

## Assessing medical mistrust in organ donation across countries using item response theory

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## Declarations

### Compliance with Ethical Standards

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Research involving human participants and/or animals – All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The protocol was approved by the Research Ethics Committees (RECs) in each site (RCSI Dublin REC1048bb; UK—Stirling University General University Ethics Panel [No. 188]; Malaysia, RCSI PU REC—PUIRBH0097; India—Kasturba Hospital Institutional Ethics Committee IEC 134/2017).

Informed consent – Informed consent was obtained from all individual participants included in the study.

Data, Materials and/or Code availability – The current article includes the complete raw dataset collected in the study including the participants' data set, syntax file and log files for analysis. Pending acceptance for publication, all of the data files will be automatically uploaded to the Figshare repository.

Authors’ contribution statements –

- 1) made substantial contributions to the conception or design of the work; or the acquisition, analysis, or interpretation of data; or the creation of new software used in the work: AG, REOC, SD, MM, KM, FD
- 2) drafted the work or revised it critically for important intellectual content: AG, FD

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1 **Assessing medical mistrust in organ donation across countries using item response theory**

2 **Abstract**

3 Although medical mistrust (MM) may be an impediment to public health interventions, no MM  
4 scale has been validated across countries and the assessment of MM has not been explored using  
5 item response theory, which allows generalization beyond the sampled data. We aimed to  
6 determine the dimensionality of a brief MM measure across four countries through Mokken  
7 analysis and Graded Response Modelling. Analysis of 1468 participants from UK (n=1179),  
8 Ireland (n=191), India (n=49) and Malaysia (n=49) demonstrated that MM items formed a  
9 hierarchical, unidimensional measure, which is very informative about high levels of MM.  
10 Possible item reduction and scoring changes were also demonstrated. This study demonstrates  
11 that this brief MM measure is suitable for international studies as it is unidimensional across  
12 countries, cross cultural, and shows that minor adjustments will not impact on the assessment of  
13 MM when using these items.

14 **Keywords**

15 medical mistrust; organ donation; Mokken analysis; Item response theory.

16

1 **Main text**

2 **INTRODUCTION**

3 Medical mistrust (MM) is a tendency to distrust medical systems and personnel believed to  
4 represent the dominant culture in a society. Medical “distrust” and “mistrust” are different terms,  
5 but sometimes are used interchangeably in literature – “distrust” is most correctly based on a  
6 specific experience or information, whereas, “mistrust” expresses a general sense of unease  
7 toward someone or something (Smirnoff et al., 2018). MM is an active response to direct or  
8 vicarious experiences of marginalization or poor experiences, including medical error (Williams  
9 and Mohammed, 2009). For example, having a higher mistrust, a person receiving a cancer  
10 diagnosis may doubt the doctor's advice and seek a second opinion(Guadagnolo et al., 2009), or  
11 a family member with high mistrust may be less likely to consent to organ donation when it is  
12 raised(Morgan, Harrison, et al., 2008), or a person with high mistrust may be less likely to seek  
13 medical attention when experiencing symptoms that they can't explain(Taber et al., 2015).

14 MM is often context specific and has significant negative public health implications, like lower  
15 adherence to cancer screening guidelines (Adams et al., 2017), lower adherence to antiretroviral  
16 medication among men with HIV (Galvan et al., 2017), poor patient-provider relationships  
17 (Saunders, 2017), engaging in risky behaviours (Hardin et al., 2018), conspiracy theories (Quinn  
18 et al., 2018), and lower use of vaccinations (Benkert et al., 2019; Larson et al., 2018), and even  
19 the recent resurgence of anti-vaccination movement in Western countries (Hussain et al., 2018;  
20 Opel et al., 2021).

21 [Practicing organ donation has proven to be lifesaving, but m](#)[Mistrust in the healthcare system is](#)  
22 [also associated with reduced intentions for organ donation \(Miller et al., 2019; Russell et al.,](#)  
23 [2012\). In the US alone, 64.02% of candidates failed to receive a transplant in 2020](#) (Detailed

1 Description of Data | [organdonor.gov](http://organdonor.gov), n.d.), [highlighting](#) ~~Indeed, anti-vaccination has been listed~~  
2 ~~as one of the top ten threats to global health (Aranda, 2019), highlighting~~ the importance of  
3 appropriate assessment of MM ~~internationally and across cultures. Mistrust in the healthcare~~  
4 ~~system is also associated with reduced intentions for organ donation (Miller et al., 2019; Russell~~  
5 ~~et al., 2012), and is the area of interest of this paper.~~

6 However, few studies have attempted an in-depth exploration of the assessment of MM.  
7 In a recent systematic review (Ozawa and Sripad, 2013), around 20% studies used measures with  
8 2-3 items or single item, such as “It is difficult for me to trust doctors and other health  
9 professionals” (Williamson and Bigman, 2018). Commonly-used, multi-item scale measures  
10 include: the 12-item Group-Based Medical Mistrust Scale (Thompson et al., 2004), which was  
11 developed to measure race-based medical mistrust; the 7-item Medical Mistrust Index (Sheppard  
12 et al., 2019), which assesses the association between mistrust and five measures of underuse of  
13 health services; and the 10-item Health Care System Distrust Scale (Rose et al., 2004).

