Rehabilitation needs and activity limitations of adults with a visual impairment entering a low vision rehabilitation service in England

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Abstract

Purpose

To evaluate outcome measures of the Participation and Activity Inventory (PAI) in a sample of adults with acquired visual impairment entering vision rehabilitation. Both Priority Scores, indicating level of rehabilitative need, and Person Measures indicating goal difficulty were considered.

Methods

Participants were newly registered adults with visual impairment within Leicestershire, UK. The importance and difficulty of 48 goals of the PAI were assessed, as were demographic factors, clinical visual function (visual acuity, contrast sensitivity, reading function) and psychosocial function (adjustment to visual loss, depression, anxiety and fear of falling). Priority scores were calculated as the product of importance and difficulty of each goal. All questionnaires were Rasch analysed, and person and item measures of perceived difficulty with goals derived.

Results

60 people (mean age ±S.D. = 75.8±13.8 years) took part. PAI goals with greatest rehabilitative need were reading (6.82±2.91), mobility outdoors (6.55±3.92), mobility indoors within an unfamiliar environment (5.52±3.93) and writing (5.27±3.02). Greater rehabilitative need was associated with younger age (β=-0.46, p<0.001), and with higher depressive symptomatology (β=0.35, p<0.01; model R^2 34%). Goals with greatest difficulty were mending clothing (-1.95±0.35 logits) and hobbies and crafts (-1.32±0.23 logits). Greater difficulty was associated with higher depressive symptomatology (β=0.39, p<0.001), lower visual acuity (β=0.42, p<0.001) and lower adjustment of visual loss (β=0.31, p<0.01; model R^2 53%).

Conclusions

Key rehabilitation needs for adults at entry to services require both optical and non-optical interventions. As rehabilitative need was not associated with the level of visual impairment, eyecare professionals should not wait until the end of medical treatment before referral for support. Similarly, rehabilitative need was associated with younger age, indicating the importance to refer younger people with sight loss at an early stage. The use of structured assessment such as the PAI ensures goals that have an impact upon quality of life are specifically identified. Depression screening on entry to rehabilitation is relevant as it predicts both perceived difficulty and rehabilitative need.

Key words: Activities of daily living, visual impairment, low vision, rehabilitation, Rasch analysis,

1 Introduction

2 The practical implications that acquired vision loss have upon the performance of daily activities will vary
3 between individuals. Furthermore, the disabling effect resulting from the inability to read, or the loss of
4 independent mobility following the withdrawal of a driving licence, may lead to additional emotional
5 consequences. Therefore, being able to assess the impact of vision loss and understand the key factors
6 that may influence rehabilitation needs for each individual are fundamental at entry to vision
7 rehabilitation services. (1–4)

8 It is well understood that the number of individuals with visual impartment will rise as a consequence of
9 demographic ageing, (5,6) increasing the pressure upon service providers to deliver timely and effective
10 rehabilitation services. The Care Act 2014 now requires that all local authorities (LA) support the
11 emotional well-being and personal independence of people in need of assistance and support to reduce
12 the long-term burden on health and social care. (7) Historically, the delivery of rehabilitation services to
13 adults with sight loss in the UK has been described as fragmented (8) which subsequently led to a call for
14 a multidisciplinary approach to service delivery. (9–11) The response to change has been slow, and
15 although there has been a shift towards multidisciplinary service provision, there is no standard model of
16 delivery. (12) A national survey of LAs and voluntary (not-for-profit) organisations providing vision
17 rehabilitation services commissioned by the Thomas Pocklington Trust, reviewed 87 providers across
18 England (57% response rate). (13) Over a 2-year period between 2012 and 2014, the survey found that
19 61% of services were delivered by the LA and a further 28% from the voluntary sector.

20 Although the importance of rehabilitation interventions has been highlighted, there is little evidence on
21 the priority needs of people with a visual impairment entering rehabilitation services in England that
22 could assist in the planning of an effective, patient-centred approach to service delivery. Empowering
23 patients to be actively involved in the management of their own health and care is a move towards a
24 person-centred National Health Service. (14) In the context of visual impairment services, rehabilitation
25 aims to minimise the disabling effects of sight loss and improve quality of life. Arguably, these are aspects
26 that only people with a visual impairment themselves can assess. In recent years the development and
27 use of patient-reported outcome measures (PROMs) has expanded to include the assessment of vision-
28 related activity limitations. (15) Despite this, PROMs are not routinely used by service providers in the
29 UK despite evidence to suggest that more personalised commissioning of support could potentially
30 enhance clinical care and reduce costs. (16)

31 In comparison, multidisciplinary service providers in the Netherlands are using PROMs routinely as a
32 means of identifying personalised rehabilitation needs at service intake. The Participation and Activity
33 Inventory (PAI), (17) formerly known as the Dutch ICF Activity Inventory, (18,19) is a validated
34 instrument used to investigate the priority rehabilitation needs of adults with a visual impairment in a
35 systematic way. The PAI builds upon the hierarchal goals and task structure of the Activity Inventory
36 (AI) (20) and combines it within the nine Activity and Participation domains of the World Health
37 Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF), (21)

together with an additional domain of 'Emotional Health.' By using a systematic approach, the PAI has been shown to more comprehensively identify the needs of people with visual impairment by preventing personal goals from being overlooked. (22) This study compared two methods of assessment of priority needs, semi-structured and structured, and found that only 22% of the rehabilitation needs identified by the PAI were present in the 'usual' semi-structured intake records. Consequently, the PAI is now used by many Multidisciplinary Rehabilitation Centres across the Netherlands to set individual rehabilitation needs and to evaluate rehabilitation outcomes.

The PAI was developed and validated using Classical Test Theory. (23) To determine self-reported priority rehabilitation needs, Likert scales are used to create ordinal priority scores for individual goals of activities of daily living and social participation as a product of importance and difficulty of goals. The original conceptual framework of the AI is based upon the assumption that goals with both high importance and high difficulty together indicate a higher rehabilitative need.(20) However, the use of Likert scale categories assumes that all goals are of equal difficulty and contribute the same amount to the measurement of the underlying construct. (24,25) The PAI has subsequently been further validated using Rasch analysis. (26,27) The Rasch model converts raw ordinal scores into an interval scale and creates person measure and item measure estimates for the underlying construct. (28) A person measure expresses the individual's perceived difficulty across all of the goals of the PAI, whereas an item measure is a measure of the overall difficulty of each item or goal.

The purpose of this study was to evaluate the use of the PAI in a sample of adults with an acquired visual impairment entering vision rehabilitation in England; to compare both the Priority Scores (PAI-PS) calculated from the raw ordinal score data indicating participants' priority rehabilitation needs and the Rasch Person Measures (PAI-PM) measuring participants' difficulty level with goals or activities of daily living and social participation. This enables comment on both the priority rehabilitation needs, and those activities found to be the most difficult facing people with a visual impairment in order to guide service commissioning decisions.

