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Comprehensive measurement of the prevalence of dementia in low- and middle-income countries: STRiDE methodology and its application in Indonesia and South Africa

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**Comprehensive measurement of the prevalence of dementia in low- and middle-income
countries: the STRiDE methodology and its application in Indonesia and South Africa**

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Abstract

Background: A core element of the Strengthening Responses to Dementia in DEveloping countries (STRiDE) programme was to generate novel data on the prevalence, cost, and impact of dementia in low- and middle-income countries in order to build better health policy. Indonesia and South Africa are two middle income countries in need of such data.

Aims: To present the STRiDE methodology and generate estimates of dementia prevalence Indonesia and South Africa.

Method: We conducted community-based, single-phase, cross-sectional studies in Indonesia and South Africa, randomly sampling participants aged 65 years or older in each country. Dementia prevalence rates for each country were generated using the 10/66 short schedule and applying its diagnostic algorithm. Weighted estimates were calculated using national socio-demographic data.

Results: Data were collected between September and December 2021 in 2,110 older adults in Indonesia and 408 in South Africa. The adjusted weighted dementia prevalence was 27.9% (95%CI 25.2-28.9) in Indonesia, and 12.5% (9.5-16.0) in South Africa. Our results indicate there could be over 4.2 million people with dementia in Indonesia, and over 450,000 in South Africa. Only five participants (0.2%) in Indonesia and two (0.5%) in South Africa had been previously diagnosed with dementia.

Conclusions: Despite prevalence estimates being high, formal diagnosis rates of dementia were very low across both countries (<1%). Further STRiDE investigations will provide indications of the impact and costs of dementia in these countries, but our results provide evidence that dementia needs to be prioritised within national health and social care policy agendas.

50

Introduction

There are currently an estimated 50 million people with dementia worldwide, with this expected to rise to 152.8 million by 2050.[1] The growth in numbers of people with dementia is largely driven by increasing life expectancy in low- and middle-income countries (LMICs). However, many LMICs lack basic national prevalence data on dementia, and so are reliant on estimates based on regional statistical modelling, as used within the Global Burden of Disease (GBD) study.[1] These estimates, whilst useful for their global coverage, are limited by the robustness of the model and the availability of country-specific data. They are also less powerful than local data in making the case for national policy priority. The Strengthening Responses to Dementia in DEveloping countries (STRiDE) programme identified that policymakers and key stakeholders wanted robust national estimates of dementia prevalence, and that there was a reluctance to act on data derived even from geographically close or socioeconomically similar settings.[2] In two STRiDE countries, South Africa and Indonesia, local prevalence data were identified as a priority need.[3]

In South Africa, there are few studies which explore dementia prevalence. The single best evidence comes from 1,394 Xhosa-speaking older adults in Cape Town.[4] The study used a dementia screening tool, the brief Community Screening Instrument for Dementia (CSI-D) (Prince et al., 2011), and estimated dementia prevalence to be 11% for those aged 65 years and older.[4] Other estimates of dementia prevalence come from studies with small sample sizes and potentially non-representative samples.[6] Evidence on dementia prevalence from Indonesia is geographically limited to the islands of Java and Bali.[7–9] Though issues of generalisability excluded, these studies have often reported unusually high prevalence estimates (>20%) compared with many international estimates (e.g., 4-9%, aged 60 years and older).[10]

STRiDE aimed to develop and deliver a pragmatic methodology to generate accurate dementia prevalence estimates in LMICs, sampling from rural and urban areas, using South Africa and Indonesia as exemplars. This methodology seeks to improve on existing evidence by minimising internal and external bias, and simultaneously generating data to measure both the impact and cost of dementia in these two settings, and with appropriate cultural adaptation in other LMICs.

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Method

The STRiDE programme developed a common data collection approach with the capacity for methods to vary pragmatically to access and use existing sampling frames.

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83 *Participants*

84 Recruitment occurred in two sites in each country: Jakarta and North Sumatra in Indonesia; and

85 Limpopo and Western Cape in South Africa. Sites were selected for pragmatic reasons and to ensure

86 heterogeneity in terms of socioeconomic status and rurality. Random sampling was used: simple

87 randomisation in Limpopo and proportionate to population size (PPS) randomisation in other sites.

88 Details of sites and sampling strategy are in the Appendix A.

89 To be eligible participants were required to be aged 65 years or older at the date of consent, speak one

90 of the languages of the adapted toolkits (Afrikaans, Bahasa Indonesian, English, isiXhosa, Sepedi),

91 and live within the defined sampling areas. We checked the age of participants informally prior to

92 consent and more rigorously confirmed following consent (e.g., from official documents, and calendar

93 method). All participants were required to identify an informant who could provide supplementary

94 information. The informant could be anyone with a close relationship with the older adult and who

95 spoke the appropriate language. Potential participants were excluded if they resided in care or nursing

96 homes, or they lacked capacity to consent and could not identify a personal consultee to assist in the

97 consent process.

98

99 *Procedure*

100 Researchers visited potential participants' homes (or another location convenient to participants) in

101 pairs. Informed consent was obtained (written or oral) from the older adult and an identified

102 informant. Researchers initially completed a core set of questions related to age and household with

103 both the informant and older adult. Subsequently, the older adult and informant completed the

104 remaining questionnaires independently of each other, one with each of the researchers. Measures

105 pertaining to the identification of dementia (as described below) were prioritised. In a single stage

106 process, all participants were asked the same set of questions, with the exception of some branching

107 (e.g., care-related questions were skipped if no care was provided). Study data were collected and

108 managed using REDCap electronic data capture tools hosted at the London School of Economics and

109 Political Sciences.[11]

110 All researchers were provided standardised training in how to administer the questionnaires prior to

111 testing. We developed a series of presentations and standard operating procedures (SOPs) centrally to

112 guide researchers. Data collection occurred between September 2021 and December 2021.

113

114 *Measures*

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A series of demographic measures were collected including: age (ascertained through a hierarchy of self-report, informant report, official documentation and calendar method), sex, literacy (ability to read and write), and self-report receipt of a diagnosis of dementia or Alzheimer's disease. The following instruments were completed:

The 10/66 short schedule [12] - composed of the following measures: 1) *The Community Screening Instrument for Dementia* (CSI-D), a screening instrument for dementia for use in cross-cultural studies[13] with both a cognitive assessment component and an informant-reported functional impairment component; *2) EURO-D,* a self-report measure to screen for depression;[14] and 3) *The Consortium to Establish a Registry for Alzheimer's Disease* (CERAD), a 10-word list learning task with delayed recall.[15] We used the 10/66 short algorithm to generate an estimate of dementia caseness[12] which uses data derived from the CSI-D, CERAD word list, and EURO-D (Appendix B). The 10/66 short algorithm has been demonstrated to have good sensitivity across multiple settings,[12] including against clinical diagnosis in Singapore (AUC=0.87)[16], Switzerland (AUC=0.74)[17] and Pakistan (AUC=0.85)[18].

The Dementia Severity Rating Scale (DSRS) - a brief informant report measure of 12 functional abilities similar to those in the Clinical Dementia Rating (CDR) scale.[19] The DSRS predicts the CDR sum of boxes score.[20] Scores range from 0 to 54, with higher scores representing greater impairment.

Lawton Activities of Daily Living Scale - a short questionnaire that covers eight instrumental activities of daily living (IADLs).[21] The measure was completed as an informant report measure.

