



# STRIDE GUIDANCE ON BASELINE CASE VIGNETTES:

CASE VIGNETTES TO MAP ACCESS TO DIAGNOSIS,  
CARE AND SUPPORT FOR PEOPLE LIVING WITH  
DEMENTIA AND THEIR CARE PARTNERS

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## FOR CITATION PURPOSES

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# INTRODUCTION

We have developed and used case vignettes for several purposes as part of the situational analysis conducted within the STRiDE project, such as to map existing models of dementia care, treatment and support, to inform the development of scenarios for improved access to care and to inform the development of policy recommendations.

Part A of this document provides:

1. The research questions behind the vignettes and the purposes for which we have used vignettes in the STRiDE project
2. A brief overview of how vignettes have been used for similar purposes in the literature
3. The process we have used to develop the case vignettes
4. The steps undertaken to complete and validate the vignette scenarios
5. The analytical process to identify gaps, barriers and existing best practice interventions that could help to mitigate or overcome identified gaps and barriers

Part B contains a working document that can be used to fill in the STRiDE case vignettes.

Part C includes a template of the framework we have developed to analyse the completed vignettes.

In a second short vignette guidance document (forthcoming) we outline how we build on the processes outlined here to develop future case vignettes. A process that informs the development of scenarios for improved access to care.

# PART A: STRIDE VIGNETTES: AN OVERVIEW AND GUIDANCE DOCUMENT

## 1 USING CASE VIGNETTES IN STRIDE

### 1.1 The research questions we aimed to answer

- How are people with dementia and their family carers being supported in country x?
- What are likely services and support structures available for people with dementia and their family carers in country x?
- What are the service and support structures available to people with dementia and carers who live with different circumstances (e.g., urban/rural, socio-economic status)?
- Are the current provision of services and their likely trajectories similar across different countries? Where do they differ and why?

### 1.2 The purpose of using Vignettes

The vignette case studies have been developed to help complete the relatively little information available in some countries about the care and support available to people with dementia and their carers, and to explore availability of services and routes of access for different groups within society. This is particularly important when there is limited information available from published sources or data. The vignettes have also enabled the comparison of care situations for people with dementia and their families across countries.

In the STRiDE project we have used the vignettes to:

- Describe likely situations of people with dementia and their families living under different circumstances in each of the STRiDE countries using a narrative approach.
- Identify gaps in and barriers to diagnosis, treatment and care for people with dementia and their families, as well as to identify best practice examples within the countries and lessons from the literature on how these gaps and barriers could be overcome. This evidence also informs cost of dementia and simulation models as well as contributing to the development of policy messages and recommendations.
- Compare the situation of people with dementia and their carers, the pathways, gaps and barriers to diagnosis, treatment and support, as well as possibilities to overcome the gaps and barriers between the STRiDE countries.

## 2 BACKGROUND OF USING VIGNETTES FOR RESEARCH

This section provides examples of how case vignettes have been used in other studies. Vignettes have been previously used to explore the provision of services to people with dementia as well as to estimate the costs of care. We provide a brief overview of considerations from the literature for designing and using vignettes and present relevant studies conducted in the field to show some of the different ways in which vignettes can be used in research.

Vignettes have been used for qualitative and quantitative data collection in fields, such as psychology, social work, and public health (Mah et al. 2014, Cong and Silverstein 2019, Soydan 1998). Mah and colleagues (2014) describe vignettes 'as short stories based on fictional or fictionalised (hypothetical) scenarios, in which respondents are asked to draw upon their own experience to predict how characters will – or should – behave'. Soydan (1998) adds to this description by stating that vignettes 'must be representative of the phenomena they intend to describe, and that they must be realistic'. The hypothetical, descriptive nature of vignettes has been recognised as useful in collecting information about the provision of health and social care, and for enabling cross-national comparisons (pp.125-127).

Vignettes can be designed using different approaches. Mah and colleagues (2014), for instance, based their vignettes on an extensive review of the literature, decoding key concepts found in the literature to identify relevant variables and language and expert feedback to establish construct validity. Giebel and colleagues (2019), on the other hand, based the characteristics of their vignettes on an existing dataset to ensure that the hypothetical vignettes were based on real world data. Other studies, such as Cong and Silverstein (2019), do not describe the development of their vignette. However, contrary to the other studies who used vignettes as a stand-alone research tool, Cong and Silverstein's research embedded the vignette by exploring preferences around generational economic support in rural China in a survey. Participants were presented with a moral dilemma of finite resources and four scenarios of need and were asked to decide on the allocation of resources. In the first scenario, both a grandparent and child had chronic needs. In the second, the grandparent had acute needs and the child chronic needs. In the third, the child had acute needs and the grandparent chronic needs and in the final scenario, both grandparent and child had acute needs. This data was analysed using quantitative analysis.

