



## RESEARCH ARTICLE

# Health and economic correlates of autonomy among older people in Peru, Mexico and China: The 10/66 INDEP study [version 1; referees: awaiting peer review]

Martin J. Prince <sup>1</sup>, Mariella Guerra<sup>2</sup>, Yueqin Huang<sup>3</sup>, Peter Lloyd-Sherlock<sup>4</sup>, Ana Luisa Sosa<sup>5</sup>, Richard Uwakwe<sup>6</sup>, Isaac Acosta<sup>5</sup>, Peter Ezeah <sup>7</sup>, Sara Gallardo<sup>8</sup>, Maëlenn M. Guerchet<sup>1</sup>, Zhaorui Liu<sup>3</sup>, Rosie Mayston<sup>1</sup>, Veronica Montes de Oca<sup>9</sup>, Hong Wang<sup>3</sup>

<sup>1</sup>Health Service and Population Research Department, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, SE5 8AF, UK

<sup>2</sup>Psychogeriatric Unit, National Institute of Mental Health "Honorio Delgado Hideyo Noguchi", Lima, Peru

<sup>3</sup>Institute of Mental Health, Peking University, Beijing, 100191, China

<sup>4</sup>School of Development Studies, University of East Anglia, Norwich, NR4 7TJ, UK

<sup>5</sup>National Institute of Neurology and Neurosurgery of Mexico, Universidad Nacional Autónoma de México, Mexico City, 14269, Mexico

<sup>6</sup>Nnamdi Azikiwe University Teaching Hospital, Nnewi, Anambra, Nigeria

<sup>7</sup>Department of Sociology/Anthropology, Nnamdi Azikiwe University, Awka, Nigeria

<sup>8</sup>Depresión y Enfermedades de Riesgo (IMEDER), Instituto de la Memoria, Lima, Peru

<sup>9</sup>Instituto de Investigaciones Sociales, Universidad Nacional Autónoma de México, Mexico City, 14269, Mexico

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## Abstract

**Background:** While autonomy is highlighted as central to older people's wellbeing, there has been little empirical research to inform a measurement approach, support construct validity, or establish its determinants. We aimed to study the health and economic correlates of self-perceived autonomy among community-dwelling older people in Peru, Mexico and China, using a hypothesis-driven approach.

**Methods:** Cross-sectional household surveys in urban and rural catchment areas in each country, comprising household, informant, and older person interviews, to elicit household income and older residents' autonomy, unmet needs, and quality of life. Households, all with older residents, were selected from previous waves of the 10/66 Dementia Research Group's comprehensive surveys of ageing and health.

**Results:** Among 937 older respondents in 754 households, diminished autonomy was associated with older age, marital status, lower education, and lower household income. Physical, cognitive and mental morbidities, functional impairment and dependence were strongly and independently associated with diminished autonomy, explaining the effect of age. Controlling for these variables, an older person's current total income was inversely associated with diminished autonomy (Count Ratio per fifth of total income 0.86, 95% CI 0.81-0.91). Autonomy was positively correlated with wellbeing and life satisfaction, supporting construct validity. Counter to hypotheses, less autonomy was associated with fewer unmet needs in rural sites.

## Open Peer Review

**Referee Status:** *AWAITING PEER*

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**Conclusions:** The effects of income insecurity, disability and dependence upon autonomy should be tested prospectively to confirm causal direction. Social pensions, and measures to support the rights of frail and dependent older people may be effective policy instruments for promoting autonomy. While the negative impact of diminished autonomy upon older people's welfare is supported, the association in rural sites between more autonomy and more unmet needs should be further investigated; efforts to promote autonomy may need careful cultural nuancing, to support rather than subvert traditional family care systems.

### Keywords

Epidemiology, Aged, Successful Aging, Ageism, Intergenerational relations, Economic status

**Corresponding author:** Martin J. Prince ([martin.prince@kcl.ac.uk](mailto:martin.prince@kcl.ac.uk))

**Author roles:** **Prince MJ:** Conceptualization, Data Curation, Formal Analysis, Funding Acquisition, Investigation, Methodology, Project Administration, Resources, Software, Supervision, Validation, Visualization, Writing – Original Draft Preparation, Writing – Review & Editing; **Guerra M:** Conceptualization, Funding Acquisition, Investigation, Methodology, Project Administration, Resources, Supervision, Writing – Review & Editing; **Huang Y:** Conceptualization, Funding Acquisition, Investigation, Methodology, Project Administration, Resources, Supervision, Writing – Review & Editing; **Lloyd-Sherlock P:** Conceptualization, Data Curation, Funding Acquisition, Methodology, Supervision, Writing – Review & Editing; **Sosa AL:** Conceptualization, Funding Acquisition, Investigation, Methodology, Project Administration, Resources, Supervision, Writing – Review & Editing; **Uwakwe R:** Conceptualization, Funding Acquisition, Methodology, Writing – Review & Editing; **Acosta I:** Conceptualization, Investigation, Methodology, Project Administration, Supervision, Writing – Review & Editing; **Ezeah P:** Conceptualization, Methodology, Writing – Review & Editing; **Gallardo S:** Conceptualization, Investigation, Methodology, Project Administration, Resources, Supervision, Writing – Review & Editing; **Guerchet MM:** Conceptualization, Methodology, Writing – Review & Editing; **Liu Z:** Conceptualization, Investigation, Methodology, Project Administration, Resources, Software, Supervision, Writing – Review & Editing; **Mayston R:** Conceptualization, Investigation, Methodology, Project Administration, Writing – Review & Editing; **Montes de Oca V:** Conceptualization, Methodology, Writing – Review & Editing; **Wang H:** Conceptualization, Methodology, Writing – Review & Editing

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## Introduction

The principle of autonomy underpins legal, civil, and human rights and is the philosophical basis for resisting the coercive or paternalistic influences of others. The link between autonomy and well-being is considered by some authorities to be both axiomatic and universally relevant across cultures<sup>1</sup>, with some empirical support from cross-national ecological studies<sup>2,3</sup>. This is not to gainsay the salience of culturally-determined controlling environments, but it does question the application of cultural relativism to the study of autonomy, its determinants and consequences. The World Health Organization (WHO) considers autonomy, “the perceived ability to control, cope with and make personal decisions about how one lives on a day to day basis, according to one’s own rules and preferences”, to be an important element of active ageing; a positive process that optimizes health, participation and security, and enhances quality of life<sup>4</sup>. Structural factors clearly can constrain choices and opportunities in later life<sup>5</sup>. These may be enshrined in culture, and reinforced by economic and public policy, such that they are, in effect, institutionalised as ageist principles. However, the focus of this paper is upon individual rather than contextual determinants of autonomy in later-life, in particular those that may be common across diverse cultural settings.