Methods

Recruitment of study population

Participants with acquired visual impairment were recruited at the point of referral to Vista, which is the leading provider of low vision and rehabilitation services in Leicestershire and Rutland and one of the largest voluntary agencies for people with visual impairment in the UK. An automatic referral to Vista follows formal registration for inclusion on the UK's visual impairment register using the Certificate of Vision Impairment (CVI). (29) There was no restriction to participation due to the underlying cause of visual impairment and no restriction due to level of vision. All participants were over 18 years of age; however, those who were unable to complete the assessments in English or who were found to be cognitively impaired using the Six-item Brief Cognitive Screener (30) were excluded from the study. Only those participants who were new to visual impairment rehabilitation services were approached to

74   participate in this study. Those who had previous CVI registration or who had received rehabilitation

75   services interventions while residing within a different NHS Trust were excluded.

76   Participants were seen either at Vista's low vision clinic based in Leicester or within the participant's own

77   home. All study interviews and clinical assessments were performed face to face on the same day by the

78   one examiner (JM), an experienced optometrist. The study received ethical approval from Anglia Ruskin

79   University Faculty of Science and Technology Research Ethics Committee and was conducted in

80   compliance with the General Optical Council's Standards of Practice for Optometrists and Dispensing

81   Opticians (31) and the Declaration of Helsinki. (32) All participants gave informed consent after the

82   details and implications of the study were fully discussed.

83   Procedures

84   Demographic characteristics were determined as outlined in Table 1. Participants' cause of sight loss was

85   self-reported, and categorised according to the WHO's International Classification of Disease groupings as

86   found on the CVI document. (29,33) To assess general health, participants were asked whether or not

87   they were being currently treated for any other co-morbidities from a pre-structured list of thirteen

88   medical conditions. (34) An additional option of 'other' gave an opportunity to self-report any condition

89   not represented on the list.

90   High contrast distance visual acuity was recorded binocularly with a letter by letter scoring protocol

91   using an externally illuminated Bailey-Lovie distance acuity chart with the participant wearing any

92   current habitual correction. Participants were encouraged to guess and measurements terminated when

93   four or more mistakes were made on a line. (35) Participants who were unable to record a measurable

94   acuity (minimum 1.60logMAR) and who still had either hand motion or light perception were assigned an

95   acuity of 3.00logMAR. (27,36) There were no participants with no light perception. Additional lighting

96   was provided to ensure that chart illumination was even and within the recommended range of 80-320

97   cd/m^2.(37)

98   Contrast sensitivity was recorded binocularly using a Pelli-Robson Contrast Sensitivity Chart (38)

99   presented at 1m. No compensation for the 1m working distance was used as this has been shown to have

100   no significant influence on results. (39) Contrast sensitivity was scored by-letter giving credit of 0.05 log

101   CS for each individual letter read correctly. (40)

102   Near visual function was assessed with MNREAD Acuity Charts (41) used at 40cm (or 20cm if necessary)

103   with appropriate correction and an audio recording was created while the participant read down the

104   chart and used for later analysis. The Reading Accessibility Index (ACC) (42,43) was subsequently

105   determined to represent overall reading function. The ACC is calculated as the ratio of the mean reading

106   speed of the largest 10 print sizes on the MNREAD chart (1.3-0.4 logMAR), to the average reading speed

107   in young adults with normal vision (200wpm). (44)

A number of PROMs were administered to assess participants' psychosocial function. Adjustment to vision loss was assessed with the Acceptance and Self-Worth Adjustment Scale (AS-WAS) (45) which evaluates aspects of adjustment to visual impairment associated with self-esteem, locus of control, self-efficacy and acceptance. 19 items are assessed on a 4-category Likert Scale. Anxiety and depressive symptoms were evaluated using the Hospital Anxiety and Depression Scale (HADS). (46) The instrument presents two 7-item alternating subscales of anxiety and depression (HADS-A and HADS-D) assessed on a 4-category Likert scale. Ordinal scores across each subscale range from 0-21 with categorical grouping by score (0-7=Normal, 8-10 borderline abnormal and 11-21=abnormal). (47) Fear of falling was assessed with the Short Falls Efficacy Scale-International (Short FES-I). (48) The instrument presents 7-items assessed on a 4-category Likert scale.

The outcome measure for the study was the PAI. Participants were asked to rate the importance of the PAI's 48 goals on a 4-category Likert scale from 0-3 (not important or not applicable, slightly, moderately or very important). (23) If a goal was considered important (score ≥1) then participants were asked to consider the difficulty of that goal on a 5-category Likert scale from 0 to 4 (not, slightly, moderately, very difficult or impossible) with any aids used where relevant (such as a low vision device for reading), but without assistance from anyone else.

Analysis

PAI priority scores were calculated as the product of the importance and difficulty for each goal (minimum 0, maximum 12). Priority scores for both individual participants (PAI-PS) and individual goals were computed.

Rasch analysis was undertaken using a single Andrich rating scale model (49) using Winsteps (version 4.0.1; winsteps.com) to create person and item measures from the difficulty scores of PAI goals, and also for the responses to the other Likert-scale instruments (AS-WAS, HADS, Short FES-I). Person and item measures are described in terms of logits (or log odds units), which represent the likelihood of a person having the ability to achieve an item (or an item being achievable for a person). The average logit value for both persons and items was set to 0 for each set of analyses on each instrument. For each instrument, a higher person measure indicates that the individual perceives that they have greater difficulty with the items. A higher item measure indicates that an individual perceives the item as easier to achieve.

Where categories were underutilised or disordered, they were repaired by collapsing adjacent response categories until rescaling produced utilisation of all categories in an ordered structure. (50) Infit and Outfit meansquare (MNSQ) values lower than 2.0 were considered acceptable, (51) given that the purpose of this study was to create person and item measures reflecting difficulty levels across a wide range of rehabilitation needs and levels of difficulty, (52) and only items with MNSQ>2.0 have the potential to damage the integrity of the scale. MNSQ values >2 were removed iteratively, with the most misfitting removed first and the analysis repeated until all item fits fell below 2.0.

143 Principal components analysis (PCA) assesses the extent to which an instrument measures a single latent

144 trait or ability, or its unidimensionality. Reasonable overall unidimensionality is indicated where at least

145 60% of the variance is explained by the primary measure. (53) Also, if the unexplained variance within

146 the first contrast found within the residuals is less than two items (an eigenvalue of <2.0) or is

147 significantly lower than the raw variance explained by the items in the principal Rasch measure, then

148 unidimensionality is also indicated.

149 A person separation value of >2.0 and reliability of >0.8 was considered to indicate an ability to reliably

150 discriminate between participants, and an item separation of >3.0 and reliability of >0.9 to indicate that

151 items are reliably ordered in terms of difficulty (28,50). Ideal targeting was considered to exist when the

152 mean of person measures is within ±1.0 logits of the mean of item measures (25).

