Change in rehabilitation needs and activity limitations over time of adults with acquired visual impairment following entry to a low vision rehabilitation service in England

Jane Macnaughton[1], Marta Vianya-Estopa[1], Keziah Latham[1]

1. Vision & Hearing Sciences Research Centre, Anglia Ruskin University, Cambridge, UK.

Corresponding author: Dr Jane Macnaughton FCOptom; jane.macnaughton@aru.ac.uk

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Abstract

Purpose

Longitudinal changes in priority rehabilitation needs, vision-related activity limitation and importance of visual goals were evaluated in a sample of people with a visual impairment over a year following entry to low vision rehabilitation services in England.

Methods

Participants were adults with newly registered visual impairment within Leicestershire. Priority scores, indicating the level of rehabilitative need, were determined from the importance and difficulty scores of the 48 goals of the Participation and Activity Inventory (PAI). Rasch analysis of the difficulty and importance scores examined activity limitation and importance separately. PAI outcome measures were assessed on entry to rehabilitation services and at 4 and 12 months thereafter.

Results

48 participants (mean age 74.2, SD 14.1 years) completed 3 visits. Overall, there was a statistically significant reduction in the perceived need for rehabilitation over time ($p<0.001$, $\eta_p^2=0.29$), driven by reduced perceived difficulty ($p<0.001$, $\eta_p^2=0.32$) but stable importance ($p=0.73$) of goals, with most change occurring between baseline and 4 months. PAI goals with greatest rehabilitative need at study entry were reading, mobility and writing, and these remained of highest priority over time. The greatest priority score decrease was for the goal 'Hobbies and crafts'. The largest decrease in importance was for 'Mobility outdoors', whereas 'Relationship with loved ones' increased most.

Conclusions

Despite a decline in the perceived need for rehabilitation over the study period, there remains a need for continued support and intervention at 12 months following registration with rehabilitation services, particularly for the key goals of reading, writing and mobility. Early identification and support for individuals' important but difficult goals could prevent such goals being relinquished. Goals concerning relationships and communication became more important over time, indicating that re-evaluation of needs at follow-up is necessary to inform ongoing service provision.

Key words: Participation and Activity Inventory, activities of daily living, low vision, rehabilitation, visual impairment.

Key points:

- In the year following visual impairment registration, there was some overall decrease in perceived difficulty with visual goals and no overall change in goal importance in this UK sample.
- Some difficult goals reduced in difficulty and importance suggesting they were relinquished with time, and some goals relating to communicating with others became more important.
- Continued follow-up of people with visual impairment is indicated to address continuing and evolving rehabilitative needs.

Introduction

Acquired vision loss affects many aspects of life and results in the need for provision of rehabilitation services for people with vision loss to retain their independence and quality of life.[1,2] To provide adequate and appropriate services to people with vision loss in the United Kingdom (UK), it is important to understand the priority needs of people with a visual impairment entering rehabilitation and whether or not these needs change over time.[3] Such evidence is needed if effective multidisciplinary approaches to service delivery are to be developed,[4–6] along with evidence-based standards for follow-up or review for services.[7–10]

The Participation and Activity Inventory (PAI)[11–13] is a self-report instrument that builds upon the hierarchal goals and task structure of the Activity Inventory (AI).[14] The PAI asks people with visual impairment to rate the importance and difficulty of 48 visual goals. Each goal is nested within one of the nine Activity and Participation domains of the World Health Organisation's (WHO) International Classification of Functioning, Disability and Health (ICF),[15] plus an additional domain of emotional health. An indication of rehabilitative need is provided through the use of 'priority scores' which are calculated as the product of the importance and difficulty ratings,[12] and the those goals with the highest rehabilitative need are included in a 'Top-15 Priority List' (TPL-15).[13] Goals that are both important and difficult may then be assessed at a more granular task level, with the aim being for the instrument to provide a systematic way of identifying rehabilitation needs and prevent personal goals from being overlooked.[16]

Using the PAI, we have previously evaluated the priority rehabilitation needs and vision-related activity limitations facing adults with acquired vision loss at entry to rehabilitation services in England.[17] Reading, mobility, and writing were established as key areas for rehabilitation intervention, suggesting that early assessment for both the provision of low vision devices and training in orientation and mobility techniques are indicated at the point of referral. Reading and writing also consistently appear at the top of the TPL-15 in studies using the PAI at a single time point with Dutch participants.[12,13,16] In contrast, mobility goals do not rank as highly in these studies, with watching TV,[12,13,16] personal correspondence,[16] personal administration [12] and acceptance of visual loss [13] appearing instead.

Only segments of the PAI have previously been assessed longitudinally [18,19] to examine changes in rehabilitation needs over time in a Dutch cohort. Priority scores have not been presented, but it has been noted that goal importance remains stable over time [18,19] while the difficulty of goals of reading, writing, watching TV [18] and acceptance of visual loss decrease slightly over time, with other goals from the emotional health domain remaining unchanged in difficulty.[19]

The purpose of this study is to employ the entire PAI at goal level to evaluate changes in priority rehabilitation needs, vision-related activity limitations and goal importance in a sample of adults with acquired visual impairment over a year following entry to a low vision rehabilitation service. The aim is to identify what changes in service needs people may have after entry into low vision rehabilitation services in the UK.

