

Considerations for the use of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) in cross-country comparisons of cognitive aging and dementia

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Structured Abstract

Introduction: Informant reports are a critical component of dementia diagnoses, but the comparability of informant reports across countries is not well understood.

Methods: We compared the performance of the Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) using population-representative surveys in the US (N=3,183), England (N=1,050), and India (N=4,047).

Results: Analyses of regression splines and comparisons of model fit showed strong associations between IQCODE and objective cognition at low cognitive functioning in the US and England; in India the association was weaker but consistent over the range of cognition. Associations between IQCODE score and informant generation (ANOVA $p=0.001$), caregiver status ($p<0.001$), and years known by the informant ($p=0.015$) were different across countries after adjusting for objective cognition.

Discussion: In India, the IQCODE was less sensitive to impairments at the lowest levels of cognitive functioning. Country-specific adjustments to IQCODE scoring based on informant characteristics may improve cross-national comparisons.

Key Words: dementia, informants, cross-national, global, IQCODE, measurement

Highlights

- Associations between IQCODE and cognitive testing were similar in the US and England but differed in India.
- In India, the IQCODE may be less sensitive to impairments among those with low cognition and no education.
- Informant characteristics may differentially impact informant reports of decline across countries.
- Adjustments or culturally sensitive adaptations may improve cross-national comparability.

Research in Context

Systematic review: A literature review revealed numerous studies validating the IQCODE in specific settings. Only one study compared multiple contexts: African Americans in the US and Yoruba Nigerians. Previous work has not systematically characterized associations between the IQCODE and objective cognitive testing, or the impact of informant characteristics on IQCODE scores, across other settings.

Interpretation: IQCODE performance differed between India, the US, and England. In India, the IQCODE was less sensitive to cognitive performance at the lowest levels of cognition, particularly in those with no education. Informant characteristics were associated with IQCODE scores differently across contexts.

Future directions: Differences in the distribution of informant characteristics and in associations across contexts may help explain cross-national differences in associations of IQCODE with objective cognitive testing. Additional research is needed to probe other potential reasons. Development of adjustments for informant characteristics or culturally sensitive adaptations to the IQCODE may improve cross-national comparability.

1. Background

Informant reports of cognitive decline and everyday functioning provide critical information in population-based surveys that aim to assess cognitive functioning and dementia. Informant questionnaires are often administered to proxy respondents when participants are unable to complete objective cognitive testing [1–3]. However, some dementia studies conduct informant interviews for every study participant to assess the impacts of cognitive decline on participants' everyday functioning from the perspective of a more objective observer in close, regular contact with the study participant [4,5].

The latter approach was taken in the Harmonized Cognitive Assessment Protocol (HCAP), which has been implemented in a growing number of studies across the world. This protocol, and hence these studies, aim to provide comparable cross-national assessments of cognition and dementia in older adults [5]. The HCAP protocol includes a variety of informant questionnaires, including the Jorm Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE) [6,7]. Informant questionnaires such as the IQCODE are important in assessing dementia given potential reporting biases in self-report questionnaires among individuals with dementia [8,9]. The IQCODE plays an important role in clinical consensus processes for assessing dementia [10] as well as in study-specific algorithmic classifications of dementia [11] in studies administering the HCAP battery.

Prior research using data from the HCAP battery has shown differences between countries in associations between responses to the IQCODE items and cognitive impairment [12].

However, beyond broader explanations related to cultural differences [12–14], specific drivers of observed differences remain largely unclear. More detailed comparisons could provide insights into the reasons for differences and inform approaches to increase cross-national comparability of the IQCODE either via adjustments to the administration of the

survey items, adaptations for cultural sensitivity, or via post-hoc adjustments to scoring procedures.

A number of existing studies suggest characteristics of informants can influence informant reports [15–22]. The generation of informants (e.g., same generation vs. children), spousal status, and cohabitation status have all been shown to significantly impact reporting on informant questionnaires of cognition, although the direction of prior findings is variable [15–17,21,22]. Caregiver burden and informant depression may also influence reporting [18]. Systematic differences in family structure and the frequency and norms around multi-generational households likely leads to heterogeneity in the distributions of informant characteristics and familiarity of the informant with the primary respondent between countries [23–25], as has been shown in existing cross-national research comparing study sites in Latin America, Africa, India, and China [26]. Given findings on the impact of informant characteristics on informant reports, differences in the characteristics of informants across settings may subsequently influence comparisons of the IQCODE in cross-national studies.

Several limitations preclude the use of existing literature for the assessment of how informant characteristics may impact cross-national comparisons of the IQCODE. Existing findings on associations between informant characteristics and responses to informant questionnaires have not been consistently reported across samples [27–29] and the majority of studies have had small sample sizes and have been conducted in selected samples such as memory clinics, rather than population-representative studies. Furthermore, while most studies were conducted in high-income contexts and in homogenous populations [15,16,18,29,30], cultural differences between settings may influence the impact of informant characteristics across countries. One prior cross-national study found that spouses among African Americans in the US but siblings among Yoruba Nigerians reported more difficulties in informant reports,

controlling for objective cognitive functioning [31]. These findings emphasize the potential for differences across cultures. However, additional research is needed to better understand the impact of informant characteristics on the IQCODE questionnaire across a wider range of contexts. Comparisons among studies using the HCAP battery will enable improvements to IQCODE scoring procedures or dementia algorithms that rely on informant reports in these studies.

This study uses data from three countries (the US, England, and India) which have implemented the HCAP battery to improve the characterization of cross-country differences in IQCODE performance by 1) considering non-linearities in associations between IQCODE and objective cognitive functioning and 2) comparing estimates of associations between informant characteristics and responses to the IQCODE across countries.