Autonomy is often operationalised in relation to agency, a person with agency defined by Sen as having “the ability to act on behalf of what he or she values and has reason to value”<sup>6</sup>. An act is deemed to be autonomous when, on considered self-reflection, a person fully endorses their motivation to perform it or have it performed<sup>7</sup>. Establishing independence of thought and action is not straightforward. Many important decisions are taken jointly, for example within a household or community. Some may autonomously decide that they wish others to decide or act for them. It is important not to confound constraints upon autonomy with roles that evolve across the life course, or with the loss of independence from long-term illness and disability. Retiring from work, becoming ill or living with disabilities are not obstacles, per se, to making active and autonomous contributions<sup>4</sup>. However, certain conditions, for example advanced dementia, can rob an individual of the capacity to make, communicate and act upon decisions that reflect their long-standing values and preferences.

While autonomy is highlighted as central to older people’s wellbeing, there is surprisingly little empirical research to inform a measurement approach, support construct validity, or establish determinants<sup>8</sup>. Studies among older people in high income countries have focused mainly upon strategies to promote decision-making capacity, agency and person-centred care for those with cognitive impairment or dementia<sup>9</sup>. A large development studies literature delineates the effect of women’s autonomy on reproductive choices, help-seeking for healthcare and economic decision-making. Although older people are understood to be vulnerable, and often disempowered, no such parallel literature exists particularly from low or middle income countries. A link between contributing to household income and feeling empowered to participate in decision-making is posited<sup>10</sup>, but thinly evidenced. An evaluation of the 70 y Mas social pension

program in rural Mexico did show a significant positive benefit upon older persons’ participation on household decision making<sup>11</sup>.

We aimed to study the correlates of self-perceived autonomy among community-dwelling older people in urban and rural settings in Peru, Mexico and China. In particular, we wished to test hypotheses that:

- a) dementia and cognitive impairment are independently associated with diminished autonomy, controlling for age, gender and education
- b) functional impairment and dependence (needs for care), are independently associated with diminished autonomy, after controlling also for dementia and cognitive impairment
- c) that any effects of age on autonomy are confounded by cognitive impairment, dementia, functional impairment and dependence
- d) that higher older person’s incomes are independently associated with greater autonomy, having controlled for demographic variables, health status, functioning, and household income

We also explore the construct validity of our autonomy measure, by assessing cross-sectional associations with wellbeing, life satisfaction, and unmet needs.

## Methods

The INDEP study<sup>12</sup> conducted in China, Peru, Mexico and Nigeria, was designed to assess the effects of care dependence among older adult residents on household economic functioning. For the INDEP quantitative survey (2012), conducted in China, Peru, and Mexico, households were selected from previous waves of the 10/66 Dementia Research Groups catchment area surveys, based upon the needs for care of older residents. In these sites, the baseline wave of the 10/66 surveys was carried out between 2004 and 2006, and the incidence wave between 2008 and 2009<sup>13</sup>.

## Settings

The Peru sites comprise urban catchment area sites in Lima Cercado and San Miguel in the capital city, Lima, and rural sites in Cerro Azul, Imperial, Nuevo Imperial, Quilmana, San Luis, and San Vicente in Canete coastal province. In Mexico we sampled six urban districts in Tlalpan, Mexico City, and rural sites in nine villages in Morelos, a mountainous district 70km from Mexico City. The urban site in China was Xicheng, close to Tiananmen Square, while the rural site comprised 14 villages in Daxing, a rural district 40 kilometres away. The catchment area sites are not nationally representative, nor even necessarily representative of the city or rural region where they are located. Urban areas were selected to be predominately lower socioeconomic status, or mixed neighborhoods, avoiding middle class or professional enclaves<sup>14</sup>. Rural areas were selected to be distant from conurbations, and to include a high proportion of inhabitants with

agrarian occupations. The national policy context with respect to social protection, which varies considerably between countries and sites is described in detail in an online publication<sup>15</sup>.

### Ethical considerations

The INDEP study protocol has been approved by King's College London Research Ethics Committee (PNM/11/12-69) and relevant local authorities in each study site: Instituto de la Memoria, Depresion y Enfermedades de Riesgo (IMEDER) Ethics Committee in Peru; Instituto Nacional de Neurología y Neurocirugía Ethics Committee in Mexico (96/07); Medical Ethics Committee of Peking University the Sixth Hospital (Institute of Mental Health) in China (2012–6); Nnamdi Azikiwe University Teaching Hospital Nnewi Anambra State Ethics Committee in Nigeria. Participation was on the basis of informed, signed consent. For each household, the index older person or persons were first approached for their consent for an individual and informant interview, and invited to nominate a suitable key informant for the household interview. If the index older person did not consent, the household was excluded. If the older person lacked capacity to consent, the next of kin was asked to consider providing signed assent. Participation of those lacking capacity was conditional upon the older person not showing signs of distress or dissent when the information sheet was read to them.

### Study design

For each site, we sampled from among those households where one or more older participants had been interviewed at baseline and follow-up 10/66 population surveys<sup>14</sup>. These individuals are referred to as 'index older persons'. With the passage of time since the baseline survey (inclusion criteria age 65 or over), all index older people in the INDEP study are aged 70 years or over. Their households were categorized as follows.

- 1) Incident care households (where all older residents were independent at baseline, but in which one or more have become care dependent by the incidence survey).
- 2) Chronic care households (with one or more care dependent older people at baseline, who remained care dependent in the incidence survey).
- 3) Control households (where all older residents were independent at baseline, and remained so at the incidence survey).

All households meeting criteria for incident or chronic care were selected for inclusion in the INDEP study. Control households equivalent in number to the incident and chronic care households were selected, at random from all those eligible, and frequency matched to care households for the age of the oldest resident. All analyses are weighted back at household level for probability of selection within each age group, and non-response among those selected.