Mah and colleagues (2014) outlined five key design features of vignettes, based on their experience of a study investigating food advertising for children in Canada. First, they emphasised that vignettes need to be authentic and rooted in their relative discourse. Second, vignettes should pay attention to judicious details. On the one hand, the vignette should be detailed and relatable, giving a sense of story, on the other hand, respondents should be able and allowed to fill gaps. Respondents' ability to fill deliberately designed gaps is a key difference to case studies, where respondents usually are provided with a great level of detail. The creation of extreme scenarios – even if authentic – bears the risk that the response to the vignette may deviate from its initial purpose. Third, vignettes should be factorial, this means that they should aim to examine key variables and concepts. Fourth, vignettes can incorporate developmental aspects. This means that elements of the story can be revealed gradually allowing respondents to stage the discourse, and the stepwise exploration of specific variables. Furthermore, the ability to explore scenarios that develop over a period of time enables the investigation of social processes (Soydan 1998). Finally, the authors recommend the vignettes to be reflexive. This means that respondents can be encouraged to 'reflect on

their envision details'. It is important to note that vignettes cannot reproduce real life but allow the exploration of carefully designed, relevant scenarios (Mah et al. 2014, pp.1830-1831). Recently vignettes have also been used for a cross country comparison of care systems (Bieber et al. 2015, Muir 2017).

The ActifCare study, for instance, compared the provision of services and their access path for care and support with the help of a case vignette describing a likely but hypothetical situation of a person with dementia and their family (Bieber et al. 2015). The results of the study showed that, in the European countries investigated, general practitioners (GPs) played an important role and often were the first point of access of support for people with dementia and their carers. In many countries, GPs then referred the individual to specialist diagnostic services. Formal care services in several of the countries studied could only be accessed following a standardised needs assessment procedure. Funding structures, and whether the responsibility falls into the realm of health or social care, varied between countries. Informal carer support appeared to be predominantly provided by the voluntary sector (Bieber et al. 2015, Bieber et al. 2018).

The OECD combined a comparison of long-term care services of some of their high-income country member states with an estimate of overall cost of care. The study by Muir (2017) compared the level of social protection coverage, out-of-pocket costs incurred by service users and their implications on users in terms of affordability with the help of five vignette scenarios outlining detailed LTC needs of a typical case. Each case is described in terms of ADL and IADL needs as well as social needs and other details, providing information such as whether the care needs can be met through informal care and whether the person lives alone or cohabitates. Specific ADL needs described include aspects of mobility, hygiene and food intake, while IADL needs cover shopping, cooking, cleaning and laundry. The social needs describe whether or not the hypothetical person is able to maintain social activities independently or requires assistance. Each case vignette is then further broken down describing how each of the care needs are being met by paid and unpaid care. The tasks that were estimated to be provided by paid carers were described with exact time estimates to enable costing. The study found that costs for long-term care were high across all countries and that social protection was important for service users. The study also showed considerable variation in cost between countries and variation in terms of access to service for people with low levels of need. Furthermore, while most countries aim to support people with low-income, vulnerable individuals in most countries are still most exposed to the cost of long-term care (Muir 2017).

In addition, vignettes have been used to explore the costs of care (Giebel et al. 2019). This study focused on the share of informal and formal care costs and explored the perceptions through the use of case vignettes with paid and unpaid carers in England. The case vignettes were developed based on an existing English data set and reflected care needs of prominent groups in the dataset at risk of institutionalisation. During small group consultations 14 unpaid carers and 14 paid carers separately developed a typical weekly care plan for each of the vignette cases. This included the amount of care time each of the participants in the consultation groups considered appropriate for paid and unpaid carers to provide for each of the five vignette cases. Each of the care plans were then costed using appropriate unit costs. The study found differences in the care plans developed by paid and unpaid carers in terms of hours of care provided and services recommended (Giebel et al. 2019).

## 3 DEVELOPING THE STRIDE VIGNETTES

### 3.1 The development process

During a workshop at the annual STRiDE meeting in March 2019, we discussed key variables affecting the care and support people with dementia and their family carers receive. This process was informed by the expertise of researchers from the participating countries, covering a wider range of disciplines and experience in care and support for people with dementia (including nurses, neurologists, psychiatrists, community-based supporters of people with dementia and carers, health systems researchers, epidemiologists, long-term care systems researchers, advocates etc.). The following variables (summarised in Figure 1) were suggested during the workshop:

*(1) What variables may affect the care and support people with dementia receive?*

Urban/rural; available workforce; available respite care; available care pathways; health system financing; cultural background; mental and general health status; political situation; diagnosis (late); mental health clinics; severity; gender (isolation/ social class); insight; stigma/awareness; relationship with family (structure/cultural/care); distance to services; co-morbidities; priorities; training of professionals

*(2) What variables may affect the situation of family carers and the support they receive?*