2. Methods

2.1 Data

We included data from three surveys that have implemented the HCAP battery: the Health and Retirement Study HCAP (HRS-HCAP) in the United States, the English Longitudinal Study of Ageing HCAP (ELSA-HCAP) in England, and the Longitudinal Aging Study in India – Diagnostic Assessment of Dementia (LASI-DAD) in India [5,32,33]. All three studies are probability-based sub-samples of the broader HRS-International Partner Studies (HRS-IPS) in each country and are therefore population-representative. LASI-DAD included participants 60 years and older, while HRS-HCAP and ELSA-HCAP included participants 65 years and older. All respondents in these studies were asked to nominate family members or friends to participate in informant interviews. All studies requested that respondents nominate informants who knew the respondent well and interacted with them frequently. Studies were designed to be as comparable as possible, although all survey questions were translated into

local languages and some modifications were made, particularly to cognitive testing, to ensure cultural appropriateness and acceptability given varying levels of literacy and numeracy [34]. The studies were not always successful in conducting both a cognitive assessment with the primary respondent as well as an informant interview. We only used observations that included both a cognitive assessment of the participant and an informant interview (HRS-HCAP N = 3,183; ELSA-HCAP N = 1,050; LASI-DAD N = 4,047). Study protocols were approved by the relevant Institutional Review Boards for each study and all respondents and informants gave informed (written or thumbprint) consent.

2.2. IQCODE

The HCAP battery included the 16-item short version of the IQCODE questionnaire [7,20]. The IQCODE is an informant questionnaire designed to measure cognitive changes in a respondent over a 10-year reference period. Each item asks the informant about the respondent's ability to do everyday cognitive tasks compared to their previous ability. A five-item response scale is used for each item with the following options: much improved (1), a bit improved (2), not much improved (3), a bit worse (4), and much worse (5), such that higher scores represent greater worsening. Instances when the respondent never did a specific task preclude comparisons to previous levels of functioning. Both HRS-HCAP and LASI-DAD provided specific options for "Never did"; while in ELSA-HCAP, this response was not offered as an option a priori, but was recorded if spontaneously reported as an answer by informants. The phrasing of IQCODE items was equivalent across settings; appropriate translations and back-translations were conducted for LASI-DAD [35]. Each study imputed missing data using similar methods based on information from other informant interview questions, objective cognitive testing, demographics, and information from the prior wave of the broader HRS-IPS study [36]. The proportion of imputed responses by item and study is available in Supplemental Materials 1; proportions are below 10% in all cases except items

with high proportions of “doesn’t do” responses in LASI-DAD. In previous work in LASI-DAD, we did not find meaningful differences when using imputed data versus when creating alternative scores based on dropping items with the highest proportions of “doesn’t do” responses [21]. We generated a IQCODE summary score by taking the mean across the 16 IQCODE items, after imputation for missing data. Because imputations incorporated information from a wide variety of sources, using the mean of imputed items would be expected to perform better than the mean of non-missing items. For simplicity, throughout the paper we use the term IQCODE score to refer to this summary score, and we use the names of items to refer to specific item-level results.

2.3 Measurement of cognition

In all three studies, cognitive functioning of respondents was assessed using neuropsychological batteries covering multiple cognitive domains, including orientation, memory, executive functioning, language, and visuospatial functioning (full list Supplemental Materials 2). Prior work used both pre-statistical and statistical harmonization procedures to derive harmonized scores of cognitive functioning across studies despite some differences in included items [34,37]. These methods included careful interrogation of potential differences due to translation or administrative procedures, and the application of modern psychometric methods to minimize potential sources of bias. Statistical harmonization was conducted using an item banking approach. Harmonized scores were standardized to have a mean of 0 and standard deviation of 1 in HRS-HCAP. Further details on these methods can be found elsewhere [34,37]. In this study, we used two versions of these cognitive factor scores: 1) the harmonized scores, which are directly comparable between studies, and 2) internally scaled scores, which were scaled to a mean of 0 and standard deviation of 1 within each country independently. A score of 1 SD unit is directly comparable across countries using the harmonized scores. However, the distributions of cognition vary considerably across

contexts, which complicate some comparisons. The choice of which score to use across analyses is discussed further in Section 2.5.

2.4 Measurement of informant characteristics and other covariates

Informants answered questions on their relationship with the respondent, the number of years they had known the respondent, whether they were a caregiver of the respondent, and the frequency of contact they had with the respondent (lives with respondent/daily/one to several times per week/less than a few times per month). We used information on informant relationship to construct a variable for informant generation, which was classified into same generation (spouse, sibling), younger generation (child, child-in-law, grandchild), or other (friend, neighbor, other relative).

The data include both informant and respondent self-reported age, gender, and educational attainment, as well as respondent marital status. We created two categories for marital status: married or partnered and divorced, separated, or other. We used two different categorizations of education across studies. First, we constructed a harmonized measure of education based on the International Standard Classification of Education (ISCED) (no formal education/early childhood to lower secondary education/upper secondary to short-cycle tertiary/bachelor's or higher) [38]. Using ISCED classifications, categories denote the same absolute level of education across settings. Second, we created independent (internally-scaled) classifications of low, medium, and high levels of education in each country based on the distributions of the data, which reflects differences between those with relative advantage or disadvantage in each setting (details in Supplemental Materials 3). We used both education variables in assessments of descriptive statistics but used internally-scaled educational attainment in regression models described in Section 2.5.

2.5 Statistical methods

We assessed the characteristics of both respondents and informants across countries using descriptive statistics. We used chi-squared tests and analysis of variance (ANOVA) to assess the statistical significance of differences between countries for informant characteristics. We also characterized the distributions of responses on the IQCODE questionnaire across settings. Initial descriptive statistics used unimputed data; all later analyses used imputations for IQCODE items. We used scree plots with parallel analysis using polychoric correlations for ordinal data to confirm the unidimensionality of the IQCODE battery in each country (Supplemental Materials 4) and calculated ω as a measure of scale reliability [39]. We then used exploratory factor analysis with a single factor to assess construct validity and compare item loadings across settings. Differences in item loadings across settings may indicate poor performance for individual items or underlying differences in the structure of the construct. We conducted separate factor analysis models by country and used polychoric correlations to account for the use of ordinal items.

To evaluate the potential impact of leaving out the “never did” response in the ELSA-HCAP survey, we compared responses from ELSA-HCAP and HRS-HCAP, as these two contexts are more similar culturally. We calculated the difference in mean score at the item level comparing ELSA-HCAP to HRS-HCAP. We then regressed this difference on the calculated proportion of recorded “never did” responses in HRS-HCAP to assess whether the removal of this category as a pre-specified option for informants may have influenced IQCODE scores.