Methods

Participants

Adult participants with acquired visual impairment who were new to visual impairment rehabilitation services were recruited at the point of referral to Vista, the leading provider of low vision and rehabilitation services in Leicestershire and Rutland.[17] An automatic referral to Vista follows formal registration for inclusion on the visual impairment register using the Certificate of Vision Impairment (CVI).[20] There was no restriction to participation due to cause of visual impairment or level of vision. Exclusion criteria included participants under 18 years of age, those unable to complete the assessments in English or who were found to be cognitively impaired using the Six-item Brief Cognitive Screener.[21] Participants were recruited between May 2016 and March 2017, and data collection was completed prior to the COVID-19 pandemic.

When an individual is included on the visual impairment register, a member of Vista's team of rehabilitation officers for the visually impaired (ROVIs) arranges to visit the person in their home environment for a needs assessment within 6 weeks. Following a semi-structured discussion and assessment of needs, the ROVIs provide appropriate equipment, practical assistance, and emotional support services. Although there is no structured follow-up assessment, individuals are encouraged to contact Vista if their personal circumstances or level of vision change. Optical low vision aids are provided by optometrists working for the University Hospitals of Leicester NHS trust, in low vision clinics hosted at and co-managed with Vista. Referral to the low vision clinic is a separate pathway to CVI registration and/or referral for onward social care from the rehabilitation teams.

Participants were assessed at three time points. Visit 1 (V1, 0 months) took place following referral to Vista, an average of 8 (SD 5) weeks after the date on the CVI. Visit 1 took place after the initial ROVI visit for 45 people by an average of 4 (SD 3) weeks, and before the ROVI visit for the other 3 participants. Visit 2 (V2) took place 4 months later and Visit 3 (V3) 12 months after V1.

Participants were seen either at Vista's low vision clinic based in Leicester or within the participant's own home. All assessments were conducted face to face by JM, an optometrist with expertise in visual impairment evaluations, using the same methodology regardless of location. The study received ethical approval from Anglia Ruskin University Faculty of Science and Technology Research Ethics Committee and all participants gave informed consent.

Protocol

At each visit, demographic and clinical measures that describe the study population were recorded. Rehabilitation interventions received by participants were obtained from patient notes after delivery.

Priority rehabilitation needs, together with vision-related activity limitations and activity importance, were identified and evaluated by using the Participation and Activity Inventory (PAI).[11–13] The 48 goals of the PAI relate to activities of daily living and social participation covering 10 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). For each goal, participants were asked to rate the importance of the goal on a Likert scale of 0 (not important / relevant) to 3 (highly important). For goals that were of some importance, participants were asked to rate the difficulty of the goal without another person's help but using compensatory aids where appropriate on a scale of 0 (not at all difficult) to 4 (impossible without help).

Analysis

Priority rehabilitation needs were determined by calculating priority scores as the product of the ordinal importance (0 to 3) and difficulty (0-4) scores for each goal (minimum 0, maximum 12), where a higher score infers a higher level of need.[12] The rationale for the calculation of priority scores is that the original conceptual framework of the PAI is based on the assumption that goals with both high importance and high difficulty together indicate a higher rehabilitative need.[14]

Since priority scores are comprised of the product of the elements of perceived activity limitation (or difficulty) and importance of the goal, differences between goals or across time may be due to variations in either difficulty or importance scores, or both. It is therefore also worth examining each element separately to see where change is occurring.

Evaluation of ordinal Likert scores would assume that all goals are of equal difficulty and contribute the same amount to the measurement of the underlying construct.[22] Therefore, the Rasch model was used to convert raw ordinal scores into an interval scale.[23,24] Rasch analysis was undertaken using a single Andrich rating scale model [25] using Winsteps (version 4.0.1; winsteps.com). To review changes in both difficulty and importance measures of the PAI over time, data from the three visits was 'racked'.[26] Each person was entered once into the analysis and associated with ordinal scores entered for each goal separately for each visit. Racking fixes the ability of each person and forces all the change into the item measure to consider which goals change over time. Measures were initially calculated in terms of logits (or log odds units), which represent the likelihood of an item being achievable for a person. Scales were then transformed to run from 0 to 100 for ease of interpretation, with higher numbers indicating greater difficulty or importance.

Category functioning of the PAI was examined to evaluate whether categories were underutilised or disordered. Where indicated, adjacent response categories were collapsed until rescaling produced utilisation of all categories in an ordered structure.[27] Given that the purpose of this study was to create measures reflecting a wide range of rehabilitation needs,[28] further changes to the instrument beyond category collapse were avoided so that the wealth of data was retained. Therefore, although fit parameters (infit and outfit meansquare, MNSQ) >2.0 are not ideal,[29] persons with poor fit were retained in the analysis. Further parameters of the scale were evaluated, and where parameters were not ideal, scales have not been amended but the relevant figures highlighted. Reasonable overall unidimensionality of a scale is indicated if at least 60% of the variance is explained by the primary measure in principal components analysis,[30] and if the unexplained variance within the first contrast found within the residuals is less than an eigenvalue of 3.0.[31] A scale can reliably discriminate between participants if

person separation is >2.0 and person reliability is >0.8, and items are reliably ordered if item separation is >3.0 and item reliability is >0.9.[24,32] Ideal targeting is indicated when the mean of person measures is within ±1.0 logits of the mean of item measures.[22]