### Data collection

For each household, we aimed to conduct a household interview with a suitably qualified key informant (the self-defined head

of household), brief interviews with each of the surviving index older people, and an informant interview for each older person to provide an independent perspective on their health and needs for care. We also linked INDEP interviews with the clinical information gathered at the last (incidence phase) 10/66 survey conducted two to three years previously. Our open access protocol paper provides a full account of the interviews administered in the INDEP study<sup>12</sup>. Here we summarise those elements used for analyses presented in this paper.

### Measures

**Autonomy.** The INDEP interviews with older residents included information on decision-making autonomy using four ad hoc questions developed for the survey. Only first two questions were asked of proxies in the event that the older person lacked capacity to respond. The third and fourth items, missing by design, were imputed for these participants.

- i. Would you say that family members consult you about important decisions affecting you? (options - always, usually, sometimes or never)
- ii. Would you say that family members consult you about important decisions affecting the household as a whole? (options – as for i. above)
- iii. Who decides what to do if you need to consult with a doctor, or buy medicines? (options – I decide for myself, I need to ask others in the family or household, others in the family or household decide)
- iv. Who decides what to do if you need to buy clothes, shoes, toiletries or other necessities of daily life? (options – as for iii. above)

Four points were subtracted from the final scale to base it at zero. A score of zero therefore reflected full autonomy, and a score of 10 maximally constrained autonomy. Higher scores are referred to throughout as 'diminished autonomy'; this is intended to signify a decrement from the optimal 'full autonomy' rather than any assumption of change over time. Formative analysis indicated that these items formed a robust hierarchical (Mokken) scale with Loevinger's H-scale coefficients of 0.52, and exceeding 0.45 for each item. For individual countries, the scale Loevinger H coefficients were, 0.72 (for Peru), for 0.51 (Mexico), and 0.60 (China). Cronbach's alpha was 0.78 overall (Peru 0.88, Mexico 0.78, and China 0.72), and item-total correlations were 0.65 for Q1, 0.68 for Q2, 0.50 for Q3 and 0.51 for Q4.

### Socioeconomic status

The INDEP household interview was used to gather data on:

- a. Household composition and roles. Current household composition, with the ages, genders, marital, educational and occupational status of all residents
- b. A household assets index covering household goods and amenities (telephone or mobile phone, stove, electricity supply, television, radio or stereo, refrigerator, sewing machine, bicycle, computer, and motor vehicles).

c. Monthly household income, estimated by enquiring systematically about 20 different sources of income and allocating each to an individual resident, or to the household if not specifiable. Income sources were clustered into five groups; pensions, paid work, income from assets, government transfers and private transfers. This approach allows us to estimate total household income and income for each household member, by source. Total monthly household income was calculated by summing after tax income across all sources and all residents. This monthly amount was then equivalised by dividing by the modified OECD equivalence scale (1.0 for the first adult, 0.5 for all other adults, and 0.3 for children) to account for economies of scale and converted into 2011 international dollars using purchasing power parity exchange rates.

d. Household indicators of financial strain. These included; asking for help from friends, relatives or others; borrowing from a bank or moneylender; cutting down on food consumption; trying to find extra work; running up an account with a shop; applying for a grant; apply for food parcels or vouchers; drawing on savings, selling stocks or shares; any other action to address the financial difficulty

**Health and functional status of the older person.** Detailed information regarding the health status of the older person was obtained at the follow-up phase of the 10/66 DRG survey, which preceded the INDEP survey. For the purposes of this analysis, this included; a) the cross-culturally calibrated and validated 10/66 Dementia diagnosis<sup>16</sup>; b) cognitive impairment, assessed using the Community Screening Instrument for Dementia (CSI-D) COGSCORE<sup>17</sup>; c) depression – meeting diagnostic criteria for ICD-10 depressive episode<sup>18</sup>; and d) a self-reported list of 12 commonly occurring physical impairments<sup>19</sup>. The INDEP survey brief interview with each index older person updated information on their status since the last 10/66 survey, including self-reported disability (World Health Organization Disability Assessment Scale (WHODAS 2.0))<sup>20,21</sup>.

The main purpose of the INDEP key informant interview was to update the assessment of the older person's needs for care. The informant is first asked whether the older person requires extra help, support or supervision, because of a health condition or disability, and about critical intervals of care. Seven additional open-ended questions were used to inform a final interviewer rating that the older person does not need care; needs care occasionally; or needs care much of the time<sup>22</sup>. For those requiring care, we enquired about the daily time spent assisting with specific activities of daily living; getting around, dressing, eating, grooming, toileting, and bathing<sup>23</sup>.

**Construct validators for the autonomy scale.** The INDEP survey interview with the index older person included assessment of wellbeing (In general, how happy would you say you are: very happy, fairly happy, not very happy, or not happy at all?) and life satisfaction (Taking everything into consideration how would you describe your satisfaction with life in general at the present time; good, fair or poor?). Self-reported needs for comfort and shelter, food, medical care, basic necessities (clothes and other items) and

transport were coded as completely met, partly met, or not met, the last two categories being combined for the purposes of this analysis.

## Analyses

All of the analyses were performed using Stata version 11 (StataCorp. 2009. Stata Statistical Software: Release 11). All analyses were weighted to take account of sampling fractions of care and control households, and non-response at household level, aiming for generalizability to the incidence phase of the 10/66 surveys in each catchment area site<sup>12,14</sup>.

1. We summarize, by site a) individual characteristics (the age, gender, educational level, marital status, health and functioning of older adults, needs of care, their total income, and pension coverage), and b) household characteristics (household composition, assets, and equivalised household income).

2. Negative binomial regression was used to estimate the effect (count ratio) of demographic variables, health variables, functioning variables, and indicators of household economic status on the older person's decision making autonomy, controlling for the older person's age, gender and educational level. Robust standard errors were generated, accounting for household clustering.

3. The independent effect of a) the older person's total income, b) the older person's pension income and, c) older residents' income as a proportion of total household income on the older person's decision making autonomy was estimated using negative binomial regression, controlling in sequential blocks for demographic, health, functioning and economic variables, identified as potential confounders in 2. above.

4. Associations between autonomy, wellbeing and life satisfaction, were estimated using Spearman non-parametric correlations between scale scores. Associations between autonomy and individual unmet needs were estimated using Poisson regression controlling for age, gender, education and disability (WHODAS 2.0) representing the prevalence ratio for each quarter of the autonomy scale, from least to most diminished autonomy.