We then assessed the performance of the IQCODE in each country by comparing IQCODE scores with objective cognitive performance. We fit unadjusted linear regression models with a single spline term, specified as a natural cubic spline with internal knots at the 25th, 50th, and 75th quantiles of the data distribution, and boundary knots at the 10th and 90th

percentiles of the data distribution. We compared results using both harmonized cognitive performance and cognitive performance scaled to the distribution of cognition in each country. Examination of the relationship between IQCODE and internally scaled cognitive performance illustrates associations between the IQCODE and cognitive performance, conditioning on the distribution of cognition in a specific context. Because the IQCODE questionnaire asks informants to make comparisons to prior levels of functioning in respondents, which implicitly hold context (as well as the specific individual) constant, assessments of associations with internally scale measures may better match the intended function of the IQCODE. In addition to comparing these relationships across the three countries, we also compared subsets of the LASI-DAD sample with any education and no education, as the group with education may be more similar to the HRS-HCAP and ELSA-HCAP samples. For analyses using these LASI-DAD subgroups and internally scaled cognitive functioning, we re-calculated the internally scaled measure in each subgroup independently.

Based on visual inspection of these flexible spline fits, the relationship between the IQCODE and internally-scaled objective cognition seemed to be either 1) linear or 2) piecewise linear with two segments and a knot around -0.5 SD units of the cognitive score. Comparison of model Bayesian Information Criterion (BIC) confirmed this visual assessment; BIC was either lower or similar for models with a piecewise linear spline compared to models with flexible spline fits (Supplemental Materials 5). To compare the fit of the linear and piecewise linear parameterizations, we used chi-squared tests for nested models to test the statistical significance of improved fit due to adding the knot to the piecewise linear model. We ran these tests both for the IQCODE score and each individual item for HRS-HCAP, ELSA-HCAP, and the no education and some education groups in LASI-DAD. Models for

individual items used proportional odds models rather than linear regression given the ordinal nature of responses to individual IQCODE items.

We used linear regression models to estimate associations between informant characteristics (relationship, generation, caregiver status, years known respondent, contact frequency) and IQCODE score across the four groups included (the three studies, with LASI-DAD divided into those with any and no education). There were small amounts of missing data in some of the informant characteristics (<2%, numbers included in Table 1); regression models used a complete case analysis. We estimated three sets of models with 1) no adjustment, 2) adjustment for age, sex, and education (demographics), and 3) adjustment for demographics + objective harmonized cognition. We used internally scaled classifications of low, medium, and high education to adjust for relative disadvantage or advantage in educational attainment, given our interest in understanding the performance of the IQCODE given the distribution of cognition and education in each study. Models for the LASI-DAD no education group did not include education as a covariate as there was no variability in education among this subgroup. We used chi-squared tests to assess the statistical significance of adding the interaction between study group and the informant characteristic (allowing this to be different across groups). We assessed assumptions of linear regression using plots of model residuals versus predictions, and quantile-quantile plots of model residuals. Although there was some evidence of violation of normality of residuals, in studies with large sample sizes ($N > 10$ per predictor) violations to normality are unlikely to lead to bias in confidence intervals or p-values [40].

Because analyses were focused on the performance of the IQCODE questionnaire in the HCAP surveys, which does not require the generalization of evidence to the population level, we did not account for sampling weights in analyses. We did re-calculate descriptive statistics presented using sampling weights (Supplemental Materials 6 & 7); application of weights did

not change paper conclusions or descriptions included in the results. Because sample size differed across the studies, we focused conclusions on point estimates and comparisons of point estimates in addition to examining statistical significance of findings. All analyses were conducted in R version 4.2.2.

3. Results

Respondents were younger in LASI-DAD (69.7 years; Inter-Quartile Range [IQR] 64.0-74.0) than HRS-HCAP (76.4 years; IQR 70.0-81.4) and ELSA-HCAP (74.5 years; IQR 68.0-80.0), but differences were larger for informants (LASI-DAD: 44.3; IQR 30.0-60.0; HRS-HCAP: 64.7 IQR 56.0-75.0; ELSA-HCAP: 66.1 IQR 58.0-76.0) (Table 1). Participant educational attainment (harmonized ISCED) was higher in HRS-HCAP and ELSA-HCAP than in LASI-DAD. Characteristics of informants were all significantly different between studies ($p < 0.001$): informants were most likely to be from the same generation as the respondent in ELSA-HCAP (70.4%), followed by HRS-HCAP (62.3%), while less than half of informants were from the same generation as the respondent in LASI-DAD (32.0%). A higher proportion of informants lived with the respondent in LASI-DAD (75.5%) compared to the other two studies (HRS-HCAP 25.3%; ELSA-HCAP 53.4%), but the number of years for which the informant knew the respondent was longest in ELSA-HCAP (47.1 IQR 40.0-57.0). A larger proportion of informants reported being caregivers in LASI-DAD (82.8% vs. 31.1% in HRS-HCAP and 29.4% in ELSA-HCAP), potentially due to a broader interpretation of caregiving combined with a larger number of informants living in multi-generational households with respondents in this setting.

Mean IQCODE scores across items were on average higher in LASI-DAD compared to HRS-HCAP and ELSA-HCAP (Table 2). Across the studies, there was a consistent set of items with higher numbers of “never did” responses (how to work machines, how to use a new

gadget, handling money, financial with bank). The proportion of “never did” responses across items was highest in LASI-DAD (median across items: 7.4%), followed by HRS-HCAP (1.3%), and was lowest in ELSA-HCAP (0%). Based on unadjusted regression analysis comparing item-level mean scores and the proportion of “never did” responses in HRS-HCAP and ELSA-HCAP, each percentage point higher of “never did” responses in HRS-HCAP was associated with a 0.016 (95% Confidence Interval [CI] 0.008-0.024) unit higher mean score on a given IQCODE item in ELSA-HCAP compared to HRS-HCAP, despite the fact that respondents were older on average in HRS-HCAP compared to ELSA-HCAP and therefore may be expected to have higher levels of impairment due to the strong association between impairment and age.