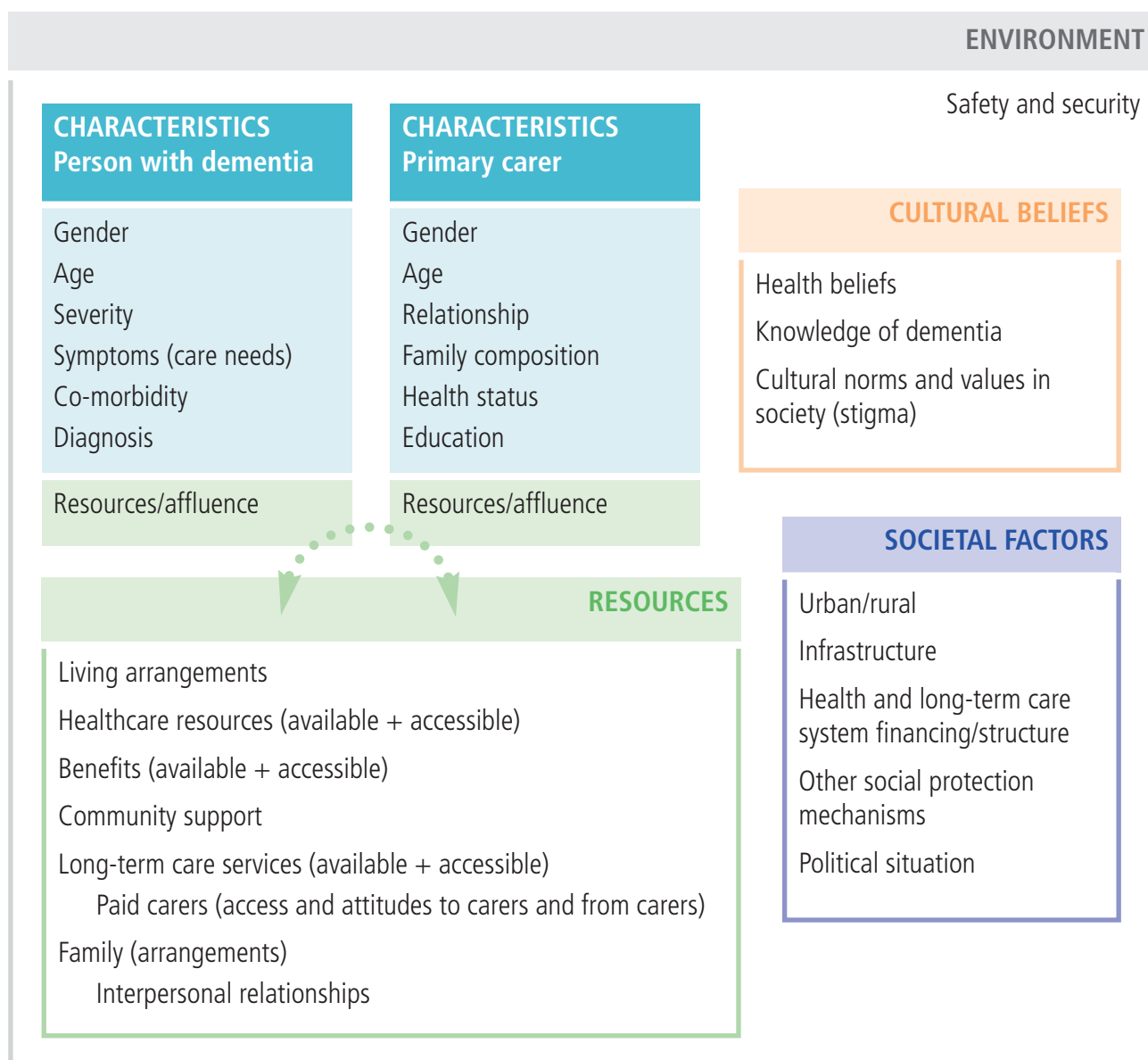
Own children; marital status; gender/stigma; age; finance; health & social care system (absence of structure); government support; urban/rural; burnout (support); health status (own care needs); health beliefs; community support; interpersonal relationships (coping); education/literacy (health education); migrant communities; cultural context/beliefs (own responsibility, not looking for support, social expectations, choice – expectations); affluence of family (employment/work policies); household composition; family stress; access to social protection mechanisms (e.g. old age grant in South Africa)

Following this conversation, workshop participants got together in small groups to identify three key variables that would affect the situation of a person with dementia and their carer. The findings are summarized in Table 1.

These aspects were then arranged into groups of proximal and distal factors as outlined in Figure 2. In this part of the STRiDE project, as in the work described by Muir (2017), the emphasis was on creating case vignettes that describe realistic scenarios. This corresponds to the interpretation of vignettes outlined by Mah and colleagues (2014). They state that ‘vignettes need to be authentic’ and provide a snapshot of a situation, employing ‘judicious detail’. This means that the case vignettes were designed to create a ‘sense of story and character but permit [...] to fill in gaps’. The paper further states that it is important that vignettes clearly identify key variables that can be ‘deductively tested’ (p.1830).

For this reason, the STRiDE vignette scenarios have focused on variables describing the situation of people with dementia and their families (see Figure 2 – shaded circles). We have developed five core vignettes that build on the process of the identification and organisation of key variables outlined above. These core vignettes describe short but relatable situations of people with dementia and their families. They enable us to explore different living situations and social realities based on the aforementioned key variables (e.g. gender, age, urban/rural, socio-economic status, availability of family support), while remaining sufficiently broad that they remain applicable (with minor tweaks) in different countries.