14 Previous psychometric work has identified three subscales within the Group-based  
15 Medical Mistrust Scale: (1) Lack of Support from doctors and health care workers; (2)  
16 Discrimination and group disparities in health care; and (3) Suspicion of doctors, health care  
17 workers, and medicine (Shelton et al., 2010). There are important differences among these scales  
18 with regards to the object of mistrust (e.g., system, individual physician), referent specificity  
19 (e.g., group), health topic, and sample population in which they were developed, with around  
20 88% being US-based. In addition, most were not used internationally nor validated across  
21 countries (Williamson and Bigman, 2018) though research shows that mistrust varies by  
22 ethnicity and within countries (Henrich et al., 2012). To establish psychometric validity, the  
23 Medical Mistrust Index and the Health Care System Distrust Scale relied on Classical Test

1 Theory (CTT) parameters (DeVellis, 2006), reporting Cronbach’s alpha reliability for scale  
2 performance, without first adopting the recommended factor analytic techniques to establish  
3 dimensionality (Crutzen and Peters, 2017). In addition, while the Group-Based Medical Mistrust  
4 Scale used exploratory factor analysis (Gaskin and Happell, 2014), and structural equation  
5 modelling (SEM) (Tarka, 2018) in its development process, these methods can be criticised for  
6 being sample-dependent (Hays et al., 2000) – so it is unknown if the findings generalise across  
7 countries and cultures. To overcome limitations such as these, a psychometric technique  
8 increasingly used is the Item Response Theory (IRT) approach – a family of mathematical  
9 models that attempt to explain the relationship between latent traits (unobservable characteristic  
10 or attribute) and their manifestations (i.e. observed outcomes, responses or performance) (Hays  
11 et al., 2000). IRT has several advantages over CTT, including that rather than looking at the  
12 reliability of the test as a whole, IRT looks at each item individually. IRT suggests that a  
13 respondent's latent [ability-trait](#) is independent from the item or question on a test (Jabrayilov et  
14 al., 2016). It produces person-parameter invariance (i.e. test scores are not dependent on the  
15 particular choice of test items) when the model fit is present, while test information functions  
16 provide the amount of information or “measurement precision” captured by the test on the scale  
17 measuring the construct of interest (Petrillo et al., 2015). IRT can, therefore, provide information  
18 for scale development and scoring that is not sample-dependent, is generalisable across cultures,  
19 countries, and contexts that is not readily available via CTT methods, and arguably robust  
20 psychometric scale evaluation is incomplete without such assessments. Individuals might have  
21 different opinions about MM, but IRT methodology ensures that the results do not vary with  
22 population characteristics (Hambleton, 2009). Rasch analysis is a special case of IRT, which  
23 requires the data to fit the model in order to generate invariant, interval-level measures of items



1 and persons, but is prescriptive by nature and assumes that each item has the same discrimination  
2 level (Boone et al., 2014). Rasch analysis was used to determine the validity of an instrument for  
3 measuring patients' trust in medical technology (Montague, 2010), but to date, no studies have  
4 assessed MM using more flexible and powerful IRT analyses.

5 To summarise, there is limited psychometric evaluation of MM scales, including a lack of  
6 exploration across countries and cultures which limits comparability and generalisability, and no  
7 study to date has investigated MM using IRT. In addition, with challenges such as the current  
8 global threat of the anti-vaccination movement and the need for organs for transplant, robust  
9 measures are urgently needed to better understand potential contributors to MM. We therefore  
10 aimed to fill this gap in the literature, by analysing MM items that were previously developed by  
11 Morgan, Stephenson, Harrison, Afifi, & Long (2008) and used in several studies of MM in the  
12 context of attitudes to organ donation (Doherty et al., 2017; Doyle et al., 2019; O'Carroll et al.,  
13 2016). Specifically, we applied nonparametric and parametric IRT to investigate the  
14 dimensionality of MM across four countries. We explored whether the MM latent trait is  
15 adequately assessed by the MM items developed by Morgan ~~et al.~~ [and et al.](#) and investigated the  
16 MM items and the scoring of these items, with a view to determining whether item reduction or  
17 scoring changes would impact on MM assessment.

## 18 **METHODS**

### 19 Participants and procedure

20 We used combined data from four randomised experiments on attitudes to organ donation, for  
21 secondary analysis of medical mistrust (Doherty et al., 2017; Doyle et al., 2019; O'Carroll et al.,  
22 2016). In brief, these studies ascertained the effects of affective attitudinal items on intention and

1 registration for organ donation. The sample consisted of participating adults recruited from the  
2 community, shopping centres, libraries, campuses, and online from 4 countries — United  
3 Kingdom (313 in-person, 616 online, 864 postal), Ireland (586), Malaysia (148) and India (175).  
4 All procedures performed in studies involving human participants were in accordance with the  
5 ethical standards of the institutional and/or national research committee and with the 1964  
6 Helsinki Declaration and its later amendments or comparable ethical standards. The protocol was  
7 approved by the Research Ethics Committees (RECs) in each site (RCSI Dublin REC1048bb;  
8 UK—Stirling University General University Ethics Panel [No. 188]; Malaysia, RCSI PU REC—  
9 PUIRBH0097; India—Kasturba Hospital Institutional Ethics Committee IEC 134/2017).