Parallel analysis revealed a unidimensional underlying trait in all three studies (Supplemental Materials 2). Factor loadings were highest across items in ELSA-HCAP, indicating stronger intercorrelations between items in this setting (Supplemental Materials 8). There were some differences between studies at the item level; for example, the item for remembering family, friends, and dates was less strongly related to other items in LASI-DAD (standardized loading: 0.72 95% CI 0.70-0.73) than in HRS-HCAP (0.86 95% CI 0.85-0.88) and ELSA-HCAP (0.81 95% CI 0.79-0.84). Reliability for the unidimensional scale was excellent in all three studies ($\omega=0.94$ in LASI-DAD, 0.94 in HRS-HCAP, and 0.96 in ELSA-HCAP).

Spline fits for the nonlinear association between cognition and the IQCODE were similar comparing HRS-HCAP and ELSA-HCAP, but notable differences were evident comparing LASI-DAD to the two other studies (Figure 1 Panel A). While the fit for LASI-DAD appeared largely linear across the distribution of cognitive functioning, there was evidence of nonlinearity in fits for HRS-HCAP and ELSA-HCAP, with evidence of a strong relationship between IQCODE score and cognition for cognitive scores under -0.5 SD units of cognition and almost no relationship above this threshold. Because harmonized cognitive scores were

standardized such that the mean was 0 in the HRS-HCAP study and because the distributions of harmonized cognitive scores are similar between HRS-HCAP and ELSA-HCAP, the observed -0.5 SD unit threshold was consistent when comparing plots using harmonized and internally scaled cognitive functioning.

Although the observed pattern in LASI-DAD was less dramatic than what was observed in HRS-HCAP and ELSA-HCAP, there was some evidence of a similar thresholding effect in LASI-DAD participants with some education but not LASI-DAD participants with no education (Figure 1 Panel B). At lower ends of cognitive functioning, the association between objective cognition and IQCODE score was stronger among those with no education; however, the inverse was true at the higher end of cognitive functioning. Based on visual inspection, this threshold was at approximately -1.5 SD units using harmonized cognitive functioning but was at -0.5 SD units using internally scaled harmonized functioning, as was the case in HRS-HCAP and ELSA-HCAP. Comparing all four groups using internally scaled cognitive factor scores, the thresholding effect observed in HRS-HCAP and ELSA-HCAP was less extreme but present among those with some education in LASI-DAD, but not among those with no education (Figure 1 Panel C).

Statistical assessment of observed patterns through the comparison of models for the association between objective internally scaled cognition and IQCODE score including a linear spline with a single knot at -0.5 cognitive SD units to simple linear models confirmed the visual assessment of flexible spline models (Figure 2). Though the improvement in model fit due to the addition of the linear spline term was significant across all four groups defined by study, and by education in LASI-DAD, differences in the estimated magnitudes of the two slope segments were larger for HRS-HCAP and ELSA-HCAP. Although all items had significantly improved fit with the addition of the spline term in HRS-HCAP and ELSA-

HCAP, this was true for 15 out of 16 items for individuals in LASI-DAD with some education and only 2 out of 16 items for individuals in LASI-DAD with no education.

We observed evidence of strong associations between informant characteristics and IQCODE score, which differed between the four groups considered, defined by study, and by education in LASI-DAD (Figure 3). Adjusting for respondent demographics, including age, and objective cognition, informants in younger generations reported higher IQCODE scores than informants in the same generation in HRS-HCAP (0.06 95% CI 0.03-0.10) and ELSA-HCAP (0.15 95% CI 0.08-0.23). This finding was likely driven by higher IQCODE scores from children of respondents than from spouses of respondents, particularly in ELSA-HCAP (difference of 0.15 (95% CI 0.07-0.23). Similar differences were not observed in the LASI-DAD sample. However, in the LASI-DAD sample, other informants (not spouses or younger generation family members) reported lower IQCODE scores than spouses (differences: -0.13 95% CI -0.23- -0.03 [some education], -0.10 95% CI -0.20-0.01 [no education]). In comparison, the difference was small and not statistically significant in HRS-HCAP and was imprecise in ELSA-HCAP due to the small number of informants in this category (7). Caregivers reported higher IQCODE scores than others in HRS-HCAP (difference: 0.11 95% CI 0.07-0.14) and ELSA-HCAP (difference: 0.06 95% CI -0.02-0.13), but the opposite pattern was found in the LASI-DAD education and no education groups (differences: -0.14 95% CI -0.19- -0.09 [some education], -0.09 95% CI -0.15- -0.03 [no education]). How many years the informant has known the participant had a small association with IQCODE score, but the association was statistically significant for individuals without education in LASI-DAD (difference: 0.03 95% CI 0.01-0.04). Contact frequency was not associated with IQCODE score across studies. Differences between studies for informant generation, caregiver status, and how long the informant has known the participant were statistically significant (Supplemental Materials 9).

4. Discussion

We found cross-national differences in the performance of the IQCODE as an informant-based measure of declines in everyday cognition, as assessed through comparisons with objective cognitive performance. Informant characteristics, including informant generation and caregiver status, were associated with IQCODE scores and associations persisted after adjusting for objective cognition. Associations varied cross-nationally, and differences in associations and the distribution of informant characteristics may help explain differences in the association between the IQCODE and objective cognitive functioning between countries. In general, IQCODE performance in the United States (HRS-HCAP) and England (ELSA-HCAP) was similar, but there were larger differences between these two settings and India (LASI-DAD), a lower-middle income country with larger cultural differences compared to the US and England.

Prior validation studies showing adequate performance of the IQCODE questionnaire in a variety of languages and cultural settings [41–45] align with our findings from exploratory factor analyses and regression models showing strong correlations between IQCODE score and objective cognitive functioning across settings. However, the primary goal of conducting harmonized studies using the HACP battery is not only to enable dementia research in each specific geographic setting, but also to further facilitate cross-national comparisons, which requires a higher threshold of comparability. In this study, when we directly compared associations between continuous IQCODE scores and continuous cognitive functioning, we uncovered patterns suggestive of differences in performance which may challenge direct comparisons. In India, the absence of a sharp change in the slope of the association between IQCODE score and objective cognitive function in combination with a weaker slope of the lower range of cognitive functioning may suggest that in this setting the IQCODE questionnaire is less sensitive to difficulties attributable to the lowest levels of cognition.

Additionally, observed patterns may be partially attributable to the IQCODE picking up on difficulties not directly attributable to cognitive functioning.

