STRiDE

STRiDE:

Strengthening responses to dementia in developing countries

An introduction

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Economic and Social Research Council

Global Challenges Research Fund

www.stride-dementia.org / @STRiDEDementia

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Acknowledgements

Strengthening Responses to Dementia in Developing countries (STRiDE) was funded by UK Research and Innovation through the Global Challenges Research Fund, project reference ES/P010938/1

UKRI Economic and Social Research Council

GCRF Global Challenges Research Fund

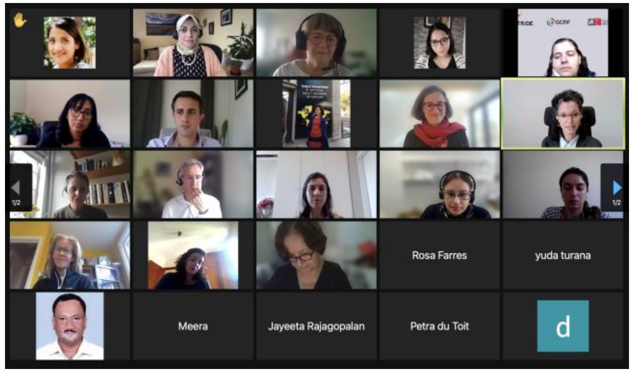
CPEC
CARE POLICY AND EVALUATION CENTRE
Research at LSE

LSE THE LONDON SCHOOL OF ECONOMICS AND POLITICAL SCIENCE

STRiDE

What is STRiDE

- A four year **research capacity building** programme funded by the UK's Global Challenges Research Fund
- Synthesizing and generating **policy-relevant evidence** to support development of policies to respond to dementia
- **Formative research to inform dementia policies**
- Find out more at https://stride-dementia.org/ and on twitter: @STRiDEDementia



Economic
and Social
Research Counci

GCRF
Global Challenges Research Fund

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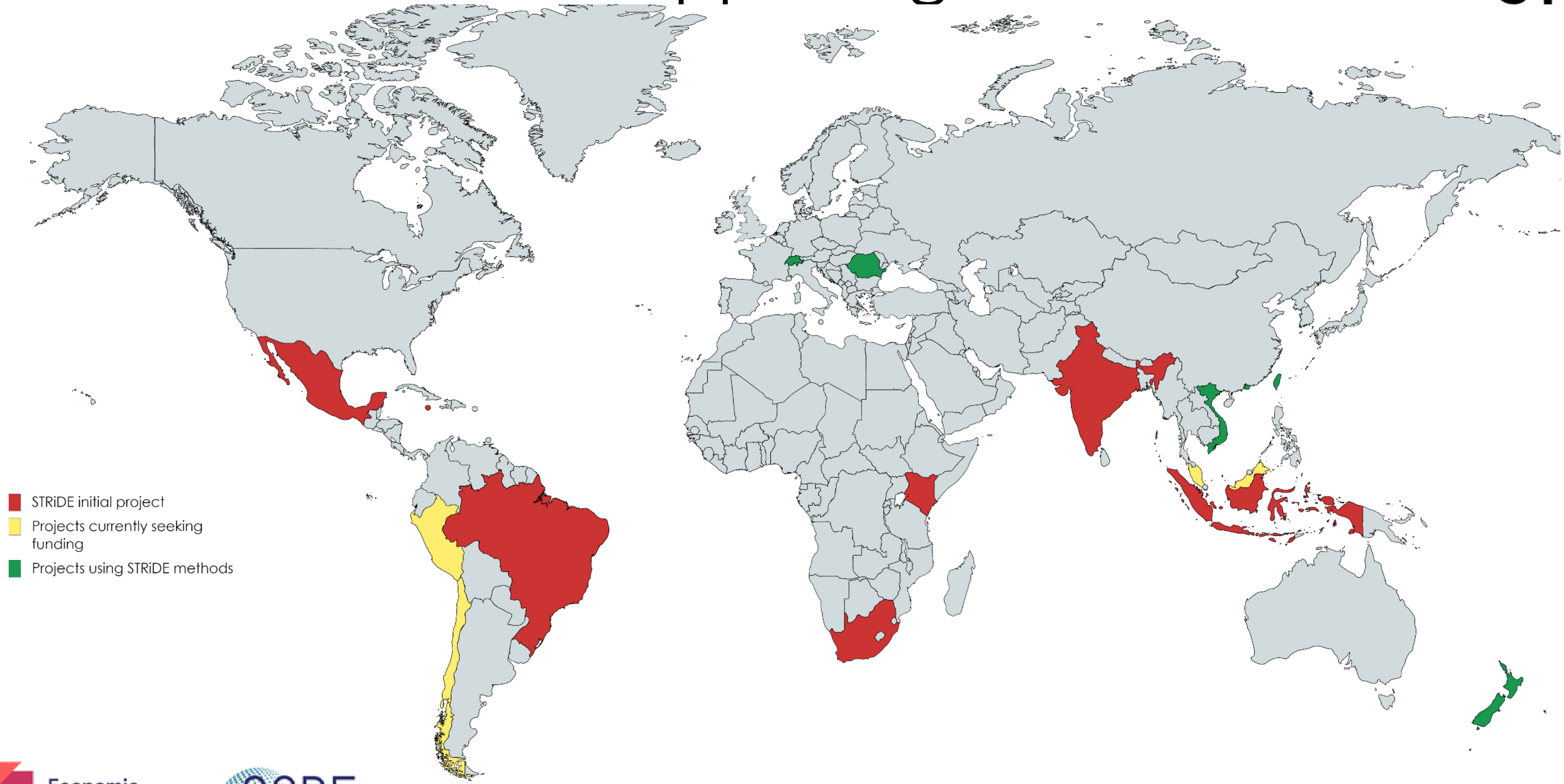
Where is STRiDE happening so far?



🟥 STRiDE initial project

🟨 Projects currently seeking funding

🟩 Projects using STRiDE methods

Economic
and Social
Research Council

GCRF
Global Challenges Research Fund

Core STRiDE project collaborators

STRiDE

Academics

- London School of Economics and Political Science (UK)
- University of Cape Town (South Africa)
- Brighton and Sussex Medical School (UK)
- University of Plymouth (UK)
- Universidade Federal de São Paulo (Brazil)
- National Institute of Mental Health and Neuro Sciences (India)
- Atma Jaya Catholic University of Indonesia (Indonesia)
- University of the West Indies (Jamaica)
- Africa Mental Health Foundation (Kenya)
- National Institute of Geriatrics (Mexico)

NGOs

- Alzheimer’s Disease International (ADI)
- Dementia Alliance International (DAI)
- FEBRAZ - Federation of Brazilian Alzheimer's Associations
- ARDSI - Alzheimer's and Related disorders Society of India
- Alzheimer’s Indonesia
- Alzheimer’s Jamaica
- Alzheimer’s & Dementia Organisation Kenya
- FEDMA - Mexican Federation of Alzheimer's
- Alzheimer’s South Africa NPC

Policy advisers

- WHO
- Inter-American Development Bank
- Asian Development Bank
- Help Age International
- National stakeholders – governments, universities, other NGOs, GCRF (RCUK)

UKRI
Economic and Social Research Council
GCRF
Global Challenges Research Fund

STRiDE components: all countries

Co-production of priorities (for the project and for national policy) through Theory of Change

Qualitative research to learn about understanding and attitudes towards dementia and stigma

Analysis of "dementia situation"/political economy: health/LTC systems, policies, contextual factors, views of stakeholders

Case vignettes to capture expert knowledge of dementia care experiences, filling evidence gaps and enabling systems analysis

Systematic reviews of prevalence of dementia in 7 countries and of dementia interventions evaluated in LMICs

Research and policy/advocacy capacity building, "learning by doing" approach

STRiDE components: in some countries

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Qualitative study of the costs and impacts to families providing care to people with dementia (India, Jamaica & Mexico)

Development, implementation and evaluation of an intervention to reduce stigma (Brazil and Kenya)

Survey of households with older to people to establish prevalence of dementia and other care-relevant needs, use of care and services and costs of care (Indonesia and South Africa)

Estimates of costs of the care of people with dementia and of the resources needed for improved access to care (close to completion in India, later on in other countries?)

