lack of political will or changes in government that reshuffled ministry of health contacts. However, each country team was able to assemble policy summaries using data and evidence from STRiDE work packages to highlight key gaps and make practical recommendations to make the case for a standalone dementia plan or for dementia to be integrated into another plan.

The unique partnership between researchers and Alzheimer's associations was a strong point and all agreed should be continued in future, particularly toward the goal of policy change. The project helped identify the most appropriate ways to plan for dementia in each country; whether a stand-alone dementia plan was feasible or if an integrated plan and policy was more practical. We also reflected on the challenges and successes of including people with dementia in our stakeholder engagement activities, with recommendations for action (Breuer et al., 2022b). An important theme in the discussion was an acknowledgement by partners that outside forces had impacted STRiDE,

delaying and, in some cases, halting activities. The Covid-19 pandemic was the most significant of these, interrupting data collection across the project, greatly affecting how we were able to proceed with stakeholder engagement and substantially changing the priorities of policy makers. In addition, funding cuts from the UK government limited our ability to disseminate our findings and to gather stakeholders together across the project to share project outcomes.

Finally, the STRiDE group suggested ways in which we can continue to share experiences, processes, and findings – both across and beyond STRiDE countries – to disseminate outcomes and to plan for further impacts in the future.

Specifically, future areas of work include:

- **Research** replicating the STRiDE methodology across regions, with a focus on developing, adapting, and implementing interventions using rigorous methods, including implementation science to translate research into practice and health interventions.
- **Advocacy** creating a clear case for dementia care and the development of dementia plans or inclusion of dementia in other plans in some contexts.
- **Remaining connected** to amplify existing work and develop a network to apply for funding to continue and expand on the above work.

With this in mind, the senior team of the project and many team members across the STRiDE community are developing the STRiDE Network to encourage and enable STRiDE-like research to be conducted across different countries and regions.

In conclusion, STRiDE was a unique and ambitious project that brought together individuals in academia and civil society to tackle an issue they felt equally passionate about, using their unique strengths. Although levels varied from country to country, overall, the project achieved policy impact. But policy *change* takes time. Beyond the fact that Covid-19 impacted data collection and distracted policy makers, it became clear that STRiDE's policy-wins were around building capacity around the *process* of policy change. The collaborative collection of data, building stakeholder coalitions, creating policy messaging and strategic advocacy are only small pieces of a broader, more complex, puzzle. Developing a dementia policy that incorporates key elements of the WHO Global action plan requires sustained and ongoing collaboration with policy makers combined with political will.

The STRiDE Network aims to continue this work, disseminating a methodology that works from the bottom up, gathering evidence and giving a voice to those who are affected by dementia to impact policy. The result, we hope, will be policy change across many countries that will enable people living with dementia and their carers to have better access to care and support, and to live better with dementia for as long as they can.

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