Our finding that differences in IQCODE performance were more apparent in comparisons with wider cultural differences (e.g. between India and the US versus England and the US) aligns with prior evidence suggesting that cultural differences, such as differences in gender norms or beliefs about personal control, can impact reporting on functional limitations and may affect informant reports [13,46]. One study using data from the Honolulu Asia Aging Study (HAAS) found that wives of participants were less likely to report memory problems if they had closer ties to traditional Japanese culture, which also suggests cultural factors likely play an important role in observed responses to informant questionnaires like the IQCODE [19].

In addition to differences between countries, we observed differences in the performance of the IQCODE between those with some versus no education in India. Those with some education and lower levels of cognitive functioning had a stronger association between IQCODE score and objective cognitive testing than those at higher levels of cognitive functioning. This pattern was similar to, but weaker than, what was observed in the US and England. In comparison, among those with no education, the observed association at low levels of cognition was even weaker and there was no difference between the association at higher and lower levels of cognition. In India, educational attainment is an important marker of socio-economic status, and is highly correlated with other forms of social stratification, such as caste [47]. Educational attainment is also an important marker and potential contributor to the demographic transition, and therefore, may divide the population into groups that are more or less similar to countries that have already undergone the demographic transition, including the US and England [48,49]. These differences may explain why observed findings from high-income settings seemed to generalize better to those with some

education than to those with no education in India and highlights the heterogeneity within the Indian context.

Prior research has largely found that informant characteristics affect informant reports, in agreement with our results [15–19,50,51]. However, there has been less consensus on which specific characteristics are most important, and the evidence on any specific attribute is mixed. For example, while multiple studies have found no evidence of differences in informant reports by informant relationship or generation [29,51,52], another study found that spouses and adult children both reported more impairments than other types of informant (sibling/other relative/friend) [17], and another study found that spouses reported more impairments compared to other types of informants only among those with normal cognition, but not in those with cognitive impairment [15]. One prior cross-national comparison found differences between the two settings examined: spouses reported more problems among African Americans in the US, whereas siblings reported more problems among Yoruba Nigerians [31]. Our results also illustrate cross-national differences and suggest that observed heterogeneity in the literature could be due to differences in specific samples or the cultural context across settings. This heterogeneity was clear from a simple descriptive characterization of informants across the studies; for example, 27.1% of informants were children-in-law in India, while this category did not exist in the US or England.

Observed differences raise important questions about appropriate methods for the analysis of data from informant reports in future cross-national research. Prediction equations or adjustments, as are commonly used to allow for appropriate comparison of biomarkers collected using different assays or analysis methods [53,54], may be one option to improve the comparability of data from different types of informants. Given observed differences in the associations between informant reports and IQCODE score, such adjustments would likely need to vary across settings. The development of prediction equations and adjustments

in biomarker data typically requires a validation sample for which data has been collected using both measurement methods (in this case, from multiple types of informants) [53,54]; in comparison, this study relied on regression modeling with a set of adjustment factors to estimate differences between individuals with different types of informants. Future efforts to develop prediction equations should consider the collection of data from multiple informants for the same individuals to enable the estimation of such adjustments. Additionally, assessments of which informant type should be considered most reliable would be needed to inform decisions on the appropriate implementation of potential adjustments. After adjustment for differences in the impact of informant characteristics across settings, we may observe smaller differences in IQCODE scores across settings. Refinement of the measurement of cognitive decline and everyday functioning through such adjustments to the IQCODE could have important implications for improving estimates of dementia prevalence, reducing measurement error in epidemiologic studies, and providing evidence to drive decision-making around policy and the development of interventions.

Study strengths include the use of large population-representative samples with harmonized information on cognitive functioning and similar administrations of informant questionnaires, as well as the flexible modeling of associations between objective cognitive functioning and informant reports and the assessment of a wide range of informant characteristics.

Limitations should also be considered. First, we noted differences in the administration of the ‘never did’ option between ELSA-HCAP and the other studies included, and our analysis suggested this may have impacted observed mean scores in ELSA-HCAP. To minimize potential biases, we used imputed data throughout analyses, which included imputations for informants who responded that participants ‘never did’ activities. Nevertheless, our analysis highlights the potential importance of seemingly small administration details, which may impact observed means without post-hoc adjustments or data processing steps. Second, there

were some differences in the interview mode between studies for informant interviews; in LASI-DAD and HRS-HCAP interviews were preferentially completed in person by trained interviewers, though some interviews were completed by telephone. In contrast, in ELSA-HCAP most informant interviews were done by self-completion questionnaire (81.5%), with the remainder conducted via telephone interviews. Third, while we assessed the performance of the IQCODE questionnaire through the estimation of the association between responses on the IQCODE and objective cognition, the IQCODE and objective cognitive testing seek to measure slightly different constructs. While the IQCODE questionnaire is focused on cognition, items on this questionnaire assess components of cognition that are more embedded in tasks focused on everyday functioning and the ability of participants to interact with their surrounding environment [6]. Additionally, the IQCODE focuses on changes in functioning compared to 10 years previous; in comparison our measure of objective cognitive functioning was assessed at a single time point. Although these discrepancies likely create an upper limit on the potential strength of observed associations, because of the tight links between these constructs, comparisons of the association strength and characteristics (non-linear nature) between studies still provide an important indication of the relative performance of the IQCODE questionnaire.

This study provides new evidence illustrating the importance of culture and context in the measurement of cognition and daily function using informant reports. We found that the IQCODE was less sensitive to impairments associated with the lowest levels of cognition in India than in the US and England. Furthermore, some informant characteristics were associated with informant reports after adjusting for respondent demographics and objective cognitive functioning, and the magnitude, and sometimes the direction, of associations differed between contexts. Differences in associations and in the distribution of informant types may contribute to observed cross-national differences in informant reports between

settings. Post-hoc adjustments of scores from informant report questionnaires may be possible and may improve the comparability of data. Future research should consider the use of validation samples with multiple informants to refine estimates and potentially calculate adjustments. Assessments of new cultural adaptations to ensure IQCODE comparability across diverse populations should also be considered.