## Results

We interviewed 709 households, with an overall household response rate of 71% (60% Peru urban; 63% Peru rural; 59% China urban; 86% China rural; 86% Mexico urban; 82% Mexico rural). In an additional 45 'care exit' households (where all those requiring care had died) individual interviews were carried out with other surviving older residents, even though this was not required in the protocol. These interviews were also included in the analysis. In the 754 households, we interviewed 937 index older persons with an overall response rate for older persons within responding households of 81% (82% Peru urban; 90% Peru rural; 84% China urban; 75% China rural; 78% Mexico urban; 84% Mexico rural). Almost all of the individual non-response was accounted for by death (18%) with only two older people refusing interviews and 11 not traced.

The mean age of index older participants was close to 80 years in all sites (Table 1). Educational levels of older participants were markedly higher in urban Peru (12% not completing primary education), than in other sites where 48% to 90% had not completed primary education. The norm in all sites was for older people to be living in multigenerational households, with working age adults, and, often, children under the age of 16 years.

However, multigenerational households were more common in urban Peru, and much rarer in urban China than in other sites. Between 24% and 30% of older participants required at least some care, while between 7% and 18% were involved in providing childcare. Levels of perceived autonomy varied between sites, being generally higher in Peru than in Mexico and China. In Mexico and China, but not in Peru, autonomy was

**Table 1. Characteristics of index older residents and households (weighted analyses).**

	Peru Urban	Peru Rural	Mexico Urban	Mexico Rural	China Urban	China Rural
Number of index older residents (weighted)	164 (844)	61 (419)	190 (632)	175 (665)	218 (642)	129 (664)
Age (mean, SD)	80.0 (6.1)	78.8 (5.7)	80.0 (5.8)	79.6 (5.6)	80.1 (5.5)	78.9 (4.7)
Autonomy (median, IQR)	0 (0-3)	1 (0-3)	1 (0-3) MV=2	4 (2-6)	2 (0-4) MV=20	3 (1-4) MV=23
Full autonomy (score of 0, %)	58.1	49.4	38.9 MV=2	6.9	33.2 MV=20	19.1 MV=23
Gender (F, %)	66.6	54.6	69.9	67.5	62.1 MV=3	56.5 MV=13
Education (did not complete primary, %)	12.3 MV=2	73.0	53.4	81.1	47.7 MV=9	89.5 MV=1
Marital status (%)			MV=8			
Currently married	37.7	65.3	35.1	45.9	61.3	50.1
Never married	9.1	5.0	5.1	2.5	0.0	0.2
Widowed	45.5	27.1	59.0	48.8	38.4	47.1
Separated or divorced	7.6	2.6	0.8	2.8	2.7	2.7
Living with working age adults (%)	87.4	67.8	65.9	62.1	58.0	76.1
Living with children <16 (%)	36.5	30.3	21.9	25.6	3.6	20.2
Providing childcare (%)	17.9	11.2	15.4 MV=2	6.7	6.8 MV=11	15.1
Dementia (%)	6.1 MV=4	4.6 MV=2	6.2	10.8 MV=5	9.4	7.9
Depression (%)	2.5	0.0	6.3	5.3	2.6	0.3
Number of physical impairments (median, IQR)	0 (0-1)	0 (0-2)	1 (0-2)	1 (0-2) MV=5	1 (0-3)	1 (0-2)
WHODAS 2.0 (median, IQR)	8.3 (0.0-33.3)	8.3 (0.0-19.4)	19.4 (5.6-30.6)	33.3 (13.9-50.0)	12.9 (2.8-33.3)	6.3 (0.0-27.8)
Dependence (%)						
No care	77.0	87.8	76.3	70.3	71.0	77.0
Some care	4.7	5.7	11.4	15.2	13.0	16.8
Much care	18.3	6.5	12.3	14.5	16.0	6.1
Number of Households (weighted)	132 (689)	51 (362)	164 (574)	143 (570)	158 (470)	106 (549)
Household assets (median, IQR)	9 (8-10)	8 (6-9)	8 (7-9)	6 (5-7)	8 (7-10)	9 (7-10)
Household income (median, IQR)	831 (588-1200)	388 (294-564)	355 (246-488)	108 (58-184)	738 (988-1366)	1257 (509-4972)
Income pooling (%)	MV=54	MV=77	MV=48	MV=10	MV=105	MV=57
All	17.4	3.8	18.7	25.8	46.5	27.8
Some	65.0	90.6	68.3	57.2	23.3	30.3
None	17.6	5.6	13.1	15.4	13.9	33.3

more constrained in rural than urban catchment areas. Even in Peru around half of older participants reported less than full autonomy within the domains ascertained.

Having controlled, in the base models, for age, gender and educational status, diminished autonomy was associated with older age, lower educational level, marital status (less autonomy for those who were never married or separated/divorced) (Table 2).

Diminished autonomy was more evident among residents of households with lower incomes. However, there was no association with household economic strain, and the effect of household assets was highly heterogeneous. The association with autonomy of older residents' propensity to pool their income with other household members also varied markedly between settings – in Peru more income pooling was associated with diminished autonomy, while in rural China the association was in the

**Table 2. Associations of demographic and socioeconomic factors with diminished autonomy, controlling for age, gender and education level (weighted analysis).**