#### 10 Measures

11 As part of the above studies, participants completed 4 items measuring medical mistrust, adapted  
12 from Morgan et al. (2008). Items were rated on a seven-point scale (1 =strongly disagree; 7 =  
13 strongly agree) and evidenced good reliability ( $\alpha = .84$ ). Items included were as follows: MM1:  
14 ‘Hospitals sometimes prescribe medication as a way of experimenting on people without their  
15 knowledge or consent’; MM2: ‘If I sign an organ donor card, doctors might take my organs  
16 before I’m actually dead’; MM3‘Sometimes, medical procedures are done on people without  
17 their consent’; and MM4: ‘If I sign an organ donor card, doctors might not try so hard to save my  
18 life’.

#### 19 Statistics

20 We used non-parametric and parametric Item Response Theory (IRT) analysis. Mokken scaling  
21 is a non-parametric, iterative scale-building technique, especially suitable for skewed and  
22 polytomous items (van Schuur, 2003), which is ideal for establishing unidimensionality (Dima,

1 2018). Mokken scaling is a stochastic extension of Guttman scales (Rothman, 2004), which are  
2 unidimensional, ordinal scales of binary items along a continuum. A positive answer to one item  
3 of a certain ‘difficulty’ indicates that all other items of lesser difficulty have also been answered  
4 positively. Mokken scaling facilitates analyses of polytomous items with probabilistic ordering.  
5 Mokken scaling has several advantages over the typically adopted factor analytic techniques: it is  
6 suitable for binary or highly skewed polytomous items, it can be used in relatively small samples  
7 ( $n = 300-400$ ), and it systematically orders items (Watson et al., 2012). Loevinger’s H-  
8 coefficient is used for interpretation. According to (Sijtsma and Molenaar, 2011),  $0.3 \geq H < 0.4$ ,  
9  $0.4 \geq H < 0.5$ , and  $H \geq 0.5$  indicate weak, moderate, and strong scales, respectively. Higher H  
10 values indicate higher item discrimination power, and thus more confidence in the ordering of  
11 respondents. Although this project is a secondary analysis, so sample size was not considered a  
12 priori, tThe total sample size far exceeds the required estimates to establish scalability (Watson  
13 et al., 2018), and therefore was used to assess the unidimensionality assumption of parametric  
14 IRT employed in the next steps of validation. Mokken scaling is an established method for IRT  
15 analysis with wide application in the social sciences. It provides psychometricians with an  
16 additional tool in the development of questionnaires and in the study of individuals and their  
17 responses to latent traits (Watson et al., 2012).

18 Model fit for parametric IRT (see appendix) was considered using the likelihood ratio test of  
19 Akaike and Bayesian information criteria (Swaminathan et al., 2006), which indicated that the  
20 unconstrained Graded Response Model (GRM) was most appropriate. The IRT GRM approach  
21 constructs a nonlinear relationship between latent traits and item responses (Samejima, 2016).  
22 The GRM is especially suited to ordinal response items, as it does not assume that each item  
23 discriminates equivalently along with the latent trait (unlike Rash models) (Pallant and Tennant,

1 2007). The GRM characterizes item functioning via two types of item parameters for each item:  
2 the item discrimination and item difficulty parameters. We report test-level and item-level  
3 parameters. The **test information function**, a function of the true score  $\theta$  (in this case,  
4 MM), is a measure of the amount of information provided by the item responses about MM. The  
5 **test characteristic curve** is the functional relation between the true score and the [ability-trait](#)  
6 scale. **Item Characteristic Curve** shows the behaviour of individual items on a scale relative to  
7 the latent trait. Steeper curves indicate higher discrimination. **Item information function** is a  
8 measure of how much statistical information a test item provides. Item information is a function  
9 of MM. **Category characteristic curves** were used for the polytomous response categories of  
10 MM items. Each CCC depicts the probability of endorsing a single response category (Fayers,  
11 2004; Ockey, 2013; Reckase, 2009).

12 Mokken scale analysis was conducted using a procedure written for Stata (StataCorp,  
13 2019), by Jean-Benoit Hardouin (Hardouin, 2004), GRM IRT was conducted in Stata SE 15  
14 (StataCorp, 2017). Other analyses were done in RStudio Version 1.3.959 (The R Foundation,  
15 2018), using the procedure described by van der (Ark, 2007).

16 Data Sharing Statement: The current article includes the complete raw dataset collected  
17 in the study including the participants' data set, syntax file and log files for analysis. Pending  
18 acceptance for publication, all of the data files will be automatically uploaded to the Figshare  
19 repository.