Measures of cost and impact were also completed but these did not contribute to the dementia prevalence calculations and are not reported here. Indonesian participants were interviewed in Bahasa Indonesian, and South Africa participants were interviewed in isiXhosa, Sepedi, Afrikaans, or English. Details of the full STRiDE toolkit, and the underlying cross-cultural adaptation and translation process are described elsewhere.[3]

Ethics

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. All procedures involving human subjects/patients were approved by London School of Economics and Political Sciences, the University of Cape Town, University of Sumatera Utara (862/KEP/USU/2020) and Atma Jaya Catholic University (01/12/KEP-FKIKUAJ/2020).

148   *Sample size calculation*

149   Precision calculations indicated that an overall sample of 2,039 would allow the estimation of an

150   expected dementia prevalence of 4.5% with a precision of ±0.9% within each country. The

151   recruitment target was increased to 2,200 to allow for missing data.

152

153   **Analysis**

154   Demographic data were generated separately for each country; we present key demographics for

155   dementia occurrence and assessment (age in 5-year intervals, sex, literacy) in line with previous

156   dementia prevalence research.[22] We investigated representativeness of the study sample in a series of

157   Pearson's chi-square analyses which were used to ascertain whether demographic factors differed

158   between those with complete or missing data (i.e., those in which we had sufficient data to run the

159   diagnostic algorithm).

160   We calculated total prevalence (10/66 short algorithm) estimates unweighted, with 95% confidence

161   intervals (CIs). We then weighted data by national demography (age, sex, and literacy), and computed

162   national proportions from Indonesia and, from South Africa. We generated weights based on

163   sequential computation (Appendix C).

164   Next, we ran logistic regression models to explore factors potentially associated with increased risk of

165   dementia, and subsequently calculated age-adjusted odds ratios (ORs) for sex and literacy. We also

166   ran supplementary Poisson regression models to generate prevalence ratios (PRs). We explored

167   convergent validity of the 10/66 short algorithm against: cognitive impairment (Brief CSI-D screening

168   tool cognitive scale), functional impairment (Brief CSI-D screening tool informant scale, Lawton

169   ADL scale), and care needs (Older adult needs care (Yes/No)) reporting the effect size between

170   populations (Hedges *g*). For hedges *g,* a value over 0.5 indicates a medium effect size, and value over

171   0.8 indicates a large effect size. In addition, participants who scored positive for dementia on the

172   10/66 short algorithm were compared against existing cut-offs of dementia on the DSRS and the Brief

173   CSI-D (Appendix D). For these comparisons, we calculated the area under the curve (AUC,

174   (sensitivity + specificity)/2) between measures. We interpreted the AUC using existing criteria: a

175   score of 0.5 to 0.6 is considered to indicate poor accuracy, 0.6-0.7 is considered acceptable accuracy,

176   0.7 to 0.8 is considered good accuracy, and >0.8 is considered very good or excellent accuracy.[23]

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179 **Results**

180 See Fig 1 for a flow diagram of participant recruitment. In Indonesia we recruited to target. In South

181 Africa we adhered to the planned recruitment strategy and procedures, but we were unable to reach

182 the target sample size due to disruptions caused by the COVID-19 pandemic.

183

184 *****FIG 1 HERE*****

185

186 *Missing Data*

187 In Indonesia, we recruited 2,216 participants. In South Africa, we recruited 490 participants. Across

188 sites, there were instances in which only partial data were available due to participant refusal, or

189 researcher or technical error. In the Indonesian cohort, there were 106 participants (4.8%) with

190 insufficient data to run the 10/66 short algorithm. Missing data were not associated with age (n=2,216,

191 χ^2=2.64, p=0.76), literacy (n=2,173, χ^2=0.37, p=0.54), or sex (n=2,216, χ^2=0.88, p=0.35). In the South

192 African cohort, there were 82 participants (16.7%) for whom we were unable to run the 10/66 short

193 algorithm, predominantly due to refusal to answer the EURO-D (n=64). Ability to run the algorithm

194 was not associated with age (n=489, χ^2=4.04, p=0.54), literacy (n=470, χ^2=0.33, p=0.56), or sex

195 (n=467, χ^2=0.01, p=0.92).

196

197 *Demographics*

198 Dementia prevalence was estimated in 2,110 older adults in Indonesia and 408 in South Africa. Mean

199 age of participants was 71.1 (SD=5.42) in Indonesia and 74.8 (SD = 7.42) in South Africa. Both

200 country samples contained higher proportions of females than males (up to 63.5% in South Africa)

201 (Table 1). Males were 2.50 times more likely to be literate in Indonesia than females (Mantel Chi-

202 square 49.66, p<0.001). Males were 1.73 times more likely to be literate in South Africa than females

203 (Mantel Chi-square 4.71, p=0.03). See Appendix E for the number of participants by country, age, sex

204 and literacy.

205 Only five participants (0.2%) in Indonesia and two (0.5%) in South Africa had been previously

206 diagnosed with dementia.

207 *****TABLE 1 HERE*****

208 *Prevalence*

209   Unweighted estimates of dementia for those aged 65 years and older were 26.6% (95%CI 24.8 to

210   28.6) in Indonesia and 14.5% (95%CI 11.2-18.3) in South Africa. After national weighting, estimates

211   marginally increased to 27.9% (95%CI 25.2-28.9) in Indonesia and decreased 12.5% (95%CI 9.5-

212   16.0) in South Africa. Unweighted prevalence estimates by country, age, sex and literacy are reported

213   in Table 2.

214   *****TABLE 2 HERE*****

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217   *Associations with dementia*

218   Across both countries, dementia increased with age and decreased in literate compared to illiterate

219   participants. Dementia prevalence was lower in males compared to females in Indonesia, but no such

220   association was found in South Africa. After adjusting for age, the associations remained largely

221   unchanged in Indonesia, though illiteracy was no longer associated with dementia prevalence in South

222   Africa (Table 3). Similar findings were found when calculating PRs (Appendix F).

223

224   *****TABLE 3 HERE*****

225

226   *Concurrent validity*

227   In both countries, the 10/66 short algorithm was able to differentiate scores based on the Brief CSI-D

228   cognitive score, Brief CSI-D screening tool informant score, DSRS, Lawton ADL scale and need for

229   care (p<0.001). All outcome variables had a large effect size between dementia positive and negative

230   cases, with the exception of the need for care in Indonesia ($g = 0.70$). The 10/66 short algorithm

231   demonstrated good accuracy in Indonesia (AUC=0.75, 95%CI 0.72-0.77) and very good accuracy in

232   South Africa (AUC=0.82, 95%CI = 0.76-0.88) against the DSRS screening cut-off. Similarly, the

233   10/66 algorithm demonstrated good accuracy in Indonesia (AUC=0.79, 95%CI 0.76-0.81) and very

234   good accuracy in South Africa (AUC=0.80, 95%CI 0.73-0.87) against the Brief CSI-D screening tool

235   (Appendix D).