**Figure 1: Overview of variables identified in the plenum conversation**

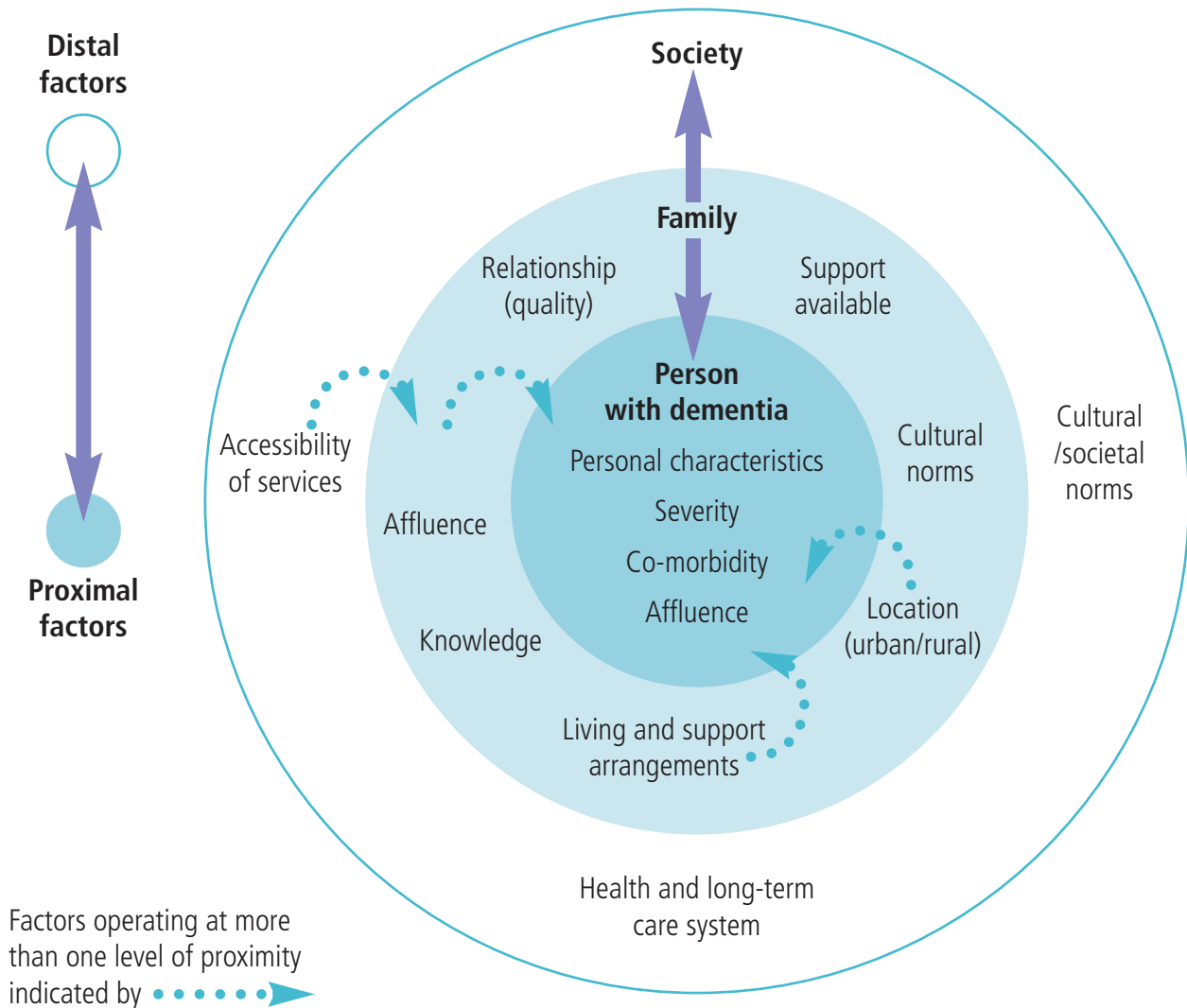


**Table 1: Key variables identified in group discussions**

<b>Group 1</b>	Dementia care system	Stigma/cultural beliefs	Support
<b>Group 2</b>	Cultural norms/values	Organisational factors (services)	Interpersonal factors
<b>Group 3</b>	Living arrangement	Severity	Rural/urban
<b>Group 4</b>	Personal characteristics	Medical history	Support system
<b>Group 5</b>	Health beliefs (cultural)	Education	Interpersonal relationships
<b>Group 6</b>	Severity	Affluence (resources)	Rural/urban
<b>Group 7</b>	Cultural beliefs	Availability resources	Knowledge gap
<b>Group 8</b>	Cultural norms/health beliefs	Co-morbidity	Severity (diagnosis)



**Figure 2: Key factors influencing care and support available to people with dementia and their families**



Once the first draft of the core vignettes was developed, the STRiDE country teams provided feedback on the vignettes, which was then incorporated into subsequent drafts. The final version of the five core vignettes can be found below:

### 3.2 The core STRiDE vignettes

#### ■ STRiDE case 1

Mrs A is in her 70s and lives with her husband in a small village in rural [country]. Mrs A's daughter and her family live nearby. Over the last year her family has become increasingly worried about Mrs A, as she keeps losing things and puts items into odd places. A friend has told the daughter that Mrs A had been wandering in the village and seemed a bit lost. The daughter is worried about what people may think or say about, and how they may react to, her mother. Mrs A used to have a very neat house and looked after her appearance. She also helped her daughter with the children. Over the last few months, Mrs A seems to have become no longer interested in these things. Mother and daughter used to have a good relationship, but recently there have been a number of arguments. The daughter is thinking of taking Mrs A to the community health centre, but she knows that her mother does not like to go there.