To determine any overall change in the three outcome measures over time, a univariate approach using repeated measures analysis of variance (ANOVA) was used. Sphericity was established using Mauchly's test, and results are reported using a Greenhouse-Geisser correction where sphericity was violated. Where significant change was observed, Bonferroni-corrected post-hoc pairwise comparisons were used to establish between which visits the significant difference existed. Effect sizes (partial eta squared (η_p^2) values of small (0.02), medium (0.13) and large (0.26)) are reported where relevant.[33,34]

Results

Sixty participants were recruited to the study.[17] As the repeated measure methods employed require complete data sets, analyses are based upon the 48 study participants who completed the study at all three visits. Of the 12 individuals lost to follow-up 8 passed away, 1 was hospitalised, 1 moved away and 2 were uncontactable. Demographic characteristics describing the longitudinal study population are outlined in Table 1. Rehabilitation interventions received by each visit were mapped to the 10 domains of the PAI and are shown in Figure 1. For example, provision of optical low vision aids was considered to assist the goal of reading, nested in domain 1 (learning and applying knowledge).

Table 1. Descriptive statistics of the longitudinal study population (*n* = 48 unless otherwise stated).

Age (years) on study entry	
Mean (SD)	74.2 (14.1)
Range	30 to 91
Sex *n* (%)	
Male	16 (33%)
Female	32 (67%)
Ethnicity *n* (%)	
White British	46 (96%)
Indian	1 (2%)
Caribbean	1 (2%)
Primary self-reported cause of vision loss *n* (%)	
Age related macular degeneration ('wet')	17 (35%)
Age related macular degeneration ('dry')	6 (13%)
Primary open angle glaucoma	6 (13%)
Retinal vascular occlusions	4 (8%)
Visual cortex disorder	3 (6%)
Cerebrovascular disease	2 (4%)
Hereditary retinal dystrophy	2 (4%)

Diabetic retinopathy/maculopathy	2 (4%)
Optic atrophy	2 (4%)
Other (unspecified)	4 (8%)
Living arrangements *n* (%)	
Alone	22 (46%)
Living with others	26 (54%)
Registration (CVI) Status *n* (%)	
Sight Impaired (SI)	40 (83%)
Severely Sight Impaired (SSI)	7 (15%)
Not Registered	1 (2%)
Primary low vision aid at study entry *n* (%)	
None	11 (23%)
Illuminated hand magnifier	25 (52%)
Non-illuminated hand magnifier	8 (17%)
Illuminated stand magnifier	1 (2%)
Portable electronic visual enhancement system	1 (2%)
Personal computer software	1 (2%)
Field expander	1 (2%)
Source of primary low vision aid (of n=37) *n* (%)	
Low vision clinic	19 (51%)
Self-purchased	13 (35%)
Rehabilitation Officer for the Visually Impaired (ROVI)	3 (8%)
Family / friend	1 (2%)
Access to Work	1 (2%)

Figure 1 here

Changes in priority rehabilitation needs

Priority scores from the PAI were computed for each participant at each visit to determine how the participants' perceived overall need for rehabilitation changed over the study period, and for comparison to previous studies.[12,13,16]

Mean priority scores across all goals and participants were 2.72 (SD 1.75) at V1, 2.32 (SD 1.63) at V2, and 2.29 (SD 1.70) at V3. A significant reduction over time was found in the PAI priority scores ($F(2, 94) = 19.62$, $p < 0.001$, $\eta_p^2 = 0.29$; Mauchly's test indicated sphericity observed: $X^2(2) = 4.86$, $p=0.09$) indicating

that perceived need for rehabilitation decreased over time with a large effect. Post-hoc pairwise comparisons established that significant change occurred between V1 and V2 (mean difference 0.41; $p<0.001$) and between V1 and V3 (mean difference 0.43; $p<0.001$), but not between V2 and V3 (mean difference 0.02; $p = 1.00$).

A comparison of the priority scores for all 48 goals of the PAI across the three visits is presented in Table 2. The TPL-15 goals of greatest rehabilitative need [13] have been shaded grey at each visit. To assist comparisons between visits, Table 2 also presents the data as a percentage of the highest priority score (goal 101, Reading, V1), and colour codes the scores by quartile.

Table 2. Priority scores for PAI goals at each visit. V1 = enrolment (0 months); V2 = 4 months; V3 = 12 months. The first digit of the item number indicates the domain: 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, 0: Emotional health. 'Top 15' goals (TPL-15) of greatest rehabilitative need are shaded grey. Percentage values are calculated relative to the goal with the highest priority score (Reading, V1, 6.7*). Colour coding indicates the percentage scores by quartiles: Red = 100-76%, Orange = 51 -75%, Yellow = 26-50%, Green = 0-25%.