Demographic factors	Site-specific estimates (Count Ratios, with 95% confidence intervals)						Meta-analysed estimate with Higgins I <sup>2</sup>
	Peru Urban	Peru Rural	Mexico Urban	Mexico Rural	China Urban	China Rural	Meta-analysis
Age (per year)	1.09 (1.05-1.13)	1.09 (1.00-1.19)	1.04 (1.00-1.08)	1.01 (0.98-1.04)	1.03 (1.00-1.06)	1.04 (1.00-1.07)	1.04 (1.02-1.05) I <sup>2</sup> =56.7%
Gender (M vs F)	2.85 (1.47-5.53)	1.74 (0.48-6.35)	0.93 (0.54-1.59)	0.89 (0.69-1.14)	0.96 (0.74-1.25)	0.81 (0.56-1.18)	0.97 (0.83-1.12) I <sup>2</sup> =59.5%
Education (per level)	0.68 (0.53-0.88)	0.83 (0.54-1.28)	0.96 (0.75-1.24)	0.89 (0.76-1.04)	0.85 (0.75-0.97)	1.00 (0.69-1.45)	0.85 (0.79-0.93) I <sup>2</sup> =0.0%
Marital status <sup>1</sup>	8.7 0.03	1.7 0.43	7.2 0.06	23.2 <0.0001	13.1 0.002	18.9 0.0001	
Married	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Never married	0.93 (0.43-2.00)	1.71 (0.70-4.15)	3.30 (1.28-8.51)	1.72 (1.33-2.22)	No cases	0.55 (0.39-0.78)	1.21 (1.00-1.46) I <sup>2</sup> =87.7%
Widowed	0.50 (0.26-0.97)	1.09 (0.39-3.05)	1.07 (0.62-1.86)	1.20 (0.87-1.64)	1.63 (1.17-2.26)	0.98 (0.65-1.46)	1.17 (0.98-1.39) I <sup>2</sup> =55.3%
Separated or divorced	0.09 (0.01-0.73)	DNC	1.54 (0.66-3.58)	1.66 (1.09-2.53)	1.59 (1.20-2.12)	DNC	1.56 (1.24-1.95) I <sup>2</sup> =56.5%
Living with working age adults	2.59 (0.70-9.60)	0.37 (0.08-1.65)	0.84 (0.51-1.39)	0.99 (0.76-1.29)	1.45 (1.04-2.04)	1.53 (0.95-2.46)	1.15 (0.96-1.37) I <sup>2</sup> =47.8%
Living with children <16	1.06 (0.63-1.77)	1.01 (0.37-2.75)	1.02 (0.59-1.75)	1.00 (0.72-1.41)	0.84 (0.54-1.32)	0.58 (0.34-0.97)	0.91 (0.74-1.10) I <sup>2</sup> =0.0%
Providing childcare	0.56 (0.26-1.21)	0.22 (0.05-0.92)	0.47 (0.24-0.90)	0.75 (0.54-1.04)	1.36 (0.92-2.02)	0.92 (0.45-1.88)	0.83 (0.67-1.02) I <sup>2</sup> =63.1%
Household assets	1.01 (0.80-1.27)	0.67 (0.61-0.75)	0.98 (0.82-1.18)	1.01 (0.89-1.15)	1.04 (0.93-1.16)	0.85 (0.75-0.95)	0.85 (0.83-0.93) I <sup>2</sup> =88.4%
Household income (per fifth)	1.02 (0.85-1.22)	0.77 (0.60-1.00)	0.84 (0.70-1.01)	0.87 (0.78-0.96)	0.86 (0.76-0.97)	0.78 (0.71-0.86)	0.84 (0.80-0.89) I <sup>2</sup> =35.4%
Economic strain (past 3 years)	1.12 (0.96-1.31)	1.87 (1.02-3.42)	1.02 (0.82-1.28)	0.88 (0.78-1.00)	1.05 (0.86-1.29)	0.46 (0.31-0.70)	0.97 (0.90-1.05) I <sup>2</sup> =79.0%
Income pooling <sup>1</sup>	20.4 <0.0001	21.2 <0.0001	4.5 0.11	0.6 0.74	2.2 0.34	19.1 <0.0001	
All	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)
Some	0.27 (0.13-0.56)	0.37 (0.23-0.59)	0.83 (0.47-1.45)	0.91 (0.68-1.22)	1.19 (0.77-1.83)	2.98 (1.64-5.41)	0.85 (0.71-1.03) I <sup>2</sup> =87.8%
None	0.10 (0.03-0.31)	0.65 (0.32-1.08)	1.78 (0.79-4.01)	0.91 (0.69-1.19)	1.39 (0.90-2.14)	3.49 (1.99-6.11)	1.10 (0.90-1.33) I <sup>2</sup> =87.5%

1. Likelihood ratio test for overall effect of categorical variable – chi squared statistic and p-value

opposite direction, and in Mexico and urban China no association was apparent.

Both dementia and cognitive impairment were independently associated with diminished autonomy, as were depression, and physical impairments (Table 3). Functional impairment and dependence (needs for care) were particularly strongly associated with diminished autonomy. The effect of the WHODAS 2.0

disability score, summarising the impact of cognitive, mental and physical impairments on overall activity and participation, was barely attenuated after controlling for dementia and cognitive function. The same pattern of independent association was apparent for dependence. The association of older age with diminished autonomy was somewhat reduced when controlling for cognitive impairment and dementia, and abolished after controlling also for functioning and dependence.

**Table 3. Hypothesis testing - Independent effects (count ratios with 95% confidence intervals) of cognitive impairment and dementia, functioning, dependence, age and older person's income on diminished autonomy, controlling sequentially for potential confounders (weighted analysis).**