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Figure Legends

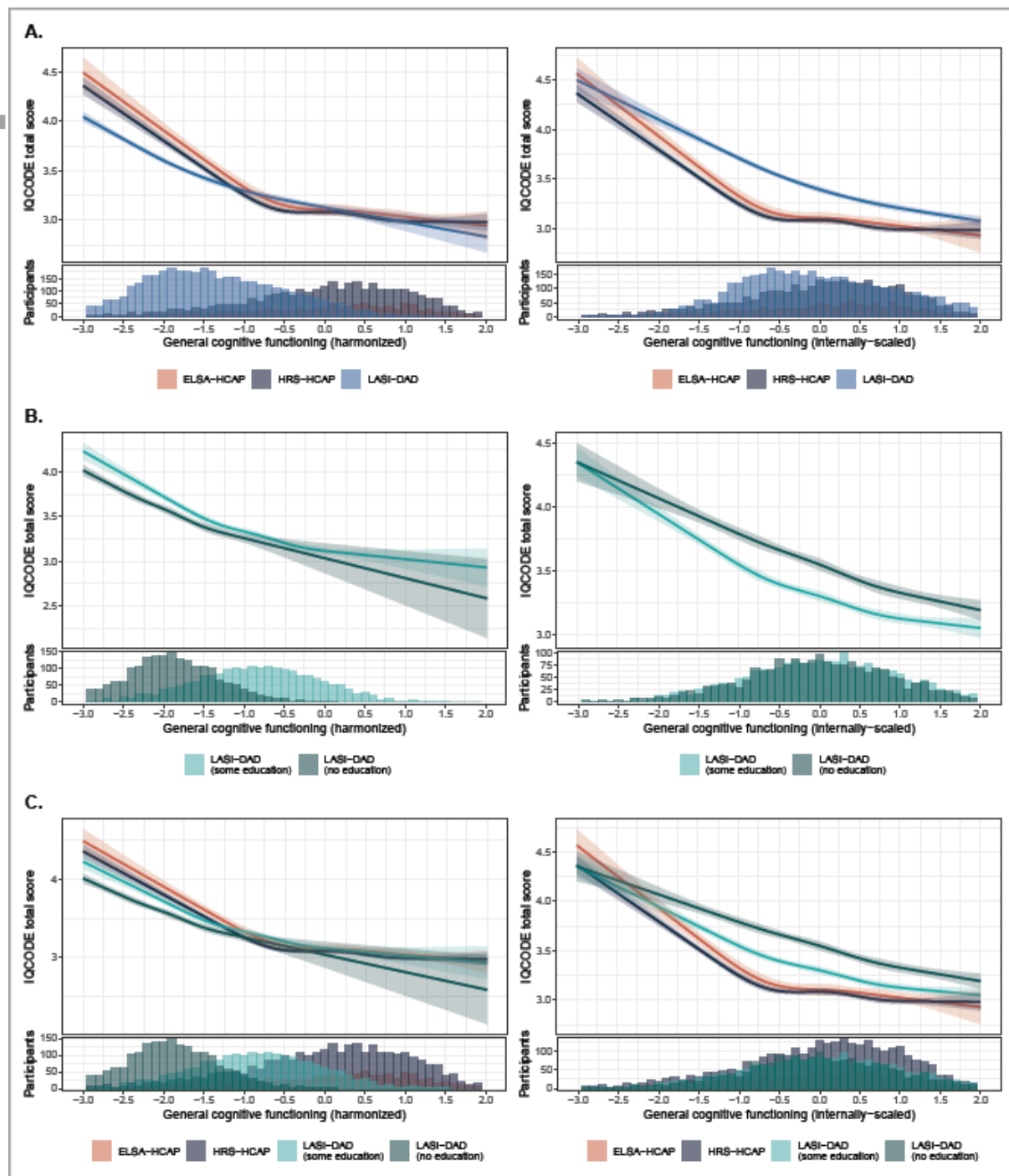


Figure 1. Non-linear associations between IQCODE score and harmonized as well as internally scaled cognitive functioning in the HRS-HCAP ($N = 3,183$), ELSA-HCAP ($N = 1,050$), and LASI-DAD ($N = 4,047$) studies, as well as in groups with some education ($N = 2,064$) and no education ($N = 1,983$). Histograms under the spline fits illustrate the distributions of cognitive functioning across the different study or subgroup categories for each comparison. Panel A shows all three studies, without education subgroups, Panel B shows the education subgroups in LASI-DAD, and Panel C shows all three studies, including the education subgroups in LASI-DAD.