Whole team academic publications so far:

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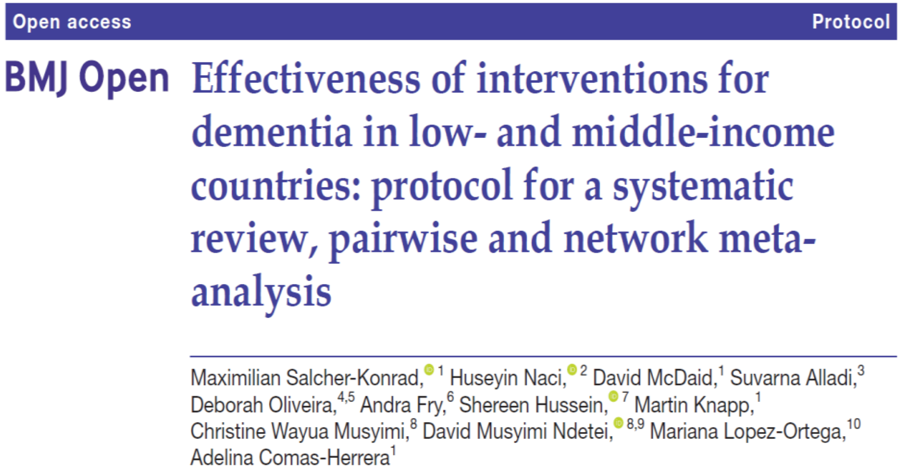
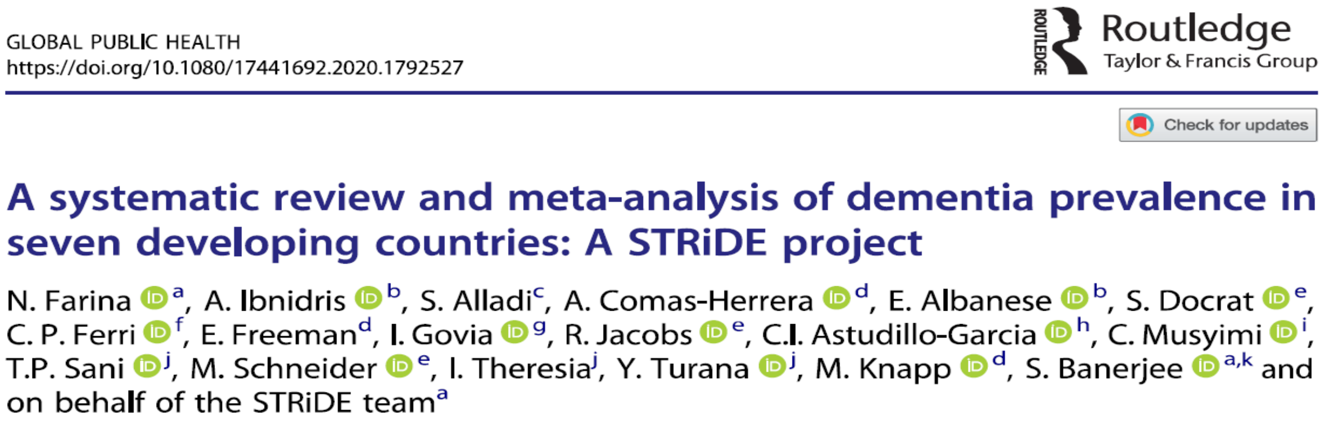


Open access | Protocol

BMJ Open

Effectiveness of interventions for dementia in low- and middle-income countries: protocol for a systematic review, pairwise and network meta-analysis

Maximilian Salcher-Konrad,[1] Huseyin Naci,[2] David McDaid,[1] Suvarna Alladi,[3] Deborah Oliveira,[4,5] Andra Fry,[6] Shereen Hussein,[7] Martin Knapp,[1] Christine Wayua Musyimi,[8] David Musyimi Ndetei,[8,9] Mariana Lopez-Ortega,[10] Adelina Comas-Herrera[1]



GLOBAL PUBLIC HEALTH
https://doi.org/10.1080/17441692.2020.1792527

A systematic review and meta-analysis of dementia prevalence in seven developing countries: A STRiDE project

N. Farina[a], A. Ibnidris[b], S. Alladi[c], A. Comas-Herrera[d], E. Albanese[b], S. Docrat[e], C. P. Ferri[f], E. Freeman[d], I. Govia[g], R. Jacobs[e], C.I. Astudillo-Garcia[h], C. Musyimi[i], T.P. Sani[j], M. Schneider[e], I. Theresia[j], Y. Turana[j], M. Knapp[d], S. Banerjee[a,k] and on behalf of the STRiDE team[a]

Beyond the project: Building a strategic theory of change to address dementia care, treatment and support gaps across seven middle-income countries

Erica Breuer, Adelina Comas-Herrera, Emily Freeman, Emiliano Albanese, Suvarna Alladi, Rochelle Amour, Sara Evans-Lacko, Cleusa P Ferri, Ishtar Govia, Claudia Iveth Astudillo García, Martin Knapp, Michael Lefevre, Mariana López-Ortega, Crick Lund, Christine Musyimi, David Ndetei, Deborah Oliveira, Tiffany Palmer, Meera Pattabiraman, Tara Puspitarini Sani, Dubglas Taylor, Eileen Taylor, Imelda Theresia, Priya Treesa Thomas, Yuda Turana, Wendy Weidner, Marguerite Schneider

First Published July 1, 2021 | Research Article | Find in PubMed

https://doi.org/10.1177/14713012211029105

Active inclusion of people living with dementia in planning for dementia care an services in low- and middle-income countries

Erica Breuer, Emily Freeman, Suvarna Alladi, , , , , , , , , , , , , Marinda Breedt, Ishtar Govia, Mariana López-Ortega, Christine Musyimi, Déborah Oliveira, Meera Pattabiraman, Tara Puspitarini Sani, Marguerite Schneider, Kate Swaffer, Dubhglas Taylor, Eileen Taylor, Adelina Comas-Herrera

First Published September 1, 2021 | Research Article | Find in PubMed

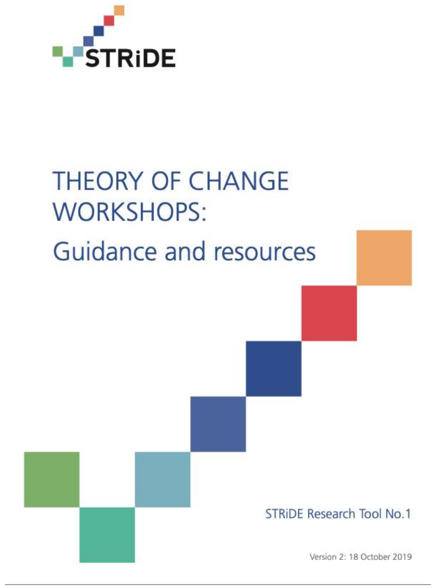
https://doi.org/10.1177/14713012211041426

Article information

Abstract

Involving people living with dementia in service design and planning has become more common in h income countries. It remains rare in low- and middle-income countries where two-thirds of the world people with dementia live. In this commentary article, we explore the barriers to inclusion of people with dementia in planning in low- and middle-income countries and make a case for the inclusion of

”How to do STRiDE”: Research tools so far (many more under development)



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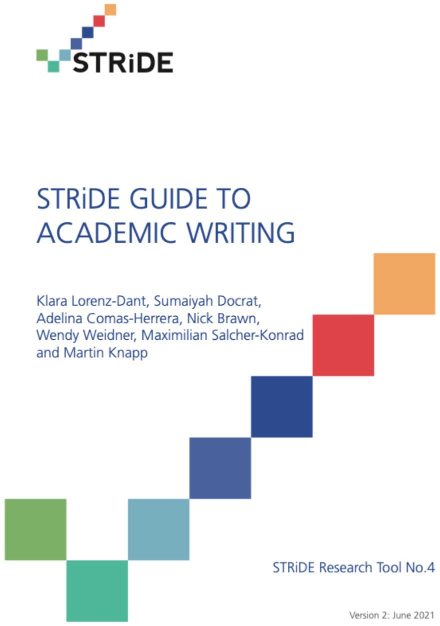
THEORY OF CHANGE WORKSHOPS:
Guidance and resources

STRiDE Research Tool No.1

Version 2: 18 October 2019



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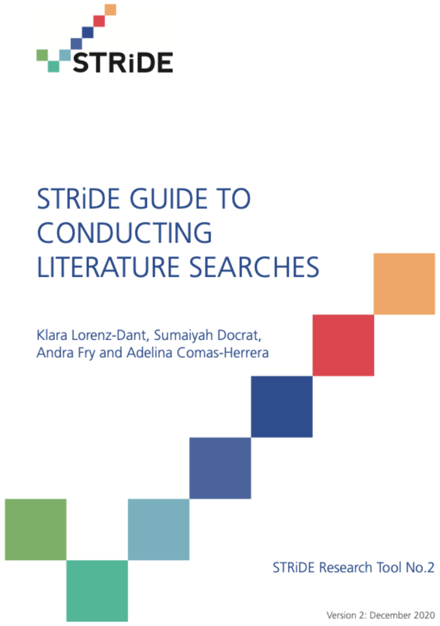
STRiDE GUIDE TO ACADEMIC WRITING

Klara Lorenz-Dant, Sumaiyah Docrat,
Adelina Comas-Herrera, Nick Brawn,
Wendy Weidner, Maximilian Salcher-Konrad
and Martin Knapp