## ■ STRiDE case 2

Mrs B is in her 70s and lives in mid-size town in [country]. When her son got married, she moved in with her son and his wife. For the last few years, she has helped the family by looking after the grandchildren, doing housework and cooking while her children were working in the business they own. About two years ago, Mrs B's family became worried about her behaviour and memory. Now Mrs B mostly stays at home. She does not go out unless someone from the family accompanies her. Mrs B has also stopped cooking, which she always enjoyed. Her daughter-in-law reminds her to take medication she needs for other health issues and helps with dressing. Mrs B does not like being left alone in the house. Mrs B's daughter-in-law is worried about her hygiene, but having to look after the business, taking over the cooking and shopping for the family as well as making sure that Mrs B is safe and well during the day takes a lot of her energy and so she postpones thinking about this aspect. Once a week Mrs B's son takes his mother to [church].

## ■ STRiDE case 3

About five years ago Mrs C started to become forgetful. Now, 75 years old, Mrs C hardly ever leaves her room in her daughter's house where she was moved when it became clear that she could no longer look after herself. The daughter and her granddaughter help her with dressing, eating, washing and going to the bathroom. The family has to make sure that food is not too chunky as Mrs C has difficulty swallowing. It is difficult for the daughter's family to go away together for the day as someone always needs to be around to look after her. The constant care needs in addition to her own family responsibilities also pose a strain on Mrs C's daughter who has her own health issues. Mrs C's other children visit during holidays but find it difficult, as she cannot always remember who they are.

## ■ STRiDE case 4

Mr D lives by himself in a mid-size town in [country] since his wife passed away last year. His children have moved to the bigger city to work and can only visit once a month. Over the last few months Mr D has found it more difficult to look after the house and himself. His son noticed that his father does not seem himself and is worried about him and what people may think if they see his father.

## ■ STRiDE case 5

Mr E left his family many years ago to work in [big city] in [country]. While he visited his family once a year, his children have become increasingly estranged and he has lost contact after his wife passed away five years ago. He lives on his own in a small flat. Mr E finds it difficult to find his way to the shops and back, has difficulty remembering appointments and often forgets about eating.

Some teams have developed additional vignettes to illustrate the situation for specific groups within their countries (see Box 1 for an example from Brazil).

### Box 1: Example of the process undertaken by the STRiDE Brazil team to develop additional vignettes

Brazil is a highly diverse country when it comes to culture, geographical regions, and socioeconomic status. To depict some of these diverse characteristics, we developed five additional case vignettes. During a virtual meeting, the Brazilian STRiDE team discussed the existing core STRiDE vignettes and identified missing realities commonly found in the country.

Then, we brainstormed life situations and tried to think how people with dementia and their carers would fit in and respond to those scenarios. In the end, we decided to create five new vignettes that included the missing realities identified during the brainstorm. The group jointly conceptualized the additional scenarios as well as completed them.

As a result, we included a vignette of an indigenous-descendent woman who lived in a riverside community in the Amazon forest. In addition, we developed two case vignettes: one that made a parallel between a less-educated man who lived with his son, daughter-in-law, and grandchildren in a slum in Rio de Janeiro, and another with a more-educated man who lived in a large middle-class condominium with his wife, also in Rio de Janeiro. Finally, we created two case vignettes contrasting the stories of a woman with dementia living in a very remote rural area and working as the maid of a large-sized cattle farm owner, with the story of another woman with dementia living with her husband and owning a cattle farm in a remote rural area.

These vignettes aimed to raise attention to how aspects such as socioeconomic status and geographical areas (rural vs. urban) may influence the possible pathways people with dementia may follow in Brazil.

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## 4 THE PROCESS OF COMPLETING THE VIGNETTES

The main purpose of the completed vignettes has been the outlining of available support structures and underlying societal and cultural aspects (e.g. social expectations, stigma), therefore providing insights on key variables of interest highlighted by the teams during the workshop (see Figure 2). Below we describe the different steps involved in the completion of the STRiDE baseline vignettes.

### STEP 1 Completing the vignettes

The first step has been to describe the likely support available to the person with dementia and the family carers for each of the five core STRiDE vignettes on 1–3 pages. Teams have found it useful to draw on information from the in-depth desk review (Comas-Herrera et al. 2021) and individual's professional and personal experience. A similar approach was used in the studies by Bieber and colleagues (2017) and Muir (2017).

In most of the STRiDE countries the case vignettes were completed by a team consisting of researchers and members of non-governmental organisations (NGOs) (in the case of STRiDE the Alzheimer Associations in the different countries belonging to the umbrella organisation Alzheimer Disease International (ADI)). This has brought rich expertise to the process.