## 20 **RESULTS**

### 21 Sample profile

1 The baseline profile of the larger samples has been described in detail elsewhere (Doherty et al.,  
2 2017; Doyle et al., 2019; O’Carroll et al., 2016). The mean age for the total sample (n=2702) was  
3 42.3 years (SD = 16.9), with 58% being women. The number of subjects who completed all MM  
4 items was 1468 (54% response rate; [due to the differing exposures across the experimental](#)  
5 [groups](#)) (mean age = 44 years, 60% were women). The details of responses as obtained from 4  
6 countries were: United Kingdom (107 in-person [mean age = 46 years, 42% were women], 211  
7 online [mean age = 51 years, 51% were women], 861 postal [mean age = 45 years, 66% were  
8 women]), Ireland (191; (mean age = 37 years, 48% were women), Malaysia (49; mean age = 19  
9 years, 55% were women) and India (49; mean age = 24 years, 81% were women).

#### 10 Mokken scaling results

11 The overall scale H score of 0.51 (for individual items = 0.47 - 0.54) indicates a ‘strong’ scale,  
12 showing that all items in this scale tapped a hierarchical, unidimensional variable of medical  
13 mistrust measure (Table 1). We also found unidimensionality for each country (Ireland: H=.51,  
14 UK (in person): H=.53 UK (online): H=.61, UK (postal): H=.54, Malaysia: H=.56, India: H=.48  
15 (3 items). It should be noted that one item was dropped from the analysis for India [as because the](#)  
16 [item was not selected by the Mokken scaling procedure as it did not discriminate along the latent](#)  
17 [trait; it did not appear to discriminate along the MM trait](#): ‘If I sign an organ donor card, doctors  
18 might not try so hard to save my life’.

#### 19 Graded Response Model results

#### 20 Test level parameters

21 The Test Information Function for the overall assessment of the MM latent trait is shown in  
22 Figure 1.1. Most information is provided at mid-higher levels of the latent trait, but very little

1 about lower levels of MM. As shown in Figure 1.2, the Test Characteristic Curve, there was a  
2 substantial spread of scores evident, as here we expect 95% of people to score between 5 to 23.

### 3 Item level parameters

4 The Item Information Curves (Figure 2.1) show how well and precisely each item measures the  
5 latent trait at various levels of the attribute. Items 1 and 3 provide more information at low levels  
6 of the trait (MM) and across a broader range of scores, while items 2 and 4, which specifically  
7 refer to organ donation, provide more information overall. As shown in the Item Characteristic  
8 Curve (Figure 2.2), items 2 and 4, which concern mistrust in doctors, show significantly higher  
9 levels of discrimination (95% CIs do not overlap), with the discrimination indices available in  
10 Table 2. Also clearly indicated is that the discrimination parameters for scores of 3 and 4 within  
11 individual items lie very close together, suggesting that, if necessary, these could be combined to  
12 form an overall 1-6 scoring range without losing much information. (Also see correlation matrix  
13 in appendix 2).

14 Category characteristic curves for MM items (Figure 3) represents the probability that a  
15 respondent will select a response option, given the respondent's latent trait (MM) value. It  
16 displays the probability of a person endorsing a particular response category based on their level  
17 of support for the item and the intensity or difficulty of the item. The range of latent trait (MM)  
18 value is plotted along the x-axis. The probability of selecting each category is plotted along the  
19 y-axis. An item is better at discriminating between individuals when the curves are peaked and  
20 dispersed across all levels of the latent trait. For example, an item with high discrimination  
21 would have 7 peaks dispersed from low levels of the latent trait to high levels of the latent trait.  
22 Here, there is an overall well-spaced response category across MM1-4, with MM4 having well  
23 dispersed peak signifying better discrimination between individual scorings.

## 1 **DISCUSSION**

2 To our knowledge, this is the first study to apply flexible IRT analyses to the measurement of  
3 MM, which highlights a robust measure that is generalisable across cultures and countries that is  
4 preferable to scales developed in single-country settings. Although the items here relate to organ  
5 donation, and the test has implications for the organ donation context, the test is measuring  
6 something more than just attitudes towards organ donation, but towards medical professionals  
7 and medical treatment in general. We used Mokken scaling to demonstrate that the 4 MM items  
8 developed by Morgan et al. (Morgan, Stephenson, et al., 2008) formed a unidimensional scale  
9 across 4 countries. The parametric IRT GRM approach demonstrated that the measure assesses  
10 medium to higher levels of MM very well, but unsurprisingly provides less information at lower  
11 levels of MM. Furthermore, it was clear that items relating to doctors are significantly more  
12 highly discriminating MM than other items, which is a novel addition to the literature.

13 Our results support the original findings of Morgan et al., who used structural equation  
14 modelling on data from 4426 participants at six different geographic locations in the United  
15 States, and showed that MM was a unidimensional scale and one of the most influential  
16 noncognitive beliefs of an individual having a direct influence on organ donor card status  
17 (Morgan, Stephenson, et al., 2008). In addition, IRT analysis has enhanced the validity of the  
18 scale across 4 different countries and cultures and has highlighted unique aspects of overall scale  
19 and item level parameters. Incidentally, the scale with 4 items did not show validity for India,  
20 and one item ('If I sign an organ donor card, doctors might not try so hard to save my life') had  
21 to be dropped. This is probably due to lower sample size in this population, which does not meet  
22 the criteria for obtaining a valid overall scale H-value (Watson et al., 2012). It could also be due  
23 to high level of awareness of organ donation protocols in the same geographical region as has

1 been shown in a study by (Mithra et al., 2013), potentially introducing nonresponse bias (Sax et  
2 al., 2003), or due to high proportion of women responders as Data from the National Organ  
3 Transplantation and Tissue Organization show that majority of living donations in India are from  
4 women and majority of organ recipients are men (National Organ & Tissue Transplant  
5 Organization, n.d.)(Sahay, 2019). Further research is needed to explore this aspect in other parts  
6 of India as has been acknowledged elsewhere (Vincent et al., 2019).