PAI Goal		V1		V2		V3		% value compared to highest priority score*		
		Priority score	SD	Priority score	SD	Priority score	SD	V1	V2	V3
101	Reading	**6.7***	2.8	6.1	2.8	5.8	2.9	100%	92%	87%
403	Mobility out of doors	6.5	3.9	5.2	3.4	5.5	3.8	97%	78%	82%
402	Mobility indoors (unfamiliar environment)	5.6	3.7	4.3	3.4	4.4	3.7	83%	64%	66%
102	Writing	5.3	3.0	5.4	3.1	5.5	3.5	80%	80%	82%
605	Cash withdrawal, paying by cash and card	4.7	4.0	4.2	3.2	4.4	3.7	70%	62%	65%
606	Grocery Shopping	4.6	4.2	4.9	3.7	4.6	3.9	69%	74%	69%
607	General Shopping	4.5	4.3	3.4	3.2	4.5	4.5	67%	51%	68%
202	Following a schedule	4.4	4.0	3.7	3.3	3.8	3.4	66%	55%	57%
904	Dining out	4.4	3.6	3.6	2.4	4.0	3.7	65%	54%	60%
907	Hobbies and crafts	4.3	4.8	2.5	3.6	2.0	3.4	65%	37%	30%
201	Personal admin	4.3	4.1	4.3	4.0	4.1	3.9	64%	64%	61%
302	Dealing with personal correspondence	4.2	3.8	4.6	3.4	4.9	3.7	63%	69%	74%
905	Day trips and holidays	4.1	4.1	3.2	3.0	3.4	3.6	62%	47%	51%
103	Watching TV	4.0	2.8	3.9	2.3	3.9	2.7	60%	58%	58%
802	Researching information	3.9	4.0	2.8	3.6	1.8	2.8	59%	42%	27%
303	Using the telephone or smartphone	3.9	3.4	3.1	3.0	3.3	2.9	58%	46%	49%
601	Cleaning and tidying up	3.6	3.7	1.8	2.4	2.1	3.0	53%	26%	31%
406	Using public transport	3.4	3.8	3.8	4.0	2.9	3.9	51%	57%	44%
903	Attending social events	3.4	3.7	2.7	3.2	2.5	3.3	51%	41%	37%
701	Communicating with people face to face	3.4	3.3	3.5	3.6	3.2	3.3	50%	53%	47%
608	Meal preparation	3.3	3.5	3.1	3.0	3.0	2.8	49%	46%	45%

002	Coping with fatigue & balancing energy levels	3.1	3.7	2.2	3.0	3.3	3.5	46%	33%	52%
001	Emotional life	3.0	3.6	2.8	3.0	3.1	3.0	45%	41%	46%
301	Using a computer or tablet	2.9	3.5	3.0	3.5	3.2	3.4	43%	45%	47%
801	Managing finances	2.9	3.4	2.5	3.3	2.9	3.4	43%	38%	43%
603	General and home maintenance (DIY)	2.3	3.9	1.6	3.2	0.8	2.7	34%	23%	12%
502	Personal hygiene	2.2	3.1	0.9	2.1	1.1	2.0	33%	13%	16%
704	Interaction with strangers	2.0	3.2	1.6	3.2	1.7	3.3	30%	24%	26%
604	Mend clothing	1.8	3.7	1.6	3.3	1.3	3.1	27%	24%	19%
602	Managing the laundry	1.8	3.1	1.3	2.4	1.2	2.7	26%	19%	18%
401	Mobility within the home	1.7	2.6	1.0	1.9	1.4	2.4	25%	15%	21%
504	Eating and drinking	1.6	2.8	1.5	2.1	1.6	2.6	24%	23%	23%
901	Following the news	1.6	2.5	1.8	2.4	2.0	2.7	23%	27%	30%
503	Personal healthcare and medication	1.5	2.3	1.5	2.8	1.1	2.3	22%	22%	17%
906	Physical activity and sport	1.3	2.9	2.1	3.9	0.9	2.5	20%	31%	13%
702	Relationship with loved ones	1.2	2.2	0.8	1.9	1.6	3.0	17%	12%	23%
611	Caring for a pet	1.0	2.6	0.5	1.5	0.3	1.2	15%	7%	5%
902	Having visitors in the home	0.9	1.8	0.7	1.8	0.2	0.8	13%	10%	3%
501	Getting dressed	0.9	1.7	0.9	1.9	0.6	1.3	13%	14%	9%
610	Caring for a (grand)child	0.8	2.4	0.5	1.4	0.4	1.6	12%	7%	5%
404	Riding a bicycle	0.8	2.2	0.7	2.3	0.2	1.0	11%	10%	3%
805	Activities at work	0.7	2.0	0.5	1.4	0.3	2.1	10%	7%	5%
804	Looking for work	0.6	2.2	0.1	0.6	0.0	0.0	9%	1%	0%
703	Interaction with colleagues	0.5	1.7	0.4	1.4	0.4	1.9	7%	7%	7%
609	Healthcare for another adult	0.4	2.1	0.1	0.4	0.1	0.4	7%	1%	1%
806	Mobility within the workplace	0.4	1.5	0.4	1.3	0.6	1.4	6%	5%	9%
405	Driving a car	0.3	1.7	0.1	0.5	0.1	0.6	4%	2%	1%
803	Participating in education	0.2	1.3	0.1	0.9	0.2	1.3	3%	2%	3%

Table 2 shows that the ranking of priority scores remains similar across visits. Thirteen goals remain in the TPL-15 at all visits, with reading (101), mobility out of doors (403) and writing (102) of highest priority throughout, and other goals remaining of similarly high need across visits such as shopping (605, 606, 607), administration (201, 202, 302), and leisure activities (904, 905, 103). A further 6 goals make up the final 2 goals at one visit only, as might be expected by relative values varying close to the margins of the TPL-15, including using a telephone or smartphone (303), use of public transport (406) and communicating with people face to face (701).