STRiDE Research Tool No.4

Version 2: June 2021



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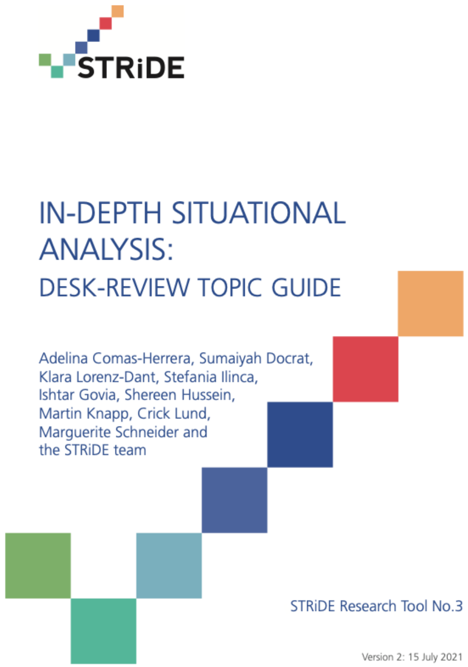
STRiDE GUIDE TO CONDUCTING LITERATURE SEARCHES

Klara Lorenz-Dant, Sumaiyah Docrat,
Andra Fry and Adelina Comas-Herrera

STRiDE Research Tool No.2

Version 2: December 2020



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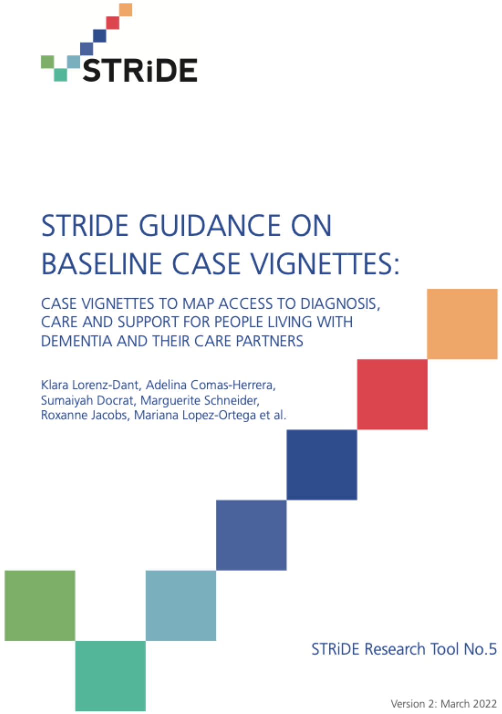
IN-DEPTH SITUATIONAL ANALYSIS:
DESK-REVIEW TOPIC GUIDE

Adelina Comas-Herrera, Sumaiyah Docrat,
Klara Lorenz-Dant, Stefania Ilinca,
Ishtar Govia, Shereen Hussein,
Martin Knapp, Crick Lund,
Marguerite Schneider and
the STRiDE team

STRiDE Research Tool No.3

Version 2: 15 July 2021



STRiDE

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

Klara Lorenz-Dant, Adelina Comas-Herrera,
Sumaiyah Docrat, Marguerite Schneider,
Roxanne Jacobs, Mariana Lopez-Ortega et al.

STRiDE Research Tool No.5

Version 2: March 2022

Costing unpaid dementia care in India

Emily Freeman (e.freeman@lse.ac.uk), Jayeeta Rajagopalan, Saadiya Hurzuk, Priya Treesa Thomas, Meera Pattabiraman, Narendhar R, Suvarna Alladi

Strengthening responses to dementia (the STRiDE project)

International Long-term Care Policy Network (ILPN) Conference
09 September 2022

Economic and Social Research Council
Global Challenges Research Fund

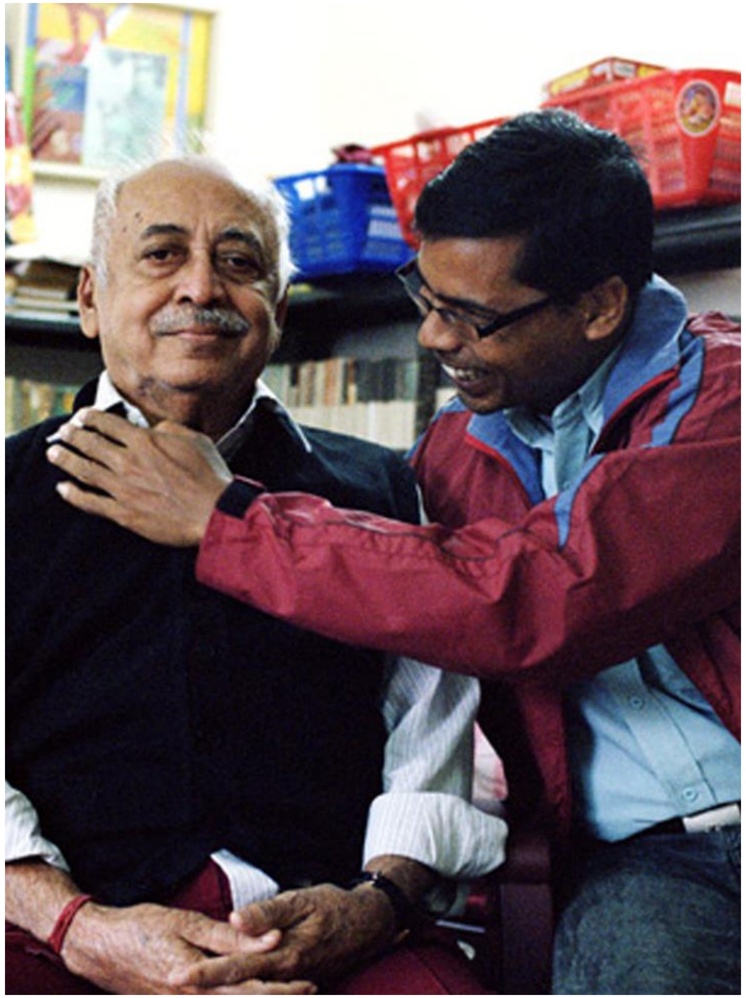
www.stride-dementia.org |@STRiDEDementia

MONEY MATTERS

- Especially to those tasked with building, maintaining and funding systems for long term care
- Demonstrating that unpaid care is not ‘no cost’ care is therefore a key goal for researchers and care advocates alike
- Answers to the key question of how unpaid care should be economically valued are not yet sufficient, especially outside high-income countries
- Along with questions about which direct and indirect costs should be measured (Mattap 2022), are the knottier issues about how care itself and its costs should be conceptualised

STRiDE FOCUS

- We reflect on the economic cost of unpaid care for people with moderate or severe common dementias (PWD) in Bangalore and Hyderabad, South and East India
- Here, the LTC system relies on families to pay for access to private or subsidised public specialist healthcare, and to provide needed social care, either directly, or indirectly through securing it from the unorganised care labour sector
- India is now among the most economically unequal countries in the world; focus on families with low- and middle-income



ARDSI, https://ardsikolkata.org/

DATA

- Data were generated in March-September 2021 using remote audio-recorded repeat in-depth interviews (N=56) with family members of PWD (N=24) and simultaneous review of translated transcripts to direct further interviews
- Where relevant, and where possible, we interviewed multiple members of a family
- Iterative and in-depth theme- and case-based analysis following generation of dataset is ongoing

NATURE OF ECONOMIC COSTS

- Exploring PWD’s care pathways from the family’s first recognition of symptoms to the moment of the interview, identified costs that are, and are not, routinely considered in quantitative costing studies

- Nature of costs are routed in the specific geographic, economic, health system and social context of study locations and individuals’ situations, and may or may not be shared elsewhere → Calls to improve quality of international evidence base by using standardised indicators not unproblematic

- Costs were not experienced by all. Where they were, they were manageable for some families and catastrophic for others

→ highlighting and exacerbating economic and care inequalities

DIRECT COST	SIGNIFICANCE
Healthcare Consultations with GPs, Specialists, Ayurveda practitioners; Diagnostic tests; hospital stays	For some met by private insurance or Government subsidies, for others these are out-of-pocket expenses
Medication To address dementia symptoms and co-morbidities	*If someone buys medicines at least it will be good I feel. I don't know what to do. Nothing, no wealth… nothing is there … just pain, torment. What else can I do?* [P23, 70-79, Spouse, Moderate dementia, Very low income] → 1.75 higher than reported monthly income
	All her medicines and all medical expenses are borne by [participant's former workplace] [P4, 80-89, Spouse, Severe dementia, Middle income]
Travel to healthcare Inter- and intra-state travel for health services (e.g. train, bus, auto, taxi) and accommodation	*Last time we came [to specialist hospital] we took [loans] from people from our village…what will we do? We are poor people, we don't get enough money for food then how will we manage the medicines and travel cost?* [P6, 30-39, Son, Moderate dementia, Very low income] → 6 times higher than reported monthly income

DIRECT COST	SIGNIFICANCE
Supportive services ('social care') Home-based care (attenders, domestic workers), Daycare	P4, paid R15K for an attender and R2K for daycare monthly. He sold land to meet costs → 42.5% of reported monthly income
	P10, 30-39 years, Daughter, Severe dementia, Middle/upper-middle income, paid R35K monthly for two domestic workers 2015-2018 → 88% of reported monthly income
Supporting goods Specific foods, vitamin supplements, incontinence aids, housing modifications	Only purchased by those who can afford them *[PWD always asking for food, but] the gas will get over, if we cook many times a day right? So, I will think who will again go and get? So, I will cook once in the morning...We will keep that and eat that only till night...[if he asks for food] I will keep prolonging saying I will give, I will give* [P23]