Teams have been encouraged to consider the questions below in their answers, some of those were identified by Bieber et al. (2015, pp.208-220):

- what medical profession would be most likely to provide a diagnosis?
- what profession would most likely support xx with his/her needs after a diagnosis?
- what family arrangements would likely be made (and how this may affect the carer(s))?
- where would family members likely turn to in order to receive advice and support?
- who would likely be the main (unpaid family) carer?
- what other care and social support may be available for people with dementia and their carers (paid carers, church groups, voluntary groups, state services, live-in (migrant) carers)?
  - How would families access this support?
  - Would families be likely to accept available services?
  - Can families afford these services?
- would the person with dementia and his/her family be likely to experience stigma?
- what kind of health care providers would the person with dementia and their carer be likely to access? Would they be likely to choose public or private providers? Would health care demands be likely to be covered by health insurance or would they require out-of-pocket payments?
- what kind of care and support would the main unpaid carer be likely to provide? What kind of support would they be likely to get from others?
- what might be reasons for families not to access services?
- what proportion of the population in your country is likely to be represented by the different vignettes?

After the teams completed the vignettes, they reflected on the amount of time the unpaid carer(s) are likely to spend on the different tasks they describe in their response

## **STEP 2** Validating the vignettes

For the purpose of validation, the case vignettes for people with dementia and their family carers have been shared with key stakeholders, for example those participating in qualitative interviews (as part of the STRIDE situational analysis (guidance forthcoming)) as well as members of the project's National Advisory Group (NAG) in each of the countries. The comments and feedback from key stakeholders and NGO partners were then discussed and incorporated into the vignette responses. In the STRiDE project, we have found that this feedback provided important validation of the vignettes and the consultation of a diverse stakeholder group also ensured that potential gaps could be addressed. Mah and colleagues (2014) pursued a similar approach to establish construct validity of their case vignettes.

## Box 2: The India approach to validating the vignettes

To ensure our vignettes represent the heterogeneous situations that persons with dementia and their families experience in the Indian context, the India team sought feedback from their STRIDE National Advisory Group (NAG), which consists of 21 members with varied fields of expertise that include healthcare professionals, government officials, non-governmental organization representatives, caregivers and a health economist. Six NAG members provided us with detailed feedback on the vignettes. This was consolidated and discussed by the core team to identify and address any further changes to be made to the vignettes.

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## 5 THE ANALYTICAL PROCESS

### STEP 3 Framework analysis of the vignettes

Before we started the analysis process, we found it important to distinguish between the variables that we pre-determined to explore and the findings identified through the vignette completion and validation process. To help make this distinction, we prepared a table providing an overview of the key variables that the vignettes were based on. Each team was asked to add the characteristics of the additional vignettes they created to the table.

Table 2: Overview of key vignette characteristics

		Case 1	Case 2	...
Person with dementia	Sex	female		
	Age	70s		
	Characteristics	losing things/items in odd places; loss of interest in appearance/house; supporting daughter		
	Relationship	married; mother of at least one daughter		
	Relationship quality	recently some arguments with daughter		
Setting	Living situation	lives with husband; daughter and family live nearby		
	Urban/ rural	rural, village		
	Community	friend told daughter about wandering/being lost		
Potential carer	Sex	male and female		
	Age	older (husband); middle-aged (daughter)		
	Relationship to person with dementia	married, no further information (husband); daughter, recent arguments, daughter thinking of introducing mother to services; concern about stigma		
Services included	Health care	potential community health centre		
	Other services			

After this we started analysing the information provided in each of the case vignettes by using an approach that builds on framework (Smith and Firth 2011, Srivatstava and Thomson 2009).

For this we have identified 11 key questions (see Table 3) that build on the three main research questions:

- How are people with dementia and their family carers being supported in country x?
- What are likely services and support structures available for people with dementia and their family carers in country x?
- What are the service and support structures available to people with dementia and carers who live with different circumstances (e.g. urban/rural, socio-economic status)?

**Table 3: Overview of key questions identified**

a. Who takes on the main caring role?
b. What are the implications for the carer(s)?
c. What kind of support is available for carers?
d. Where would people with dementia and their families go if they have memory concerns?
e. What ongoing health support would they get? Where would this be provided?
f. What other types of support are available for people living with dementia
g. What support is available for people who do not have family/friends who will support them?
h. What are the barriers and gaps identified to access diagnosis, care and support for people with dementia?
i. How could these challenges be overcome?
j. Are there any best practice examples in your country that address any of the barriers, gaps and challenges?
k. How would the situation of case x likely have changed during the COVID-19 pandemic?

The information from the case vignettes in response to questions a. to f. were then charted into an Excel template (see Table 4). A full table template can be found in Part C.

Each question has been presented in one column and each case vignette in an individual row. After the responses for each of the questions have been charted for every case vignette, the country teams reflected on the responses to the different questions for each vignette. They then identified responses to questions, h. 'What are the barriers and gaps identified to access diagnosis, care and support for people with dementia?', i. 'How could these challenges be overcome?' and j. 'Are there any best practice examples in your country that address any of the barriers, gaps and challenges?'