153 Non-parametric tests were used to establish the existence of any significant relationships between each

154 predictor variable and the two outcome measures of the PAI (PAI-PS, PAI-PM). Mann-Whitney *U* tests

155 were used in the analysis of dichotomous predictor variables and Kruskal-Wallis tests in the analysis of

156 categorical data. Two-tailed Spearman's rho bivariate analysis was used in comparison with continuous

157 predictor variables, including the PROM person measures, with a p-value of <0.05 considered significant.

158 Despite the multiple comparisons made, a Bonferroni correction was not used since the purpose was to

159 identify parameters of potential interest for inclusion in multiple regression analysis.

160 To investigate the significant unique variance in perceived difficulty of activities of daily living and social

161 participation (PAI-PM) and priority rehabilitation needs (PAI-PS) explained by significant predictor

162 variables, regression models using a forward stepwise method were used. To determine if any individual

163 cases were influencing the model, a maximum Mahalanobis distance was determined to be 11.07

164 (p<0.05) and a maximum leverage value as 0.167, with a Cook's distance of >1 suggesting a case was

165 exerting influence on the regression model. Both multiple regressions presented had one potential

166 outlier on this basis. However, in both cases standardised DFBetas of <2 confirmed that deleting the

167 possible outlier would have no significant influence on the analysis. Intercorrelations among the

168 independent variables were considered acceptable (r <0.8), and variation inflation factor values of <1.5

169 suggest an absence of bias from multicollinearity within the model. A Durbin-Watson statistic was close

170 to 2 supporting independence of the residuals. Homoscedasticity with normal distribution was

171 confirmed by inspecting normal probability P-P plots of the standardised residuals.

Results

173 Sixty participants (22 male, 38 female) took part in the study, with a mean age of 75.8 years (range 30-

174 97) (Table 1). 97% were white British, 80% were retired, 53% lived with someone and 47% lived alone.

175 32% had a previous history of anxiety or depression, and there was a mean of 2.6 comorbidities (range 0-

176 8). The primary self-reported cause of vision loss was macular degeneration (50%) followed by

177 glaucoma (12%), diabetic retinopathy (5%), hereditary retinal disorder (5%).

178   The Reading Accessibility Index (ACC) was established for 55 participants; two participants were unable

179   to read aloud following brain injury associated with their visual impairment, and a further 3 were found

180   to have corrupt audio files. Contrast sensitivity measure was established for 59 participants. It was not

181   possible to record one participant; due to ultra-low visual acuity, the participant was unable view the

182   chart.

Rasch analysis

184   The principal psychometric properties of the PAI are shown in Table 2. Category functions of the PAI

185   were not initially ordered, so categories 1 (slightly difficult) and 2 (moderately difficult) were collapsed

186   together. One item was removed (Goal 610 – Caring for a Grandchild; applicable to 11 participants

187   (18%)), with infit 2.36 and outfit 5.14. Final Rasch analysis produced ordered category thresholds with

188   acceptable person separation (3.16), person reliability (0.91) and targeting (0.79). Item separation (2.47)

189   and item reliability (0.86) were less than ideal. PCA of the residuals demonstrated that the instrument

190   showed moderate unidimensionality with 46% variance explained by the primary measure. However,

191   the raw variance explained by the items in the principal Rasch analysis (22%) was 4-5 times greater than

192   the unexplained variance in the first contrast (5%; 3.9 eigenunits).

193   Table 2 also shows the psychometric properties of all other instruments following Rasch analysis. No

194   further category amendments were made, and two poorly fitting items were removed from the HADS-D

195   (D2, "I can laugh and see the funny side of things," and D3, 2"I feel cheerful"). Sub-optimal parameters are

196   indicated in italics. Although person separation and reliability indices were less than ideal for the HADS-

197   D and Short FES-I, item separation and reliability were good. Person measures were computed for each

198   instrument and examined in further bivariate analysis with the outcome measures of the PAI. However,

199   for the HADS-A, both person and item statistics were poor, suggesting that it may not be appropriate to

200   use Rasch parameters derived from this PROM. Bivariate analyses were therefore conducted both using

201   Rasch person measures, and also using categorical HADS-A responses (normal, borderline or abnormal).

202   No differences in outcome were found between either measures of the HADS-A; therefore person

203   measure results are presented below for consistency with other PROMs.

Priority rehabilitation needs

205   Priority scores for each of the 48 goals of the PAI are presented in Table 3. The goals with the highest

206   priority need for rehabilitation were reading (item 101, 6.82±2.91), mobility out of doors (item 403,

207   6.55±3.92), mobility indoors within an unfamiliar environment (item 402, 5.52±3.93), and writing (item

208   102, 5.27±3.02). Priority scores were also computed for each participant to establish individual self-

209   reported rehabilitation need over all 48 goals of the PAI, with a mean priority score of 2.61±1.28 (Table

210   1).

211

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Bivariate analyses showed that higher priority scores, (indicating greater levels of rehabilitative need), were significantly related to younger age (r=-0.48, p<0.001), higher levels of depressive symptoms (r=0.31, p=0.02), poorer adjustment to visual loss (r=0.31, p=0.02), and higher levels of anxiety (r=0.28, p=0.03). No other predictor variables (demographic, visual function or psychosocial) were significantly related to rehabilitation need.

The significant predictor variables outlined above were entered into a stepwise multiple regression analysis to determine which independently explained significant amounts of variance in priority scores (Table 4a). Priority rehabilitation needs as described by the overall priority scores were most influenced by age, accounting for 22% of the variance (R^2) in the data with younger age reflecting greater need for rehabilitation; increasing severity of depressive symptoms was an additional significant factor associated with greater need for rehabilitation (R^2 change 12%), which together accounted for 34% of the variance.

Perceived difficulties with activities of daily living and social participation

Table 5 summarises the item measure characteristics of the PAI. Item difficulties for individual PAI goals ranged from -1.95 logits (item 604, mend clothing; most difficult) to 2.12 logits (item 501, getting dressed; least difficult). Other goals considered amongst the most difficult at entry into rehabilitation included undertaking hobbies (-1.32 logits), driving (-1.31 logits), home maintenance (DIY) (-1.25 logits). The relevance or applicability of each PAI goal is indicated by the percentage of non-zero responses for each item measure. A graphical representation of item relevance and difficulty is shown in Figure 1. The item found to be most difficult (604, mend clothing; -1.95 logits) was relevant to only 23% of the sample; however, the item found to be easiest (501, being able to get dressed without assistance; 2.12 logits) was relevant to 93% of the sample. As with priority scores, the goals found to be both difficult and highly relevant to the sample were 101 (reading, -0.96 logits, 100% relevance) and 403 (mobility out of doors; -0.97 logits, 98% relevance).