7         The results of our IRT GRM-based analyses provide a closer look at the properties of the  
8 MM scale. The test and item information functions represent the precision with which a  
9 respondent's MM value can be estimated. Higher information indicates greater precision. The  
10 Test Information Function revealed that the measure provides most information (estimation  
11 precision) at moderate/high levels of MM, but little information at low levels. Similarly, the Item  
12 Information Function curves showed that items 1 and 3 provided more information at low levels  
13 of MM, while items 2 and 4 provide more information at higher levels. These results suggest  
14 that, if it were necessary to shorten the scale (for example when competing with other measures  
15 in large population-based surveys), researchers could base their decision on whether  
16 discrimination or latent trait coverage were considered more advantageous, along with, of  
17 course, the content validity of the items. This has been done elsewhere, for example when  
18 measuring quality of life in breast cancer survivors (Xia et al., 2019). However, the final decision  
19 about the exclusion of items should be based on substantive reasons and not merely through the  
20 acceptance of quantitative values as candidate threshold levels, including theory and content  
21 validity. This is especially important as we may lose information about part of the measured  
22 domain that might be useful or important otherwise (Edelen and Reeve, 2007).



1           The properties of the scale are depicted through the Category characteristic curves, which  
2 shows overall well-spaced response categories across MM1-4. As shown in the item  
3 characteristic curves was that the discrimination parameters for scores of 3 and 4 lie close  
4 together, suggesting that these could be combined to form an overall 1-6 scoring range, without  
5 losing precision as has been shown elsewhere (Chen et al., 2009; Edelen and Reeve, 2007).  
6 However, caution should be used when making such decisions, as the trade-off for a reduced  
7 number of response options may lead to a decline in scale precision, particularly for respondents  
8 at extremes of the latent trait (Yang and Kao, 2014). Item reduction is a pragmatic choice in most  
9 cases and should be individualized to the study as has been explained elsewhere (Kolva et al.,  
10 2017).

11           In our findings, items which concerned mistrust in doctors showed significantly higher  
12 levels of discrimination than items which referred to more systemic aspects, such as hospitals  
13 and procedures. This is in contrast to other research, which shows that while distrust in the health  
14 care system is relatively high (20% - 80% of respondents reporting distrust for each item on the  
15 Health Care System Distrust scale) (Rose et al., 2004), there is in contrast lower mistrust in one's  
16 own primary care physician (only 10% to 20% of respondents endorsing mistrust). This may be  
17 due to the wording of the items – the questions in our study concerned doctors in general, not  
18 specifically participants own doctors – future research could investigate the impact of such  
19 wording changes on this MM measure.

20           The MM measure provides a substantial amount of information about high levels  
21 mistrust, but little information around lower levels of the MM trait. We should not assume that  
22 low levels of MM correlates directly with higher levels of trust – these factors may be  
23 multidimensional, rather than unidimensional, as has been elucidated elsewhere (Goold, 2002;

1 Pellowski et al., 2017; Sullivan, 2020). To explore trust, it may be necessary to employ another  
2 measure, perhaps also including reference to one's own doctors rather than physicians in general,  
3 as outlined above. Trust is an important component of healthcare, and is elucidated as a set of  
4 expectations that the healthcare provider will do the best for the patient and has different  
5 meanings attached to it (Ozawa and Sripad, 2013). Thus, conducting cognitive interviews that  
6 focus on the wording or sense of these items may provide insight into respondents'  
7 interpretations and responses. Future research could also explore newly written items to  
8 determine if they indicate discrimination at the lower levels of the MM trait. Also, of interest  
9 would be conducting interviews in local languages in non-English speaking countries (LoCurto  
10 and Berg, 2016), and potential use of this scale for predicting participation in any future  
11 (COVID-19) vaccination programmes (Palamenghi et al., 2020).

12 *What does this study add?*

13 This is the first study to use Mokken scaling and IRT GRM in exploring properties of MM.  
14 Across countries, MM was shown to be unidimensional, with higher discrimination and broader  
15 cover of the latent trait differentially demonstrated among individual items. It seems that MM for  
16 doctors is more discriminating factor than for systemic aspects on organ donation. The two  
17 general items (1 and 3) form a unidimensional scale with the two-organ donation specific items  
18 (2 and 4). Therefore, even though the latter items are specific to organ donation, the scale could  
19 be used in different contexts

20 *Limitations and Strengths*

21 This study was conducted in the context of organ donation (Doherty et al., 2017; Doyle et al.,  
22 2019; O'Carroll et al., 2016) using the IRT parameters, so that it should be generalisable beyond