Control variables	Hypothesis/ Exposure	Sites specific estimates (Count ratios with 95% confidence intervals)						Meta-analysed estimate with Higgins I <sup>2</sup>
		Peru Urban	Peru Rural	Mexico Urban	Mexico Rural	China Urban	China Rural	Meta-analysis
Controlling for age, sex and education	Hypothesis 1 - Health status							
	10/66 Dementia Diagnosis	4.47 (2.73-7.31)	3.37 (1.26-8.99)	1.93 (1.34-2.77)	1.11 (0.89-1.37)	1.61 (0.98-2.65)	0.91 (0.55-1.52)	1.47 (1.26-1.52) I <sup>2</sup> =85.5%
	CSI-D COGSCORE (cognitive function, per point)	0.91 (0.86-0.96)	0.83 (0.72-0.96)	0.94 (0.89-0.99)	0.98 (0.96-1.00)	0.97 (0.95-0.98)	0.99 (0.97-1.01)	0.97 (0.96-0.98) I <sup>2</sup> =67.6%
	ICD-10 Depressive episode	3.79 (2.00-7.18)	Did not converge	1.53 (0.72-3.25)	1.15 (0.87-1.53)	1.61 (0.92-2.81)	2.27 (1.59-3.26)	1.63 (1.35-3.26) I <sup>2</sup> =74.8%
	Physical impairment (per condition)	1.17 (1.00-1.38)	0.88 (0.59-1.34)	1.05 (0.91-1.21)	1.13 (1.01-1.26)	1.04 (0.96-1.14)	1.00 (0.87-1.14)	1.07 (1.01-1.12) I <sup>2</sup> =0.0%
Controlling for age, sex and education	Hypothesis 2 - Functioning							
	WHODAS 2.0 disability score (per point)	1.04 (1.03-1.05)	1.04 (1.01-1.06)	1.02 (1.01-1.03)	1.01 (1.01-1.01)	1.01 (1.01-1.02)	1.02 (1.01-1.02)	1.02 (1.01-1.02) I <sup>2</sup> =87.0%
	Hours of ADL care (per hour)	1.21 (1.14-1.28)	1.22 (1.09-1.36)	1.09 (1.02-1.16)	1.05 (1.01-1.09)	1.14 (1.10-1.19)	1.21 (1.16-1.26)	1.14 (1.11-1.16) I <sup>2</sup> =84.9%
+ cognitive impairment and dementia	WHODAS 2.0 disability score (per point)	1.04 (1.03-1.06)	1.03 (1.00-1.07)	1.02 (1.01-1.03)	1.01 (1.01-1.01)	1.01 (1.01-1.02)	1.02 (1.01-1.02)	1.01 (1.01-1.02) 82.8%
	Hours of ADL care (per hour)	1.19 (1.12-1.26)	1.08 (0.91-1.29)	1.06 (0.99-1.14)	1.04 (0.99-1.08)	1.13 (1.09-1.18)	1.20 (1.15-1.25)	1.13 (1.10-1.15) I <sup>2</sup> =82.3%
Controlling for age, sex and education	Hypothesis 2 - Dependence							
	Needs for care <sup>1</sup>	64.4 <0.0001	13.8 0.001	12.8 0.002	1.1 0.57	57.4 <0.0001	51.9 <0.0001	
	None of the time	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)
	Some of the time	2.04 (0.96-4.30)	3.33 (1.50-7.40)	1.52 (0.81-2.85)	1.21 (0.82-1.79)	1.66 (1.15-2.41)	2.39 (1.63-3.52)	1.77 (1.45-2.14) I <sup>2</sup> =43.6%
	Much of the time	5.46 (3.57-8.36)	4.06 (1.80-9.16)	2.09 (1.39-3.14)	1.14 (0.83-1.58)	3.04 (2.28-4.07)	3.00 (2.22-4.04)	2.54 (2.15-2.95) I <sup>2</sup> =87.8%
+ cognitive impairment and dementia	None of the time	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)	1 (ref)
	Some of the time	2.26 (1.07-4.77)	2.26 (0.70-7.26)	1.38 (0.72-2.63)	1.23 (0.85-1.79)	1.67 (1.16-2.40)	2.29 (1.57-3.35)	1.69 (1.39-2.05) I <sup>2</sup> =22.7%
	Much of the time	4.89 (3.12-7.65)	1.73 (0.43-6.92)	1.89 (1.23-2.90)	1.07 (0.74-1.57)	2.78 (2.08-3.72)	3.08 (2.26-4.20)	2.44 (2.09-2.86) I <sup>2</sup> =84.5%

Control variables	Hypothesis/ Exposure	Sites specific estimates (Count ratios with 95% confidence intervals)						Meta-analysed estimate with Higgins I <sup>2</sup>
		Peru Urban	Peru Rural	Mexico Urban	Mexico Rural	China Urban	China Rural	Meta-analysis
	<b>Hypothesis 3 - Age</b>							
Controlling for age, sex and education	Age (per year)	1.09 (1.05-1.13)	1.09 (1.00-1.19)	1.04 (1.00-1.08)	1.01 (0.98-1.04)	1.03 (1.00-1.06)	1.04 (1.00-1.07)	1.04 (1.02-1.05) I <sup>2</sup> =56.7%
+ cognitive impairment and dementia	Age (per year)	1.07 (1.03-1.12)	1.07 (0.98-1.16)	1.03 (0.99-1.06)	1.00 (0.98-1.03)	1.02 (1.00-1.05)	1.03 (0.99-1.07)	1.02 (1.01-1.04) I <sup>2</sup> =44.7%
+ functioning and dependence	Age (per year)	1.01 (0.97-1.04)	1.03 (0.94-1.13)	0.99 (0.96-1.03)	1.00 (0.97-1.03)	1.02 (0.99-1.04)	1.00 (0.96-1.04)	1.01 (0.99-1.02) I <sup>2</sup> =0.0%
	<b>Hypothesis 4 - Older person's total income (per fifth)</b>							
Controlling for demographic variables <sup>1</sup>	Older person's total income (per fifth)	0.66 (0.54-0.80)	0.51 (0.39-0.67)	0.94 (0.76-1.15)	0.87 (0.79-0.96)	0.94 (0.84-1.05)	0.82 (0.74-0.91)	0.84 (0.80-0.89) I <sup>2</sup> =79.7%
+ health status <sup>2</sup>	Older person's total income (per fifth)	0.71 (0.58-0.86)	0.49 (0.37-0.66)	0.98 (0.79-1.20)	0.89 (0.81-0.98)	0.94 (0.84-1.05)	0.82 (0.73-0.91)	0.86 (0.81-0.94) I <sup>2</sup> =78.5%
+ functioning <sup>3</sup>	Older person's total income (per fifth)	0.70 (0.57-0.87)	0.49 (0.37-0.64)	1.01 (0.82-1.26)	0.88 (0.81-0.96)	0.93 (0.83-1.05)	0.85 (0.78-0.93)	0.86 (0.78-0.93) I <sup>2</sup> =79.2%
+ household economic status <sup>4</sup>	Older person's total income (per fifth)	0.63 (0.54-0.74)	0.77 (0.58-1.02)	1.06 (0.84-1.33)	0.91 (0.83-0.99)	0.92 (0.81-1.04)	0.81 (0.69-0.95)	0.86 (0.81-0.91) I <sup>2</sup> =77.3%

1. Age, sex, education, and marital status

2. Dementia, depression, number of physical impairments

3. Hours of ADL care received, takes on a child care role

4. Household assets, household income

After controlling incrementally for all likely confounding variables; sociodemographic characteristics (age, sex, and education), health status (dementia, depression and number of physical impairments), functioning and dependence (hours of ADL care and taking on a childcare role), and household economic status (household assets and income); an older person's total income was strongly inversely associated with diminished autonomy (Table 3). In the fully adjusted models, the effect of the absolute levels of older person's total income (CR [per fifth of total income] 0.86, 95% CI 0.81-0.91) was greater than those of either total pension income (CR [per fifth] 0.94, 95% CI 0.88-0.99), or personal income as a proportion of total household income (CR [per fifth] 0.97, 95% CI 0.95-0.99).