Person measures across the 47 retained PAI difficulty scores were computed for each participant to establish self-reported measures of difficulties of daily living (PAI-PM). Bivariate analyses showed that higher levels of difficulty with activities of daily living and social participation, as indicated by higher PAI person measures, were associated with younger age (r=-0.27, p=0.04), a lower level of distance acuity (r=0.33, p=0.01), a lower level of reading accessibility (r=-0.42, p<0.001), higher levels of depressive symptoms (r=0.50, p<0.001), poorer adjustment to visual loss (r=0.44, p<0.001) and a higher level of fear of falling (r=0.35, p=0.007).

Significant predictor variables were entered into a stepwise multiple regression analysis to determine which independently explained significant amounts of variance in person measures (Table 4b). Difficulty with goals as described by the overall person measures was most influenced by symptoms of depression, accounting for 29% of the variance (R^2) in the data with increasing severity of depressive symptoms reflecting higher goal difficulty. Additional significant factors associated with greater goal difficulty were

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248 lower level of distance VA (R^2 change 16%), and higher level of difficulty with self-reported adjustment to
249 visual loss (R^2 change 7%). Together these factors accounted for 52% of the variance.

Comparison of Priority Scores and Person Measures

251 The Rasch person and item measures focus purely on the level of difficulty expressed by people who
252 found each goal of at least some importance, and does not take the relevance of each goal into account as
253 the priority scores do. A comparison of priority scores and person measures is shown in Figure 2. In
254 general, those with higher priority scores (greater rehabilitative need) have higher person measures
255 (expressing greater difficulty) (r=0.80, p<0.001). There were two participants that contradicted this
256 general relationship, where perceived goal difficulty is high but expressed rehabilitative need is low.
257 Both participants died within a year of data collection, suggesting that poor health could have overridden
258 the importance of visual rehabilitative interventions for these individuals. Whilst the relationship
259 between priority scores and item difficulty is not perfect (r<1), indicating that the inclusion of importance
260 in priority scores has some influence beyond simple difficulty, no significant relationship was found
261 between the PAI importance scores and the PAI person measures (r= -0.05, p=0.72)."

262

Discussion

264 This study evaluates two parameters related to low vision rehabilitation in a sample of people with a
265 visual impairment entering low vision rehabilitation services in England. These are the perceived
266 rehabilitative need in terms of priority scores (PAI-PS), and the perceived difficulty with goals of
267 activities of daily living and social participation in terms of Rasch parameters (PAI-PM and item
268 difficulties). While these measures are related (Figure 2), different patient needs are highlighted by
269 consideration of each parameter, as outlined below.

270 The demographic of the sample was considered representative of those living within the counties of
271 Leicestershire and Rutland. Across the region of Leicester (city), Leicestershire and Rutland,
272 approximately 550 new registrations occur per year. This study's sample of 97% white British is
273 representative of Leicestershire County (54) where the majority of our participants resided. The range of
274 conditions causing primary loss of vision within the sample was also considered representative of adults
275 registered in the UK with sight loss, comparing well with most current published statistics of visual
276 impairment in the UK. (6)

277 Priority scores for PAI goals (Table 3) found key areas for rehabilitation intervention are reading,
278 mobility, and writing, suggesting that early assessment for both the provision of low vision devices and
279 training in orientation and mobility techniques are indicated at the point of referral for rehabilitation
280 interventions following acquired vision loss. That reading, writing and mobility are key rehabilitation
281 needs is supported by studies with older participants in the UK and Netherlands. (18,23,55,56) However,
282 where Dutch rehabilitation services are delivered on these three specific goals, (57) writing skills as a
283 specific rehabilitation need has perhaps been less well recognised as a priority need in the UK, with no

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284   specific reference to interventions concentrating on writing as an individual goal mentioned in recent

285   reviews of UK service provision. (3,13,58,59) The goal of writing is frequently coupled together with

286   reading in the literature however while handwriting is a near vision task, the ability of a person with

287   visual impairment to use a pen includes the need for additional strategies including the use of alternative

288   devices or technology to accomplish this task successfully. Therefore, separate attention to this goal is

289   implied.

290   A review of rehabilitation provision in the UK also found that only a small minority of people actually

291   receive a comprehensive programme of orientation and mobility training, with less emphasis on

292   providing assistance to older people and higher priority given to younger people of working age. (13,60)

293   Results of this study support more focus upon mobility and orientation training with adults and older

294   people with visual impairment entering low vision rehabilitation services.

295   Regression analysis of the study sample demonstrated that the most significant predictor in the need for

296   rehabilitation interventions was age, with younger age reflecting greater need. In this sample, goals

297   relating to employment or education scored low in priority, reflecting the fact that most of this study's

298   population were retired. In comparison, a study using the PAI to determine priority rehabilitation needs

299   in a younger age group (age 18-25; n=392) demonstrated priority rehabilitation needs in areas relating to

300   independent domestic life, education, employment and independent travel, supporting previous evidence

301   that these are major themes in the transition to adult life.(17) Furthermore, younger people have been

302   shown to demonstrate a higher number of needs including more intensive rehabilitation programmes

303   relating to study and employment that are not as relevant to older people.   One limitation of the present

304   study therefore, is that it can only be considered as generalisable to an older population.

305   Following regression analysis, the number of participant co-morbidities was not found to be a significant

306   factor influencing rehabilitation need; in addition, there was also no significant relationship found in our

307   sample between participant age and number of co-morbidities (p=0.17). Therefore, poor overall health

308   did not appear to contribute to the decline in rehabilitation need with age in this sample. The inevitable

309   lifestyle changes and a gradual reduction in daily activity patterns with older people (61,62) may better

310   explain lower rehabilitation needs with advancing age.

311   In the Netherlands, the two goals of the PAI that address the emotional health domain were also

312   identified as high priority needs. However, these goals (001, 002) were not included in the 'top 15'

313   priority goals in the present sample (Table 3), despite a third of the UK sample self-reporting previous

314   history of either anxiety or depression. While there is a growing body of evidence to support a high

315   prevalence of depression in individuals with a visual impairment, (63,64) there appears little evidence on

316   how patients report symptoms of depression or anxiety to healthcare professionals. In a London based

317   study, older people were found to regard depression as a ''sign of weakness''; cultural variations were

318   also thought to influence the help-seeking behaviour of elders from minority ethnic groups. (65) While

319   such evidence suggests an overall underreporting of emotional health, there is no current evidence to

320   offer a reason as to why there was a difference in attitude towards reporting depression and anxiety

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321 between the British and the Dutch samples. Our UK sample may not be as comfortable with reporting
322 depressive symptoms with eyecare professionals or may not recognise that they are suffering from
323 depressive symptoms compared to the Dutch sample. That a higher level of depressive symptoms is a key
324 factor in regression models for both greater rehabilitations needs and higher levels of difficulty with PAI
325 goals, suggests that addressing depression early in rehabilitation assessment may reduce both the need
326 and level of input of service delivery for that individual. This supports well-established evidence that
327 depression is a significant factor associated with self-reported activity limitations. (66–70) And although
328 levels of anxiety were not found to be a significant factor in our regression models, we conclude that this
329 may be a reflection on the poor psychometric performance of the HADS-A subscale. The HADS-A was
330 initially chosen as it is one of the most widely used screening instruments in psychosocial research and
331 practice. However, the HADS was developed as a screening measure for psychological distress with the
332 aim of identifying clinically significant severe depression or anxiety. The poor targeting value (1.43)
333 indicates that this group had lower levels of anxiety than the test was designed for. Therefore, the HADS
334 may be less useful for the identification of patients with moderate to mild levels of distress that existed
335 within our study population. Further investigation with a more robust measure is indicated to determine
336 whether anxiety is a significant contributory factor.