1 the sample in question (DeMars, 2011). Studies used brief questionnaire rather than interviews, a  
2 combination might provide more information as has been suggested elsewhere (Feveile et al.,  
3 2007). The inclusion criteria for the original studies were broad and the participants were  
4 sampled from the general population, increasing generalisability. While we are limited by a lack  
5 of data on ethnicity and small sample sizes from India and Malaysia, which limit sub-analyses  
6 (Şahin and Anıl, 2017), the overall sample size is adequate for the approaches taken and results  
7 should be generalisable beyond the samples obtained (Gregoire and Hambleton, 2009; Watson et  
8 al., 2018). In the included studies, it was seen that items regarding doctors are more highly  
9 discriminating in contrast to other studies and this needs to be understood in depth. Future  
10 research should concentrate on comprehensive multidimensional MM scales with bigger  
11 samples, and discrimination of MM between personalized and systemic aspects of healthcare  
12 system, for example the recent anti-vaccination movement (Hussain et al., 2018).

### 13 **CONCLUSIONS**

14 Four MM items formed a highly discriminating unidimensional scale across countries and  
15 measurement methods. An IRT GRM model showed that the measure captured moderate-high  
16 levels of MM better than lower levels of MM, and that there was significantly higher item  
17 discrimination for items concerning doctors, rather than systemic items. This MM measure  
18 should have excellent generalisability across settings.

19

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17

1 **FIGURES AND TABLES**

2 **Table 1: Mokken scaling results for total sample**

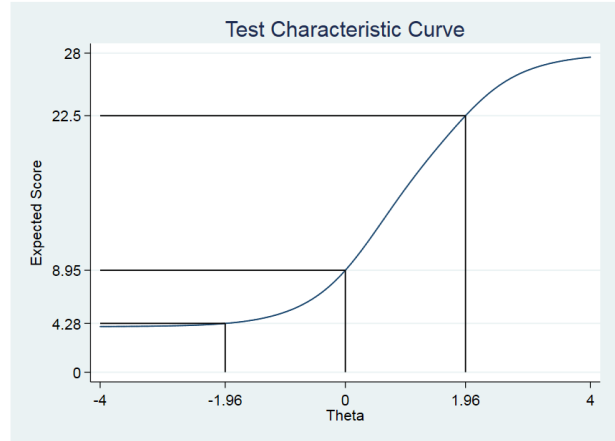
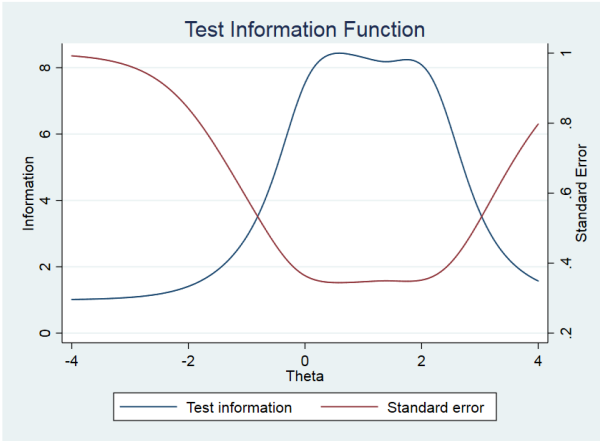
Item	N	Mean score	Observed Guttman errors	Expected Guttman Errors	Loevinger H-coefficient	z-statistic	p	Number of non-significant H
mm1	1460	2.79	6889	12929.44	0.46719	29.2225	<.001	0
mm3	1460	2.95	6302	13297.85	0.52609	32.9586	<.001	0
mm2	1460	2.28	6037	12704.04	0.52480	32.5848	<.001	0
mm4	1460	2.44	6102	13281.47	0.54056	34.0639	<.001	0
Scale	1460		12665	26106.41	0.51487	45.5618	<.001	-

3 **Table 2: Item discrimination scores**

Items	Discrimination	95% CI
MM1 = ‘Hospitals sometimes prescribe medication as a way of experimenting on people without their knowledge of consent’	1.49	1.32-1.67
MM2 = ‘If I sign an organ donor card, doctors might take my organs before I’m actually dead’	2.78	2.44-3.11
MM3 = ‘Sometimes, medical procedures are done on people without their consent’	1.94	1.73-2.15
MM4 = ‘If I sign an organ donor card, doctors might not try so hard to save my life’	3.12	2.71-3.53