236

237   **Discussion**

238   This paper presents data on dementia prevalence from the STRiDE programme, serving as a proof of

239   concept and validation of the STRiDE method for use in further studies in other LMICs. The data

reported here applies standard methods, and contributes new, directly comparable, good quality empirical data to the sparse dementia prevalence literature in two populous, and culturally diverse middle-income countries, Indonesia and South Africa. This study is the first to generate prevalence data derived from the rural regions of North Sumatra (Indonesia) and Limpopo (South Africa). The findings indicate dementia prevalence estimates which are higher than those usually generated internationally, markedly so in the case of Indonesia. Our weighted prevalence estimates indicate that there may be 4,297,000 people with dementia in Indonesia and 450,000 people with dementia in South Africa.[1] Our estimates exceed the numbers generated through modelling in the GDB 2019 study in Indonesia (768,000; 95% UI 656,000 to 895,000) and South Africa (208,000; 95% UI 179,000 to 241,000).[1] The very low level of diagnosis of dementia in both countries is striking, with less than 1% of each sample reporting that they had received a diagnosis. Without diagnosis there is no chance of effective care and treatment for the person with dementia or support for their family carers. The results of this study illustrate the size of the challenge facing many countries and the importance of prioritising dementia at a policy level.

While the estimates of dementia prevalence reported here look high, they may not be incorrect. The weighted dementia prevalence estimate for those aged 65 years and older in South Africa (12.5%) is in line with a previous study amongst isiXhosa speakers in Cape Town which used the brief CSI-D screening tool to identify cases (11% (95%CI 9-13)).[4] Similarly, our prevalence estimate in Indonesia (27.9%) is in line with a growing evidence base across geographic regions in the country, albeit in those aged 60 years and older: Borobudur (15.9%),[7] Yogyakarta (20.1%),[9] and Jatinangor (29.2%).[8] Some Indonesian studies have reported lower prevalence rates in certain settings: for example, dementia prevalence in Jakarta was estimated to be 4.5%[7] but the methodology in all these studies is sub-optimal, all previous studies used non-clinical diagnostic criteria, or brief screening tools which may introduce different and unquantified measurement bias than reported here (e.g., not accounting for depression as a co-morbidity). The 10/66 short dementia diagnostic schedule does not require administration by clinicians and so has value in estimating prevalence in LMICs, not least because it is a more affordable strategy and does not require specialists to be diverted away from their clinical practice. Its validity has been extensively demonstrated across cultures and diverse settings. [12,17,18,24]

There are a number of potential explanations for the high prevalence rates found in this study compared to regional WHO estimates. First, the 10/66 short algorithm generates variability in prevalence estimates depending on country, from 3.4% in rural China to 13.0% in Dominican Republic.[12] This country-specific variability is not dissimilar to the standard algorithm, but at present it does not appear that the short algorithm systematically overestimates prevalence compared to the standard algorithm. However, as with the standard algorithm,[25] elevated prevalence may represent

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[1] Populations of people aged 65 years and older derived from 2018 in Indonesia and 2020 estimates in South Africa (appendix pp 4-5)

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274   higher sensitivity enabling the detection of milder cases rather than generating false positives.

275   Second, there is the question of education-fairness. The 10/66 short schedule was developed to be

276   more education-fair than DSM criteria[25] but reports have suggested the false positive rate of the 10/66

277   short algorithm in low education groups may be 5.5%.[18] However, the exclusion of the illiterate

278   subgroup from our analysis still yields prevalence rates higher than other international estimates of

279   dementia. Third, the elevated prevalence could be real and explained by differences in risk factors in

280   the populations studied. The comparatively higher prevalence in Indonesia could be driven, in part,

281   by these population-level risk factors. For example, whilst Indonesia and South Africa both have a

282   high cardiovascular disease burden,[26,27] Indonesia has a higher prevalence of cerebrovascular

283   disease.[28] Selection bias and measurement error seem unlikely given our sampling and the fact that we

284   rigorously translated and cross-culturally adapted the schedule,[3] whilst implementing robust,

285   standardized procedures for data collection and management, including the training and close

286   supervision of all researchers.

287   Our observed associations between dementia prevalence and sex, age and literacy are in line with

288   previous evidence, which provides some validation of our findings. Both countries demonstrated the

289   expected age-related trend: older subgroups had greater likelihood of having dementia compared to

290   younger subgroups. As expected, literacy was protective of the likelihood of dementia in both

291   countries, though the findings become non-significant after controlling for age in South Africa. The

292   association between literacy and dementia prevalence can be explained in terms of cognitive reserve,[29]

293   with education increasing a person's cognitive reserve, thus delaying the clinical onset of the

294   condition. Males were found to have reduced likelihood of dementia compared to females in

295   Indonesia, but not in South Africa. Males are often reported to have a lower prevalence of dementia

296   compared to females,[30] which can be attributed to higher mortality, even within age groups, due to an

297   accumulation of risk factors, such as increased risk of depression and cardiovascular disease.[31] The

298   fact that in both countries females were more likely to be illiterate than males, provides additional

299   complexity. If cognitive reserve is protective of dementia onset, this might demonstrate an important

300   inequality that needs to be addressed, given that education increases cognitive reserve. Such late-life

301   disadvantage in cognitive health in females due to inequality earlier in life has also been noted in

302   other LMICs such as India.[32]

303   Strengths of our study include the use of a standardised toolkit and methodologies across two middle-

304   income countries, harmonized in terms of outcome measures and derived using a good quality cross-

305   cultural adaptation process. There are, however, important limitations to consider. First, data from

306   South Africa must be considered preliminary, as the sample is insufficiently powered and results in

307   wide confidence intervals. The COVID-19 pandemic limited recruitment in South Africa, but the data

308   are a proof of concept and allow for the design and delivery of a more definitive study. Anecdotally,

309   the pandemic may also have led to selection bias due to potentially vulnerable older adults being wary

of face-to-face contact, even in the absence of governmental restrictions. Second, the sampling strategy was pragmatic and attempted to capture both rural and urban regions within each country. Whilst weighted prevalence estimates were calculated according to the national demographic profiles to improve generalisability, it is important to acknowledge that the heterogeneous nature of both countries' populations increases the uncertainty of these estimates on a national level. The method could be used in other regions to generate more representative estimates at local and national levels. Third, our inclusion criteria may limit the generalisability of the findings. For example, it was necessary to have an informant (someone that knows the older adult well) so that the schedule could be completed. In North Sumatra, 20.7% of participants listed were ineligible, all of which were due to not having an informant available to participate. This could mean that those who are the most socially isolated are not adequately represented in our sample. However, the fact that 11.5% of both cohorts included informants that were not friends, family members or neighbours could indicate that this group might still be represented. Finally, there is the possibility of instrument-related diagnostic error as discussed above. However, within the present study we had very good convergent validity. It was able to differentiate a series of cognitive, functional and care outcomes, whilst having good discrimination ability against other estimates of dementia.

Our study provides novel, empirical evidence on the high numbers of people aged 65 years and older with dementia in Indonesia and South Africa and the low level of current diagnosis in these communities. The findings are an improvement on existing estimates in terms of the quality of sampling and diagnostic methodology used. In adopting a robust yet pragmatic approach to estimating dementia prevalence, we present the STRiDE methodology that can be used within other LMIC settings in the future. There are also questions raised by the relatively high prevalence rates observed in this study compared to other international estimates, but even with this uncertainty, it is clear that dementia is common and should be accorded policy priority within each country. The fact that so few participants received a formal diagnosis, highlights the size of the problem. Future research needs to explore how people's lives are affected by dementia within LMICs and the costs of care, particularly in the knowledge that health and social care systems are not geared up anywhere in the world to support people with dementia fully.