Bivariate correlations between autonomy and wellbeing were generally positive and statistically significant; Peru urban +0.35 (p<0.001), Peru rural +0.36 (0.01), Mexico urban +0.18

(0.02), Mexico rural +0.21 (0.01), China urban +0.30 (<0.001); other than in China rural -0.14 (0.19). A similar pattern of correlation was observed for life satisfaction but with smaller correlations; Peru urban +0.39 (p<0.001), Peru rural +0.21 (0.08), Mexico urban +0.11 (0.14), Mexico rural +0.18 (0.02), China urban +0.25 (0.001); China rural -0.06 (0.57). Associations between autonomy and unmet needs (for comfort and shelter, food, medical care, basic necessities of daily life, and transport) are reported in Table 4. Site-specific estimates suggested different patterns of associations for urban and rural sites. Following meta-analysis stratified by urban/ rural status, in urban sites more diminished autonomy was associated with a higher prevalence of unmet needs for food, medical care, and basic necessities. However, in rural sites more diminished autonomy was associated with a lower prevalence of unmet needs for comfort and shelter, food, medical care and transport. The rural/urban differences were particularly apparent for the sites in China.

**Table 4. Associations between diminished autonomy and unmet needs, controlling for age, gender, education and disability (WHODAS 2.0).**

Unmet needs	Site-specific effect sizes (prevalence ratio with 95% confidence intervals) per quarter of autonomy scale (from least to most diminished autonomy)						Meta-analysed estimates with Higgins I <sup>2</sup>	
	Peru Urban	Peru Rural	Mexico Urban	Mexico Rural	China Urban	China Rural	Urban sites	Rural sites
Comfort and shelter	0.82 (0.51-1.32)	0.69 (0.49-0.96)	1.08 (0.64-1.84)	1.67 (0.88-3.20)	1.05 (0.72-1.53)	0.66 (0.45-0.96)	0.98 (0.76-1.27) 0.0%	0.76 (0.60-0.96) 69.5%
Food	1.08 (0.59-1.95)	0.68 (0.47-0.97)	2.35 (1.52-3.63)	0.81 (0.35-1.87)	1.23 (0.94-1.60)	0.36 (0.19-0.68)	1.41 (1.14-1.75) 71.7%	0.61 (0.45-0.81) 41.4%
Medical care	1.19 (0.68-2.08)	0.60 (0.42-0.87)	1.26 (0.82-1.92)	0.62 (0.34-1.15)	1.60 (1.12-2.27)	0.69 (0.45-1.05)	1.40 (1.09-1.78) 0.0%	0.63 (0.49-0.82) 0.0%
Clothes and other basic necessities	0.76 (0.39-1.50)	1.04 (0.78-1.40)	0.95 (0.50-1.83)	5.42 (1.24-23.7)	2.12 (1.36-3.31)	0.36 (0.19-0.69)	1.38 (1.00-1.90) 74.6%	0.92 (0.71-1.20) 86.1%
Transport	0.88 (0.50-1.54)	0.63 (0.44-0.92)	0.98 (0.58-1.67)	1.09 (0.62-1.92)	1.03 (0.70-1.52)	0.63 (0.44-0.90)	0.98 (0.75-1.29) 0.0%	0.69 (0.55-0.87) 33.2%

## Discussion

### Summary of findings

In this study, less than full autonomy was reported by between 42% (urban Peru) and 93% (rural China) of older respondents. Diminished autonomy was associated with older age, not being currently married, lower education, lower household income, physical, cognitive and mental morbidities, functional impairment and needs for care. We tested four hypotheses, all of which were supported. Dementia and cognitive impairment were independently associated with diminished autonomy. Functional impairment and dependence were also associated with diminished autonomy, controlling for dementia and cognitive impairment. The crude association of older age with diminished autonomy was confounded by dementia, cognitive impairment, and, particularly, by functional impairment and dependence. Higher older person's incomes were independently associated with greater autonomy having controlled for demographic variables, health status, functioning and household income. Autonomy was associated with wellbeing, other than in the rural China site, and, less strongly, with life satisfaction. Diminished autonomy was associated with some unmet needs in urban sites, but those with more diminished autonomy reported fewer unmet needs in rural sites.

### Strengths and limitations

The strengths of our study were that, following weighting back, analyses were conducted on large, representative community samples of older persons in three middle income countries including urban and rural settings. The sample comprised mainly 'older old' participants (mean age around 80 years) among whom most needs for care are concentrated. A wide range of potential determinants of autonomy were considered, and assessed in detail using cross-culturally validated measures<sup>16,21,22,24</sup>. In particular, household and individual incomes were ascertained with rigour, enquiring after all sources of income for all household members<sup>12</sup>. Analyses of associations with autonomy were based on a priori hypotheses, and stratified

by site before meta-analytical synthesis. While heterogeneity was moderate to marked for many of the reported associations, the associations were generally in the same direction and differed mainly in degree.

The main limitation was that this was essentially a cross-sectional study, in which self-perceived autonomy, and most of its correlates were assessed simultaneously, as part of the INDEP study data collection. While INDEP was nested within the antecedent 10/66 surveys, from whence measures of physical, mental and cognitive morbidity were obtained, autonomy was not assessed in previous waves of data collection. Direction of causality is therefore impossible to establish. For some correlates, associations in either or both directions are plausible. Thus, depression may constrain the ability to think and act autonomously, but diminished autonomy may also increase the risk of becoming depressed. Health status, in general, may be compromised by the impact of diminished autonomy on health-care helpseeking. While dementia, disability and dependence are more likely to be causes than consequences of diminished autonomy, personal attributes may be common correlates of a propensity to maintain or cede both independence and autonomy in the face of adversity. Of the associations reported here, that between personal income and autonomy seems least likely to be accounted for by reverse causality. Opportunities for paid work may be more limited and private income transfers more generous for those with diminished autonomy, but these sources made a negligible contribution to older persons' total incomes, which came mainly from pensions and (in China) assets<sup>15</sup>. Associations in cross-sectional studies are also apt to be affected by information bias, but this may be mitigated by some features of our study design. Clinical diagnoses of depression and dementia were ascertained in the 10/66 surveys, independent of the later ascertainment of autonomy in the INDEP study. While both autonomy and disability (WHODAS 2.0) were ascertained from interview of the index older person, dependence and time spent supporting activities of daily living were

ascertained from key informant interview, and other variables, including the index older persons' incomes were ascertained from the household interview with the head of household. Although patterns of association seemed broadly similar across diverse study settings, the catchment area design of the 10/66 studies does not permit generalisation to the cities or rural areas where the research was conducted, let alone to the country as a whole. Finally, we have not attempted to assess the impact of structural, contextual effects upon autonomy. While levels of autonomy varied considerably between sites, the number of sites was insufficient to carry out a mixed effects multilevel analysis of contextual as well as individual level correlates. Any interpretations of site-level differences would be post hoc and speculative.