→ Impact of costs *not* linearly related to income (e.g. P4 meets healthcare costs easily, but not social care costs)

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COST OF PAID SOCIAL SUPPORT

- Discussion of paid home-based care highlights some of the nuances involved in costing seemingly straightforward cost components
- For the concept of ‘home-based supportive services’, international use of ‘formal and informal care’ as shorthand for ‘paid; organised; non-family’ and ‘unpaid family or friends’ comes unstuck: participants hired trained homebased caregivers, referred to as “attenders”, through e.g. agencies, *and* untrained “attenders” identified through their social networks
- Nevertheless, cost of these workers straightforward
- But what of previously-employed domestic workers who now provide needed supportive dementia care? Some workers perform additional or different tasks, but some don’t; Some are paid more, others are not; Some participants explicitly recognise activities as supporting dementia care, others don’t

INDIRECT COST	SIGNIFICANCE
Reduction in PWD's income Real reduction that has an impact on the participant or other caregivers	Some PWD in this sample were previously main earners and money managers within families
Reduction in family caregiver's income Real reduction in earnings due to caregiving (e.g. reducing working hours); Potential or likely reduction in earnings (e.g. not being offered or not accepting a higher paid position; not obtaining paid employment)	*So, not only in Hyderabad, I got good company offers from Bengaluru also. But I was not able to relocate myself due to family reasons [so I declined]… And here [by parents] I needed to look out for the timings and what I do and equally I need to support my family without stressing out myself. Accordingly, I chose the job [I have] now.* [P1, 18-29, Son, Moderate dementia, Middle to upper-middle income]
	We were [at specialist hospital] for 17 days [for diagnosis]. We didn't work, we lost that money [daily wages], it cost so much [P6, 30-39, Son, Moderate dementia, Very low income]
Changes to employment/higher education trajectory	*I did not get to complete my degree in the U.S. So, when I came back…my credits never transferred over, I had other things to take care of, so I finally decided to start college all over again* [P10, 30-39 years, Daughter, Severe dementia, Middle/upper-middle income]

INDIRECT COST	SIGNIFICANCE
Reduction in savings and investments	All of P1's [18-29] income is taken up with care for his parents, preparing for his sister's marriage next year and household upkeep, leaving him nothing to save for his future or prospects to increase earnings
Reduction in other unpaid work Including childcare and household work	Direct and indirect reductions in both quality and quantity of unpaid care: P17 [c.30-39, Daughter, Middle-income] was relying on her mother's childcare provision for her to manage work. When her mother needed to care for her father with dementia, she had to stop work P8 [60-69, Spouse, Middle-income] (reluctantly) relies on her son's care for her, which has lessened as he tries to find balance between caring for her husband with dementia, his work and dependants
Healthcare for ill-heath related to caregiving Obtaining care in response to physical and/or psychosocial impact of caregiving	*Early indications are that this may be obtained by those who can afford it, rather than those with medical need*
Time spent caring	

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CONCEPTUALISING CAREGIVING TIME

- Time spent caregiving is hard to conceptualise, both for families, researchers and service providers, and for the individuals experiencing them
- Perhaps not surprising, but these data contextualise challenges and highlight gaps in understanding
- P12 and P23 provide constant (‘24/7’) care, including hands-on care and indirect supervision to the PWD, but both performed many care tasks – domestic work like cleaning and cooking – for PWD and the rest of the family prior to dementia

> [PWD] was not helping [with housework]… I alone used to do everything that time also…it has been 30 to 40 years since she worked [P12]

- The *impact* of caregiving time and tasks is also difficult to decipher for participants: P12’s narratives circle between minimising the influence dementia care has on her domestic work and time, and strongly lamenting it as significant

CONCEPTUALISING CAREGIVING SPACE

- While time spent caregiving versus doing other domestic work is nuanced, the spatial dimensions of caregiving were much clearer for participants
- Caregiving ties P12 and P23 to the home and geographically shaping their time. This restriction in movement presents the biggest cost to them
- Should it be economically valued? Significantly for them, it was *not* valued by these participants’ families

> “They do not think that I am also a lady and I also need a little freedom, they think like anyways she is at home right, let her take care” [P23, I3]

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- Caregivers may not have 'accurate' answers ready for researchers → Calls into question reliability of cost data generated in cross-sectional research using single (qualitative or quantitative) interviews

PERCEPTIONS OF CARE COSTS

- When considering impact costs have on family caregivers, these data also suggest the need to pay attention to which caregiver is answering the questions
- People frequently provided primarily ‘hands-on’ *or* economic care, and the associated indirect and direct costs are not considered equal to those bearing them. For some cases in our sample, families providing care are composed of individuals who perceive themselves to be caring alone
- E.g. Across 3 interviews P12 consistently presents herself as providing all care alone. Her narrative minimises any contributions from other family members. While she reports that her brother-in-law, P11, facilitates medical care, she dismisses this as a form of 'care'

“I alone take care of her … [others] help in the sense, that when she goes out, they get her back and leave her here, that’s it, but other than that, I alone have to do everything”

PERCEPTIONS OF CARE COSTS

- Her brother-in-law, P11, on the other hand emphasises the importance of the care he gives – complete financial responsibility for PWD's healthcare ("I alone") – and appears to minimise the hands-on care provided by his brother and sister-in-law ("simply they take care that's all")

> "for treatment and all I alone take care, whatever happens, I alone take care of the treatment, if I have to bring her here, I alone send the auto, car or whatever is needed, simply they take care, that's all"

- While P12 reports it is not difficult for her brother-in-law to meet the direct costs, he reports the opposite

> "It's tough only madam, what to do, she is my mother, we have to take care right?"

CONCLUSIONS

- Our findings subsequently make three important contributions:

1. Join a growing body of research in highlighting the (re)production of long-term care inequalities
2. Highlight costs and care inputs that are not often considered in valuations of unpaid care
3. Call for greater critical engagement with ostensibly unambiguous components in the unpaid care costing debate: the enumeration of caregivers’ hours, ‘the family’ in family care, and the parity assumed in the cost and value between different caregivers’ hours

THE TEAM

Alzheimer's and Related Disorders Society of India (ARDSI)

- Meera Pattabiraman
- Narendhar Ramasamy

National Institute of Mental Health and Neurosciences (NIMHANS)

- Suvarna Alladi
- Saadiya Hurzuk
- Priya Thomas
- Jayeeta Rajagopalan

Care Policy Evaluation Centre at the London School of Economics

- Emily Freeman
- Martin Knapp (STRiDE PI)
- Adelina Comas-Herrera (Co-PI)
- Anji Mehta (STRiDE project management)

STRiDE Network
Strengthening Responses to Dementia

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Why a network

- STRiDE 2018-2022 created a network with strong links and outputs across 7 countries and the UK
- Additional countries joined in the project by using and expanding on the STRiDE methodologies
  - Hong Kong, New Zealand, Switzerland, Romania, England
- Covering additional topics and areas of policy-relevant research:
  - The COVID-19 pandemic and long term care issues
  - Rapidly changing global population demographics - increased longevity
  - Risk reduction, post-diagnostic support, etc
- A network is the next logical step to harness this interest and develop relevant methodologies and build a database on dementia – policies, services, care and financing, and appropriate methodologies to research these

What will the network be?

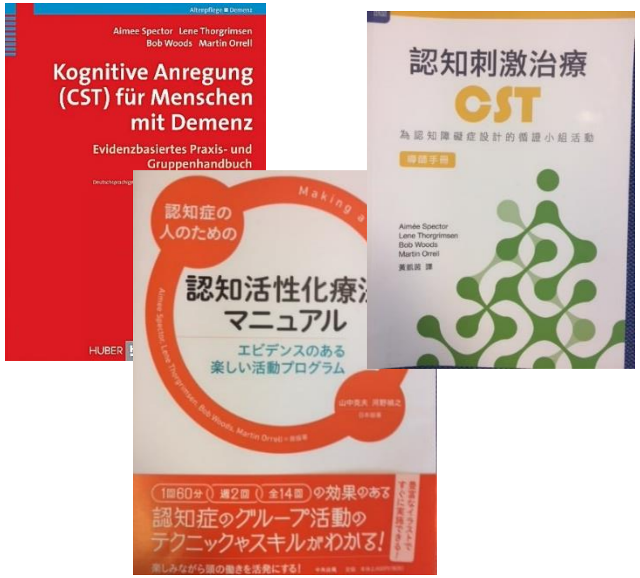
- Have a global focus
- Bringing together interested
  - Individuals (researchers, advocates, individuals living with dementia, carers, etc.)
  - Research groups
  - Advocacy groups
  - Non-profit organisations
- To
  - share information, methodologies, resources and expertise
  - collaborate on research projects
  - Build partnerships