**Table 4: Example of framework**

	Question a.	Question b.	Question c.	Question d.	Question e.	...	Question k.
Vignette 1							①
Vignette 2							
...	②						

Given the experience of the COVID-19 pandemic since starting the process of the STRiDE project vignettes in 2019, we added question k: ‘How would the situation of case x likely have changed during the COVID-19 pandemic?’ The teams briefly reflected in the appropriate cell which aspects of the case vignette were likely to have changed (see ① in Table 4).

Next, the teams worked through the responses to the different vignettes for each of the columns (see ② in Table 4), summarising similarities and identifying differences in the responses to each of the questions. They then reflected, based on the characteristics overview, whether these differences were likely to be due to key variables explored in the vignettes.

**STEP 4 Identifying gaps and barriers in access to diagnosis, treatment and care for people with dementia and their families and identifying possible responses using best-practice examples and evidence from the literature on interventions**

Following this step, the teams have grouped the gaps and barriers identified into thematic domains (e.g. limited training of healthcare workers, infrastructure posing barriers of access for rural communities) and matched, where available, possible solutions/best practice examples to the relevant domains (e.g. inclusion of dementia in university curriculum, subsidised transport for older people). In addition, we checked whether there were any relevant lessons from the literature, such as country specific interventions that address some of the gaps and barriers identified. In the STRiDE project, we were able to access this information through the STRiDE’s systematic review (see Salcher-Konrad et al. 2019).

This information can also help develop improved future care scenarios (see forthcoming guidance documents on future STRiDE vignettes and STRiDE dementia cost and simulation models).

**STEP 5 Identifying what proportion of the population have been reflected in the case vignettes**

Finally, while the vignettes enable the exploration of a range of diverse scenarios regarding the access to diagnosis, treatment and support for people with dementia and their families in the different countries, in practice each country is very complex and diverse. We have considered what proportion of the population in each country are likely to be reflected by the vignettes, but also what groups we are likely to have missed. This is important background information that helps to establish how many people are likely to be considered under each of the scenarios.

# PART B: STRIDE VIGNETTES: WORKING DOCUMENT

## Vignettes on the current situation

Describe the likely support available to the person with dementia and the family carers for each of the five the STRiDE core vignettes on 1–3 pages. You can draw from the information accumulated when populating the in-depth desk review (as part of the situational analysis). A similar approach was used in the study by Bieber and colleagues (2015) and Muir (2017).

Relevant information may include questions below, as identified by Bieber et al. (2015, pp.208–220):

- what medical profession would be most likely to provide a diagnosis?
- what profession would most likely support xx with his/her needs after a diagnosis?
- what family arrangements would likely be made (and how this may affect the carer(s))?
- where would family members likely turn to in order to receive advice and support?
- who would likely be the main (unpaid family) carer?
- what other care and social support may be available for people with dementia and their carers (paid carers, church groups, voluntary groups, state services, live-in (migrant) carers)?
  - How would families access this support?
  - Would families be likely to accept available services?
  - Can families afford these services?
- would the person with dementia and his/her family be likely to experience stigma?
- what kind of health care providers would the person with dementia and their carer be likely to access? Would they be likely to choose public or private providers? Would the cost of health care services incurred likely to covered by health insurance or would they require out-of-pocket payments?
- what kind of care and support would the main unpaid carer be likely to provide? What kind of support would they be likely to get from others?
- what might be reasons for families not to access services?
- what proportion of the population in your country is likely to be represented by the different vignettes?

Please also think about whether the vignettes exclude relevant groups of people in your country. If this should be the case, please feel free to develop (a) vignette(s) that would represent these groups.



Once you have completed the vignettes, it would be great if you could think about the amount of time the unpaid carer(s) are likely to spend on each of these tasks and to list these in the document. The NAG may be able to provide feedback on your estimates.

### ■ STRiDE case 1

Mrs A is in her 70s and lives with her husband in a small village in rural [country]. Mrs A's daughter and her family live nearby. Over the last year her family has become increasingly worried about Mrs A, as she keeps losing things and puts items into odd places. A friend has told the daughter that Mrs A had been wandering in the village and seemed a bit lost. The daughter is worried about what people may think or say about, and how they may react to her mother. Mrs A used to have a very neat house and looked after her appearance. She also helped her daughter with the children. Over the last few months, Mrs A seems to have become no longer interested in these things. Mother and daughter used to have a good relationship, but recently there have been a number of arguments. The daughter is thinking of taking Mrs A to the community health centre, but she knows that her mother does not like to go there.

#### **Step 1: Please describe the likely support available to the person with dementia and the family carers outlined in this case vignette (1–3 pages)**

Please think through the questions outlined in the section 'steps to completing the vignettes' in the context of this case vignette and describe if and how the different actors/issues listed are likely to affect this specific care situation, and how the services Mrs A and her family would access would be paid for (insurance, co-payments, out-of-pocket). Please also try to provide information on the kind of support the unpaid carer would be likely to provide and what kind of help there may be from others (family members/ neighbours). Please also add how much time you would expect the unpaid carer to spend on unpaid care.