There was some level of decrease in priority scores over time for most (n = 35; 73%) of the goals. While mobility indoors in an unfamiliar environment (402) remains in the TPL-15 across visits, its priority score decreases the most of the highest need goals (-17% between V1 and V3). Hobbies and crafts (907) and researching information (802) drop out of the TPL-15 after V1 and show the greatest declines in priority scores (-35% and -32% respectively between V1 and V3). Some domestic task goals outside the TPL-15 also show notable declines in priority scores over time, including cleaning and tidying up (601; -22%), and home maintenance and DIY (603; -22%).

Fewer goals (n=9; 19%) show an increase in priority score over time. Dealing with correspondence (302) and following the news (901) show modest increases in priority scores (+11% and +7% respectively between V1 and V3), and coping with fatigue and balancing energy levels (002; +6%) becomes a TPL-15 goal at V3.

Changes in vision-related activity limitation

Rasch analysis of the racked difficulty data showed that category functions were not ordered, with an underuse of categories 1 (slightly difficult) and 2 (moderately difficult). These categories were therefore collapsed together. The principal psychometric properties of the resultant 4-point PAI difficulty scale are shown in Table 3.

There was a significant reduction in perceived item difficulty over time with a large effect size (F(1.68, 79.02) = 22.47, p < 0.001, η_p^2 = 0.32; Mauchly's test indicated sphericity violated: X^2(2) = 9.67, p<0.01). Post-hoc pairwise comparisons established that significant change occurred between V1 and V2 (mean difference 2.49; p<0.001) and between V1 and V3 (mean difference 3.74; p<0.001), but with no significant change between V2 and V3 (mean difference 1.25; p = 0.06). Values for each goal at each visit are shown in Table 5.

Table 3. Psychometric properties of PAI difficulty scale following Rasch analysis. Non-ideal parameter values are indicated in italics. MNSQ = meansquare.

Property	**Result**
Category amendments	1&2 combined
Original scale range (logits)	-6.93 to 6.68
Value per logit on 0-100 scale	7.35
Person MNSQ Infit Mean (SD)	1.04 (0.37)
Person MNSQ Infit Range	*2.59* to 0.57
Persons with fit >2	Participant 016 (*2.59*)
Person MNSQ Outfit Mean (SD)	1.03 (0.30)
Person MNSQ Outfit Range	1.96 to 0.62
Persons with fit >2	None
Person mean (ideal 50 ± 7.35)	43.13
Person Separation	4.69
Person Reliability	0.96
Item Separation	*1.90*
Item Reliability	*0.78*
1st contrast eigenvalue	*3.89*
Variance explained by measures	*39%*
Item measure mean (SD) (range)	
Visit 1	45.21 (SD 6.99) (28.68 to 58.90)
Visit 2	42.72 (SD 7.87) (26.99 to 60.10)
Visit 3	41.47 (SD 7.92) (19.98 to 59.50)

Changes in importance

Category functions were disordered within initial racked Rasch analysis of importance scores, with an underuse of categories 1 (slightly important) and 2 (moderately important). Responses were rescaled to produce a dichotomous scale indicating that participants considered a goal as either not important (category 0) or important (categories 1-3). The principal psychometric properties of the racked PAI importance scale are shown in Table 4.

There was no significant change in importance with time ($F(1.63,76.48) = 0.25$, $p = 0.73$; Mauchly's test indicated sphericity violated: $X^2(2) = 11.97$, $p<0.001$). Values for each goal at each visit are shown in Table 5.

Table 4. Psychometric properties of the PAI importance scale following Rasch analysis. Non-ideal parameter values are indicated in italics. MNSQ = meansquare.

Property	**Result**
Category amendments	1, 2 & 3 combined
Original scale range (logits)	-4.31 to 5.45
Value per logit on 0-100 scale	10.25
Person MNSQ Infit Mean (SD)	0.99 (0.13)
Person MNSQ Infit Range	1.35 to 0.71
Persons with fit >2	None
Person MNSQ Outfit Mean (SD)	1.10 (1.05)
Person MNSQ Outfit Range	*9.90* to 0.19
Persons with fit >2	Participants 014 (*9.90*); 030 (*3.17*); 051 (*2.42*); 035 (*2.13*)
Person mean (ideal 50 ± 10.25)	59.74
Person Separation	2.92
Person Reliability	0.90
Item Separation	3.00
Item Reliability	0.90
1st contrast eigenvalue	*3.49*
Variance explained by measures	*56%*
Item measure mean (SD) (range)	
Visit 1	59.92 (SD 26.84) (0.05 to 99.96)
Visit 2	59.21 (SD 28.12) (0.05 to 99.96)
Visit 3	60.11 (SD 28.99) (0.05 to 99.96)

Table 5. Difficulty and importance (standard error, SE) of individual PAI goals across 3 visits. Goals are presented in order of difficulty at V1, most difficult first. Racked Rasch measures are presented as values scaled from 0-100, with higher values indicating greater difficulty / importance. Grey shading indicates goals that appear in the TPL-15 list of high priority score goals for at least 1 visit (Table 2). Colour coding is as follows: Red: highest quartile (difficulty: 50.1-60.1 (most difficult item: 604 V2); importance: 76-100%), Orange: second quartile (difficulty: 40.1-50.0; importance: 51-75%); Yellow: third quartile (difficulty: 30.1-40.0; Importance: 26-50%); Green: lowest quartile (difficulty: 20.0 (easiest item: 902 V3)-30.0; importance: 0-25%).