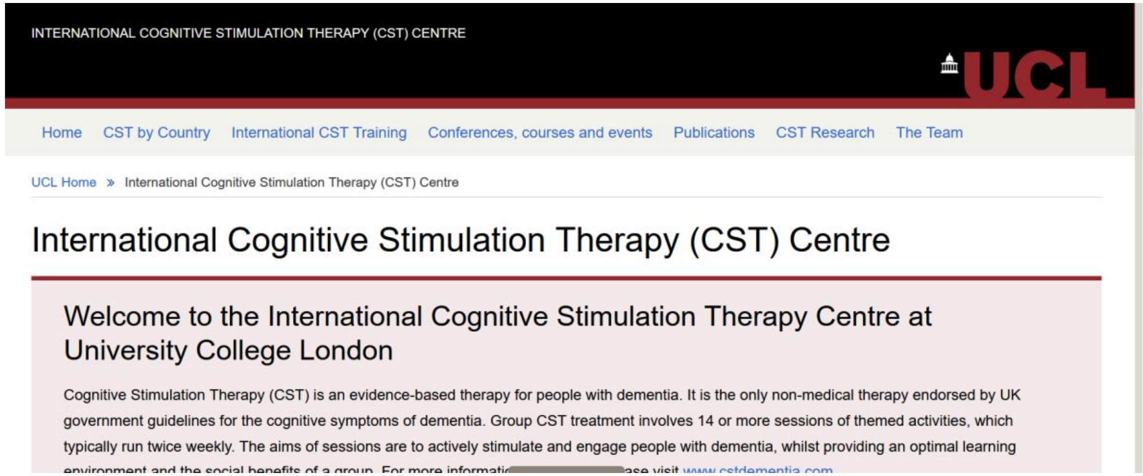
Initial aims and objectives

- Provide guidelines for research and coordination on policy-relevant research on dementia care
- Engaging with people living with dementia
- Facilitating collaborative work across regions
- Influencing and tracking policy implementation at national and global levels
- Capacity building

Examples of projects already part the STRiDE Network

Cognitive Stimulation Therapy (CST) for dementia





International Cognitive Stimulation Therapy (CST) Centre

Welcome to the International Cognitive Stimulation Therapy Centre at University College London

Cognitive Stimulation Therapy (CST) is an evidence-based therapy for people with dementia. It is the only non-medical therapy endorsed by UK government guidelines for the cognitive symptoms of dementia. Group CST treatment involves 14 or more sessions of themed activities, which typically run twice weekly. The aims of sessions are to actively stimulate and engage people with dementia, whilst providing an optimal learning environment and the social benefits of a group. For more informati[illegible]ase visit www.cstdementia.com

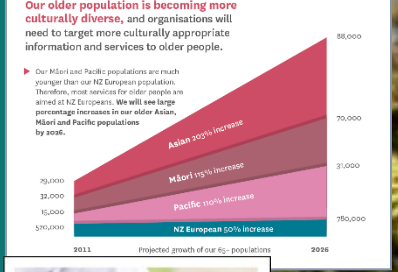
www.ucl.ac.uk/international-cognitive-stimulation-therapy

a.spector@ucl.ac.uk

CST-International
BRAZIL, INDIA & TANZANIA

MRC Medical Research Council

GACD
GLOBAL ALLIANCE FOR CHRONIC DISEASES
AN ALLIANCE OF HEALTH RESEARCH FUNDERS



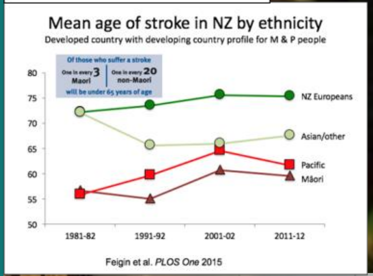
Our older population is becoming more culturally diverse, and organisations will need to target more culturally appropriate information and services to older people.

- Our Māori and Pacific populations are much younger than our NZ European population. Therefore, most services for older people are aimed at NZ Europeans. **We will see large percentage increases in our older Asian, Māori and Pacific populations by 2026.**

Projected growth of our 65+ populations

Dementia Economic Impact Report 2016
March 2017

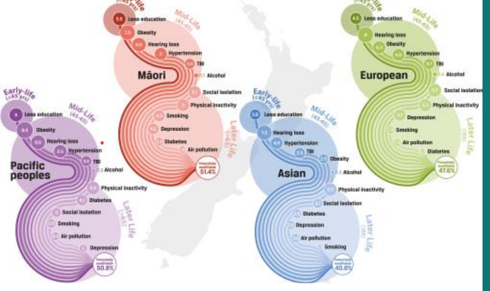
Deloitte.

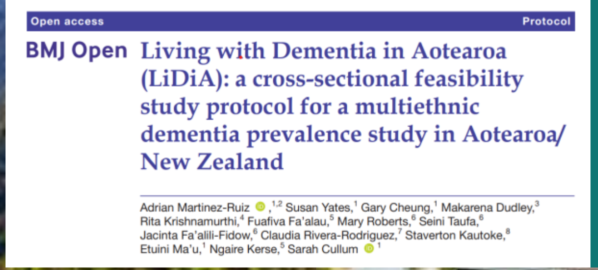


Mean age of stroke in NZ by ethnicity

Developed country with developing country profile for M & P people

Feigin et al. *PLOS One* 2015





Open access Protocol

BMJ Open **Living with Dementia in Aotearoa (LiDiA): a cross-sectional feasibility study protocol for a multiethnic dementia prevalence study in Aotearoa/New Zealand**

Adrian Martinez-Ruiz,[1,2] Susan Yates,[1] Gary Cheung,[1] Makarena Dudley,[3] Rita Krishnamurthi,[4] Fuafiva Fa'alau,[5] Mary Roberts,[6] Seini Taufa,[6] Jacinta Fa'alili-Fidow,[6] Claudia Rivera-Rodriguez,[7] Staverton Kautoke,[8] Etuini Ma'u,[1] Ngaire Kerse,[5] Sarah Cullum[1]

Improving Dementia Mate Wareware Services in Aotearoa New Zealand

Action Plan

First presented to government in May 2020
Updated and represented to government in September 2021

	European	Māori	Pacific	Asian
Average cost per person with dementia in 2020				
ARC & HBSS	$19,750	$15,001	$15,130	$9,117

Source: TAS (2021) and NZACA (2020) national datasets

Dementia Economic Impact Report 2020

Prepared for Alzheimers New Zealand
September 2021

THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

MEDICAL AND HEALTH SCIENCES

Email: sarah.cullum@auckland.ac.nz

STRiDE England

STrengthening Responses to Dementia in England

February 2022 to March 2024

About the project

- Funded as part of the NIHR Three Schools: Dementia Research Programme
- Building on methods developed as part of the STRiDE project
- Focusing on how national and local factors contribute to inequalities in access to dementia care in England
- Collaboration across multiple universities and organisations, led from the Care Policy and Evaluation Centre at LSE.

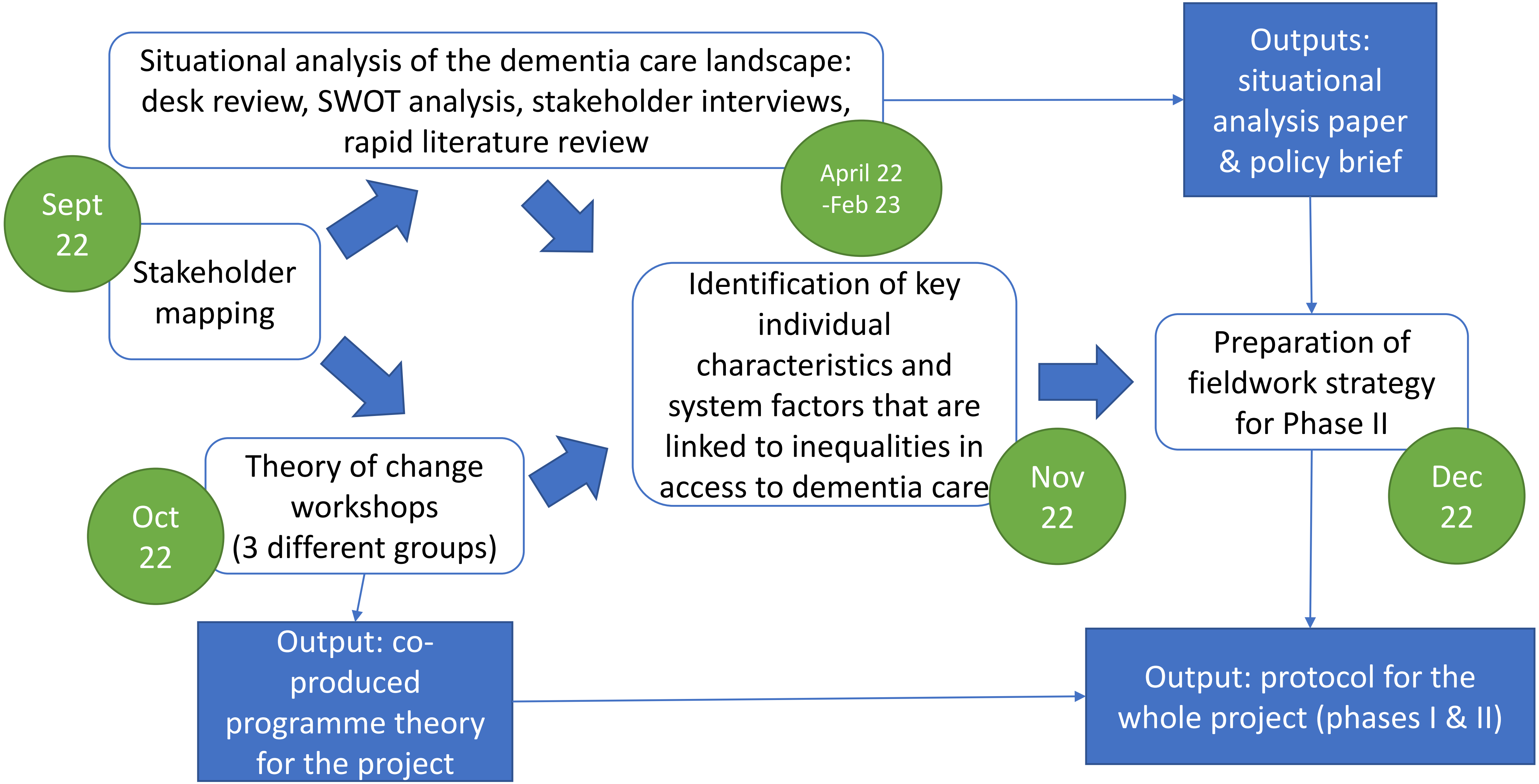
People and groups involved so far:

Care Policy and Evaluation Centre, LSE:
- Adelina Comas-Herrera (PI)
- Chiara De Poli
- Michael Clark
- Louis Compton
- Eva Cyhlarova
- Martin Knapp
- Jayeeta Rajagopalan

Newcastle University:
- Louise Robinson
- Andrew Kingston
- RO, TBA

Sube Banerjee (University of Plymouth)
Carol Brayne (University of Cambridge)
Alistair Burns (University of Manchester)
Clarissa Giebel (University of Liverpool)
Gill Livingston (University College London)
Thomas Shakespeare (LSHTM)
Innovations in Dementia: Philly Hare
Alzheimer’s Society: Hayley Hogan and Colin Capper
DEEP (UK network of dementia voices)
Erica Breuer (Theory of Change consultant)

Structure of STRiDE England, Phase I



Situational analysis of the dementia care landscape: desk review, SWOT analysis, stakeholder interviews, rapid literature review

April 22 -Feb 23

Outputs: situational analysis paper & policy brief

Sept 22

Stakeholder mapping

Identification of key individual characteristics and system factors that are linked to inequalities in access to dementia care

Nov 22

Preparation of fieldwork strategy for Phase II

Dec 22

Theory of change workshops (3 different groups)

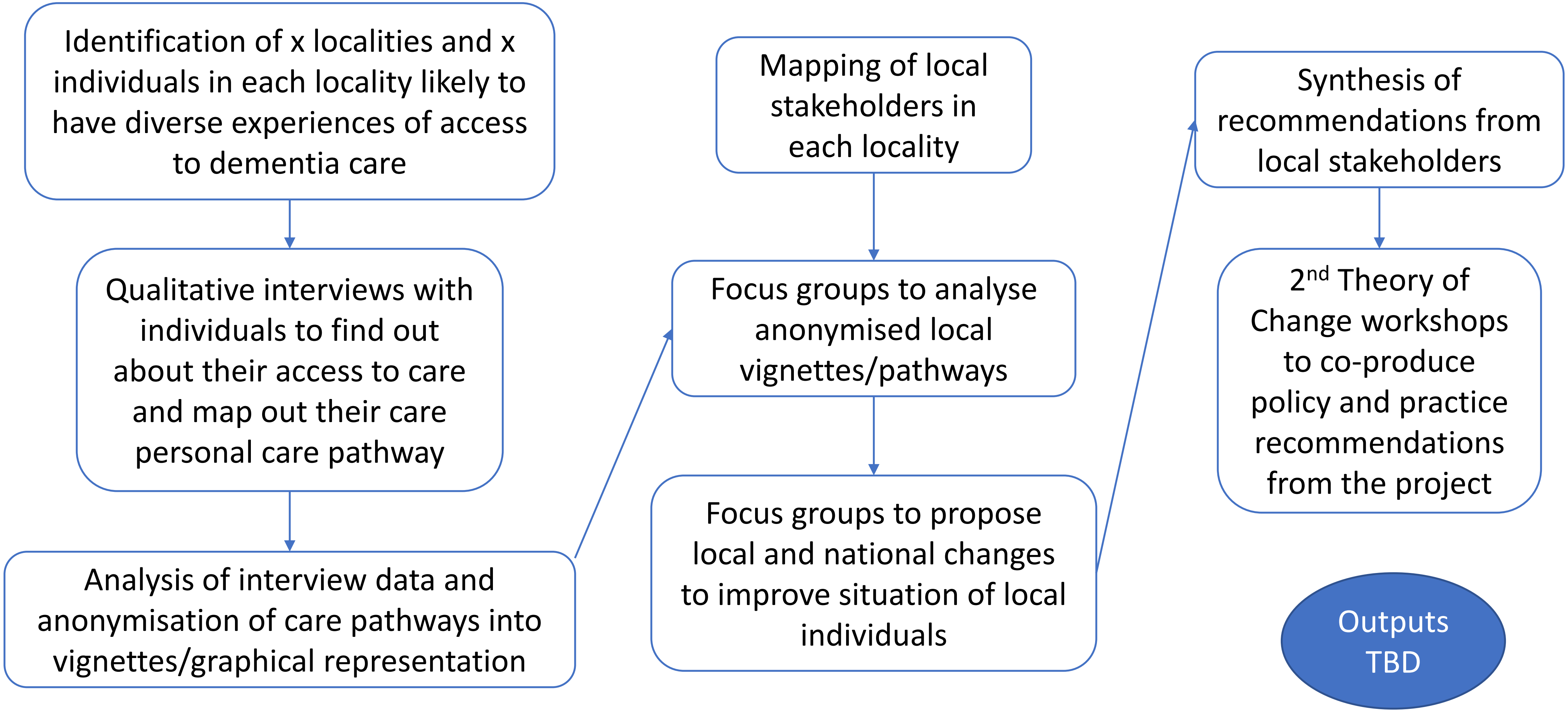
Oct 22

Output: co-produced programme theory for the project

Output: protocol for the whole project (phases I & II)

Structure of STRiDE England, Phase II

(start January 2023 if plans approved, to March 2024)



Identification of x localities and x individuals in each locality likely to have diverse experiences of access to dementia care

Qualitative interviews with individuals to find out about their access to care and map out their care personal care pathway

Analysis of interview data and anonymisation of care pathways into vignettes/graphical representation

Mapping of local stakeholders in each locality

Focus groups to analyse anonymised local vignettes/pathways

Focus groups to propose local and national changes to improve situation of local individuals

Synthesis of recommendations from local stakeholders

2nd Theory of Change workshops to co-produce policy and practice recommendations from the project

Outputs TBD

How to get involved with the STRiDE Network

- Complete the survey on what the network should look like
- Let us know what your thoughts are:
  - https://stride-dementia.org/network-questionnaire/
  - Stride.dementia@lse.ac.uk

How to improve dementia care in Hong Kong

Terry Lum

Henry G Leung Professor in Social Work and Social Administration
The University of Hong Kong

Sep 9, 2022

People with dementia in Hong Kong

- Elderly population (65 +): 19.6% in 2021.
- Median age: 46.3 years.
- 80+ population: 5.3% or 380,968 people.
- # of people with dementia: 79,400 patients receiving treatment in the public hospital system in 2020.
- Estimated: >300,000 people in less than 20 years (2039)

Health care expenditure is low

- Health care expenditure: 6.8% of GDP in 2020.
- Public: 3.6%.
- UK: 11.9% (2021)
- US: 17.8% (2021)
- Canada: 11.7% (2021)
- New Zealand 9.7% (2020)
- Korea: 8.4% (2020)
- Japan: 11.1% (2020)
- Singapore: 5.9% (2021)