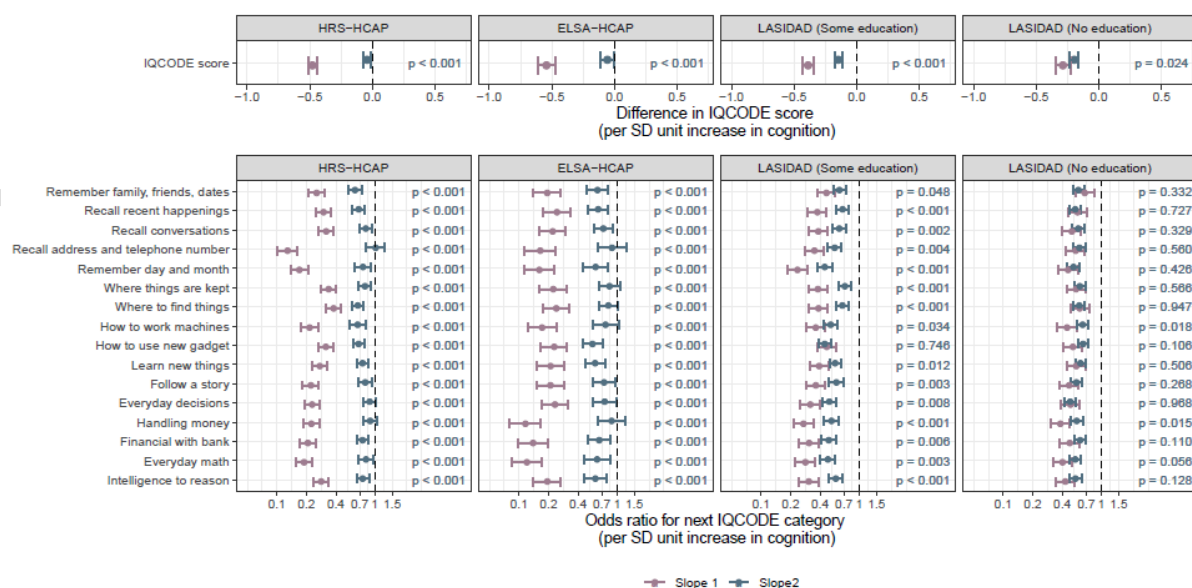


Figure 2. Slope coefficients for the association between cognitive functioning and IQCODE score for linear segments below and above a cut-point of -0.5 SD units in the HRS-HCAP (N = 3,183), ELSA-HCAP (N = 1,050), and LASI-DAD (N = 4,047) studies, with the LASI-DAD sample decomposed into groups with some education (N = 2,064) and no education (N = 1,983). Cognitive scores are internally scaled to each study or sub-group population. Results for the IQCODE score are from linear regression models while item-level results are from proportional odds models.

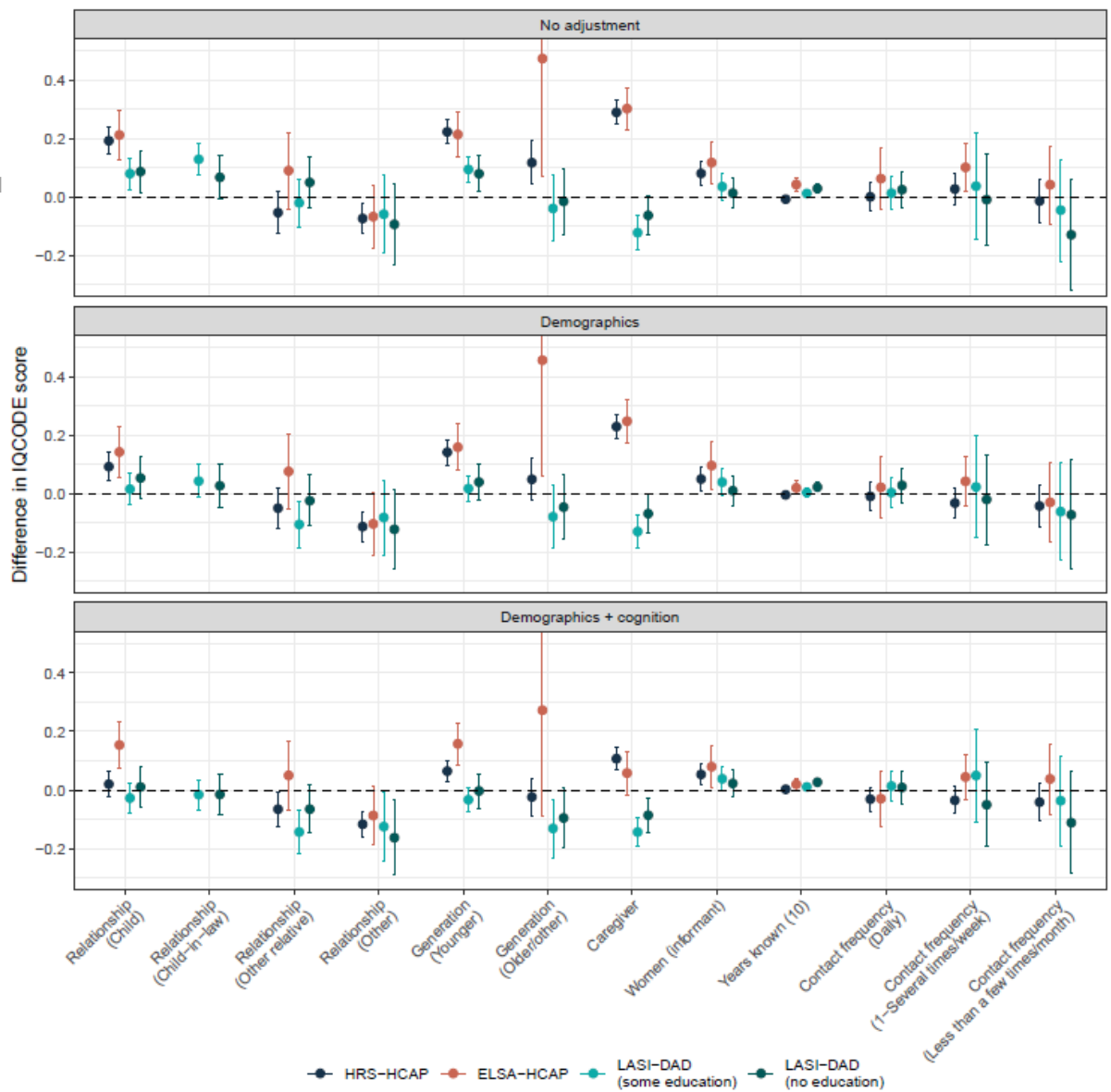


Figure 3. Associations between informant characteristics and IQCODE score in the HRS-HCAP (N = 3,183), ELSA-HCAP (N = 1,050), and LASI-DAD (N = 4,047) studies, with the LASI-DAD sample decomposed into groups with some education (N = 2,064) and no education (N = 1,983). Results are shown for three sets of multivariable linear regression models: 1) no adjustment, 2) adjustment for demographics (age, gender, education), and 3) adjusted for demographics and harmonized cognition. The reference groups are spouses (for relationship type), same generation (for generation), and lives with respondent (for contact frequency).

Table 1. Demographic characteristics of the respondents and informants in the HRS-HCAP (N = 3,183), ELSA-HCAP (N = 1,050), and LASI-DAD (N = 4,047) studies. Means and interquartile ranges are shown for continuous variables; percentages and numbers are shown for categorical or binary variables. Numbers in square brackets show the number of records with missing data.