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Declaration of Interest

None

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Author statement

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Data Availability

Data is available on the UK Data Services (PENDING) and available through contacting the corresponding author.

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References

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401   1.   GBD 2019 Dementia Forecasting Collaborators. Estimation of the global prevalence of dementia
402   in 2019 and forecasted prevalence in 2050: an analysis for the Global Burden of Disease Study
403   2019. *Lancet Public Health*. 2022;7(2):e105. doi:10.1016/S2468-2667(21)00249-8

404   2.   Breuer E, Comas-Herrera A, Freeman E, et al. Beyond the project: Building a strategic theory of
405   change to address dementia care, treatment and support gaps across seven middle-income
406   countries. *Dementia*. 2022;21(1):114-135. doi:10.1177/14713012211029105

407   3.   Farina N, Jacobs R, Sani TP, et al. Description of the cross-cultural process adopted in the
408   STRiDE (STrengthening Responses to dementia in DEveloping countries) program: A
409   methodological overview. *Alzheimers Dement Diagn Assess Dis Monit*. 2022;14(1):e12293.
410   doi:10.1002/dad2.12293

411   4.   de Jager CA, Msemburi W, Pepper K, Combrinck MI. Dementia Prevalence in a Rural Region of
412   South Africa: A Cross-Sectional Community Study. *J Alzheimers Dis*. 2017;60(3):1087-1096.

413   5.   Prince M, Acosta D, Ferri CP, et al. A brief dementia screener suitable for use by non-specialists
414   in resource poor settings—the cross-cultural derivation and validation of the brief Community
415   Screening Instrument for Dementia. *Int J Geriatr Psychiatry*. 2011;26(9):899-907.
416   doi:10.1002/gps.2622

417   6.   Ben-Arie O, Swartz L, Teggin AF, Elk R. The coloured elderly in Cape Town--a psychosocial,
418   psychiatric and medical community survey. Part II. Prevalence of psychiatric disorders. *South Afr*
419   *Med J Suid-Afr Tydskr Vir Geneeskd*. 1983;64(27):1056-1061.

420   7.   Hogervorst E, Mursjid F, Ismail RI, et al. Validation of two short dementia screening tests in
421   Indonesia. In: *Vascular Dementia: Risk Factors, Diagnosis and Treatment*. ; 2011:235-256.

422   8.   Ong PA, Annisafitrie FR, Purnamasari N, et al. Dementia Prevalence, Comorbidities, and
423   Lifestyle Among Jatinangor Elders. *Front Neurol*. 2021;12:643480.
424   doi:10.3389/fneur.2021.643480

425   9.   Suriastini N, Turana Y, Supraptilah B, Wicaksono TY, Mulyanto E. Prevalence and Risk Factors
426   of Dementia and Caregiver's Knowledge of the Early Symptoms of Alzheimer's Disease. *Aging*
427   *Med Healthc*. 2020;11:60-66. doi:10.33879/AMH.2020.065-1811.032

428   10. Prince M, Wimo A, Guerchet M, Ali GC, Wu YT, Prina M. *World Alzheimer Report 2015: The*
429   *Global Impact of Dementia*. Alzheimer's Disease International; 2015. Accessed January 10,
430   2017. https://www.alz.co.uk/research/world-report-2015

431   11. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data
432   capture (REDCap)--a metadata-driven methodology and workflow process for providing
433   translational research informatics support. *J Biomed Inform*. 2009;42(2):377-381.
434   doi:10.1016/j.jbi.2008.08.010

435   12. Stewart R, Guerchet M, Prince M. Development of a brief assessment and algorithm for
436   ascertaining dementia in low-income and middle-income countries: The 10/66 short dementia
437   diagnostic schedule. *BMJ Open*. 2016;6(5). Accessed January 1, 1AD.
438   https://www.scopus.com/inward/record.uri?eid=2-s2.0-84971276024&doi=10.1136%2Fbmjopen-
439   2015-010712&partnerID=40&md5=e62e8daac7bd70d8ba4c3186162ddba2

440   13. Hall KS, Gao S, Emsley CL, Ogunniyi AO, Morgan O, Hendrie HC. Community screening
441   interview for dementia (CSI 'D'); performance in five disparate study sites. *Int J Geriatr*

442   *Psychiatry*. 2000;15(6):521-531. doi:10.1002/1099-1166(200006)15:6<521::AID-
443   GPS182>3.0.CO;2-F

444 14. Prince M, Reischies F, Beekman AT, et al. Development of the EURO-D scale--a European,
445   Union initiative to compare symptoms of depression in 14 European centres. *Br J Psychiatry J*
446   *Ment Sci*. 1999;174:330-338. doi:10.1192/bjp.174.4.330

447 15. Morris JC, Heyman A, Mohs RC, et al. The Consortium to Establish a Registry for Alzheimer's
448   Disease (CERAD). Part I. Clinical and neuropsychological assessment of Alzheimer's disease.
449   *Neurology*. 1989;39(9):1159-1165.

450 16. Abdin E, Vaingankar JA, Picco L, et al. Validation of the short version of the 10/66 dementia
451   diagnosis in multiethnic Asian older adults in Singapore. *BMC Geriatr*. 2017;17(1):94.

452 17. Ibnidris A, Piumatti G, Carlevaro F, et al. Italian version of the short 10/66 dementia diagnostic
453   schedule: a validation study. *BMJ Open*. 2021;11(6):e045867. doi:10.1136/bmjopen-2020-
454   045867

455 18. Khan QUA, Prince MJ. Validation of the Short Version of the 10/66 Dementia Diagnosis in Urdu
456   in Karachi, Pakistan. *Alzheimer Dis Assoc Disord*. 2022;36(1):89-91.
457   doi:10.1097/WAD.0000000000000467

458 19. Clark CM, Ewbank DC. Performance of the dementia severity rating scale: a caregiver
459   questionnaire for rating severity in Alzheimer disease. *Alzheimer Dis Assoc Disord*.
460   1996;10(1):31-39.

461 20. Moelter ST, Glenn MA, Xie SX, et al. The Dementia Severity Rating Scale Predicts Clinical
462   Dementia Rating Sum of Boxes Scores. *Alzheimer Dis Assoc Disord*. 2015;29(2):158-160.
463   doi:10.1097/WAD.0000000000000031

464 21. Lawton MP, Brody EM. Assessment of Older People: Self-Maintaining and Instrumental
465   Activities of Daily Living. *The Gerontologist*. 1969;9(3_Part_1):179-186.
466   doi:10.1093/geront/9.3_Part_1.179

467 22. Chandra V, Ganguli M, Pandav R, Johnston J, Belle S, DeKosky ST. Prevalence of Alzheimer's
468   disease and other dementias in rural India: the Indo-US study. *Neurology*. 1998;51(4):1000-1008.

469 23. Šimundić AM. Measures of Diagnostic Accuracy: Basic Definitions. *EJIFCC*. 2009;19(4):203-
470   211.

471 24. Abdin E, Subramaniam M, Achilla E, et al. The Societal Cost of Dementia in Singapore: Results
472   from the WiSE Study. *J Alzheimers Dis*. 2016;51(2):439-449. doi:10.3233/JAD-150930

473 25. Prince M, Acosta D, Chiu H, Scazufca M, Varghese M. Dementia diagnosis in developing
474   countries: A cross-cultural validation study. *The Lancet*. 2003;361(9361):909-917.