PAI Goal		Difficulty						Importance					
		V1	SE	V2	SE	V3	SE	V1	SE	V2	SE	V3	SE
604	Mend Clothing	58.9	2.7	60.1	2.7	59.5	3.2	32.4	3.6	32.3	3.6	28.3	3.9
803	Participating in education	57.8	9.0	52.3	9.0	43.1	7.2	0.1	10.5	0.1	10.5	7.7	7.6
907	Hobbies and crafts	54.5	1.8	50.0	2.1	51.4	2.3	47.8	3.3	42.4	3.2	37.1	3.4
603	General and home maintenance (DIY)	53.5	2.1	56.8	2.7	50.1	3.4	38.2	3.3	32.4	3.6	26.7	4.1
101	Reading	52.0	1.4	49.2	1.4	47.8	1.4	100.0	18.8	100.0	18.8	100.0	18.8
404	Riding a bicycle	51.8	3.3	52.4	3.7	45.0	6.8	25.0	4.3	23.2	4.5	12.4	6.4
403	Mobility out of doors	51.5	1.4	47.0	1.4	49.4	1.4	100.0	18.8	100.0	18.8	79.8	7.5
906	Physical activity and sport	51.4	2.7	53.4	2.3	48.9	3.2	31.1	3.7	36.0	3.4	26.7	4.1
405	Driving a car	51.1	6.6	43.7	7.2	32.0	8.1	7.7	7.6	7.7	7.6	15.9	5.6
607	General Shopping	50.5	1.5	47.7	1.6	50.0	1.5	67.0	4.7	63.2	4.2	63.2	4.2
904	Dining out	50.3	1.5	45.9	1.5	46.3	1.5	67.0	4.7	75.3	6.3	75.3	6.3
402	Mobility indoors (unfamiliar environment)	50.3	1.4	46.2	1.5	46.3	1.5	79.8	7.5	100.0	18.8	79.8	7.5
102	Writing	50.0	1.4	50.9	1.4	50.5	1.4	79.8	7.5	87.3	10.4	100.0	18.8
201	Personal admin	50.0	1.5	48.6	1.5	47.2	1.5	65.0	4.4	63.2	4.2	67.0	4.7
301	Using a computer or tablet	50.0	1.8	47.2	1.8	50.4	1.8	48.4	3.2	49.5	3.3	47.4	3.2
802	Researching information	50.0	1.6	47.7	1.8	44.2	2.0	57.4	3.6	51.6	3.3	48.4	3.2
406	Using public transport	49.2	1.6	48.6	1.6	43.8	1.8	56.1	3.6	57.4	3.6	56.1	3.6
903	Attending social events	47.9	1.5	45.2	1.7	40.9	1.8	65.0	4.4	60.1	3.8	69.2	5.0
905	Day trips and holidays	47.7	1.6	45.4	1.6	46.1	1.6	63.2	4.2	63.2	4.2	61.6	4.0
606	Grocery Shopping	47.6	1.5	49.5	1.4	50.4	1.5	71.9	5.5	71.9	5.5	69.2	5.0

605	Cash withdrawal, paying by cash and card	47.5	1.5	44.6	1.5	46.6	1.5	79.8	7.5	79.8	7.5	75.3	6.3
804	Looking for work	47.5	4.4	34.0	8.9	32.6	15.0	18.7	5.1	7.7	7.6	0.1	10.5
002	Coping with fatigue & balancing energy levels	47.3	1.6	44.5	1.9	45.7	1.6	54.9	3.5	49.4	3.3	57.4	3.6
103	Watching TV	47.1	1.5	47.0	1.5	45.4	1.5	71.9	5.5	75.3	6.3	75.3	6.3
302	Dealing with personal correspondence	46.9	1.5	46.8	1.9	48.3	1.4	69.2	5.0	79.8	7.5	87.3	10.4
202	Following a schedule	46.8	1.5	43.6	1.6	43.8	1.6	79.8	7.5	75.3	6.3	75.3	6.3
001	Emotional life	45.0	1.7	46.2	1.6	45.8	1.6	57.4	3.6	57.4	3.6	58.7	3.7
601	Cleaning and tidying up	44.9	1.5	36.6	1.9	37.9	1.8	87.0	10.4	69.2	5.0	71.9	5.5
610	Caring for a (grand)child	44.1	3.3	42.8	3.8	34.4	4.5	28.3	3.9	25.0	4.3	26.7	4.1
303	Using the telephone or smartphone	43.9	1.6	41.8	1.6	40.3	1.7	79.8	7.5	87.3	10.4	100.0	18.8
704	Interaction with strangers	43.7	2.0	40.8	2.3	41.4	2.2	45.4	3.2	43.4	3.2	48.4	3.2
805	Activities at work	43.4	3.8	43.8	4.1	45.0	4.2	25.0	4.3	23.2	4.5	23.2	4.5
608	Meal Preparation	43.4	1.6	41.7	1.6	41.6	1.7	79.8	7.5	79.8	7.5	75.3	6.3
611	Caring for a pet	43.4	3.2	33.8	3.9	32.8	4.3	31.1	3.7	31.1	3.7	31.1	3.7
801	Managing finances	43.1	1.7	41.3	1.7	44.5	1.7	63.2	4.2	69.2	5.0	60.1	3.8
609	Healthcare for another adult	42.9	4.4	34.8	8.9	31.6	8.4	23.2	4.5	7.7	7.6	12.4	6.4
703	Interaction with colleagues	42.0	4.3	41.2	4.4	37.4	4.1	23.2	4.5	21.1	4.8	29.7	3.8
701	Communicating with people face to face	41.8	1.6	42.4	1.6	41.0	1.6	87.3	10.4	79.8	7.5	100.0	18.8
806	Mobility within the workplace	39.0	4.7	38.6	4.7	36.9	4.6	23.2	4.5	23.2	4.5	25.0	4.3
602	Managing the laundry	38.5	1.9	33.2	2.2	33.5	2.2	67.0	4.7	67.0	4.7	67.0	4.6
502	Personal hygiene	36.13	1.86	27.39	2.57	33.02	2.05	100.0	18.8	100.0	18.8	87.30	10.4
401	Mobility within the home	34.65	1.94	30.8	2.26	31.19	2.19	100.0	18.8	87.3	10.4	100.0	18.8
901	Following the news	33.98	2.14	36.46	1.95	37.38	1.86	67.0	4.7	69.2	5.0	71.9	5.5