### Inferences and potential mechanisms

The key findings from this research are, first, that functional impairment and dependence are important correlates of diminished autonomy among older people. This finding cannot be explained by the effects of cognitive impairment, since controlling for cognitive performance and dementia diagnosis did not affect the associations. Older people may have the resources and capacity to make decisions, and yet have their ability to act autonomously constrained by non-cognitive limitations. For example, they may decide that they need and wish to consult with a doctor, or make a purchase from a store, but if they cannot do so without assistance then the locus of decision-making may be transferred to those upon whom they depend for help. The observed associations might also arise from an automatic assumption among caregivers and other family members that frail or dependent older people can no longer be relied upon to exercise judgment and take decisions. Older age was not independently associated with diminished autonomy, after controlling for functional status and dependence, hence any such discriminatory tendencies could not be described, strictly speaking, as ageist. Finally, it is important to note that informal care usually involves an element of reciprocity, which in some cases may result in the care recipient more or less voluntarily ceding autonomy in return for support. Such a mechanism might account for our otherwise counterintuitive finding that in more traditional rural settings, diminished autonomy was associated with a lower prevalence of unmet needs.

The second key finding is that, independent of household income, other socioeconomic and demographic factors, and health status, older people with higher personal incomes perceive themselves to have greater autonomy. In the wider development literature intra-household bargaining power for resource allocation is seen as being determined by asset ownership and ability to work, modified by traditional rights, and support from State and nongovernmental organizations<sup>25</sup>. These influences have also been discussed with reference to older people's autonomy, for example by [Sylvia Beales of HelpAge International in her submission to a 2012 United Nations Expert Group Meeting](#):

“Reduced capacity to earn a personal income and contribute to the household income – even indirectly – has clear

implications for dignity and empowerment, of the person and within the family. Even when older persons are supported by their families in terms of food and shelter, the fact that they do not have their own resources may affect their autonomy and capacity to exercise choice, and lead to them being seen potentially as a burden.”

Such arguments form an important part of the case for social pensions. If autonomy is considered to be an intrinsic good, the preliminary evidence presented in this paper, in an otherwise under-researched area, provides important support for this and other policy instruments that promote income security and social protection for older people. Having a personal income enables older people to make strategic choices to retain or pool it with others in the household. The consequences of these decisions, however, may be culturally variable; not pooling income in Peru, and pooling income in China were strongly associated with greater autonomy.

### Implications for policy and practice

Addressing the widespread problem of diminished autonomy among older people will require targeted actions, sustained over a long period, supported by careful monitoring and analysis of key indicators to track progress. This will in turn require political will, accompanied by effective advocacy, holding governments and other key stakeholders to account<sup>26</sup>. Promoting the rights of older people, including for their autonomy to be respected, and enhancing their status and dignity through education and awareness-raising programs are important instruments for change. However, such programs may need cultural nuancing, to support rather than subvert traditional systems of informal family care. At the policy level, priority should be given to addressing structural determinants of diminished autonomy, particularly low education and poverty in general, and income insecurity among older people.

Findings from this study suggest a need to focus upon frail and dependent older people. The UN Convention on the Rights of Persons with Disabilities<sup>27</sup>, if properly implemented, would overcome many barriers to autonomous action, whether participating in the life of the community, accessing transport or healthcare. The [World Health Organization's Age-friendly Cities project](#) recommends actions to be pursued with the active involvement of older people; these target outdoor spaces and buildings, transportation, housing, social inclusion, social and civic participation, communication and information, and community and health services. In 2002, at the United Nations Second World Assembly on Ageing governments of 159 nations adopted the Madrid International Plan of Action on Ageing (MIPAA), to respond to the challenges of population ageing, including; eliminating inequalities in access to healthcare; developing health and long-term care to meet the needs of older persons; and optimising function to ensure full participation of older persons with disabilities<sup>28</sup>. In 2012, a 10 year review of MIPAA found that very little progress has been made towards achieving these objectives, particularly in LMIC<sup>29</sup>. For older people in countries with limited social protection, ‘dependency anxiety’<sup>30–32</sup> - not wanting to be a burden on relatives, fearing

inadequate support, and therefore wishing to maintain independence – is a key motivating principle. Social pensions, targeted disability and caregiver benefits address these concerns directly, providing insurance against many of the risks that older people face. Such benefits may reinforce reciprocal family ties, and allow dependent older people to be properly valued for their positive contributions. Family care could be bolstered, but also supplemented or substituted, where appropriate, by paid services.

In summary, policies that confer status and promote security of older people within families; that strengthen their capabilities and expand their choices; and that provide legal recognition of their rights; are likely to enhance autonomy and social and economic empowerment (Sylvia Beale, [submission to UN Expert Group Meeting, 2012](#)). Progress needs to be monitored through incorporation of suitable indicators into population surveys of health and ageing, linked to age-disaggregated measures of income and wealth, housing and property rights, and access to services.

### Data availability

10/66 INDEP mixed methods study of the economic and social impact (at household level) of residing with a care dependent older person in China, Mexico, Peru and Nigeria data are available from the UK Data Service database: <https://doi.org/10.5255/UKDA-SN-852071><sup>33</sup>. These data are under a UK Data Service End User Licence.

Data are available under managed access only, due to the following reasons: participants were informed during the consent process that their data would be made available to other researchers only for legitimate scientific research purposes (as approved by all ethics committees); the data have been anonymised, but there may be potentially identifiable information despite efforts at anonymization.

Data access requires [user registration](#) and signing of the End User Licence, which can be viewed [here](#). Users will then login and be able to download the data.

### Competing interests

No competing interests were disclosed.

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