475 26. Chow C, Atkins E, Shariful Islam SM, Lung T. *Reducing the Burden of Cardiovascular Disease*
476   *in Indonesia: Evidence Review.*; 2017. doi:10.13140/RG.2.2.20937.57445

477 27. Byrne J, Eksteen G, Crickmore C. Cardiovascular disease statistics reference document. *Heart*
478   *Stroke Found South Afr*. Published online 2016.

479 28. Roth GA, Johnson C, Abajobir A, et al. Global, Regional, and National Burden of Cardiovascular
480   Diseases for 10 Causes, 1990 to 2015. *J Am Coll Cardiol*. 2017;70(1):1-25.
481   doi:10.1016/j.jacc.2017.04.052

482   29. Prince M, Acosta D, Ferri CP, et al. Dementia incidence and mortality in middle-income
483   countries, and associations with indicators of cognitive reserve: a 10/66 Dementia Research
484   Group population-based cohort study. *Lancet Lond Engl*. 2012;380(9836):50-58.
485   doi:10.1016/S0140-6736(12)60399-7

486   30. Eastman J, Bahorik A, Kornblith E, Xia F, Yaffe K. Sex Differences in the Risk of Dementia in
487   Older Veterans. *J Gerontol Ser A*. Published online February 3, 2022:glac029.
488   doi:10.1093/gerona/glac029

489   31. Li R, Singh M. Sex differences in cognitive impairment and Alzheimer's disease. *Front*
490   *Neuroendocrinol*. 2014;35(3):385-403. doi:10.1016/j.yfrne.2014.01.002

491   32. Angrisani M, Jain U, Lee J. Sex Differences in Cognitive Health Among Older Adults in India. *J*
492   *Am Geriatr Soc*. 2020;68(S3):S20-S28. doi:10.1111/jgs.16732

493

Table 1: Summary of key demographic variables, split by country.

	Indonesia (n=2,110)		South Africa (n=408)	
	M (SD)	**N (%)**	**M (SD)**	**N (%)**
Age	71.1 (5.43)		74.8 (7.42)	
Site				
Jakarta		1,063 (50.4%)		N/A
North Sumatra		1,047 (49.6%)		N/A
Cape Town		N/A		169 (41.4%)
Limpopo		N/A		239 (58.6%)
Sex				
Male		853 (40.4%)		133 (32.6%)
Female		1,257 (59.6%)		259 (63.5%)
Missing		0 (0.0%)		16 (3.9%)
Literacy				
Illiterate		369 (17.5%)		95 (23.3%)
Literate		1710 (81.0%)		298 (73.0%)
Missing		31 (1.5%)		15 (3.7%)
Language				
Indonesian Bahasa		2,110 (100.0%)		N/A
isiXhosa		N/A		51 (12.5%)
Sepedi		N/A		235 (57.6%)
Afrikaans		N/A		37 (9.1%)
English		N/A		85 (20.8%)
Missing		0 (0.0%)		0 (0.0%)
Relationship of informant				
Spouse		436 (20.7%)		87 (21.3%)
Son/Daughter		1,063 (50.4%)		152 (37.3%)
Son /Daughter-in-law		175 (8.3%)		20 (4.9%)
Sibling		54 (2.6%)		5 (1.2%)
Other relative		58 (2.7%)		57 (14.0%)
Friend		1 (0.0%)		12 (2.9%)
Neighbour		81 (3.8%)		27 (6.6%)
Other		242 (11.5%)		47 (11.5%)
Missing		0 (0.0%)		1 (0.2%)

Table 2. Prevalence estimates split by age and gender, and literacy using the 10/66 short-form algorithm. Grand total prevalence is also reported in both weighted and unweighted formats.

	Indonesia 10/66 short-form dementia diagnosis algorithm			South Africa 10/66 short-form dementia diagnosis algorithm		
Male	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)
65-69	443	74	16.7 (13.4-20.5)	45	1	2.2 (0.1-11.8)
70-74	245	47	19.2 (14.4-24.7)	40	6	15.0 (5.7-29.8)
75-79	110	35	31.8 (23.3-41.4)	23	1	4.3 (0.1-21.9)
80-84	40	19	47.5 (31.5-63.9)	12	3	25.0 (5.5-57.2)
85-89	13	2	15.4 (1.9-45.4)	10	6	60.0 (26.2-87.8)
90 plus	2	0	0.0 (0.0-84.2)	3	1	33.3 (0.8-90.6)
Total	853	177	20.8 (18.1-23.6)	133	18	13.5 (8.2-20.5)
Female	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)
65-69	574	134	23.3 (19.9-27.0)	70	1	1.4 (0.0-7.7)
70-74	367	103	28.1 (23.5-33.0)	69	9	13.0 (6.1-23.3)
75-79	182	70	38.5 (31.4-45.9)	45	6	13.3 (5.1-26.8)
80-84	97	51	52.6 (42.2-62.8)	39	7	17.9 (7.5-33.5)
85-89	27	19	70.4 (49.8-86.2)	25	8	32.0 (14.9-53.5)
90 plus	10	8	80.0 (44.4-97.5)	11	4	36.4 (10.9-69.2)
Total	1,257	385	30.6 (28.1-33.3)	259	35	13.5 (9.6-18.3)
Literacy*	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)
Total Literate	1,710	373	21.8 (19.9-23.8)	298	33	11.1 (7.7-15.2)
Total Illiterate	369	181	49.1 (43.8-54.3)	95	21	22.1 (14.2-31.8)
Totals	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)	Cohort: n	Positive cases: n	Positive cases: Rate, % (95% CI)
Grand total (Unweighted)*	2,110	562	26.6 (24.8 to 28.6)	408	59	14.5 (11.2-18.3)

| Grand total (weighted)** | 2,229 | 602 | 27.9 (25.2-28.9) | 432 | 54 | 12.5 (9.5-16.0) |

*Grand total (n) may be higher than subgroups due to missing demographic details.

**Weighted by national age, sex and literacy estimates, see Appendix C for weightings.

Table 3. Odds of dementia against age, sex and literacy in Indonesia and South Africa

	Unadjusted odds ratio (95% CI)										Age adjusted odds ratio	
	65-69*	70-74	75-79	80-84	85-89	90 plus	Sex: Female**	Sex: Males	Illiterate***	Literate	Sex: Males	Literate
Indonesia	Ref	1.3 (1.0-1.6)	2.2 (1.6-2.9)	4.1 (2.8-5.9)	4.3 (2.3-8.1)	7.8 (2.3-26.1)	Ref	0.6 (0.5-0.7)	Ref	0.3 (0.2-0.4)	0.6 (0.5-0.8)	0.3 (0.2-0.4)
South Africa	Ref	9.5 (2.1-42.2)	6.4 (1.3 – 32.0)	15.6 (3.3-73.2)	44.8 (9.7-207.9)	38.7 (6.8-219.9)	Ref	1.0 (0.5-1.8)	Ref	0.4 (0.2-0.8)	1.3 (0.7-2.5)	0.5 (0.3-1.0)

*Age in comparison to 65-69 category.