337 The need for rehabilitation was not found to be associated with the level of vision loss suggesting that
338 those with even mild or early vision loss may benefit from referral for support and intervention. This
339 supports conclusions from a previous qualitative study investigating the time delay in referring people
340 with a visual impairment for UK visual rehabilitation services. The study found ophthalmologists did not
341 consider referring their patients for social care needs until all possible clinical interventions had been
342 exhausted. (71) The same study also reported that 43% of the participants (n=20) interviewed, stated
343 that they would have liked to have been offered support sooner, suggesting that individuals felt they
344 would benefit from earlier interventions. One of the limitations of the present study's sample was that 59
345 of the 60 participants were newly registered as either SI or SSI. A wider study of rehabilitation needs to
346 include those individuals living with early or lower levels of sight loss may give a more accurate
347 representation of rehabilitation needs across all groups of individuals living with sight loss.

348 When specifically considering the difficulty of PAI goals at entry into rehabilitation through the use of
349 Person Measures, the goals of highest difficulty included mending clothing, undertaking hobbies, driving
350 and DIY (Table 5). While these goals were considered most difficult, they were not relevant to all
351 individuals within the study sample. For example, the goal of mending clothes was relevant to only 23%
352 (n=14) of participants whereas the goal of reading was relevant to 100% (n=60) of the sample. Goals
353 with low relevance may reflect either that they are not common activities, or that as they are the most
354 difficult to perform, that they have already been relinquished. However, they may be of key importance
355 for those to whom they are relevant. The goal of driving also showed low relevance (5%, n=3), with most
356 subjects scoring the goal as 'not applicable.' The low relevance figure is likely to reflect that in the UK,
357 vision that is impaired to the point of visual impairment registration is incompatible with the visual
358 requirements for driving (https://www.gov.uk/driving-eyesight-rules). However, the subsequent loss of

359 independence from losing a driving licence has been reported as overwhelming, with implications on the
360 individual's quality of life and emotional health (72). Loss of other high-valued activities such as sewing,
361 hobbies or DIY, may also cause initial frustration or distress and be associated with difficulty adjusting to
362 vision loss, and subthreshold or major depression. (66,70,73)

363 Therefore, establishing the impact vision loss has had upon an individuals' high-valued activities at an
364 early stage in vision loss, with the purpose of managing expectations or assisting with compensatory
365 strategies, may assist in the adjustment process. Previous studies have associated lower levels of
366 depression with better levels of adjustment to vision loss. (2,4,67,74–76) Thus the benefit of using a
367 structured approach not only determines priority rehabilitation needs but may be used to specifically
368 identify goals with high levels of difficulty. Although the assumption from the conceptual framework of
369 the original AI, that higher need for rehabilitation is product of higher importance and levels of higher
370 difficulty, it is possible that even when a goal is important, that an individual may not wish to seek
371 rehabilitation for that goal. Therefore, it is still important that individuals are still asked whether or not
372 they wish to proceed with interventions. However, addressing such activities may have a significant
373 impact upon quality of life but would otherwise be missed in a case history, or semi-structured approach.

374 Finally, goals relating to activities of reading, writing or mobility were both high rehabilitation needs and
375 perceived as most difficult to achieve. Comparing the regression models of each outcome measure
376 suggests that it is not possible to predict rehabilitation needs as well as goal difficulties (34% vs. 52%
377 variance explained by predictor variables respectively). Understandably, what is 'important' to an
378 individual is very individual, whereas what is difficult may be realistically predicted by visual function.

379 The associations outlined above are only true for one time point. For example, as the data is cross-
380 sectional, it is not possible to conclude whether the depressive symptoms are the result of highly valued
381 goal being very difficult or impossible to achieve, or whether greater difficulty is expressed as a result of
382 the individual suffering from depressive symptoms. Similarly, it is not possible to conclude whether
383 higher levels of depressive symptoms are the result of increased rehabilitation needs or that depressive
384 symptoms result in an increased need for rehabilitation. To be able to determine whether the
385 relationship between variables are either a cause or a consequence of the outcome measures of the PAI,
386 analysis would require repeating at different time points.

Conclusions

388 Low vision rehabilitation services should offer early interventions on reading, mobility and writing to all
389 newly registered adult service users. Providing such services may involve more than one service
390 provider. As the need for rehabilitation is not associated with the level of vision loss, prompt referral for
391 support is indicated as those with early or mild vision loss may already have rehabilitation needs.
392 Eyecare professionals should not wait until the end of medical treatment programs before considering a
393 referral for support and intervention. Higher rehabilitation need is also associated with younger age,

394 indicating it is particularly important to refer younger people with sight loss for rehabilitation at an early
395 stage.

396 Service users with higher levels of depression or depressive symptoms have greater rehabilitative needs
397 and perceive greater difficulty with visual tasks, therefore an evaluation of their level of depressive
398 symptoms at an early stage in rehabilitation may be indicated which may have an impact upon either the
399 number of rehabilitation needs or the level of intervention needed to address them.

400 Rehabilitation needs identified in areas more straightforward or cost effective to provide may currently
401 overshadow needs in other domains which some service users may consider of higher difficulty, such as
402 being able to continue with hobbies or crafts. Addressing these goals may have important impact upon
403 quality of life and levels of depressive symptoms and the use of a structured assessment such as the PAI
404 would ensure that these goals are identified. Service delivery and spending may then be directed in this
405 area. Consequently, further investigation to understand the barriers that currently prevent the uptake
406 and use of a structured assessment of needs in UK rehabilitation practice would merit further
407 investigation.

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Conflicts of interest

413 The authors report no conflicts of interest and have no proprietary interest in any of the materials
414 mentioned in this article.