1

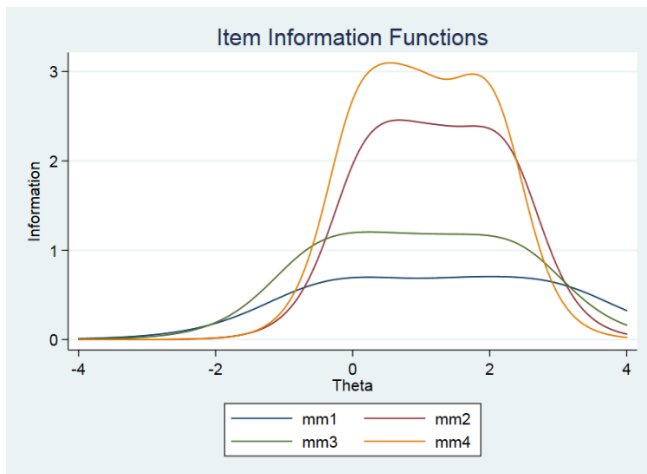
2 **Figure 1: Test level information**



1.1 **Test information function**

**Figure 1.2: Test characteristic curve**

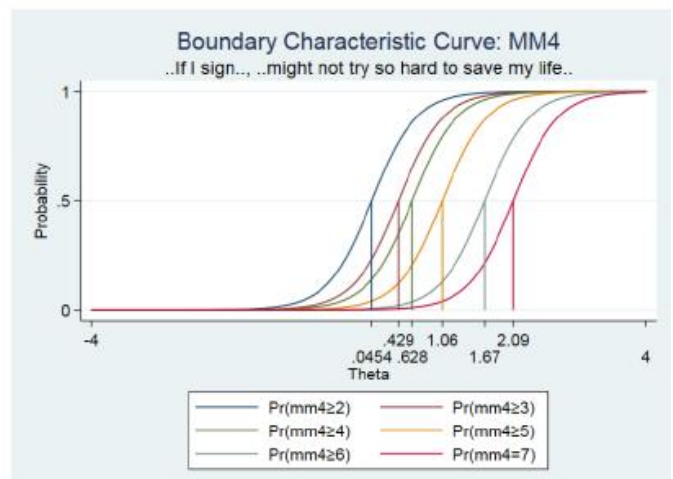
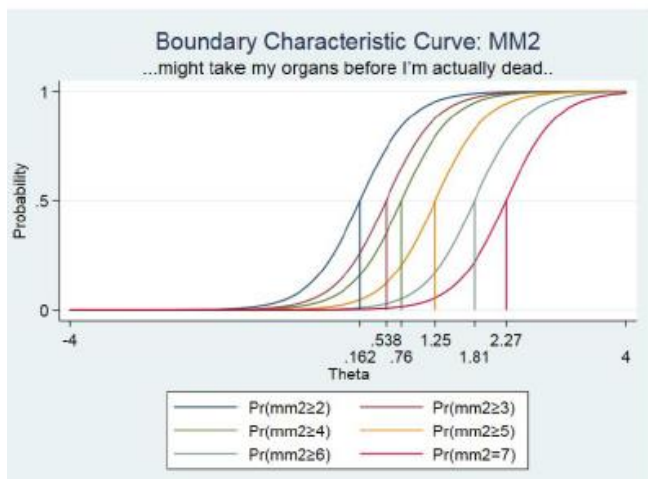
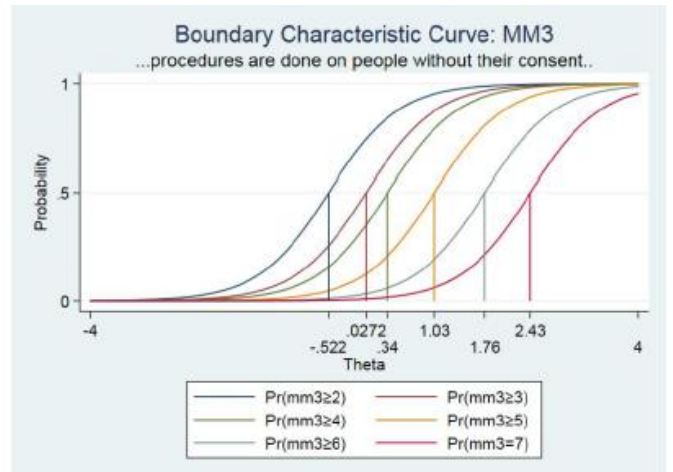
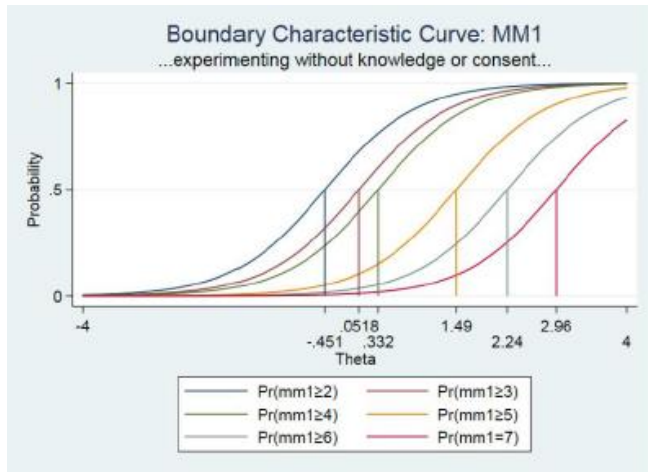
3 **Figure 2: Item level information**