** Male sex in comparison to female category.

***Literacy in comparison to illiterate category (unable to read or write).

South Africa

Purposeful selection

Cape Town
(487,927 older adults)

Limpopo
(374,425 older adults)

Random selection based on socioeconomic status

Purposeful selection

5 wards
(1 high, 2 middle and 2 low income)

Dikgale locality

Random walk

Doors knocked
(n=1,380)

All 14 villages within DIMAMO survailance area

Ineligible (n=454)
Refusals (n=98)
Unable to contact (n=343)
Outcome not recorded (n=11)

Random selection

Older adult households listed (n=474)

Older adults listed
(n=400)

Refusals (n=146)
Unable to contact (n=13)
Outcome not recorded (n=118)

Deceased (n=29)
Unable to contact (n=28)
Ineligible (n=21)
Refusal (n=28)
Other (n=1)

Older adults participated
(n=197)

Older adults participated
(n=293)

Missing a component of 10/66 short shedule (n=28)

Missing a component of 10/66 short shedule (n=54)

Diagnostic algorithm applied (n=169)

Diagnostic algorithm applied (n=239)

Diagnostic algorithm applied (n=408)

Indonesia

Purposeful selection

DKI Jakarta
(942,810 older adults)

North Sumatra
(801,366 older adults)

Random selection

Random selection

2 districts
(North Jakarta and West Jakarta)

2 districts
(Medan City and Serdang Bedagai District)

Random selection

Random selection

3 subdistricts
(Penjaringan, Cilincing, and Tambora)

6 subdistricts
(3 in Medan City, 3 in Serdang Bedagai)

Random selection

3 representative villages

2 wards in each subdistrict

Older adults listed
(n= 3,506)

Older adults listed
(n=1,498)

Random selection

Refusal (n=10)
Unable to contact (n=74)
Ineligible (n=310)

Older adults participated
(n=1,112)

Older adults participated
(n=1,104)

Missing a component of 10/66 short shedule (n=56)

Missing a component of 10/66 short shedule (n=50)

Diagnostic algorithm applied (n=1,056)

Diagnostic algorithm applied (n=1,054)
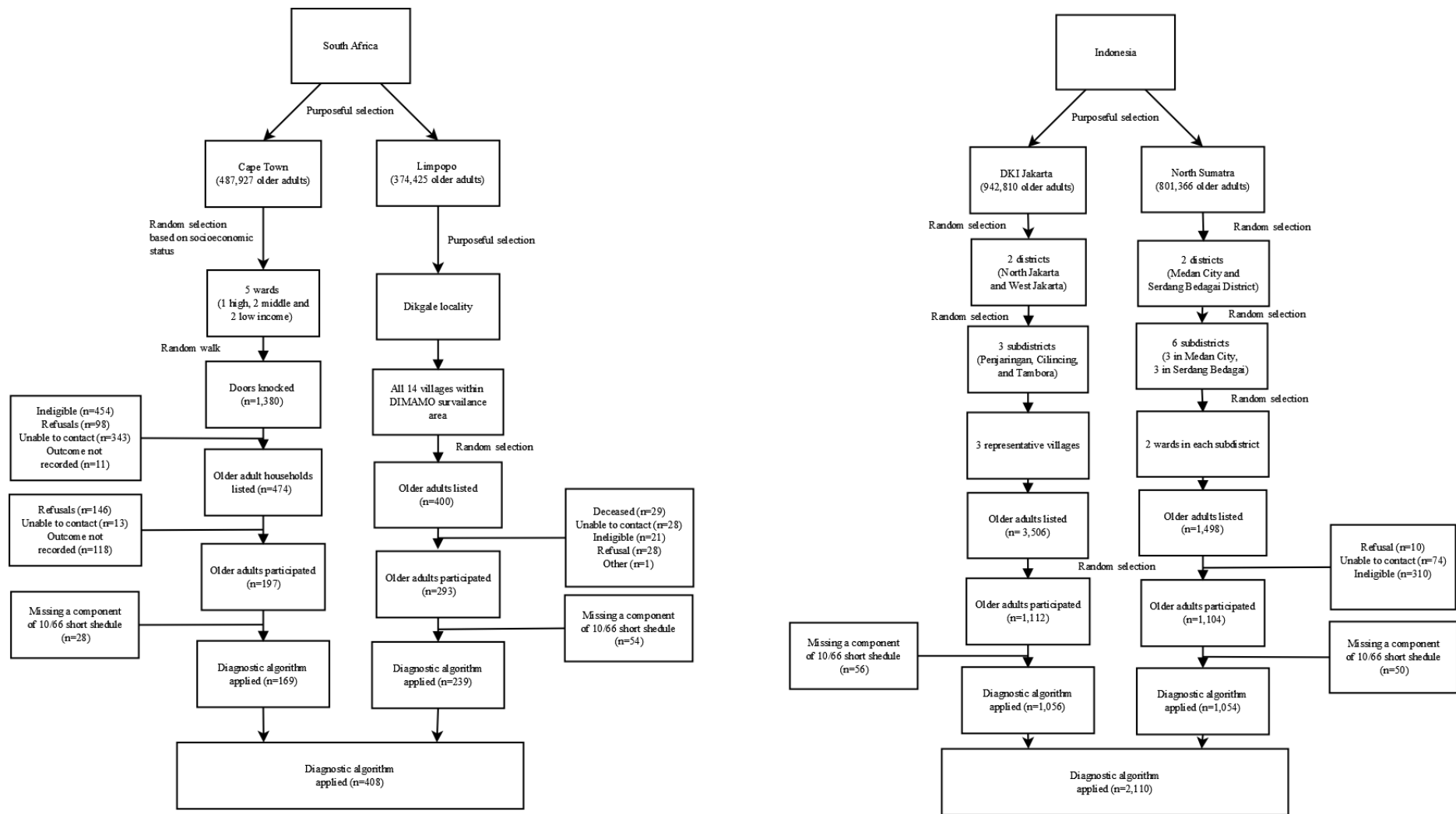
Diagnostic algorithm applied (n=2,110)

Figure 1. Participant recruitment flow diagram within each site, September to December 2021.

SUPPLEMENTARY MATERIAL

CONTENTS

APPENDIX A: SAMPLING STRATEGY
Country Context

Indonesia is a lower-middle income country with a population of 270.20 million, of whom 11.35 million (4.2%) are aged 65 years and older. It has 34 provinces spread across over 17,000 islands. Indonesia has one official language (Bahasa Indonesia) and is predominantly Muslim. South Africa is an upper-middle income country of 60.14 million people, of whom 3.69 million (6.1%) are aged 65 years and over. South Africa has nine provinces and 11 official languages, featuring a myriad of cultures and traditions. It is known as one of the most unequal countries in the world, facing a triple challenge of high poverty, inequality and unemployment.

Sampling strategy - Western Cape

The Western Cape is a predominantly urban province and is the third most populace in South Africa. There is approximately 487,927 people aged 65 years and older. Approximately, 2.4% of adults have no schooling and 10% are below the food poverty line (unable to purchase or consume food). Sampling occurred within the urban centre of Cape Town. Wards were stratified according to low-, middle- and high-income strata and then randomly selected within each stratum proportional to size to identify 3 low, 3 middle and 2 high income wards across the 115 wards of the City of Cape Town.

Since the census data available is dated and likely to underestimate population size, researchers had to include a dwelling-counting and estimation exercise using aerial maps and walkabouts in each ward included in the survey. Maps were printed for each ward and divided into sub-areas for counting. The number of dwelling units were counted in each sub-area in a ward, including the number of units for apartment blocks and plots with multiple (often informal) household structures such as shacks, "wendy houses" or any kind of backyard dwelling used for living purposes. The total estimated number of dwellings for each ward was calculated and then divided by 50 (required number of households per ward) to obtain the interval between each dwelling to be selected. Based on the interval and the estimated total number of dwellings for each sub-area, the sampling distribution for each ward was calculated using a systematic random sampling, proportionate to population size (PPS) technique.