Source: https://stats.oecd.org/index.aspx?DataSetCode=SHA

Photo Credit: Photo: Jelly Tse

Health care expenditure

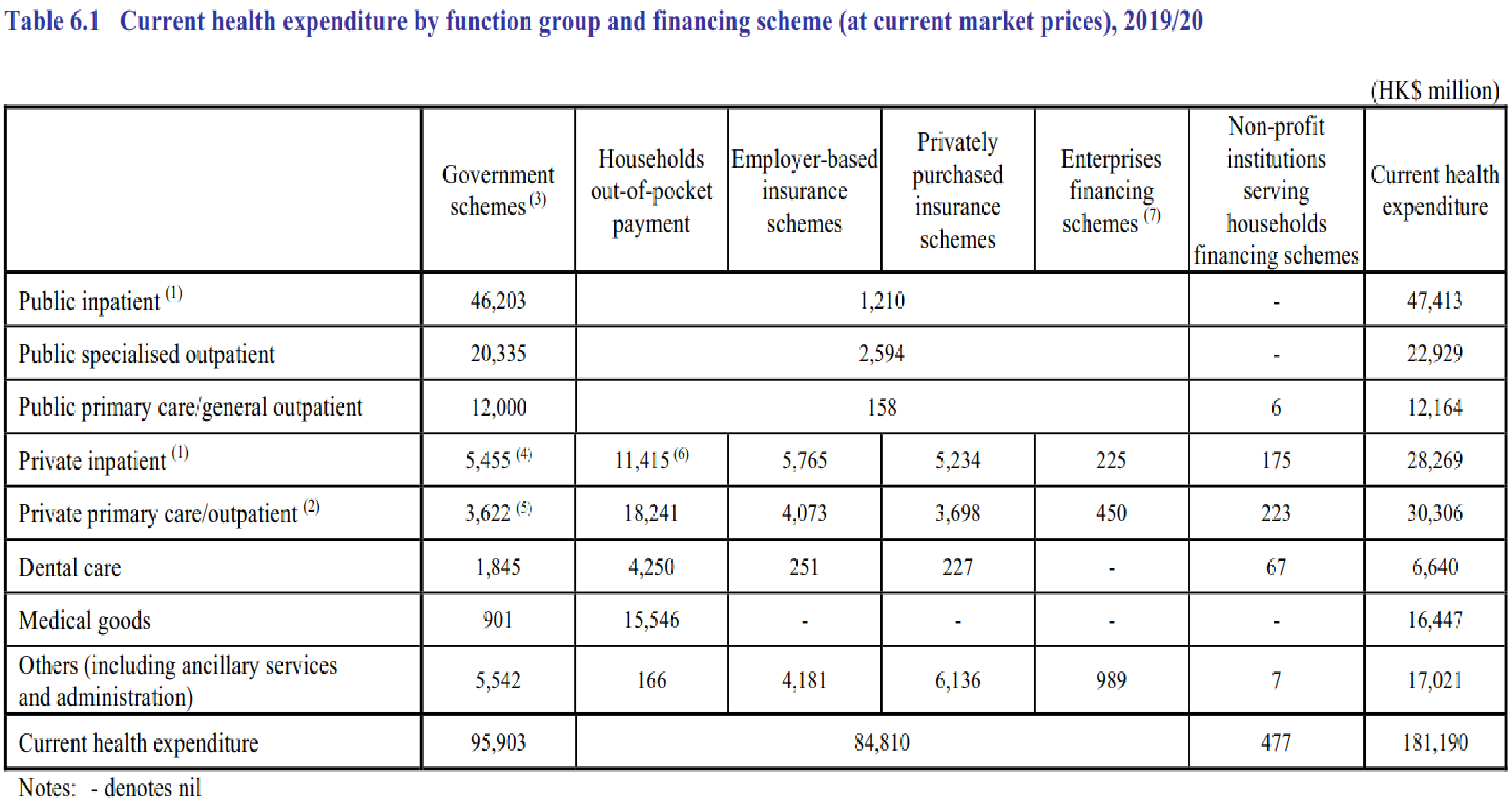


Table 6.1 Current health expenditure by function group and financing scheme (at current market prices), 2019/20

(HK$ million)

	Government schemes (3)	Households out-of-pocket payment	Employer-based insurance schemes	Privately purchased insurance schemes	Enterprises financing schemes (7)	Non-profit institutions serving households financing schemes	Current health expenditure
Public inpatient (1)	46,203	1,210				-	47,413
Public specialised outpatient	20,335	2,594				-	22,929
Public primary care/general outpatient	12,000	158				6	12,164
Private inpatient (1)	5,455 (4)	11,415 (6)	5,765	5,234	225	175	28,269
Private primary care/outpatient (2)	3,622 (5)	18,241	4,073	3,698	450	223	30,306
Dental care	1,845	4,250	251	227	-	67	6,640
Medical goods	901	15,546	-	-	-	-	16,447
Others (including ancillary services and administration)	5,542	166	4,181	6,136	989	7	17,021
Current health expenditure	95,903	84,810				477	181,190

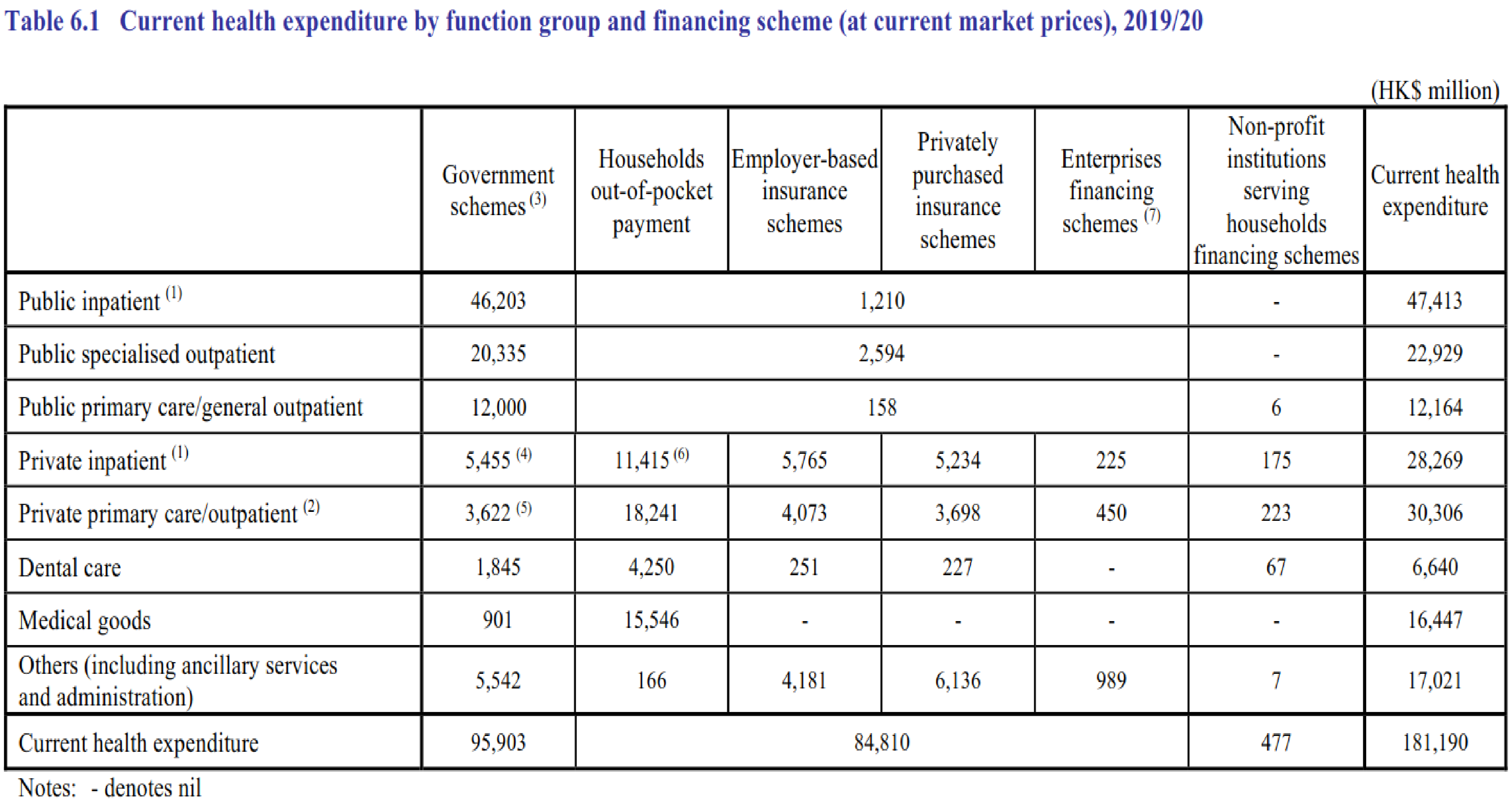
Notes: - denotes nil

26.2%

15.6%

41.8%

Health care expenditure



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Notes: - denotes nil

12.7%

6.7%

19.4%

16.8%

The health care system

- Built on the model developed for acute care.
- Most resources go to inpatient care (41.8%) and specialist outpatients (12.7%).
- Primary health care accounted for only 29.5% of health care expenditure, and most of them came from private (16.8%) and out-of-pocket (10.1%).
- The system is not “fit-for-purpose.”