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Figures and Tables
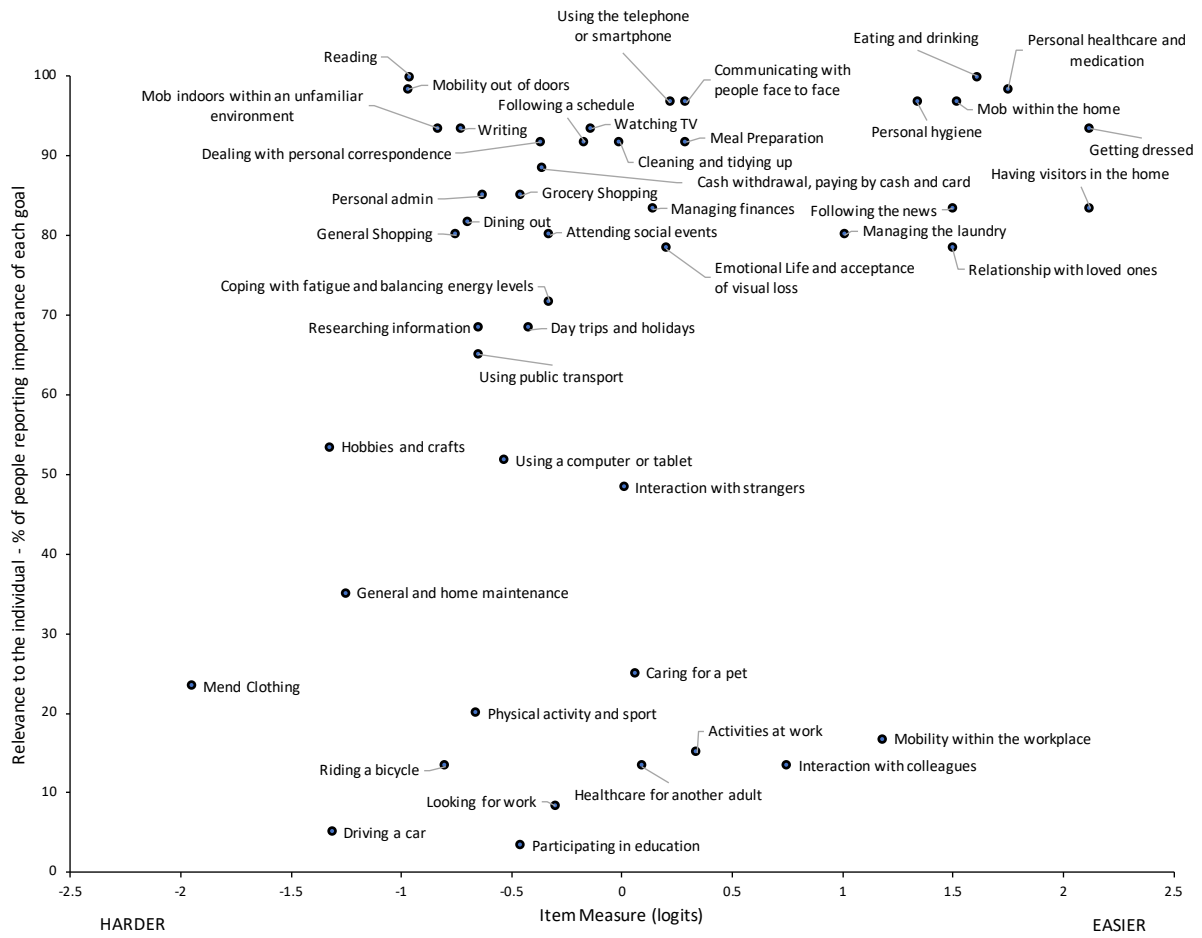
Figure 1 Self-reported difficulties with activities of daily living: 47 individual items are represented graphically. A higher item measure (logits) indicates that an individual perceives the goal as easier to achieve.
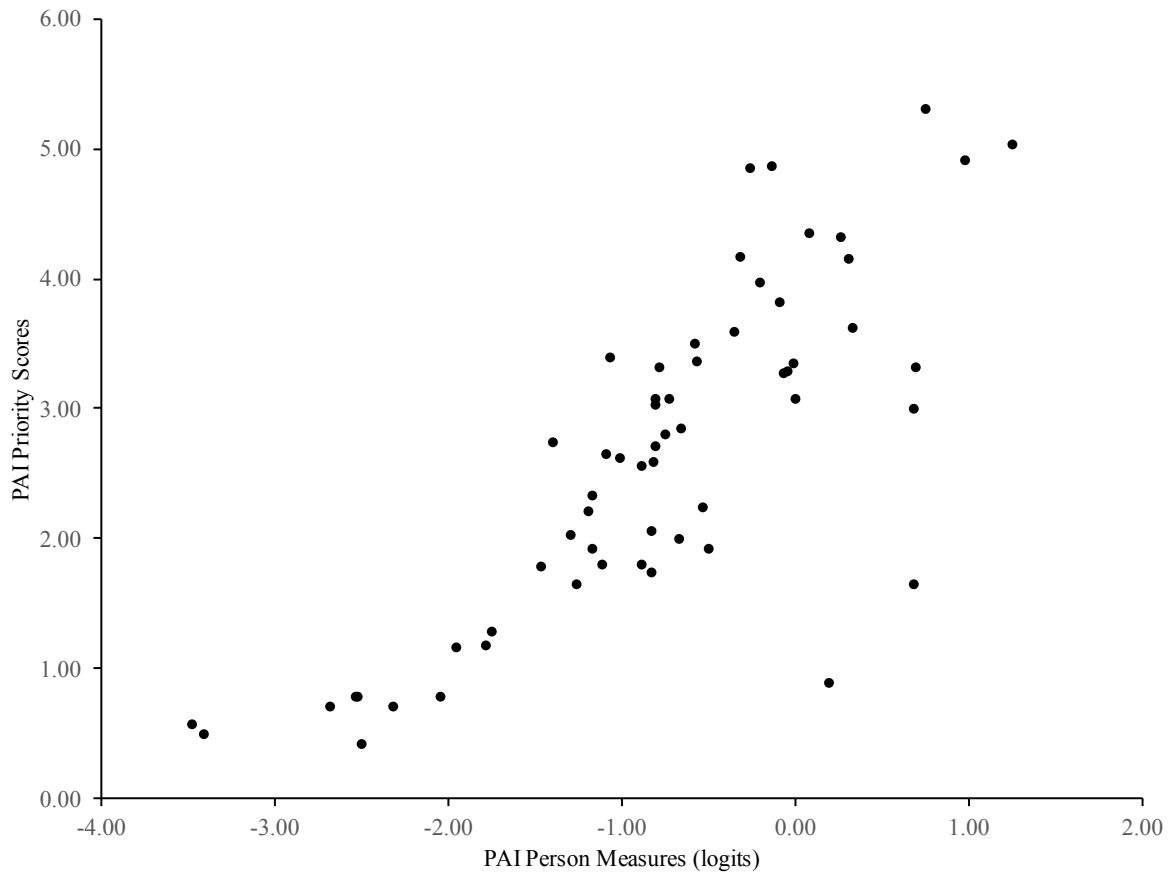
Figure 2. Scatterplot comparing participant's mean Participation and Activity Inventory (PAI) priority scores with participant's PAI Rasch person measures. Priority scores represent the product of importance and difficulty of PAI items whereas the person measures represent the level of difficulty of items (n=60).