Eligible households were identified using a door-knocking survey approach, documenting the procedure by collecting data on (1) time, date, and location; (2) whether someone is home and if it is safe for field researchers to proceed; (3) who they spoke to and if there is a person living there that is 65 years and older; (4) willingness to participate and if so, (5) when would be a good time for the interview. If no one was home, the household would be revisited a maximum of 2 times before replacing with the household on the left (and then right) of the originally selected dwelling until eligible and willing participants were found. Data were also collected on the outcome of these door-knocking visits for each household visited during the survey, as well as reasons provided by residents for refusals. However, the application of the interval became problematic in more informal areas where the layout and infrastructure of plots and dwelling posed challenges in applying strict intervals. Also, for informal areas in particular, communities tend to be characterised by a younger population, migrant labour and clustering of older adults to certain areas within communities. These realities made it near impossible to identify eligible households applying the interval method. Therefore, for informal settlement areas the interval

had to be relaxed. In these cases, the area was roughly divided into sub-areas (or zones) with field researcher pairs dropped at each of these zones. Field researchers would then walk down the road and ask community members about the community composition and to help identify persons 65 years and older living in the area. Where the interval was not successful, this flexibility still ensured a relatively equal distribution of sampling across the ward and sub-areas, while supporting the identification of eligible participants in relatively young, fluid communities. Where older adults lived in community clusters, field researchers ensured that participants were recruited with a minimum of a 50 household interval between them.

If there are multiple older adults residing within the household, the person whose birthday was next was selected.

Sampling strategy - Limpopo Province

Limpopo province is predominantly rural, land-locked region. There are 374,425 people 65 years and older. Approximately 13.9% have no schooling and 40% are under the food poverty line. Sampling occurred exclusively within 14 villages within the Dikgale locality. These villages are small and are part of a health research demographic surveillance site called DIMAMO, an ongoing partnership with the University of Limpopo (UL). Households are surveyed annually, with updated population information available for each dwelling across the 14 villages. These villages are homogenous in terms of socio-economic status and would give the study sample a representation relatively typical of the South African rural context.

The DIMAMO sampling frame was used to identify eligible households with participants who are 65 years and older. Households were selected using simple randomisation in selecting households with a member that is 65 years and over from the DIMAMO sampling frame for each of the 14 villages. In the event the selected household was unavailable, households would be replaced after 2 revisits. In the event of a refusal, the household was replaced by following the sample list of randomly selected households provided to each field research team.

Sampling strategy – Jakarta and North Sumatra

DKI Jakarta is a large urban area based on Java Island and is the capital of Indonesia. Jakarta has an estimated 530,102 people aged 65 years and older. North Sumatra in a large, predominantly rural province on the island of Sumatra. Medan is the largest city of the region. There are an estimated 144,998 people aged over the age of 65 years and older in the region.

In Indonesia, due to availability of census data, the sampling strategy was more consistent across sites. Sampling was done by multistage random sampling with the smallest unit in this study was the household. In the first stage, random sampling was conducted at the district level (DKI Jakarta- West Jakarta and North Jakarta; North Sumatera- Medan City and Serdang Bedagai District), the second stage at the urban village level, and the third stage at the household level. Sampling was based on PPS sampling.

A database of older adults living listed in the cadres' registration were extracted (July-August 2021) for each village. These data were used as a sampling frame and the list was randomized. Older adults

that were unreachable or refused to participate, the next older adult on the list were recruited. Only one older adult per household were recruited.

APPENDIX B: CHARACTERISTICS OF KEY COMPONENTS OF THE 10/66 SHORT SHEDULE

Characteristics of key components of the 10/66 short schedule in Indonesia (n=2,110) and South Africa (n=408).

	Indonesia				South Africa			
	Missing (n)	Min	Max	Mean (SD)	Missing (n)	Min	Max	Mean (SD)
Cogscore	0	2.06	37.89	27.82 (3.89)	0	10.24	34.03	29.50 (3.70)
Relscore	0	0.0	21.50	4.49 (3.67)	0	0	18.5	2.81 (2.99)
EURO-D	55*	0	12	4.09 (2.56)	24*	0	10	3.64 (2.35)

*Missing less than 4 items, sufficient to run algorithm.

APPENDIX C: WEIGHTINGS

For national weighting proportions (age, sex, literacy) were obtained from each country utilising the following criteria:

- Figures need to be derived from a reputable source
- A preference will be to select estimates from a single source to minimise heterogeneity in how they are derived.
- Identify estimates that utilise similar operational definitions as used in the present study.
- Estimates and proportions from older adults will be prioritised
- The most up-to-date estimates will be prioritised

Instances in which there are notable variations will be noted below.

Weightings used in South African cohort. National estimates used to calculate weightings were taken from Statistics South Africa (2021).

Literacy*	Sex**	Age**	Weighting
Literate	Male	65-69	1.51864
Literate	Male	70-74	1.14669
Literate	Male	75-79	1.17252
Literate	Male	80+	0.76497
Illiterate	Male	65-69	1.24447
Illiterate	Male	70-74	0.93967
Illiterate	Male	75-79	0.96084
Illiterate	Male	80+	0.62687
Literate	Female	65-69	1.27024
Literate	Female	70-74	0.95913
Literate	Female	75-79	0.98073
Literate	Female	80+	0.63984
Illiterate	Female	65-69	1.04091
Illiterate	Female	70-74	0.78597
Illiterate	Female	75+	0.80367
Illiterate	Female	80+	0.52433

*Functional literacy – ability to read and write with at least one language, aged 60 years and older, 2019 estimate.

**2020 mid-year population estimates

Weightings used in Indonesia cohort, sequentially derived (sex, literacy, age). National estimates used to calculate weightings were BPS-Statistics Indonesia (2019)

Literacy*	Sex**	Age**	Weighting
Literate	Male	65-69	1.0056
Literate	Male	70-74	1.1299
Literate	Male	75+	1.6872
Illiterate	Male	65-69	0.7478
Illiterate	Male	70-74	0.8403
Illiterate	Male	75+	1.2547
Literate	Female	65-69	0.7985
Literate	Female	70-74	0.8972
Literate	Female	75+	1.3398
Illiterate	Female	65-69	0.5939
Illiterate	Female	70-74	0.6673
Illiterate	Female	75+	0.9964

* Adults aged 50 years and older, 2018 estimates

** 2018 estimate

Data sources used for weightings were also used to generate the population figures of people living with dementia based on weighted prevalence.

References

Statistics South Africa. (2021). *Marginalised Groups Series IV: The Social Profile of Older Persons, 2015–2019*. Statistics South Africa.

BPS-Statistics Indonesia. (2019). *Statistik Indonesia: Statistical Yearbook of Indonesia 2019*. BPS-Statistics Indonesia.

APPENDIX D: CONCURRENT VALIDITY

Comparison of positive and negative cases of dementia (as determined by the 10/66 short algorithm) against established DSRS cut-offs.