4

5 **2.1 Item Information Curves**

6



1

2 **Figure 2.2: Item Characteristic Curve for each of the 4 items**

3

4

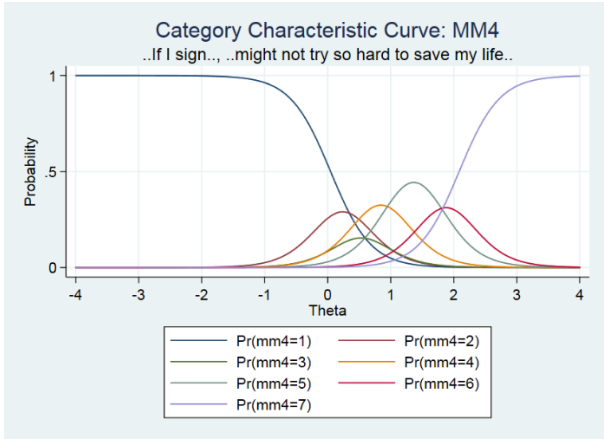
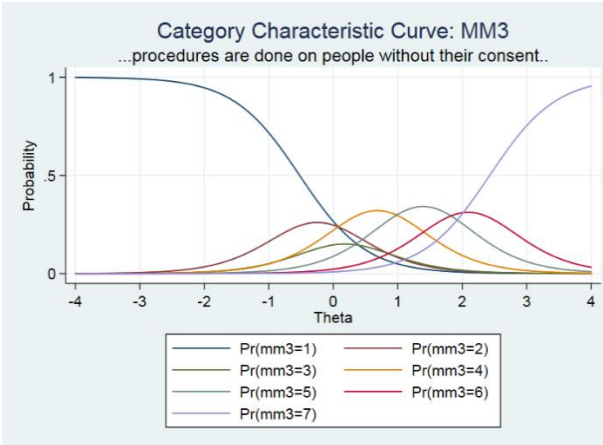
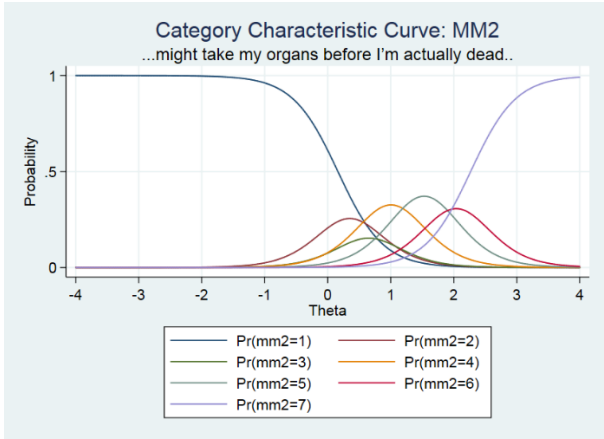
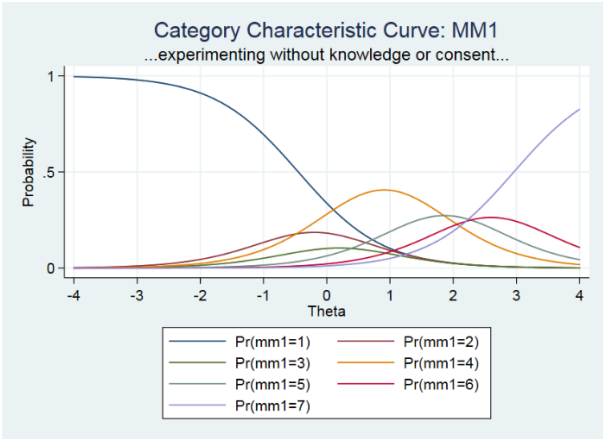
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8





1 **Figure 3. Category characteristic curves (CCCs) for each of the 4 items**

2

1 **APPENDIX**

2 1. The model fit statistics (Akaike information criterion (AIC) /Bayesian information criteria  
3 (BIC)) for IRT models were as follows (the lowest scores indicate the best fit):

4 Nominal response model 16945.98, 17200.21

5 Partial credit model 17095.25,17227.66

6 Rating scale model 17194.33,17247.29

7 Graded response model 16857.49,17005.79

8 2. The graded response model can be summarized by the equation

9  $P(X_{ij} = x_{ij} | \theta_i) = P^{*x_{ij}}(\theta_i) - P^{*x_{ij}+1}(\theta_i)$

$$P_{x_{ij}}^{*}(\theta_i) = P(X_{ij} \geq x_{ij} | \theta_i) = \frac{e^{Da_j(\theta_i - b_{x_{ij}})}}{1 + e^{Da_j(\theta_i - b_{x_{ij}})}}$$

10 Where:

- 11 •  $\theta$  represents the latent ability or trait, and its actual level in the test subject.
- 12 •  $x_{ij}$  represents the grade given.
- 13 •  $b_{jx}$  is a constant specific to the test item; the location parameter, or category boundary for  
14 score  $x$ ; the point on the ability scale where  $p = 0.5$
- 15 •  $a_{jx}$  is another constant specific to the test item, the discrimination parameter, and is  
16 constant over response categories for a given item.
- 17 •  $D$  is a scale factor

18

1      2. Correlation matrix of medical mistrust items

	mm1	mm2	mm3	mm4
mm1	1.0000000			
mm2	0.3698131	1.0000000		
mm3	0.5303012	0.4728881	1.0000000	
mm4	0.4179939	0.6377098	0.4982345	1.0000000

2