503	Personal healthcare and medication	33.59	2.01	31.84	2.14	29.05	2.39	100.0	18.8	87.3	10.4	87.3	10.4
504	Eating and drinking	33.02	2.05	33.77	2.02	33.02	2.05	100.0	18.8	87.3	10.4	87.3	10.4
702	Relationship with loved ones	32.61	2.32	28.28	2.60	31.83	2.14	58.7	3.7	67.0	4.7	100.0	18.8
902	Having visitors in the home	30.73	2.44	26.99	2.70	19.98	3.83	65.0	4.4	75.3	6.3	79.8	7.5
501	Getting dressed	28.68	2.47	28.25	2.47	26.45	2.68	87.3	10.4	100.0	18.8	100.0	18.8

Table 5 shows that some of the most difficult goals (e.g. mend clothing (604), participating in education (803)) are of low importance, explaining why they do not appear within the TPL-15 (Table 2). Equally, many important goals are of low difficulty (e.g. eating and drinking (504), getting dressed (501)), also explaining their absence from the top rehabilitative needs.

Few goals increase in difficulty with time. Minor increases are seen for following the news (901) and grocery shopping (606).

Most other goals become perceived as less difficult over time to a greater or lesser extent, including reading (101) and mobility indoors (402). Some goals decrease in both importance and difficulty: notable in this category are cleaning and tidying up (601) and home maintenance and DIY (603), as well as TPL-15 goals of hobbies and crafts (907) and researching information (802).

Some goals increase in importance over time. Some of these goals are associated with stable levels of difficulty (e.g. relationship with loved ones (702), writing (102), correspondence (302), and to a lesser extent the TPL-15 goals dining out (904) and face to face communication (701)). Other goals are both more important and less difficult with time (e.g. visitors in the home (902), using telephone or smartphone (303)).

Some goals decrease in importance, with little change in difficulty observed. These include the TPL-15 goal of mobility outdoors (403), and relatively low difficulty self-care goals of personal healthcare and medication (503), personal hygiene (502) and eating and drinking (504).

Discussion

The Participation and Activity Inventory (PAI) was used with a sample of adults with acquired vision loss in England to understand service provision priorities and to determine if these change over time. Overall, a significant decrease in rehabilitation needs was seen, driven primarily by an overall decrease in goal difficulty with little overall change in goal importance. At a more granular individual goal level, stability of the difficulty and importance of many goals was observed but specific goals changing in difficulty and/or importance are identified.

A significant decrease in the overall perceived need for rehabilitation as assessed with priority scores occurred over the 12-month period, with the most significant change occurring within the first 4 months following registration with the rehabilitation team, which was also coincident with the delivery of most rehabilitation interventions (Figure 1). Although there is a reduction in priority scores, there is still a perceived need for continued support one year following the initial interventions received, and the findings suggest that continued follow-up of people with visual impairment is still indicated. As UK services are usually commissioned at local level it is not possible to give a comprehensive overview of current arrangements for continued service provision, but formal continuity of rehabilitation support is not always offered.[3,7,9,35]

When evaluating change in specific goals within the PAI, it should be noted that the aim of the instrument is to comprehensively outline the rehabilitation needs of a person with visual impairment, and that there is overlap between goals. For example, both 'reading' and 'writing' might be required for 'personal correspondence' or 'administration'. Responses to specific goals allow consideration of the context of the rehabilitative need for an individual, and in this overview analysis, themes within and between domains can be considered.

The three goals of highest priority on entry to rehabilitation in this study are reading (101), mobility outdoors (403) and writing (102), as have previously been identified.[17] These goals also remained of highest priority over time, although reading and mobility scores declined while priority scores for writing remained similar (Table 2). Reading remained of high importance while its difficulty declined (Table 5), similar to longitudinal findings with Dutch participants,[18] and potentially reflecting the impact of interventions with low vision aids since rehabilitation interventions in this domain were the most common (Figure 1).

Mobility outdoors declined in importance with a slight decrease in difficulty (Table 5). The decline in importance may indicate that participants were leaving the home less frequently over the 12-month period, despite mobility being the third most common domain for interventions (Figure 1). PAI mobility goals have not previously been examined longitudinally.