Variable	HRS-HCAP	ELSA-HCAP	LASI-DAD
<i>Respondent characteristics</i>			
N	3183	1050	4047
Age	76.4 (70.0 - 81.4)	74.5 (68.0 - 80.0)	69.7 (64.0 - 74.0)
Female	59.5 (1894)	54.2 (569)	53.7 (2175)
Marital			
Married or partnered	58.0 (1846)	69.6 (731)	65.3 (2644)
Divorced, widowed, or other	40.8 (1300)	30.4 (319)	34.7 (1403)
Missing	0.1 (2)	0.0 (0)	0.0 (0)
Education (ISCED)			
No formal education	0.7 (21)	0.3 (3)	49.0 (1983)
Early childhood - lower secondary education	17.3 (552)	41.6 (437)	33.9 (1372)
Upper secondary	53.1 (1690)	25.7 (270)	12.4 (502)
Post-secondary	28.8 (918)	31.1 (327)	4.7 (190)
Missing	0.1 (2)	1.2 (13)	0.0 (0)
Education (Independent)			
Low	18.0 (573)	41.9 (440)	49.0 (1983)
Medium	53.1 (1690)	25.7 (270)	33.9 (1372)
High	28.8 (918)	31.1 (327)	17.1 (692)
Missing	0.1 (2)	1.2 (13)	0.0 (0)
<i>Informant characteristics</i>			
	64.7 (56.0 - 75.0)	66.1 (58.0 - 76.0)	44.3 (30.0 - 60.0)
Age	[1]	[18]	[11]
Female	67.4 (2146) [0]	64.6 (678) [2]	63.6 (2572) [11]
Relationship			
Spouse/partner	45.2 (1438)	56.4 (592)	29.8 (1206)
Child	27.0 (859)	21.5 (226)	28.0 (1134)
Child-in-law	0.0 (0)	0.0 (0)	27.1 (1098)
Other relative	8.3 (263)	7.1 (75)	11.5 (466)
Other	19.6 (623)	11.1 (117)	3.3 (132)
Missing	0.0 (0)	3.8 (40)	0.3 (11)
Generation			
Same generation	62.3 (1983)	70.4 (739)	32.0 (1294)
Younger	30.6 (973)	25.1 (264)	62.5 (2531)
Older/other	7.1 (227)	0.7 (7)	5.2 (211)
Missing	0.0 (0)	3.8 (40)	0.3 (11)
Frequency of contact			
Lives with respondent	25.3 (806)	53.4 (561)	75.5 (3057)
Daily	38.5 (1227)	13.1 (138)	20.2 (819)
1-Several times/week	24.0 (764)	24.3 (255)	2.0 (81)
Less than a few times/month	8.5 (269)	7.1 (75)	1.7 (67)
Missing	3.7 (117)	2.0 (21)	0.6 (23)
Caregiver	31.1 (991) [13]	29.4 (309) [19]	82.8 (3350) [12]
Years known respondent	29.5 (10.0 - 50.0) [20]	47.1 (40.0 - 57.0) [20]	32.0 (19.0 - 44.0) [20]

Table 2. Responses to individual IQCODE items by study for informants in the HRS-HCAP (N = 3,183), ELSA-HCAP (N = 1,050), and LASI-DAD (N = 4,047) studies. Values for never did and other missing show the percentage of records (and number of records) with that response.

Item	HRS-HCAP			ELSA-HCAP			LASI-DAD		
	<i>Mean</i>	<i>Never did</i>	<i>Other missing</i>	<i>Mean</i>	<i>Never did</i>	<i>Other missing</i>	<i>Mean</i>	<i>Never did</i>	<i>Other missing</i>
Remember family, friends, dates	3.2	0.3		3.2	0.0		3.4	1.0	
Recall recent happenings	5	(8)	0.1 (2)	3	(0)	1.0 (11)	6	(42)	0.6 (25)
Recall conversations	3.3	0.2		3.3	0.0		3.4	0.3	
Recall address and telephone number	2	(6)	0.1 (3)	2	(0)	0.8 (8)	3	(14)	0.8 (32)
Remember day and month	3.3	0.3		3.3	0.0		3.4		
Where things are kept	6	(9)	0.1 (2)	9	(0)	0.6 (6)	5	0.2 (7)	0.8 (34)
Where to find things	3.0	0.7		3.0	0.0		3.4	10.3	
How to work machines	7	(21)	0.4 (13)	5	(0)	1.1 (12)	2	(415)	0.8 (34)
How to use new gadget	3.1	0.4		3.1	0.0		3.3	2.7	
Learn new things	8	(13)	0.2 (6)	5	(0)	0.8 (8)	9	(111)	0.7 (30)
Follow a story	3.2	0.6		3.2	0.0		3.5	0.8	
Everyday decisions	8	(18)	0.4 (14)	1	(0)	1.0 (10)	1	(34)	0.7 (27)
Handling money	3.4	1.4		3.4	0.0		3.5	0.9	
Financial with bank	3	(46)	0.9 (30)	2	(0)	1.3 (14)	9	(37)	0.8 (31)
Everyday math	3.0	3.6		3.0	0.1		3.3	18.6	
Intelligence to reason	7	(113)	0.4 (12)	8	(1)	1.3 (14)	7	(751)	1.1 (45)
	3.1	6.5		3.2	0.1		3.4	28.9	
	8	(208)	0.8 (26)	8	(1)	2.3 (24)	5	(1170)	1.3 (52)
	3.1	2.4		3.2	0.2		3.5	12.8	
	5	(77)	0.4 (13)	8	(2)	2.7 (28)	2	(520)	1.2 (48)
	3.1	1.2		3.1	0.0		3.2	13.8	
	1	(39)	0.7 (23)	2	(0)	1.7 (18)	9	(559)	0.9 (37)
	3.1	1.4		3.1	0.0		3.3	6.6	
	3	(44)	0.2 (7)	7	(0)	1.7 (18)	9	(269)	0.8 (33)
	2.9	6.2		3.0	0.2		3.3	8.7	
	6	(197)	0.6 (20)	6	(2)	1.5 (16)	7	(352)	0.7 (30)
	2.9	9.1		3.1	0.3		3.3	18.8	
	7	(291)	0.9 (30)	1	(3)	1.7 (18)	9	(761)	0.8 (34)
	3.0	5.2		3.1	0.0		3.3	8.3	
	7	(165)	0.3 (10)	4	(0)	1.4 (15)	8	(336)	1.0 (39)
	3.0	0.6		3.1	0.0		3.3	1.8	
	9	(20)	0.2 (7)	4	(0)	1.1 (12)	5	(72)	0.9 (35)