Table 1. Descriptive statistics for socioeconomic and clinical variables (n=60 unless otherwise stated).

Location of study assessment	
Own home	52(87%)
Vista Low Vision Clinic	8(13%)
Age (years)	
Mean (± S.D.)	75.8 (±13.8)
Range	(30-97)
Gender n (%)	
Male	22 (37%)
Female	38 (63%)
Ethnicity n (%)	
White British	58 (97%)
Indian	1 (2%)
Caribbean	1 (2%)
Living arrangements n (%)	
Alone	28 (47%)
Living with spouse/partner/family/friend	32 (53%)
Current employment status n (%)	
Still Working	5 (8%)
Not working due to visual impairment	3 (5%)
Seeking work	1 (2%)
Retired	48 (80%)
Not working due to general health	3 (5%)
Number of co-morbidities	
Mean (± S.D.)	2.6 (±1.5)
Range	(0-8)
History of Anxiety/Depression n (%)	
Yes	19 (32%)
No	41 (68%)
Current treatment/observation for Anxiety/Depression n (%)	
Yes	8 (13%)
No	52 (87%)
Duration vision loss affected daily living (months)	
Mean (± S.D.)	38.3 (±67.3)
Range	(2-360)
Visual Impairment Registration (CVI) Status n (%)	
Sight Impaired (SI)	50 (83%)
Severely Sight Impaired (SSI)	9 (15%)
Not Registered	1(2%)
Time since Registration (weeks)(n=59)	
Mean (± S.D.)	8.1 (±4.6)
Range	(2-20)
Primary self-reported cause of vision loss n (%)	
Age Related Macular Degeneration	30 (50%)
(Dry 10,17%; Wet 20,33%)	
Diabetic Retinopathy/Maculopathy	3 (5%)
Hereditary Retinal Disorder (Retinitis Pigmentosa)	3 (5%)
Retinal Vascular Occlusions	4 (7%)

Glaucoma		7 (12%)
Other		13 (21%)
Binocular Distance Visual Acuity logMAR		
Mean (± S.D.)		0.77 (±0.48)
Range		(0.00 – 3.00)
Contrast Sensitivity logCS (n=59)		
Mean (± S.D.)		1.24 (±0.35)
Range		(0.50-2.10)
Reading accessibility Index (ACC) (n=55)		
Mean (± S.D.)		0.39 (±0.24)
Range		(0.00-0.88)
PAI priority scores		
Mean (± S.D.)		2.61 (±1.28)
Range		(0.40-5.29)

Table 2. Psychometric properties of the Participation and Activity Inventory (PAI), Acceptance and Self-Worth Adjustment Scale (AS-WAS), Hospital Anxiety and Depression Scale HADS (Anxiety, A and Depression, D) Subscales and Short Falls Efficacy Scale-International (Short FES-I) following Rasch analysis (values in logits). Sub-optimal parameter values are indicated in bold italics.

	PAI	AS-WAS	HADS-A	HADS-D	Short FES-I
Participants (n)	60	59	60	60	60
Category amendments	1&2 combined	-	-	-	-
Items removed (instrument item number)	601	-	-	D2, D3	-
Item MNSQ Infit Mean ± S.D.	+1.01 ± 0.32	+0.99 ± 0.22	+1.00 ± 0.20	+1.06 ± 0.29	+1.02 ± 0.32
Item MNSQ Infit Range	+1.86 to +0.19	+1.45 to +0.46	+1.36 to +0.73	+1.34 to +0.72	+1.73 to +0.62
Item MNSQ Outfit Mean ± S.D.	+1.00±0.33	+1.00±0.23	+0.96±0.20	+1.09±0.30	+1.00±0.26
Item MNSQ Outfit Range	+1.65 to +0.58	+1.46 to +0.49	+1.38 to +0.77	+1.54 to +0.74	+1.54 to +0.63
Targeting	0.79	0.78	*1.43*	*1.29*	*1.00*
Person Separation	3.16	2.10	*1.44*	*1.36*	*1.72*
Person Reliability	0.91	0.82	*0.67*	*0.65*	*0.75*
Item Separation	*2.47*	4.28	*2.08*	5.49	3.66
Item Reliability	*0.86*	0.95	*0.81*	0.97	0.93
1st contrast eigenvalue	*3.90*	*2.62*	1.82	1.43	1.62
Variance explained by measures	*46%*	*42%*	*44%*	62%	55%
Person Measure Average	-0.79±1.02	-0.78±0.86	-1.43±1.42	-1.29±1.56	-1.00±1.81
Person Measure Range	-3.47 to +1.25	-2.69 to +1.23	-4.52 to +1.68	-5.17 to +1.54	-4.10 to +4.16

Acceptable values: Infit & Outfit MNSQ (0.0 1.99); person separation >2.0, person reliability >0.8; Item Separation>3.0, item reliability >0.9; targeting ±1.0

Table 3. Priority Scores for Participation and Activity Inventory (PAI) goals in order of rehabilitative need (greatest first). The highlighted area indicates the 'top 15' goals of greatest rehabilitative need.

PAI Goal and Item Code	Max[†]	Mean	S.D.
101 Reading	12	6.82	2.91
403 Mobility out of doors	12	6.55	3.92
402 Mobility indoors (unfamiliar environment)	12	5.52	3.93
102 Writing	12	5.27	3.02
302 Dealing with personal correspondence	12	4.53	3.88
605 Cash withdrawal, paying by cash and card	12	4.37	4.07
606 Grocery Shopping	12	4.30	4.15
201 Personal admin	12	4.20	4.04
607 General Shopping	12	4.20	4.29
202 Following a schedule	12	4.13	4.04
904 Dining out	12	4.03	3.62
103 Watching TV	9	3.95	2.75
907 Hobbies and crafts	12	3.88	4.71
303 Using the telephone or smartphone	12	3.73	3.33
905 Day trips and holidays	12	3.60	4.13
701 Communicating with people face to face	12	3.58	3.49
802 Researching information	12	3.52	4.07
002 Coping with fatigue and balancing energy levels	12	3.45	3.89
601 Cleaning and tidying up	12	3.20	3.51
406 Using public transport	12	3.15	3.82
608 Meal Preparation	12	3.12	3.42
903 Attending social events	12	3.10	3.60
001 Emotional Life	9	3.02	3.50
801 Managing finances	12	3.00	3.56
301 Using a computer or tablet	12	2.52	3.33
603 General and home maintenance (DIY)	12	1.95	3.65
502 Personal hygiene	12	1.85	2.93
704 Interaction with strangers	9	1.85	3.11
504 Eating and drinking	9	1.75	2.72
901 Following the news	9	1.61	2.59
401 Mobility within the home	9	1.55	2.50
602 Managing the laundry	12	1.55	2.90
604 Mend Clothing	12	1.50	3.41
702 Relationship with loved ones	12	1.38	2.56
503 Personal healthcare and medication	9	1.30	2.23
906 Physical activity and sport	12	1.05	2.64
611 Caring for a pet	9	0.98	2.56
501 Getting dressed	6	0.83	1.65
902 Having visitors in the home	9	0.80	1.79
610 Caring for a (grand)child	12	0.70	2.17
404 Riding a bicycle	12	0.60	1.98
405 Driving a car	12	0.60	2.64
805 Activities at work	9	0.60	1.82
609 Healthcare for another adult	12	0.50	2.22
804 Looking for work	12	0.50	2.00
806 Mobility within the workplace	9	0.42	1.54
703 Interaction with colleagues	9	0.37	1.51
803 Participating in education	9	0.25	1.39