Writing increased in importance with time and decreased only slightly in difficulty (Table 5). In contrast, writing was found to decrease in difficulty with time and remain of similar importance in Dutch participants.[18] Although writing has previously been identified as important in low vision rehabilitation,[36,37] the high level of continued need indicated here suggests that greater attention should be paid to identification of need and provision of interventions in this area. In the present study, the primary low vision aid used at study entry was a hand magnifier for 69% of participants (Table 1), with the majority of aids (51%) having been sourced through the low vision clinic. All low vision aids used at study entry were reported for Dutch participants,[18] with 50% using a hand magnifier, 24% using a stand magnifier, 13% using 'telescopic spectacles', and 2.5% using an aid specific for writing. Differences in need regarding writing between the two groups may be related to some extent to differences in optical low vision aid provision, which in turn may relate to budgetary constraints on device supply, and an increased emphasis on provision of hands-free aids might be valuable.

We have previously shown [17] a lower perceived need for intervention to address emotional health in our English participants than is indicated by Dutch participants. Longitudinally, a slight increase in rehabilitation need is seen for coping with fatigue and balancing energy levels (002; Table 2) which brings the goal into the TPL-15 at visit 3, although there is little change in the Rasch scores for difficulty or importance (Table 5). Little change in priority scores, importance or difficulty is seen for the goal of emotional life (001). In Dutch participants, while priority scores were not presented, goal importance and difficulty with goal 002 remained stable over time while goal 001 decreased slightly in difficulty.[19] These findings further support the suggestions [17] that service users in England may not be as comfortable

reporting emotional health symptoms to eyecare professionals, or that they may not recognise the need for interventions relating to their emotional health compared to Dutch participants.

Some goals with notable changes over time were identified. The largest decreases in priority scores (Table 2) were in the goals of hobbies and crafts (907), researching information (802), home maintenance and DIY (603), and cleaning and tidying up (601). All these goals were relatively difficult at baseline and showed decreases in both importance and difficulty with time (Table 5), suggesting that they were relinquished over time by participants who found them difficult, and were retained as important only by those who had less difficulty. For the example of cleaning and tidying up, this might be considered as a reasonable adjustment in priorities or alternatively an indication that other solutions had been found, such as using cleaning services which could have been triggered through rehabilitation services. In other cases, such as hobbies and crafts, this may represent the relinquishing of valued goals that are important for quality of life. Early identification of difficult and valued goals within rehabilitation might allow interventions to be put in place to reduce the likelihood of the goal being relinquished, or to support an individual where continuation of such goals is unlikely to be feasible.

Fewer goals showed increases in priority score with time, with the largest changes being in dealing with correspondence (201), following the news (901), coping with fatigue and balancing energy levels (002), and relationship with loved ones (702). These changes were predominantly associated with increased importance rather than changes in difficulty. In particular, the goal of relationship with loved ones showed the largest increase in importance scores across time (Table 5). Communication is a theme across other goals demonstrating the greatest increases in importance with time, with using the telephone or smartphone (303), dealing with personal correspondence (302), having visitors in the home (902) and communicating face to face (701) also falling in this category. Very few rehabilitation interventions were delivered in the relevant domains of communication or interaction with others (Figure 1).

Contrary to the present findings of changes in importance in some goals, previous studies have found that PAI goal importance remained stable over time.[18,19] However, only the goals of reading, writing, watching TV [18] and emotional health [19] have been evaluated. In the present study the importance of these specific goals also remained relatively stable, apart from writing, which increased in importance. While goal importance overall did not change with time, increases in importance of specific goals that have not previously been evaluated longitudinally, particularly around interaction with others and methods of communication, suggest that re-evaluation of areas requiring rehabilitation is appropriate to inform ongoing service provision.

Previous studies suggested that a polytomous Likert scale of importance is not justified,[18,19] and advocated the use of a dichotomised question regarding importance to establish whether or not an individual would wish to incorporate a goal within a rehabilitation plan. The present study has evaluated all 48 goals of the PAI and agrees that such a dichotomous scale for relevance is indicated through examination of category functioning. Additionally, the present study finds that participants can reliably utilise a 4-point, rather than 5-point, Likert scale for difficulty. Incorporating these findings as amendments to the format of the PAI would reduce its administration time in the clinical environment for

which it was intended, and would affect the determination of priority scores as an indication of rehabilitative need.

Although it may be inferred that the reduction in perceived need could have been due to the interventions received, this study did not have a control group. It is not possible to conclude whether the trajectory for rehabilitation needs would have been similar over the same timeframe if services had not been accessed, or if need might have increased reflecting a general decline in participants' baseline function.[38] Participants also had relatively rapid access to rehabilitation services, with a ROVI home visit provided within 6 weeks of registration. Time to access rehabilitation services will vary across the UK, and may have changed as a result of the COVID pandemic. An additional potential limitation of the study is that the sample size was relatively small, and participants were volunteers. This may have introduced a degree of bias towards a less depressed and more active cohort. The findings may not be generalisable to groups of people with visual impairment who have different characteristics to the older, white participants recruited, who were also typically female and with macular degeneration. However, the sample does broadly reflect the characteristics of those registered as visually impaired in the UK.[39]

Conclusions

Despite a decline in the perceived need for rehabilitation over the study period, there remains a need for continued support and intervention at 12 months following registration with rehabilitation services. An overall decline in reported difficulty with visual goals was observed, possibly reflecting the impact of rehabilitation interventions received. However, some difficult goals were relinquished, and goals relating to communication and interactions with others became more important, indicating that re-evaluation of needs at follow-up is necessary to inform ongoing service provision.

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Figure legends

Figure 1. Number of participants receiving rehabilitation interventions by each visit. Interventions have been mapped against the 10 domains of the PAI.