### ■ STRiDE case 2

Mrs B is in her 70s and lives in mid-size town in [country]. When her son got married, she moved in with her son and his wife. For the last few years she has helped the family by looking after the grandchildren, doing housework and cooking while her children were working in the business they own. About two years ago, Mrs B's family became worried about her behaviour and memory. Now Mrs B mostly stays at home. She does not go out unless someone of the family accompanies her. Mrs B also stopped cooking, which she always enjoyed. Her daughter-in-law reminds her to take medication she needs for other health issues and helps with dressing. Mrs B does not like being left alone in the house. Mrs B's daughter-in-law is worried about her hygiene, but having to look after the business, taking over the cooking and shopping for the family as well as making sure that Mrs B is safe and well during the day takes a lot of her energy and so she postpones thinking about this aspect. Once a week Mrs B's son takes his mother to [church].

#### **Step 1: Please describe the likely support available to the person with dementia and the family carers outlined in this case vignette (1–3 pages)**

Please think through the questions outlined in the section 'steps to completing the vignettes' in the context of this case vignette and describe if and how the different actors/issues listed

are likely to affect this specific care situation, and how the services Mrs B and her family would access would be paid for (insurance, co-payments, out-of-pocket). Please also try to provide information on the kind of support the unpaid carer would be likely to provide and what kind of help there may be from others (family members/ neighbours). Please also add how much time you would expect the unpaid carer to spend on unpaid care.

### ■ STRiDE case 3

About five years ago Mrs C started to become forgetful. Now, 75 years old, Mrs C hardly ever leaves her room in her daughter's house where she was moved when it became clear that she could no longer look after herself. The daughter and her granddaughter help her with dressing, eating, washing and going to the bathroom. The family has to make sure that food is not too chunky as Mrs C has difficulty swallowing. It is difficult for the daughter's family to go away together for the day as someone always needs to be around to look after her. The constant care needs in addition to her own family responsibilities also pose a strain on Mrs C's daughter, who has her own health issues. Mrs C's other children visit during holidays but find it difficult, as she cannot always remember who they are.

#### **Step 1: Please describe the likely support available to the person with dementia and the family carers outlined in this case vignette (1–3 pages)**

Please think through the questions outlined in the section 'steps to completing the vignettes' in the context of this case vignette and describe if and how the different actors/issues listed are likely to affect this specific care situation, and how the services Mrs C and her family would access would be paid for (insurance, co-payments, out-of-pocket). Please also try to provide information on the kind of support the unpaid carer would be likely to provide and what kind of help there may be from others (family members/ neighbours). Please also add how much time you would expect the unpaid carer to spend on unpaid care.

### ■ STRiDE case 4

Mr D lives by himself in a mid-size town in [country] since his wife passed away last year. His children have moved to the bigger city to work and can only visit once a month. Over the last few months Mr D has found it more difficult to look after the house and himself. His son noticed that his father does not seem himself and is worried about him and what people may think if they see his father.

#### **Step 1: Please describe the likely support available to the person with dementia and the family carers outlined in this case vignette (1–3 pages)**

Please think through the questions outlined in the section 'steps to completing the vignettes' in the context of this case vignette and describe if and how the different actors/issues listed are likely to affect this specific care situation, and how the services Mr D and his family would access would be paid for (insurance, co-payments, out-of-pocket). Please also try to provide information on the kind of support the unpaid carer would be likely to provide and what kind of help there may be from others (family members/ neighbours). Please also add how much time you would expect the unpaid carer to spend on unpaid care.

## ■ STRiDE case 5

Mr E has left his family many years ago to work in [big city] in [country]. While he visited his family once a year, his children have become increasingly estranged and he has lost contact with them after his wife passed away five years ago. He lives on his own in a small flat. Mr E finds it difficult to find his way to the shops and back, has difficulty remembering appointments and often forgets about eating.

### **Step 1: Please describe the likely support available to the person with dementia and the family carers outlined in this case vignette (1–3 pages)**

Please think through the questions outlined in the section 'steps to completing the vignettes' in the context of this case vignette and describe if and how the different actors/issues listed are likely to affect this specific care situation and how the services Mr E (and his family) would access would be paid for (insurance, co-payments, out-of-pocket). Please also try to provide information on the kind of support the unpaid carer would be likely to provide and what kind of help there may be from others (family members/ neighbours). Please also add how much time you would expect the unpaid carer to spend on unpaid care.

# PART C: STRIDE VIGNETTES: FRAMEWORK TEMPLATE

This table will be easier to work with if transferred to Excel

	[add completed vignette 1]	[add completed vignette 2]	[add completed vignette 3]	[add completed vignette 4]	[add completed vignette 5]	[add additional vignette x]
Who takes on the main caring role?						
What are the implications for the carer(s)?						
What kind of support is available for carers?						
Where would people with dementia and their families go if they have memory concerns?						
What ongoing health support would they get? Where would this be provided?						
What other types of support are available for people living with dementia?						
What support is available for people living with dementia who do not have family/friends who will support them?						
What is the societal response to dementia?						
Family conflict						
Impact on life						
How would the situation have changed during the COVID-19 pandemic?						
What are the gaps? What challenges need to be overcome?						
What are the strengths in the system?						
Are there any best practice examples of interventions to support people with dementia and/or their family carers?						

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