The first digit of the item number indicates the PAI Domain 1:Learning & Applying Knowledge, 2:General Tasks & Demands, 3:Communication, 4:Mobility, 5:Self-care, 6:Domestic life, 7:Interpersonal interactions & relationships, 8:Major life areas, 9:Community, social & civic life, 10:Emotional health
[†]All minimum values were recorded as zero

Table 4. Results of stepwise regression analyses to determine which demographic, clinical or psychosocial variables best represent a) need for rehabilitation Participation and Activity Inventory Priority Scores (PAI-PS) and b) difficulties with goals Participation and Activity Inventory Person Measures (PAI-PM) (n=60)

	B	SE *B*	β	R^2 change	*p*
a) Self-reported priority rehabilitation needs (PAI-PS)					
Age	-0.04	0.01	-0.46	0.22	<0.001
HADS-D Person Measures	0.29	0.09	0.35	0.12	0.002
b) Self-reported difficulties with activities of daily living (PAI-PM)					
HAD-D Person Measures	0.26	0.07	0.39	0.29	<0.001
Distance VA	0.89	0.20	0.42	0.16	<0.001
AS-WAS Person Measures	0.37	0.13	0.31	0.07	0.006

Hospital Anxiety and Depression Scale (HADS), Depression Subscale, D
B, unstandardized regression coefficients; SE *B*, standard errors; β standardised regression coefficients; R^2 change, amount of additional variance by including predictors from sample

Table 5. Item characteristics of Participation and Activity Inventory (PAI) goals in order of perceived difficulty (greatest first). The highlighted area indicates the 'top 15' goals of greatest difficulty.

PAI Goal and Item code		Item Measure (logits)	Model SE	Infit MNSQ (logits)	Outfit MNSQ (logits)	Applicability (non-zero responses)	
604	Mend Clothing	-1.95	0.35	1.06	1.18	14	23%
907	Hobbies and crafts	-1.32	0.23	1.34	1.35	32	53%
405	Driving a car	-1.31	0.74	1.86	1.78	3	5%
603	General and home maintenance (DIY)	-1.25	0.28	0.90	0.86	21	35%
403	Mobility out of doors	-0.97	0.17	0.87	0.86	59	98%
101	Reading	-0.96	0.17	0.77	0.83	60	100%
402	Mobility indoors (unfamiliar environment)	-0.83	0.18	0.85	0.88	56	93%
404	Riding a bicycle	-0.80	0.46	1.45	1.47	8	13%
607	General Shopping	-0.75	0.19	1.25	1.26	48	80%
102	Writing	-0.73	0.18	0.64	0.70	56	93%
904	Dining out	-0.70	0.19	1.09	1.20	49	82%
906	Physical activity and sport	-0.66	0.37	0.54	0.52	12	20%
406	Using public transport	-0.65	0.22	0.84	0.87	39	65%
802	Researching information	-0.65	0.21	1.34	1.33	41	68%
201	Personal admin	-0.63	0.19	0.94	0.91	51	85%
301	Using a computer or tablet	-0.53	0.24	0.83	0.85	31	52%
606	Grocery Shopping	-0.46	0.19	0.74	0.71	51	85%
803	Participating in education	-0.46	0.87	0.19	0.09	2	3%
905	Day trips and holidays	-0.42	0.21	0.82	0.92	41	68%
302	Dealing with personal correspondence	-0.37	0.18	0.71	0.69	55	92%

605	Cash withdrawal, paying by cash and card	-0.36	0.19	1.36	1.45	53	88%
002	Coping with fatigue and balancing energy levels	-0.33	0.20	1.11	1.23	43	72%
903	Attending social events	-0.33	0.20	1.54	1.65	48	80%
804	Looking for work	-0.30	0.61	0.69	0.59	5	8%
202	Following a schedule	-0.17	0.19	1.12	1.05	55	92%
103	Watching TV	-0.14	0.18	0.55	0.58	56	93%
601	Cleaning and tidying up	-0.01	0.19	0.91	0.90	55	92%
704	Interaction with strangers	0.01	0.26	1.45	1.51	29	48%
611	Caring for a pet	0.06	0.36	1.22	1.36	15	25%
609	Healthcare for another adult	0.09	0.53	1.20	0.98	8	13%
801	Managing finances	0.14	0.20	0.83	0.77	50	83%
001	Emotional Life and acceptance of visual loss	0.20	0.20	1.04	1.20	47	78%
303	Using the telephone or smartphone	0.22	0.19	0.72	0.72	58	97%
608	Meal Preparation	0.29	0.20	0.78	0.69	55	92%
701	Communicating with people face to face	0.29	0.19	1.09	1.07	58	97%
805	Activities at work	0.34	0.48	0.20	0.22	9	15%
703	Interaction with colleagues	0.75	0.57	1.26	1.26	8	13%
602	Managing the laundry	1.01	0.24	1.23	1.00	48	80%
806	Mobility within the workplace	1.18	0.55	1.02	0.87	10	17%
502	Personal hygiene	1.34	0.24	1.18	1.09	58	97%
702	Relationship with loved ones	1.50	0.27	1.22	1.00	47	78%
901	Following the news	1.50	0.26	1.18	0.92	50	83%
401	Mob within the home	1.52	0.25	1.13	1.41	58	97%
504	Eating and drinking	1.61	0.25	1.05	1.05	60	100%
503	Personal healthcare and medication	1.75	0.26	1.19	0.98	59	98%
902	Having visitors in the home	2.12	0.32	1.14	0.90	50	83%
501	Getting dressed	2.12	0.30	1.02	1.26	56	93%

Item difficulty (item measure) and Standard Error (SE) of goals in logits are shown in difficulty order from most difficult to least difficult. PAI Domains 1:Learning & Applying Knowledge, 2:General Tasks & Demands, 3:Communication, 4:Mobility, 5:Self-care, 6:Domestic life, 7:Interaction, 8:Major life areas, 9:Community, social & civic life, 10:Emotional health. The number of non-zero responses (maximum 60) indicates the general relevance of the question to the sample.