Social welfare expenditure

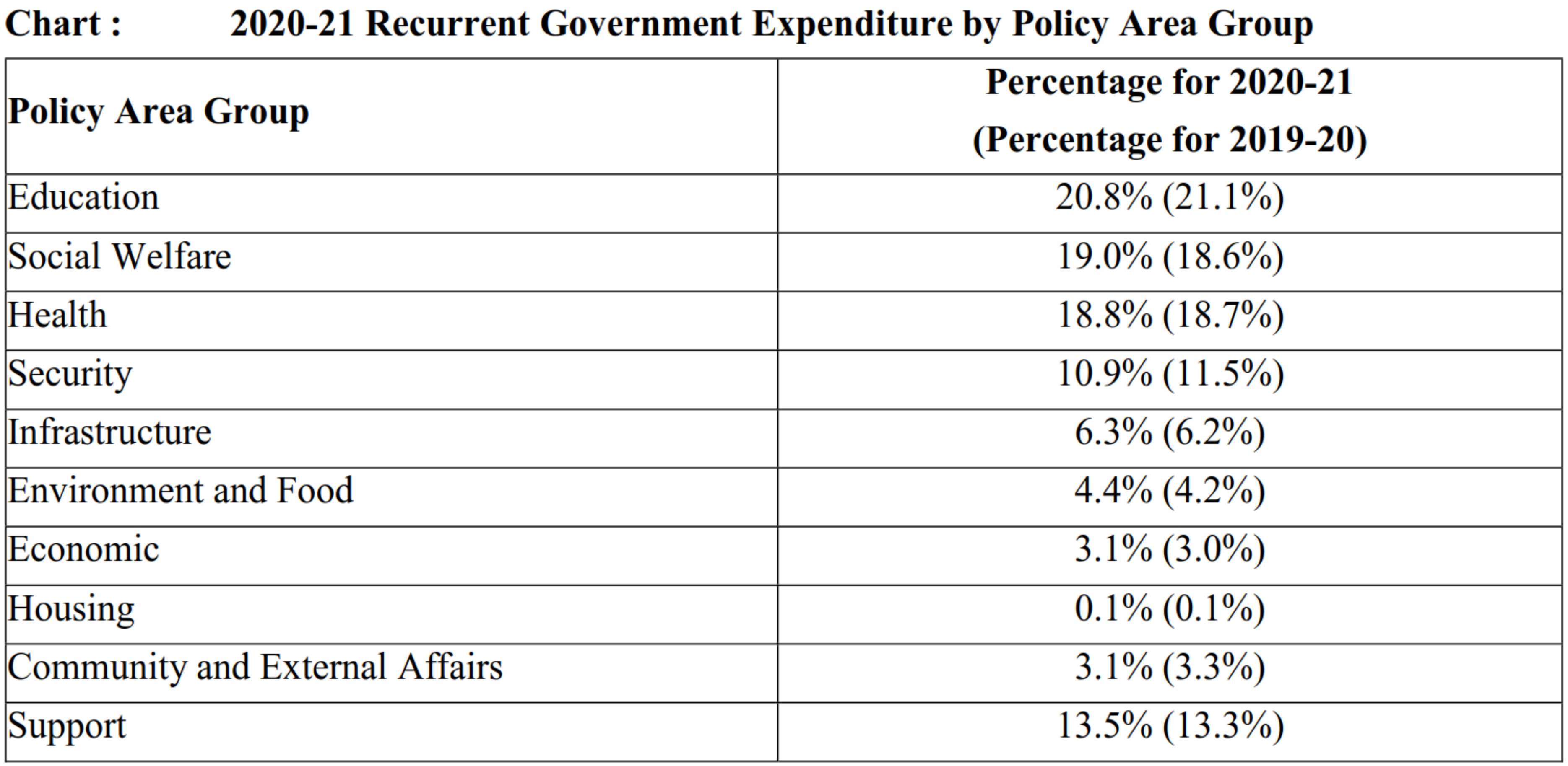

Chart : **2020-21 Recurrent Government Expenditure by Policy Area Group**

Policy Area Group	**Percentage for 2020-21** **(Percentage for 2019-20)**
Education	20.8% (21.1%)
Social Welfare	19.0% (18.6%)
Health	18.8% (18.7%)
Security	10.9% (11.5%)
Infrastructure	6.3% (6.2%)
Environment and Food	4.4% (4.2%)
Economic	3.1% (3.0%)
Housing	0.1% (0.1%)
Community and External Affairs	3.1% (3.3%)
Support	13.5% (13.3%)

Social welfare expenditure

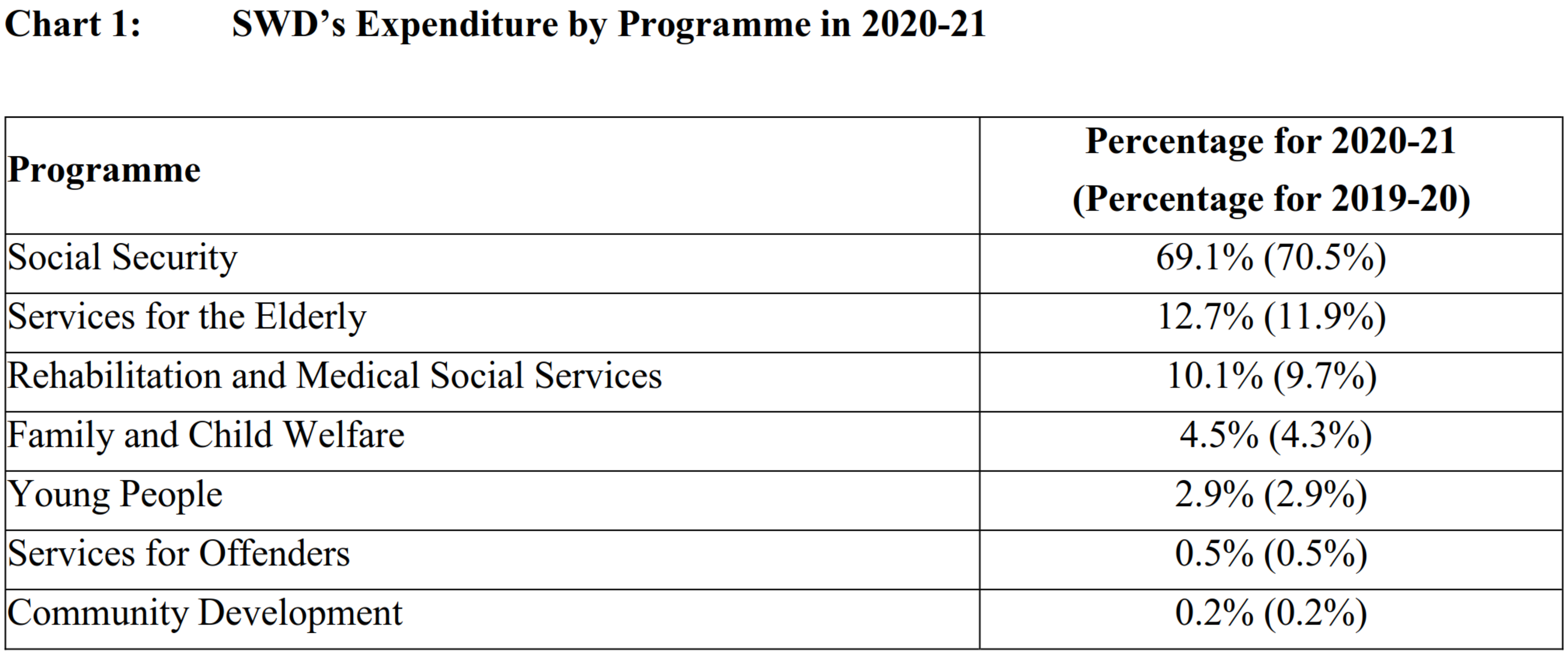

Chart 1: SWD’s Expenditure by Programme in 2020-21

Programme	**Percentage for 2020-21 (Percentage for 2019-20)**
Social Security	69.1% (70.5%)
Services for the Elderly	12.7% (11.9%)
Rehabilitation and Medical Social Services	10.1% (9.7%)
Family and Child Welfare	4.5% (4.3%)
Young People	2.9% (2.9%)
Services for Offenders	0.5% (0.5%)
Community Development	0.2% (0.2%)

2.4% of total government expenditure

About 34% of elderly care expenditure went to community care.

Dementia care system

- There is no citywide dementia care plan or strategy for Hong Kong.
- Dementia care is mainly provided in specialist clinics. However, we have very few psychiatrists, geriatric psychiatrists, and geriatricians (400+ psychiatrists, 300+geriatricians, & 40-50 geriatric psychiatrists). Most are working in public hospital system.
- Primary healthcare professionals are not involved in the diagnosis and management of dementia.
- LTC system was built before the dementia era. The government uses supplemental funding to provide incentive for LTC providers to take care of people with dementia.
- The medical-social collaboration is weak. E.g Dementia community support scheme in 2017.

Building a fit-for-purpose dementia care system

- Top-down decision making: lack of consensus on what are the purposes for supporting people living with dementia. In other words, what are we trying to optimize?
- We definitely need to shift away from a specialist-driven modle to a specialist-supported primary care driven system.
- The system needs to be supported by the existing health care infrastructure:
  - Public-private partnership to provide private primary care to get involved.

Building a fit-for-purpose dementia care system

- Strong medical–social collaboration to optimize healthy aging for people with dementia.
- Training to enhance the skills of social care staff to provide support to people with dementia and their family members.
- How about a stepped-care model for people with dementia and their families.
- Please come to section F.3.A at 2:15-3:30 today @4.02 to engage in a discussion on supporting developing countries/places to develop a “fit for purpose” dementia care system.

Thank You

For more information, please

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For public: https://jcjoyage.hk/
For researchers: https://research.jcjoyage.hk/

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