	Indonesia 10/66 short-form dementia diagnosis algorithm		South Africa 10/66 short-form dementia diagnosis algorithm	
	Negative cases	Positive cases	Negative cases	Positive cases
DSRS: negative cases	1,124 (74.6%)	139 (25.1%)	261 (77.2%)	8 (13.8%)
DSRS: positive cases	382 (25.4%)	414 (74.9%)	77 (22.8%)	50 (86.2%)

The threshold of DSRS <3 has previously been used to differentiate healthy controls with people with dementia (Roalf et al., 2013). DSRS = Dementia Severity Rating Scale

Comparison of positive and negative cases of dementia (as determined by the 10/66 short algorithm) against established Brief CSI-D screening tool cut-offs.

	Indonesia 10/66 short-form dementia diagnosis algorithm		South Africa 10/66 short-form dementia diagnosis algorithm	
	Negative cases	Positive cases	Negative cases	Positive cases
Brief CSI-D screen negative	1,242 (80.2%)	130 (23.1%)	321 (92.0%)	19 (32.2%)
Brief CSI-D screen positive	306 (19.8%)	432 (76.9%)	28 (8.0%)	40 (67.8%)

The threshold of Brief CSI-D < 5 has previously been used to screen for dementia. CSI-D = Community Screening Instrument for Dementia,

References:

Prince, M., Acosta, D., Ferri, C. P., Guerra, M., Huang, Y., Jacob, K. S., Llibre Rodriguez, J. J., Salas, A., Sosa, A. L., Williams, J. D., & Hall, K. S. (2011). A brief dementia screener suitable for use by non-specialists in resource poor settings—The cross-cultural derivation and validation of the brief Community Screening Instrument for Dementia. International Journal of Geriatric Psychiatry, 26(9), 899–907. https://doi.org/10.1002/gps.2622

Roalf, D. R., Moberg, P. J., Xie, S. X., Wolk, D. A., Moelter, S. T., & Arnold, S. E. (2013). Comparative accuracies of two common screening instruments for the classification of Alzheimer's disease, mild cognitive impairment and healthy aging. Alzheimer's & Dementia : The Journal of the Alzheimer's Association, 9(5), 529–537. https://doi.org/10.1016/j.jalz.2012.10.001

Differences between positive and negative cases of dementia (as determined by the 10/66 short algorithm) on cognitive performance, functional performance and care need outcomes.

| | Indonesia | | | South Africa | | |
| | 10/66 short-form dementia diagnosis algorithm | | | 10/66 short-form dementia diagnosis algorithm | | |
	Negative cases	Positive cases	Diff	Negative cases	Positive cases	Diff
	M (SD)	M(SD)	Effect size – Hedges g (95%CIs)	M (SD)	M(SD)	Effect size – Hedges g (95%CIs)
Brief CSI-D screening tool - Informant score (Higher = more impairment)	1.2 (1.1)	2.7 (1.4)	-1.32 (-1.42 to -1.21)	0.9 (0.9)	2.6 (1.3)	-1.76 (-2.06 to -1.45)
Brief CSI-D screening tool – cognitive score (Lower = more cognitive impairment)	7.0 (1.3)	5.7 (1.4)	0.92 (0.82 to 1.02)	7.8 (1.3)	5.6 (1.9)	1.59 (1.29 to -1.89)
DSRS (Higher = more impairment)	1.8 (2.9)	8.9 (8.8)	-1.35 (-1.46 to -1.25)	1.7 (2.9)	10.1 (8.2)	-2.03 (-2.34 to -1.71)
Lawton ADL scale (Lower = more impairment)	5.5 (2.0)	3.2 (2.3)	1.12 (1.02 to 1.23)	7.0 (1.4)	4.3 (2.4)	1.72 (1.42 to 2.02)
	N (%)	N (%)	Effect size – Hedges g (95%CIs)	N (%)	N (%)	Effect – Hedges g (95%CIs)
Needs care: Occasionally or much of the time	356 (23.0%)	323 (57.9%)	0.70 (0.61 to 0.78)	101 (29.2%)	51 (86.4%)	0.92 (0.71 to 1.13)

ADL = Activities of Daily Living, CSI-D = Community Screening Instrument for Dementia, DSRS = Dementia Severity Rating Scale

APPENDIX E: DEMOGRAPHICS OF PARTICIPANTS SPLIT BY AGE, SEX AND LITERACY.

Demographics of participants in each country split by age, sex and literacy (valid cases only).

	Indonesia						South Africa					
	Male			**Female**			**Male**			**Female**		
Age	**Illiterate**	**Literate**	**All male**	**Illiterate**	**Literate**	**All female**	**Illiterate**	**Literate**	**All male**	**Illiterate**	**Literate**	**All female**
65-69	49 (11.3%)	386 (88.7%)	435	111 (19.4%)	461 (80.6%)	572	7 (15.6%)	38 (84.4%)	45	17 (24.3%)	53 (75.7%)	70
70-74	22 (9.1%)	219 (90.9%)	241	73 (20.3%)	286 (79.7%)	359	6 (15.0%)	34 (85.5%)	40	15 (21.7%)	54 (78.3%)	69
75-79	11 (10.3%)	96 (89.7%)	107	53 (29.8%)	125 (70.2%)	178	3 (13.0%)	20 (87.0%)	23	14 (31.1%)	31 (68.9%)	45
80-84	5 (12.5%)	35 (87.5%)	40	24 (25.0%)	72 (75.0%)	96	2 (16.7%)	10 (83.3%)	12	10 (26.3%)	28 (73.7%)	38
85-89	1 (7.7%)	12 (92.3%)	13	13 (50.0%)	13 (50.0%)	26	3 (30.0%)	7 (70.0%)	10	11 (45.8%)	13 (54.2%)	24
90 plus	0 (0.0%)	2 (100.0%)	2	7 (70.0%)	3 (30.0%)	10	0 (0.0%)	3 (100.0%)	3	6 (54.5%)	5 (45.5%)	11
Total	88 (10.5%)	750 (89.5%)	838	281 (22.6%)	960 (77.4%)	1,241	21 (6.8%)	112 (93.2%)	133	73 (28.4%)	184 (71.6%)	257

APPENDIX F: POISSON REGRESSION MODELS FOR PREVALENCE RATIOS

Prevalence ratios (95% Wald CIs) of dementia against age, sex and literacy in Indonesia and South Africa. Poisson regression models with robust variance.

						Prevalence ratio (95% CI)					**Age adjusted prevalence ratio**	
	65-69*	**70-74**	**75-79**	**80-84**	**85-89**	**90 plus**	**Sex: Female****	**Sex: Males**	**Illiterate****	**Literate**	**Sex: Males**	**Literate**
Indonesia	Ref	1.2 (1.0-1.5)	1.8 (1.4-2.2)	2.5 (1.9 – 3.3)	2.6 (1.6 – 4.0)	3.3 (1.6 – 6.6)	Ref	0.7 (0.6-0.8)	Ref	0.4 (0.4-0.5)	0.7 (0.6-0.8)	0.5 (0.4-0.6)
South Africa	Ref	8.3 (1.9 - 35.2)	5.9 (1.3 - 27.6)	12.5 (2.9 - 54.3)	25.7 (6.2 - 106.4)	23.6 (5.2-106.6)	Ref	1.0 (0.6-1.7)	Ref	0.5 (0.3-0.8)	1.2 (0.7-2.0)	0.6 (0.4-1.0)

*Age in comparison to 65-69 category.

** Male sex in comparison to female category

***Literacy in comparison to illiterate category (unable to read or write)